Using the International Classification of Functioning, Disability and Health (ICF) to enhance healthcare communication: an action research project with an acute stroke service

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Abstract

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Background: Effective communication is key to team working in healthcare. It can be negatively impacted upon by existing cultures, logistical challenges, role confusion, and a lack of collaborative approaches to practice. Clinical guidelines recommend using the International Classification of Functioning, Disability and Health (ICF) to aid communication within stroke teams. Yet no empirical evidence exists on the process or outcomes of such implementation.

Aims: This project aimed to explore ways the ICF could be used with an acute stroke service and identify key learning from the implementation process.

Methods: Using an action research framework, iterative cycles were used within exploratory, innovatory and reflective phases. Content analysis was used to map patient notes' entries to ICF categories. Thematic analysis was undertaken, using a model of immersion and crystallisation, on data generated via interview and focus group, e-mail communications, minutes from meetings, field notes and a reflective diary. Descriptive statistics were used to analyse quantitative questionnaire data. Data from all sources were combined to determine key findings.

Findings: Participants chose to develop an ICF-based team transfer of care report with an ICF glossary to aid completion. Five overall themes were determined; the need to: (1) adopt the ICF in ways that met local service needs; and (2) adapt the ICF language and format. Once implemented, the ICF: (3) fostered communication within and beyond the stroke team; (4) promoted holistic thinking; and (5) helped to clarify team roles.

Conclusions: These are the first empirical findings within stroke services that demonstrate how to make the ICF a clinical reality. Participants needed to adapt and own the ICF to adopt it. When implemented, it enabled specific team communication challenges to be overcome. The use of action research to implement the ICF has facilitated sustained change and improvements to communication, thus benefiting patient care.

Contents

List of Tables

List of Figures

Dialogue boxes

List of Appendices (see volume 2)

1. Ethical approvals
2. A reference list of the retrieved articles comprising the literature review
3. Summary of the action research studies within stroke care
4. Copy of the self-reflective form completed at the end of each exploratory phase interview
5. The medical notes topic guide used in the exploratory phase
6. The multidisciplinary team notes topic guide used in the exploratory phase
7. The ICF based questionnaire, subsequently discarded from the analysis, used in the exploratory phase with members of the acute stroke service
8. The questionnaire sent to staff beyond the service, during the innovatory phase, when evaluating draft 6 of the TOC report
9. The Multi-disciplinary meeting (MDM) observational tool, subsequently discarded from the data analysis, in the exploratory phase
10. The exploratory phase interview topic guide final version (number 10)
11. The reflective phase interview topic guide (final version 2)
12. The exploratory phase focus group topic guide, employing the nominal group technique
13. The reflective phase focus group topic guide (final version 3)
14. A copy of the small findings summary booklet in the exploratory phase
15. The exercise in the exploratory phase interview: reading current notes entries
16. Version one of the transfer of care report
17. Version six of the transfer of care report
18. Version fourteen (final) of the transfer of care report
19. The ICF checklist (version three) that proved unsuccessful
20. The ICF glossary (version four; final) used as an aide memoir with the TOC report
21. Published article 1. Tempest, S. Harries, P. Kilbride, C. and De Souza, L. (2013) ‘Enhanced clarity and holism: The outcome of implementing the ICF with an acute stroke multidisciplinary team in England’ *Disability and Rehabilitation* 35 (22) pp.1921- 1925.
22. Published article 2. Tempest, S. Harries, P. Kilbride, C. and De Souza, L. (2012) ‘To adopt is to adapt: The process of implementing the ICF with an acute stroke multidisciplinary team in England’ *Disability and Rehabilitation* 34 (20) pp.1686- 1694.

List of abbreviations

A&E: Accident and Emergency Unit

AHP: Allied Health Profession

AR: Action Research

ARG: Action Research Group

ASU: Acute Stroke Unit

BASP: British Association of Stroke Physicians

CEEu: Clinical Effectiveness and Evaluation Unit

CMHT: Community Mental Health Team

CSU: Comprehensive Stroke Unit

DALYS: Disability-adjusted life years

EP: Exploratory Phase

FAST: Face, Arm, Speech, Time to call 999

FDRG: Functioning and Disability Reference Group

FMEA technique: Failure Mode Effects Analysis technique

GPRD: General Practitioner Research Database

HASU: Hyper Acute Stroke Unit

ICD: International Classification of Diseases

ICF: International Classification of Functioning, Disability and Health

ICIDH: International Classification of Impairments, Disability and Handicaps

IP: Innovatory Phase

ISWP: Intercollegiate Stroke Working Party

IT team: Information Technology team

LC1: Cerner electronic records brand name

MDM: Multidisciplinary team meeting

MDT: Multidisciplinary team*

NHS: National Health Service

NICE: National Institute for Health and Care Excellence

OR: Operating Room

PAR: Participatory Action Research

RCN: Royal College of Nursing

RCP: Royal College of Physicians

RHBs: Regional Health Boards

RSU: Rehabilitation Stroke Unit

RP: Reflective phase

SINAP: The Stroke Improvement National Audit Programme

SNOMED: Systemised Nomenclature of Medicine

STEP: Stroke Treatment for Every Person

SSNAP: Sentinel Stroke National Audit Programme

SUTC: Stroke Unit Trialists’ Collaboration

SOAP: Subjective, Objective, Assessment / Analysis, Plan

SBAR: Situation, Background, Assessment, Recommendation

TIA clinic: Transient Ischemic Attack clinic

TOC: Transfer of Care report

WHO: World Health Organisation

WHO-FIC: World Health Organisation-Family of International Classifications

*The term MDT is used within this thesis because the team at the research site refer to themselves in this way.

Declaration

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Published papers

*Tempest, S. Harries, P. Kilbride, C. and De Souza, L. (2013) 'Enhanced clarity and holism: The outcome of implementing the ICF with an acute stroke multidisciplinary team in England', *Disability and Rehabilitation* 35 (22) pp.1921- 1925.

Tempest, S. Harries, P. Kilbride, C. and De Souza, L. (2012) 'To adopt is to adapt: The process of implementing the ICF with an acute stroke multidisciplinary team in England', *Disability and Rehabilitation* 34 (20) pp.1686- 1694.

Peer-reviewed conference presentations

Tempest, S. Harries, P. and De Souza, L. (2007) 'Exploring ways to implement the International Classification of Functioning, Disability and Health (ICF) to aid communication within an acute stroke multidisciplinary team (MDT)'. 2nd UK Stroke Forum

Invited conference presentations

Tempest, S. (2013) 'Communication challenges within the multidisciplinary team: the benefits of using the ICF?' The 6th Southern African Neurological Rehabilitation Association Conference (*International Keynote Speaker*)

Tempest, S. (2010) 'Using the ICF to aid communication within the stroke MDT', College of Occupational Therapists Specialist Section Neurological Practice Annual Conference

**Subsequently cited by the journal as one of the top three most downloaded articles in November 2013 and offered as a free download*

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Chapter 1: Introduction

This thesis is written as an in-depth case study. In this introductory chapter, I will set the scene with a description of the research site which leads into an outline of the research question and general aims, before explaining my interest in the topic. This will provide contextual detail, on the research setting, the participants and my own role as an insider/outsider action researcher, to help the reader judge the relevance of the findings to their own clinical setting and interests. The introduction is the only chapter to be written entirely in the first person to communicate and locate my position effectively within the project.

1.1 Setting the scene: background description of the stroke service

This section provides a description of the key milestones, from recent years, that shaped the development of the specific stroke service and research site within this project. Table 1 charts the evolution of the individual service and, later; chapter two will critically explore national stroke service development in more detail.

In 1998, the Royal College of Physicians Clinical Effectiveness and Evaluation Unit (CEEu) conducted the first National Sentinel Stroke Audit with a second one the following year (Royal College of Physicians: RCP 2009). The hospital Trust, where this project was undertaken, performed poorly on both the initial audits. Since then nationwide, bi-annual audits have been undertaken. At the time of the project, the data were retrospective, with the results becoming accessible the following year in the public domain, for example, the audit in 2010 was publically reported in 2011 (Intercollegiate Stroke Working Party: ISWP 2011). Now, data are collected prospectively and also reported much quicker.

Whilst there have been some changes to the audit questions, indeed the audit itself has been relaunched as the Sentinel Stroke National Audit Programme (SSNAP: RCP 2012), the objectives of the audit have remained constant: 1) to assess the quality of care for people who have had a stroke and; 2) to help National Health Service (NHS) Trusts use the audit data in order to develop the quality of the stroke service they provide (RCP 2009).

The questions within the Sentinel Audits are based on the evidence based standards within The National Clinical Guidelines for Stroke of which there have been four editions (ISWP 2000, 2004, 2008, 2012); work on the fifth edition has recently commenced. The audit tool focuses on the standards relating to the process and organisation of stroke care and, along with the clinical guidelines, has been developed with representation from the Intercollegiate Stroke Working party, lay people and third sector organisations (RCP 2009).

The National Clinical Guidelines and the Sentinel Audits were central to the establishment, and subsequent continued development, of the stroke services at the research site. As mentioned, the individual results for the Trust from the audits in 1998 and 1999 were poor and confirmed the concerns raised by clinicians (Kilbride et al. 2005). At the time in the research site, stroke care was uncoordinated and spread over eighteen wards; patients could be moved five or six times onto different wards, during their admission following a stroke, and this negatively impacted on the quality of their care (Kilbride 2007).

Therefore, in November 2000, a coordinated stroke service was established within the large teaching hospital in England. It was across two geographical sites; an acute stroke unit (ASU), comprising eight beds within the main hospital, and a rehabilitation stroke unit (RSU), containing eleven beds, at the rehabilitation hospital located half a mile away. I joined the team, as an occupational therapist, two months after it was established, in January 2001.

At the start of the coordinated stroke service, funding was also awarded by the Hospital Trust for an action researcher - Dr Cherry Kilbride, who was to become my critical friend in my own project - to work with and for the team, to evaluate the process and outcome of establishing the stroke service. Therefore from its inception, the service had experience of participating in action research. However, by the start of this, the second action research project, many of the original staff had left the service, as is common due to rotational posts and a high staff turnover in busy, metropolitan hospitals. Therefore, not many of the participants in this project had been previous research participants.

By 2004, the Trust had gone from one of the most poorly performing sites in the National Sentinel Audit (CEEu 1998) to the best service in the country (CEEu 2005) receiving a national award for health service redesign. The four factors contributing to the local success were identified as: building a team; developing and sharing practice-based knowledge and skills in stroke; valuing the central role of the nurse in stroke care; and creating an organisational climate for supporting change (Kilbride et al. 2011).

Central to the four factors was a forum which had been established to aid service development and continues to do so. From the outset in November 2000, the STEP team had been formed (which referred to ‘Stroke Treatment for Every Person’, reflecting the ethos of the service). The STEP team was a local initiative aligned to the first action research project which continues to this day, although the core membership evolves in line with staff changes. Today, the STEP team has representation from all the professions involved in the service: nursing, medicine, occupational therapy, physiotherapy, speech and language therapy, dietetics, psychology and carer support.

The remit of the STEP team is to lead on all service development issues, in a two-way process with the stroke oversight committee (see section 1.3) in line with the recommendations from the National Clinical Guidelines for Stroke (Intercollegiate Stroke Working Party 2012), and to organise the continued participation in the National Sentinel Audits. As with the first action research project, the STEP team have been the driving force for this project although, as will be outlined in the next subsection, they were not the only participants.

The co-ordinated stroke service has now been operational for over thirteen years. However, within that time, it has undergone substantial restructuring, some of which has been in response to financial restraints but also due to a major reconfiguration of stroke services in London (Healthcare for London 2009). Table 1 outlines the changes to the service, from its formation as a linked acute and rehabilitation service in 2000, to its present structure as a local acute stroke unit on one site.

Table 1: Changes to the research site stroke service structure 2000-2013

Date	**Change event to the research site stroke service** Key: *ASU: acute stroke unit; RSU: rehabilitation stroke unit; CSU: comprehensive stroke unit; HASU: hyper acute stroke unit*
November 2000	Stroke service with ASU (7th floor) and RSU (rehabilitation hospital site) established
November 2001	Bed numbers increase to reflect local need. ASU increased to 12 beds (from 8) and RSU increased to 15 beds (from 11). Staffing levels also increased to reflect demand
October 2005	ASU and RSU are merged to form a comprehensive stroke unit (CSU) based on the 7th floor in the main hospital offering acute and early post-acute rehabilitation (20 beds). RSU closed. Reasoning behind merger due to local Primary Care Trusts opting to fund longer term rehabilitation within their own hospital settings
April 2006	CSU moved from 7th floor to 11th floor to merge with Neurosciences Unit. Newly formed acute stroke service (ASU) has bed numbers reduced to 14 (from 20). Focus is solely acute stroke care, as local Primary Care Trusts establish their own stroke rehabilitation services including early supported discharge services. *(N.B. This study commenced in the autumn of 2006 when the team were still adapting to this enforced restructure)*
July 2007	Healthcare for London (2007) publish a framework for action with recommendations for a major reconfiguration of stroke services including specialist emergency stroke centres (HASUs: Hyper Acute Stroke Units). Hospital Trusts are required to submit bids which would be subject to a public consultation
January 2008	HASU established at research site, in addition to the acute stroke service, in a bid to secure status as specialist centre for stroke
June 2008	Launch of electronic records within the Trust (research site is a pilot for upgraded version named Cerner (Brand abbreviation:LC1)
July 2008	ASU moved from 11th floor (with the Regional Neuroscience service) to the 6th floor, no change in bed status but ward is a dedicated acute stroke unit
December 2008	Recommendations *for public consultation* on stroke services published; the research site has not been recommended as first choice to be a specialist HASU centre
January 2009	Launch of public consultation on Trauma and Stroke Services by Healthcare for London until May 2009. Research site subsequently becomes a local stroke service providing specialist treatment and rehabilitation (Healthcare for London 2009 pg. 39) to a wider but still local population, i.e. it was not designated as a specialist centre for stroke. HASU closed *(NB: This study finishes in the autumn of this year.)*
March 2010 to date	Catchment area expanded to cover five London Boroughs (from two). Bed numbers increased to 24 beds to include an assessment clinic for Transient Ischemic Attacks (TIA clinic). Focus remains local acute stroke care. Forms part of the North Central London Stroke Network

Therefore, since coming top in the Sentinel Audit in 2004 (CEEu 2005), Table 1 clearly demonstrates the service has undergone significant changes and should be viewed as continually shifting ground. We will return to this issue, in section 4.1, when exploring the selection of the methodological framework for this project. Nonetheless, the stroke service consistently remains in the upper quartile for the provision of acute stroke services in England, Wales and Northern Ireland (ISWP 2011).

1.2 My interest in the research topic

Although the service was, and remains, a high performing stroke service there was a persistence of day-to-day challenges that are commonly faced by multidisciplinary teams.

Over time my experience as an occupational therapist, within the stroke service, included a growing frustration with the amount of abbreviations and profession specific language used in team documentation. On many occasions I found I was unable to understand fully the written entries, from my multidisciplinary team colleagues, yet I did not feel able to seek clarity. In all honesty I felt, as a senior therapist, that I should know the information; admitting knowledge gaps would somehow make me feel vulnerable and seem out of place in my senior position. Furthermore I was not without blame myself and remember feeling extremely embarrassed when a nurse, who was a friend of mine, asked me for a verbal summary of my own notes, as she had not understood the occupational therapy specific jargon I had just written. In short, we all wrote in language that was comfortable to us, often developed within the course of our own different professional education and experience. In addition, writing notes was often the last task of the day or written on the move between patient sessions. They were not something we spent time deliberating over. This is not an issue unique to this clinical service and challenges with communication in healthcare professional teams will be critically explored in the literature review (chapter three).

There were many implications to these communication challenges within the stroke service. Of primary importance was the fact that, if we did not fully understand what each other was writing, it was highly likely that our patients and their families did not understand the written communication either. Potentially, their care could be compromised.

It was at this time the World Health Organisation (WHO) endorsed the International Classification of Functioning, Disability and Health (ICF: WHO 2001). This will be introduced in more detail in section 2.6.2 but one of the main aims of the ICF is to provide a unified language for the description of health and health-related states (WHO 2001). It is in two parts: 1) a framework which depicts the inter-relationship between a health condition and the impact on the body, activities and participation; and 2) a detailed classification (comprising 1424 categories). Yet, unlike its predecessor, the International Classification of Impairments, Disability and Handicap (ICIDH: WHO 1980), it acknowledges the impact of the context in which a person lives including the environment (physical, social and attitudinal) as well as an individual's personal factors e.g. coping style.

The hospital wide occupational therapy team, of which I was a part, had used the ICIDH although had experienced its limitations in its lack of contextual consideration. The head occupational therapist convened a documentation working party, the remit of which was to implement the new ICF into the occupational therapy paperwork. I was invited to join.

The process of implementing the ICF with the occupational therapy team proved difficult and one which we reflected on subsequently in publication (Appleby and Tempest 2006). We felt the challenges were two-fold: learning the ICF itself and the process of implementation. During the life of the documentation working party, I was also participating in the first action research project within the newly formed stroke service. I began to experience, for myself, the value of using this methodological process to enable learning and success in implementing new ideas into practice. The research questions within this thesis emerged from these experiences as I began to consider whether action research could be used to implement the ICF into clinical practice and, if so, what could be learnt from the process and outcomes.

At this early stage in the thesis, it is important to make a distinction between the research outcomes from this project and patient outcomes. When referring to the research outcomes, I mean the outcomes from implementing the ICF in relation to enhancing communication within and beyond the team. While patients and their families contributed to the evaluation process i.e. by sharing their opinions on the paperwork subsequently developed, at no point did this project focus on measuring the actual impact on patient care.

Two final factors helped move my research ideas into reality. Firstly, in 2004, the second edition of the National Clinical Guidelines for Stroke (Intercollegiate Stroke Working Party 2004) was published and it recommended the use of the ICF to aid communication within stroke multidisciplinary teams. Secondly, an opportunity arose to move into higher education which, at that time, offered the chance to study for a PhD.

1.3 The research question

The overall research question was:

To evaluate the process and outcome of implementing the International Classification of Functioning, Disability and Health (ICF) with an acute stroke service

From this research question, four aims were originally defined by me, working in collaboration, with some of the prospective participants, all of whom were members of the stroke oversight committee at the hospital. The original remit of this committee had been to negotiate medical involvement in the newly established stroke service. Once the neurologist and geriatrician had agreed upon a shared model of care, the remit of the committee broadened; it started to act as an executive group to oversee the continued development and management of stroke services in the hospital. It was a senior management group comprising the two consultants but now also included the stroke coordinator and the respective leads for the different allied health professions. A number of clinicians on the stroke oversight committee also attended the weekly STEP team meeting enabling the two forums to work in collaboration rather than in a hierarchy. To begin with I discussed the potential project with the Chair of the committee who subsequently invited me to present the idea at their next meeting. A supportive and productive meeting ensued resulting in a letter of support from the committee to aid ethical approvals (University and NHS) for the project to commence (see Appendix 1).

There are three main phases within action research projects - exploratory, innovatory and reflective - I loosely defined initial aims across all the phases. But they were still quite broad as, the nature of action research is such that, the participants would subsequently refine them during the research process. Table 2 outlines the purpose of each action research phase and the original aims specifically defined for this project:

Table 2: The phases common in action research projects and the broad aims specific to this project

Phase and purpose of action research projects	**The original aims for this action research project as defined by the researcher**
Exploratory phase: issues and problems are identified prior to taking action	Aim one: Identify which of the ICF domains and categories are already addressed within the service Aim two: Identify the current challenges within the service which may benefit from the use of the ICF framework and classification
Innovatory phase: taking action by implementing ways to address the problem areas, using 'action cycles'	Aim three: Develop, pilot and evaluate ICF based tools
Reflective phase: evaluates the actions and the processes that have been undertaken	Aim four: Evaluate the process and the outcomes from the project

1.4 Background description of the researcher and participants

I had worked as an occupational therapist within the stroke team between January 2001 and August 2004 and the idea for the project evolved during that time. In addition, my involvement in the first action research project meant I had gained experience of the methodological framework as a research participant. Previous clinical experience of the research site enabled me to have insider knowledge however, as indicated in Table 1, the service underwent significant restructuring in between my leaving as a clinician and returning as a researcher. The strengths and limitations of my insider/outsider role will be considered in sections 5.5 and 6.3.

Initially, the participants in this study represented all health and social care professions that worked within the acute stroke service during the fieldwork period. As the project progressed, participants also chose to engage and seek involvement from patients, informal carers, family members and community health care professionals who interfaced with the service.

In order to provide some contextual details of the research participants, the following clinical staff within the stroke service were initially invited to, and subsequently participated in, the project:

- Nursing
- Occupational Therapy
- Physiotherapy
- Speech and Language Therapy
- Dietetics
- Carer and Family Support Worker
- Clinical Psychology
- Medical
- Social Work

Subsequently, on invitation from the stroke service participants, the following groups of people also contributed:

- Managers and logistical support staff within the hospital, e.g. audit officer, electronic records development team, information technology colleagues
- Patients discharged from the acute stroke unit, their family members and carers
- Community therapists from physiotherapy, occupational therapy, dietetics, speech and language therapy and clinical psychology.

The final contextual factors, regarding the service, concern the existing knowledge and use of the ICF itself and the dissatisfaction with a particular aspect of the rehabilitation process. As briefly described, the ICF comprises a framework and a detailed classification. The broader occupational therapy service was familiar with the ICF framework, but not the classification. Therefore the occupational therapists within the stroke service had some experience of using the ICF in clinical practice, albeit limited to one component. At the start of the project, no other member of the acute stroke multidisciplinary team had theoretical knowledge or experience of using the ICF. However, during the life of the project a new, part time member of staff joined the clinical team and brought knowledge, experience and opinions on the framework and classification. Nonetheless, at the start of the project, the team were familiar with the clinical recommendation from the stroke guidelines which advocated the use of the ICF within stroke care (ISWP 2004).

In my previous clinical role, as an occupational therapist, leading on the ICF implementation within the general occupational therapy department, I had significant clinical experience of using it in the hospital site. But I also had a substantial amount of theoretical knowledge about the framework and classification from post-graduate studies and previous research (Tempest and McIntyre 2006), although the latter was limited to a clinical commentary and written, in part, to stimulate debate and justify the need for this research.

Finally, within the clinical setting, there had been a long held dissatisfaction, which I had first-hand experience, with the discharge process. Individual professions wrote their own transfer of care reports, which were rarely seen by each other and, on occasions, had conflicting information which was queried by funding panels. The occupational therapists and physiotherapists had developed a joint report but attempts to broaden the scope had not been successful. Yet the dissatisfaction remained.

1.5 Clarifying the research phases and parameters for writing purposes

As outlined, there are three distinct phases to action research projects. However, as action research is neither linear nor prescriptive in reality, it must be appreciated that a clear demarcation of phases is presented in the thesis for the ease of the readers' journey, rather than a reflection of the research reality.

Furthermore, the research parameters can also be viewed as arbitrary. For the purposes of writing the thesis, the project 'started' on the 1st September 2006 and 'ended' in September 2009. However, as previously described in section 1.2, the idea of the project began to evolve whilst I was working in clinical practice (from

2001 onwards) so there was a five year period prior to the research beginning, particularly the 12 months leading up to September 2006, where the scope of the project was being formed and discussed.

1.6 Overview of the thesis

Following this introduction, Chapter Two will comprise a review of the background topics which inform this project namely the development of stroke services, with a focus on England, and the historical development of the ICF (WHO 2001). The exploration will also refer to the initiatives briefly described in this introduction, i.e. the National Clinical Guidelines for Stroke and the Sentinel Audits, but place these in a wider context.

Chapter Three is the literature review. As the National Clinical Guidelines for Stroke (ISWP 2012) recommend using the ICF to aid stroke multidisciplinary team communication, the literature review will critically explore, in a broader sense, the current communication challenges within healthcare teams, which may have warranted a recommendation to seek an alternative communication approach.

Chapter Four is the methods chapter. It will begin by outlining and evaluating the decision making process that led to the selection of action research as the appropriate methodological framework. It will relate action research theory to the aims of this project. Attention will also be paid to the development of the data collection tools; methods for each phase which will be taken in turn and critically discussed. Markers of quality, that have been recommended for action research theses (Zubler-Skerrit and Fletcher 2007; Bradbury Huang 2010), will form the structure to evaluate the key topics.

Chapter Five comprises the findings. It will outline the overall findings from the process of implementing the ICF and the outcomes of so doing. There are two inter-related elements within the findings chapter. The first set of findings report on the knowledge-in-practice: i.e. findings that informed each subsequent action research phase. For example, at the end of the exploratory phase the participants identified a number of ways the ICF could be used in their practice, which subsequently helped them to select the innovations for the next phase. The second set of findings relate to the knowledge-in-theory. Using a model of crystallisation and immersion for analysis (Borkan 1999), I sought to elicit the overall theoretical findings, from the entire project, in terms of what was learned from the process and outcome of implementing the ICF with an acute stroke multidisciplinary team. Chapter Five will also detail findings in relation to the action research project itself and my role as the researcher, alongside issues of participation and engagement.

Chapter Six is the discussion chapter. The discussion will critically consider the practical and theoretical knowledge, generated from the project, in relation to two sets of literature: the contributions to the ICF debate and communication challenges within healthcare teams. It will also reflect on the methodological approach used, myself within the process, and summarise the conclusions and recommendations for future research from the project. References and relevant appendices will draw this thesis to a close.

1.7 Chapter summary

This introductory chapter has sought to set the scene for a variety of elements within this thesis. It has detailed the overall aim of the project; how this aim was initially discussed and agreed with the stroke oversight committee; and then subsequently developed into specific aims, with the research participants within the stroke service, for individual phases of the action research project.

As this is an in-depth case study, it was also considered essential to describe the setting in which the project took place. Whilst it was acknowledged that the acute stroke service, since 2004, has been considered one of the best in the country (as indicated by the Sentinel Audit data), there continues to be substantial change and restructuring, which has impacted on team working. Nonetheless, the service consistently remains in the upper quartile for the delivery of stroke care in England, Wales and Northern Ireland.

The other important factor to consider is that the acute stroke service was not new to action research, although it was new to many individual team members who had joined the team at a later date: i.e. after the first action research project. The impact of this will be explored in the discussion but it must be appreciated that the dynamics and functionality of how the team worked was, in part, built from the foundations of previous work; for example, the fact that the STEP team remained in place as a cultural artefact from the previous project and was a firmly established and influential forum, which aided this project.

Finally, the introduction has briefly outlined the chapter structure with the intention to aid the readers' journey.

Chapter 2: Background to key topics

2.1 Introduction and search strategies

Chapter Two is a historical exploration of the key topics within the research: namely, stroke as a health condition; the evolution of stroke services; and the development and clinical application of the International Classification of Functioning, Disability and Health (ICF: World Health Organisation 2001). All of these topics have changed over time and a historical exploration enables an appreciation of the contextual factors that influence current thinking and practice.

A range of sources were used to obtain the relevant literature including various government departmental records at The National Archives; online archives from the Department of Health; clinical guidelines published through the Royal College of Physicians; and minutes from relevant WHO meetings. Eleven electronic databases were accessed through the university resources: Blackwell Synergy, ScienceDirect, British Nursing Index, Cinahl, Medline, Ovid databases, Scopus, Web of Knowledge, Amed, Zetoc and Intute Health and Life Sciences. Google Scholar was also used. The reference lists from all the articles were also searched, especially pertinent where the nature of the debate was historical, thus presenting a risk that information could be missed from texts which predated those archived within the electronic databases.

2.2 Stroke as a health condition

This section will start by defining stroke and discussing the impact of stroke at a global and national level. It will explore the cost in terms of the personal and economic burden. The perception and awareness of stroke will also be evaluated as these factors have contributed to the evolution of stroke services, which will be explored in section 2.3.

The World Health Organisation (WHO: 1978) defines stroke as a focal or global neurological impairment with sudden onset, the effects of which last for over 24 hours or lead to death. It is of presumed vascular cause. A transient ischaemic attack (TIA; also known as a mini stroke) presents with symptoms that resolve within the first 24 hours (WHO 2006b). Whilst the definition of stroke has remained unchanged from the World Health Organisation since 1978, the International Classification of Diseases has evolved through to version ten (ICD-10: WHO 2006), which is currently used in clinical practice to code and classify diseases. The development of version eleven is now underway, with an anticipated publication year of 2017 (WHO 2014). As an aside, but of interest, the ICD-11 will be the first compiled through a collaborative process with clinicians and patient groups (WHO 2012) suggesting a move towards greater engagement with the populations served by the WHO's family of classifications.

Within the ICD-10, the following codes apply to stroke: I61 intracerebral haemorrhage, I63 cerebral infarction and I64 stroke, not specified as haemorrhage or infarction (WHO 2008). However, these are not universally applied in clinical practice or research. From a clinical perspective, a person with a subarachnoid haemorrhage, on admission to hospital in England, will be under the care of a neurologist or neurosurgeon, rather than a stroke physician. From a research perspective, it could be argued that the robustness of longitudinal, epidemiological data has been undermined by revisions made to the ICD, which has weakened the ability to draw comparisons over time.

The World Health Organisation, in its last large global analysis of the impact of stroke (2006b) stated that, worldwide, stroke is the second highest cause of death with an estimated 5.54 million people losing their lives to the disease. Furthermore, the gap in prevalence between the developed and poorer countries continues to widen (WHO 2006b), although populations in rural Bolivia and Papua New Guinea have little or no recorded accounts (WHO 2006b). However, these findings are questionable due to lower life expectancy in these countries, variations in data collection methods and different cultural values when accessing medical care.

Another factor which impacts on our understanding of the global stroke picture is the lack of standardised, comparative data across different countries (Thrift et al. 2014). In a review of published data, incorporating the WHO analysis above (WHO 2006b), Thrift et al. (2014) were only able to extract data from 51 countries (for incidence) and 123 countries (for mortality). Nonetheless, the findings showed a vast difference in crude incidence. The highest was Denmark with 306 strokes per 100,000 population, although the data were collected in 1989-90 so may be out of date. The lowest was Dijon, in France, with 58 strokes per 100,000, although this was an age-adjusted incidence. Mortality rates were the highest in Kazakhstan with lower rates in countries such as Bahrain and Kuwait (Thrift et al. 2014).

Yet, geographical variations occur within countries as well as between them, for example, Bhatnagar et al. (2010) concluded the incidence of stroke for men in South London was 124 per 100,000, in contrast to 185 per 100,000 men in Scotland.

Nonetheless, it is known that, in England, stroke is the third most common cause of death and accounts for 11% of all deaths each year (ISWP 2012). Someone in England will have a stroke approximately every five minutes (The Stroke Association 2014). Of the 110,000 people per year who have a stroke, approximately one third will die and one third will make a full recovery. The other third of people will survive but with persisting difficulties, making stroke the leading cause of disability in adults (ISWP 2004).

The personal burden of stroke is also significant as it negatively impacts on a multitude of factors including social, emotional, physical, cognitive and economic well-being. It has been estimated that stroke accounts for the loss of 49 million disability-adjusted life years (DALYS) across the globe every year (WHO 2006b).

It is difficult to calculate the cost of acute stroke care in the UK, as the health condition is not homogenous and different types of treatment are needed for different types of strokes. However, the cost burden is twice that for coronary heart disease and accounts for six percent of the annual health and social services budget (WHO 2006b). The estimated cost of acute stroke care per patient is estimated at £6607, although this calculation is based on all people with acute strokes including those not admitted to hospital and those with TIAs. When examining the cost of those admitted to hospital for acute care, the average cost rises to £10,474 (Luengo-Fernandez et al. 2006). Overall, it has been estimated that stroke costs the UK economy £7 billion a year: £2.8 billion in NHS direct care costs; £1.8 billion in lost productivity and disability and £2.4 billion in care costs (Department of Health 2005).

However, mortality rates from stroke are on the decline in England. For example, the rates in the Oxford region have halved between 1979 and 2000 (Gibbs et al. 2001). Furthermore, in an analysis of over 32,000 patients in another study, the incidence of stroke in the UK fell by 29% between 1999 and 2008 (Lee et al. 2011). But there have been significant changes to the classification of stroke during this time which makes longitudinal comparisons difficult (Goldacre et al. 2008). Regional variations remain for both mortality rates and service organisation (Royal College of Physicians 2012). As the population ages and the rates of obesity increase, there is concern that the incidence of stroke will also increase (Department of Health 2005).

A stroke is the brain's equivalent of a heart attack and there are similar numbers of brain attacks to heart attacks every year in the UK (Department of Health 2005). However, it could be argued that the impact and meaning of stroke is not apparent in the immediate use of the word and could affect the perception of the disease. For example, the word stroke can have positive connotations in everyday English, as in a 'stroke of luck' or a 'stroke of genius'. The passive nature of the word itself does not conjure images of an emergency, unlike the phrase 'heart attack' who's meaning is explicit in its description.

Stroke has been viewed as the 'Cinderella' disease and falls between neurology, elderly medicine and general medicine in the UK (Markus 2007). This perception has impacted on the development of stroke services in England, which in 2005 were deemed to be where coronary care services were at in the early 1990s. For example, in 2005, there were only approximately 80 dedicated stroke consultants in comparison to 700 cardiologists (Department of Health 2005). Nearly a decade on and this has risen to 350, but this is still a predicted shortfall of 163 stroke consultants for the British population (British Association of Stroke Physicians 2011).

The poor perception and awareness of stroke is not unique to the UK. Stroke incidence in Japan used to be the highest in the world at over four hundred per one hundred thousand. Following a government led education and awareness campaign, alongside an increase in the treatment of hypertension, the rate of stroke fell by 70% (WHO 2006b). Whilst this is a success story, there are also examples of an increase in the incidence of stroke, e.g. Eastern European countries. There have been many socioeconomic changes in parts of Eastern Europe in the last fifteen years and whilst some are positive, i.e. better access to healthcare, there has also been increased exposure to risk factors associated with stroke, e.g. smoking and alcohol consumption (WHO 2006b).

A further reason for the poor awareness of stroke is that historically, in the UK, it has been viewed merely as a consequence of old age. In reality, 25% of all strokes occur in the under 65's (The Stroke Association 2014). There may also be an element of ageism that continues to affect the perception and the treatment offered; older people are less likely to be treated on a stroke unit or have goals that focus on leisure, driving or work (Rudd et al. 2004). This perception is inherently UK held, as other European countries regard stroke primarily as a neurological disorder (Department of Health 2005) and not one of old age.

Another misperception of stroke is that it is not a medical emergency (Department of Health 2007) and it is this fatalistic attitude that has long blighted the development of stroke services in England (Department of Health 2006). Challenging this perception will be explored, in section 2.3, when evaluating the evidence that has shaped the evolution of stroke services in this country.

Efforts to raise both public and professional awareness have been made over the past two decades. In 1998, The Stroke Association began to publicise the FAST test (Facial weakness, Arm weakness, Speech problems, Test all three symptoms) to educate people on the early signs of stroke. However, a Mori poll conducted seven years later showed that 50% of people could still not identify a stroke, with only one third saying they would call an ambulance (The Stroke Association 2005), showing that further work was required to raise public awareness of stroke.

In 2009, therefore, The Stroke Association, with funding from the Department of Health as part of the National Stroke Strategy (Department of Health 2007), launched a multi-media campaign including the first use of television adverts to raise the profile of stroke and to encourage stroke to be viewed as a medical emergency. To this end, the 'T' in the FAST test was redefined and now stands for 'Time to call 999'. However, funding for specific health promotion campaigns, such as the one for the FAST test, is no longer available from the Department of Health, as the recent health reforms have moved public health and their budgets over to local government, in conjunction with a newly formed national body called Public Health England (King's Fund 2013). Their public health priorities focus on mental health, obesity, smoking, alcohol and drugs, HIV and sexual health (Public Health England 2014). However, a commitment was also made to the FAST campaign, which was re-launched in 2012, albeit with a less visible television presence.

In the mid noughties, stroke started to become a political priority. For example Alan Johnson MP, then Secretary for State for Health, gave a keynote address at the 2nd UK Stroke Forum in December 2007. It was the first time a minister had addressed a stroke specific conference in the UK and came just over a year after the then Prime Minister, Tony Blair, had spoken publicly about stroke care (the first time in his ten year leadership). Both were seen as positive indicators for the increasing profile of stroke on the political agenda.

There was also a call in 2007 for further education about stroke for healthcare professionals as well as the public (Department of Health 2007) but this was not the first time the issue had been raised. In the early to mid-1990's, a significant variation in referral rates to specialist stroke physicians was found across health care regions, with no relationship between incidence and referral rate (Gibbs et al. 2001). One reason for this was the perceived lack of understanding of stroke as a specialist medical emergency. The data for the study was collected from the General Practitioner Research Database (GPRD). However, the GPRD uses a different coding system to the ICD-10 (WHO 2006) as it includes diagnostic codes such as brain tumour, multi-infarct dementia and epilepsy, i.e. health conditions which traditionally do not warrant a referral to a stroke specialist physician. Therefore the method of data collection raises questions when interpreting the findings.

There are other historical developments to indicate that the perception of stroke lags behind other diseases, such as heart attacks and cancer. For example, it took until 2004 for the Joint Committee on Higher Medical Training to accredit stroke as a sub-speciality, therefore enabling a stroke specific career structure for doctors (Department of Health 2005).

Information provided to health care professionals also warrants further attention. An online educational summary on stroke was produced for nurses (nursingtimes.net 2007). However, there were key facts missing as there was no references to the FAST test, as promoted prior to this date by The Stroke Association; stroke as a medical emergency; nor the evidence showing the single, most effective treatment for all people with strokes is admission to a stroke unit.

Therefore, further work is still needed to raise both public and professional awareness of stroke. It was estimated that one thousand people could regain independence rather than die or be left disabled from stroke, if more people perceived stroke as a medical emergency (Department of Health 2005).

This section has explored the prevalence and economic burden of stroke. The poor perception of stroke has been debated including the impact of this on the development of services to meet the needs of those affected by stroke. However, this is just one factor that has impacted on service organisation. The next subsection will explore the historical evolution of stroke services in England and also includes the debates within the research.

2.3 The evolution of stroke services

It is relevant to explore the evolution of stroke services for this project in order to understand the impact of the historical context on service development and implementing change. A sixty-five year time span has been chosen to allow an exploration of the topic from 1948, i.e. the year the National Health Service and the World Health Organisation were founded, to 2013. The focus will be on stroke services in England, the country of the research site, but other UK countries and the global perspective will be considered. Persisting challenges will also be explored.

2.3.1 From 1948 to the1960s

In these decades, stroke was still largely referred to as apoplexy; a loss of consciousness with some paralysis most common in elderly people (The Universal Home Doctor Illustrated 1949). It was arguably the perception of the disease as a consequence of old age that hindered the development of rehabilitation services.

The legacy of the Second World War also meant that illnesses, such as stroke, were not a priority. Complex rehabilitation services were established but mainly in response to the needs of wartime military and civilian casualties (Cooksey 1960) thereby focusing on health needs such as amputations, traumatic head injuries and war related mental health problems. The focus of this rehabilitation effort was return to work; the emphasis of treatment was to restore the capacity and the ability of an individual to regain employment (Eagger 1958). Health conditions associated with the older, non-working population, such as stroke, were not going to be top of the political or rehabilitation agenda.

Furthermore, rehabilitation was essentially viewed as a medical problem and not one for multidisciplinary input; it was recommended that rehabilitation efforts should be coordinated and controlled by medics (Eagger 1958). It could be argued that the medicalisation of the complete rehabilitation process was unhelpful as it encouraged the establishment of the hierarchy seen within multidisciplinary teams to this day; a hierarchy which sometimes can prove challenging when trying to implement service development changes. However, the emphasis on medically led rehabilitation was a likely solution to the issue of the day; rehabilitation was poorly coordinated and involved a number of central and local ministries, industrial services, medical and paramedical services (Cooksey 1960). Therefore, placing rehabilitation in the hands of the medics enabled better coordination of the services at that time.

Nonetheless, as the success of the war time rehabilitation services became apparent, a number of other rehabilitation services were also established, including an early functional assessment unit whereby “elderly patients ... particularly with cases of hemiplegia” could benefit from hospital based physiotherapy and occupational therapy assessment (Cooksey 1960 pg. 29). This suggests the beginnings of acute stroke multidisciplinary team work for stroke.

To summarise, in the decades immediately after the Second World War, there was recognition and development of rehabilitation services. Whilst, service development included provision for people with stroke, the emphasis was mainly on war-related conditions and for the working population. As stroke was mainly perceived as an older person’s disease, it was not deemed a priority. There was, however, recognition for the need to coordinate rehabilitation services, including those for the wider population and there began an emphasis for rehabilitation to be coordinated and controlled, albeit by medics. Examples of multidisciplinary team working within acute stroke care were beginning to be discussed.

2.3.2 The 1970s – 1980s

Research evidence continued to be sparse in the 1970's with little information on the best way to manage people with stroke in hospital (Mulley and Arie 1978). The published literature tended to be small studies on the effectiveness of organised stroke care (e.g. Garraway et al. 1980) or continued to be written by interested medics reflecting upon their experiences. Yet, there were developments within rehabilitation services for people with stroke in the 1970's and 1980's, which will be critically explored in this subsection, centring on the organisation of care, the establishment of demonstration centres and different methods of stroke care delivery.

At the beginning of the 1970's, there was still geographical variation in the provision and quality of general rehabilitation (McMillan 1972 pg. 1). The solution was thought to be the development of regional demonstration centres, for rheumatism, arthritis and stroke, which would be deemed examples of best practice in their particular fields (Joseph cited by Anon 1972 pg. 1).

Best practice meant that the demonstration centres needed already to be existing services with established reputations in both clinical work and research, with the hope that other local services nearby would benefit from learning from their expertise (Wilson 1972). Therefore, in practice there were funding implications for these services; a dual remit of health and education meant they cut across two different government ministries.

The development of the demonstration centres was not universally supported. The availability of the qualified manpower to undertake the work was questioned (Gelding 1972); it was felt there was too much emphasis placed on the research component of the centres (Godber 1972); and also concern that Research and Development money could not be expected to underwrite centres with a strong service element

(Ower 1972). Some of the lead politicians of the era remained disinterested in the need for the rehabilitation of “medically unglamorous subjects” (Reeve 1972 pg1) or felt they were not academically viable (Reeve 1972). All these factors impacted on the evolution of stroke services.

Nonetheless, most Regional Health Boards (RHBs) nominated suitable centres to be designated as demonstration centres, although a small number of hospitals chose not to nominate themselves, including the hospital site where this research was subsequently undertaken (Bardgett 1972). By the end of 1978, there were twenty-five demonstration centres in the UK, however, there were different remits for the centres and not all admitted people with strokes. For example, the Royal National Hospital for Rheumatic Diseases only admitted those with Rheumatology problems (Bywater 1981). Therefore, as the regional centres of excellence did not all practice stroke rehabilitation, it was not possible to share best stroke care practice at all geographical locations; comprehensive countrywide rehabilitation services for people with stroke remained elusive.

Work to develop local stroke services also continued but opinion was divided on the best approach to deliver it. The debate centred on two differing viewpoints, i.e. whether it was delivered by a wandering team (Stone 1987) or in a geographically defined space (Garraway et al. 1980). In a single case description of a ‘wandering stroke team’, who would visit general medical wards and teach others, some of the components described remain within stroke care today - care which is delivered in a geographically defined space - including family meetings, goal setting, a stroke specialist MDT and the development of a team approach; yet the argument presented was that the latter could be over-specialised and expensive (Stone 1987). In contrast, research into dedicated acute stroke units showed the patients who were discharged from them were proportionally more independent at the time of discharge to those treated on an acute medical unit (Garraway et al. 1980). However, in a follow up study one year after discharge, the functional benefits were not maintained; but this may be due to the need for improvement in long term community rehabilitation post hospital discharge (Garraway et al. 1980) rather than a comment on the quality of the acute stroke care.

There were many gaps in the evidence base to support the establishment of dedicated acute stroke units including their composition (Garraway 1985). Previous to this, there had been much criticism of the weak evidence base and subsequent establishment of specialist units for coronary care (Garraway 1985). Thus, placed in the context of the time, it is likely there was more caution around the notion of universal adoption of specialist services. However with the benefit of hindsight, by 2005, stroke services were deemed to be a decade behind those for coronary care and waiting for robust evidence was seen as a contributing factor (Department of Health 2005).

The development of stroke units, in the 1970's, was also advocated to facilitate research as well as to enhance patient care. For example, in the final report on a drug trial to their funding body, the Medical Research Council, Matthews (1975) raised the need for a dedicated acute stroke unit in order to manage the logistics associated with researching different drug regimes. But this conclusion did not reach the public domain as the published paper, in relation to the trial, focused on the drug itself (Matthews et al. 1976). The same research team advocated the establishment of acute stroke units for clinical reasons as well as for research (Oxbury et al. 1975), in order to facilitate early intervention for those at risk of developing cerebral oedema.

Therefore, in the 1970's and 1980's, there were unresolved issues within stroke care including the evidence base, or lack thereof; selection of patients; composition of the multidisciplinary team and how to identify those who would benefit most from an acute stroke service. Nonetheless, towards the end of the 1980's, there was recognition of the need for guidance on stroke care, in the absence of robust empirical evidence.

To this end in June 1988, The King's Fund held a consensus conference on the treatment of stroke, focusing on the acute phase and the first six months (Anon 1988). Recommendations included the rapid identification of need; early assessment and implementation of a multiprofessional plan; development of integrated stroke services; education for healthcare professionals; and clear information for patients and carers. There was also consensus agreement on the need to develop research careers for all health care professionals to address the paucity of stroke research.

Yet the recommendations made by the Kings Fund were largely ignored (Lindley et al. 1995), even though subsequently they all appear in the National Clinical Guidelines for Stroke 13 years later (Intercollegiate Stroke Working Party 2008). A study five years after the publication of the Kings Fund recommendations showed acute stroke services were still poorly organised; only five percent of the 2923 consultants responding to the survey indicated they had access to an acute stroke unit and furthermore, 51% were uncertain of the benefits of such a unit (Lindley et al. 1995).

Therefore, to summarise, the 1970’s saw the development of regional demonstration centres which aimed to share best clinical and research practice with local services but not all of the centres provided stroke rehabilitation. Local development of stroke services occurred in parallel and recommendations were made for services to be multidisciplinary and integrated. However, whilst there was recognition of the need to improve local stroke services, by the end of the 1980’s, this had not transferred into practice.

2.3.3 The 1990s: a big decade for stroke in England

The 1990’s was a significant decade for stroke care involving the publication of cornerstone evidence and the establishment of an infrastructure both of which have heavily influenced and guided acute stroke service development to this day.

A meta-analysis of the available evidence in 1993 showed that mortality rates reduced by 28%, if a person was treated on a stroke unit (Langhorne et al. 1993); this paved the way for the formation of the Stroke Unit Trialists Collaboration. The collaboration is part of the Cochrane Collaboration; establishing this infrastructure meant that a database of all randomised controlled trials for stroke unit care could be stored and subjected to further meta-analysis (Sinha and Warburton 2000). This was the beginning of integrated research evidence to support the delivery of coordinated multidisciplinary stroke care.

By 1997, a larger data set was available for meta-analysis by the Stroke Unit Trialists' Collaboration (SUTC 1997). It concluded that survival rates were higher and disability rates were lower, with an increased likelihood of a discharge home, if a person was treated by a coordinated, multidisciplinary team on a geographically defined stroke unit (SUTC 1997). The data and conclusions from this collaboration were significant; robust research was now supporting the development of acute stroke services. The findings continue to be widely cited and are seen as cornerstone in the subsequent developments within stroke care.

In 1998, the Intercollegiate Stroke Working Party (ISWP) was formed, with representation from all health care professionals; people nominated by their own professional colleges who were considered experts in the field of stroke (Royal College of Physicians 2012). Their remit was twofold; first to conduct a National Stroke Sentinel Audit for the organisation and process of care, a tool which it was hoped local providers would use to improve the quality of stroke care; and second to compile evidence based clinical guidelines for stroke - the first edition was published in the same year. With regards the audit, in 1998, 80% of Trusts in England, Wales and Northern Ireland participated and in the last National Sentinel Audit (ISWP 2011) all eligible Trusts took part. It has since been replaced by the Sentinel Stroke National Audit Programme (SSNAP) which also incorporates another audit on stroke care in the first three days of hospital (SINAP: The Stroke Improvement National Audit Programme). Therefore the new SSNAP audit has become the single source of stroke data nationally (Royal College of Physicians 2014).

Also in 1998, the medical profession formally recognised stroke as a medical speciality by founding the British Association of Stroke Physicians (BASP) (Rogers et al. 2003). However, by this time, oncologists (cancer specialists) and cardiologists (heart specialists) were long established specialities within the medical profession, adding further weight for the need to raise the profile of stroke with the medical profession and the potentially negative impact on service development caused by the perception of the disease.

The Stroke Association was also formally established in 1992. The roots of the association can be traced to the 1890's (The National Association for the Prevention of Consumption and other forms of Tuberculosis); it subsequently became known as The Chest, Heart and Stroke Association in 1976. However, 1992 saw the foundation of the first charity with the specific purpose to raise awareness of stroke, fund stroke specific research and support stroke survivors and their families (The Stroke Association 2008).

The research foundations that were put in place in the 1990's came to fruition at the start of the new millennium as a number of key evidence-based policy documents were produced that were supported by the evidence generated from the 1990s.

2.3.4 2000 – 2013

The momentum from the previous decade continued to gather pace in the noughties and in this decade there were a number of policies that shaped the future direction of stroke services both nationally and at a local level.

The National Clinical Guidelines for Stroke have been regularly revised and are now on their 4th edition (ISWP 2012). Separate guidelines have also been published specifically for the diagnosis and initial management of acute stroke (National Institute for Health and Care Excellence: NICE 2008).

The National Stroke Strategy was launched (Department of Health 2007) and outlined a ten point action plan including the need to raise public awareness and the minimum requirements for an acute stroke unit. However, the latter was not evidence based and there remains no consensus opinion on the definition and composition of an acute stroke team within any of the key policy documents. On a positive note with the Stroke Strategy came ring-fenced money to help implement it into practice.

A London stroke strategy was published to complement the national strategy (Healthcare for London 2008) which proposed a major reconfiguration of the services. This included the establishment of Hyper Acute Stroke Units (HASUs) which subsequently discharge patients within 72 hours of their stroke to local acute stroke units. As previously outlined in the introduction, section 1.1, the research site was involved in this service redesign and was subsequently designated as a local acute stroke unit. It is the development of organised stroke care that has been the key to improving the overall outcome for every person who suffers a stroke (WHO 2006b).

So, since the new millennium, it has been established that a person with an acute stroke should be treated within a geographically defined stroke unit with a stroke-skilled multidisciplinary team (Department of Health 2007; Royal College of Physicians 2002; National Institute for Health and Care Excellence 2008), and that organised and coordinated stroke care delivered by a specialist multidisciplinary team has been shown to save lives, lessen disability and improve quality of life. Effective communication is seen as the cornerstone (O'Rouke and Walsh 2010; Stroke Unit Trialists Collaboration 2007). The multidisciplinary team should work together using a shared philosophy and common goals (Royal College of Physicians 2006). A seamless transfer of care has also been identified as one of twelve markers of a quality stroke service within England (Department of Health 2007). And finally, stroke units have been shown to be value for money and cost less per day a stroke survivor is alive than other types of services, although the cost remains high at an estimated £11,450 per inpatient on a stroke unit (Kalra et al. 2005).

Whilst more work is needed, the perception of stroke held by the general public, health care professional and politicians is beginning to rise. Tabloid papers are publishing editorials on the unknown threat of stroke (Scott 2008) and private healthcare companies are marketing their screening services based on the profile of the disease (Life Line Screening 2008). However, challenges persist in the delivery of services, i.e. when looking inside the 'black box of stroke care' (Kilbride et al. 2005) and these will be discussed next.

2.4 Persisting challenges which impact on the evolution of stroke services

This section will explore a number of challenging factors that continue to impact on the evolution of stroke services in England: namely implementing change in the healthcare setting (with particular reference to stroke specific literature where available), delivering efficient and coordinated services, lifestyle choices, defining acute stroke, evolving terminology, and research funding.

Decisions about change within the National Health Service depend on a number of factors including the local culture, the organisational structure and interpersonal factors (Barosi 2006). A multilevel approach is required to build systematic improvements in the quality of stroke services and four levels have been identified for activity to occur: national, regional, institutional and service level (Leatherman et al. 2008).

A National Director for Heart Disease and Stroke was appointed in England and Wales with a remit to embrace change in order to transform stroke services (Department of Health 2006); he advocates change at a local level with national momentum to empower change. This view was also supported by the then Health Minister Lord Darzi in his ten year vision for the NHS (Department of Health 2008). His report 'High Quality for All' advocates change that is locally led, patient centred and clinically driven. However, the question remains about how local change occurs in practice.

When implementing guidelines at a local level, such as the Clinical Guidelines for Stroke (ISWP 2012), it has been argued that interventions fall into five different categories: the use of education materials; decision support systems and reminders; educational meetings; educational visits; and audit (Barosi 2006). However, this list does not recognise the role that research principles can play in identifying the challenges and solutions to implementing clinical guidelines into practice.

The change process itself also needs to be evaluated in order to share examples of best practice. Therefore, a multilevel approach to research is required in order to evaluate and report on the effectiveness of the changes at the different levels. The National Clinical Guidelines for Stroke (ISWP 2012) is an example of an attempt to draw upon different levels of evidence to facilitate improvements in stroke services including expert opinion from patients, carers and clinicians. However, the typology remains hierarchical and favours meta-analytical data or randomised controlled trials.

The cost of stroke care in the UK is as high as in other European countries and is attributed to problems in the organisation and service delivery of the resources

(Markus 2007). However, this is misleading as there is no consideration to the variation in lifestyle choices across Europe. For example, the higher levels of obesity in the UK impact on the rate of cardiovascular disorders (Leatherman et al. 2008).

Yet variations remain in the organisation and level of coordination of services within England. For example, only 20 out of 189 Trusts in the 2006 Sentinel Audit reported that all their patients had documented rehabilitation goals (Royal College of Physicians 2006). Staffing levels vary considerably with only 31% of stroke units employing a clinical psychologist in 2006, with little improvement from previous audit findings (26% in 2002, 28% in 2005).

A further challenge is the lack of a universally agreed definition for the acute element of stroke care. Acute care was defined as 0-7 days (Department of Health 2007a) for funding purposes but the term ‘rehabilitation’ has been replaced by early post-acute care (7-12 days) and later post-acute care (12 days+). In contrast, the National Institute for Health and Care Excellence (NICE 2008) quantify the acute stroke phase as the first 48 hours but acknowledge that some of the interventions in the acute stroke guidelines cover the first fortnight (NICE 2008). The National Clinical Guidelines for Stroke (ISWP 2008) define acute stroke care as primarily the first 48 hours but acknowledge that, for most people, the acute phase may continue for three days. However, the use of number of days post stroke to define the acute phase is arbitrary, given that each stroke presents differently and some people require acute care beyond the first two weeks.

It is not just the time span for acute stroke care that is vague; the definition of what constitutes an acute stroke unit is also unclear. Whilst it is agreed that an acute stroke unit is a discrete area in a hospital that is staffed by a specialist stroke multidisciplinary team with access to equipment and imaging (NICE 2008, Intercollegiate Stroke Working Party 2008), there is no strong evidence and no consensus on what professions are in the team and their roles. For example, in most acute hospitals in England, the lack of social workers means that other professions (including nurses and occupational therapists) are assuming additional tasks traditional to social work (Intercollegiate Stroke Working Party 2008). Further research is required on the components of stroke unit care, some of which remain at the expert opinion level of evidence only (Govan et al. 2008). Future research trials also need to recruit sufficient numbers of older people in order to close the evidence gap for this population (Rudd et al. 2004).

Yet research into stroke care remains grossly underfunded (WHO 2006b) especially in comparison to research funding for other health conditions. The Stroke Association estimate that for every person living with cancer, in the UK, £295 is spent per year on medical research, compared to just £22 per year for every person with a stroke (The Stroke Association 2012). However, as services for acute stroke continue to evolve, there are more opportunities to increase the research effort in acute stroke care (Sinha and Warburton 2000).

Many of these persisting challenges apply to the development of acute stroke services at a national level, i.e. the need for clarity of definitions for all and a call for a national change in practice. There are also persisting challenges at a micro level, i.e. challenges that impact on multidisciplinary team working and these will be evaluated next.

2.5 Multidisciplinary team work within acute stroke care

While the recommendations on the composition of the team and time frame for defining an acute stroke remain unclear, it has been established that effective stroke care depends on a coordinated multidisciplinary team (ISWP 2008). The National Sentinel Audit (ISWP 2008) acknowledged that a coordinated team is essential, yet, its measure of teamwork was the existence of a weekly meeting and this is insufficient as an outcome measure (Baxter and Brumfitt 2007). Furthermore, in the new SSNAP audit, the measures of teamwork include the frequency of formal team meetings; membership of the team and whether or not all stroke patients are discussed in the meetings (RCP 2014a). Therefore the new audit is also of limited detail when gathering data on the effectiveness or existence of a coordinated team.

This section will explore some of the key challenges to effective multidisciplinary acute stroke team working in more detail. In particular, it will focus upon: understanding team roles, the different philosophies held by individual professions, organisational constraints and the need for effective communication.

2.5.1 Understanding team roles

Effective stroke care needs good teamwork where everyone understands their role and has confidence to identify and improve deficit areas including with communication (Power 2008). Yet describing individual professional roles within stroke care is complex in nature (Burton 2000). For example, studies into the role of the nurse within the multidisciplinary team have identified a range of roles including care manager, facilitator of personal recovery (therapy carry-on) and the nurse as care giver (Burton 2000, Long et al. 2002). The descriptions of the roles tend to be broad and this could present a challenge when communicating the unique contribution of the nurse to the multidisciplinary stroke team. Indeed, it is acknowledged that nurses and therapists need to recognise, value and feel more confident in understanding and communicating their roles within stroke rehabilitation in order to facilitate effective team work (Long et al. 2002, Tempest and McIntyre 2006).

2.5.2 Different philosophies

Another challenge is the different, and often conflicting, theoretical models and philosophies that underpin different professions. The medical model focuses on the disease diagnosis and aetiology; nursing traditionally focuses on the ‘doing for’ rather than a rehabilitative approach of facilitating independence and standing back (Long et al. 2002). In addition, nurses view themselves as advocates for their patients and align this responsibility to the social model (Burton 2000); this philosophy is placed under pressure when working within an acute stroke unit where the medical model may prevail.

In contrast, allied health professions (AHPs) work within a rehabilitation model where the focus is on facilitating independence. Yet, differences exist between AHP groups, for example, occupational therapy takes a whole-person approach, enabling individuals to achieve their full potential (College of Occupational Therapists 2014), whereas dietetics is more reductionist in its world view, with a focus on the interpretation and communication of the science of nutrition, to enable people to make informed choices specifically about food (British Dietetics Association 2014).

2.5.3 Organisational constraints

Teamwork is also affected by the organisational conditions including working patterns, rotational staff and the structures that are in place, however, effective teamwork is a more complex process (Baxter and Brumfitt 2007). An in-depth single case study (Kilbride et al. 2005) identified four inter-related factors that led to the success of implementing a stroke team; building a team; developing practice-based knowledge and skills in stroke: valuing the central role of the nurse in stroke care; and creating an organisational climate for change. Whilst limited to a single site, this study provides a rare glimpse inside the black box of stroke care to identify the components that contribute to successful team working.

2.5.4 Effective communication

Effective communication is essential in acute stroke care in order to make informed decisions about care (NICE 2008), yet the language routinely used in practice can cause great confusion (Dean and Ballinger 2012). One factor that is recognised as impeding effective multidisciplinary stroke communication is the lack of widely accepted terminology. Yet, the multidisciplinary team need to be able to understand each other especially as uniprofessional jargon can have a negative impact. A survey of people with stroke revealed that 30% of them did not understand *everything* the doctor told them (and, similarly, 31% of them did not understand *everything* told to them by the nursing staff), with an additional 7% reporting they could not understand *anything* that was said by the doctors (Healthcare Commission 2005). Therefore there is a need to review the way the members of the team communicate with each other and with patients, families and carers in order to make informed decisions about patient care.

Effective communication is also essential across teams as well as within them. In the largest review of the NHS since it was established, Lord Darzi called for joined up services to bring health and social care staff into one integrated care organisation (Daloni 2008). Common, agreed upon terminology is a key component to facilitate integrated care (ISWP 2008).

To this end the International Classification of Functioning, Disability and Health (ICF) has been recommended to aid team communication (ISWP 2004). However, the level of evidence is expert opinion only in the absence of any empirical studies. Furthermore, in the second edition of the clinical guidelines (ISWP 2004), the use of the ICF was a specific clinical recommendation but subsequent editions have absorbed the language into the guideline, as if to make the assumption that its use is now prevalent. The introduction section to the fourth edition (ISWP 2012, pg. 8) identifies the use of the ICF, as an underlying model for the guideline development, but it remains to be seen if the removal of it from the actual recommendations negatively impacts on the uptake of the framework and classification in clinical practice. The next section will explore the ICF and the current evidence for its use in clinical practice.

2.6 The International Classification of Functioning, Disability and Health (ICF)

This section will explore the background to the ICF (and its predecessor the International Classification of Impairments, Disability and Handicaps: ICIDH) and the World Health Organisation (WHO), as the developing body of the ICF. It is important to evaluate the historical developments and background of the organisation and the ICF framework and classification, as the reputation of both may impact on the related change process. Finally this section will critically examine the current evidence for the use of the ICF in clinical practice.

2.6.1 Background to the World Health Organisation and the developments of the ICF

The World Health Organisation (WHO) was established in 1948, the same year the National Health Service was founded in the UK, with a main objective to attain the highest possible level of health for all people, as a fundamental human right (WHO 1947). However, the organisation was founded in response to the new problems arising from the Second World War (WHO 1947); therefore diseases such as stroke were not seen as priorities. This mirrors post-war healthcare service development in the UK when rehabilitation priorities focused on war-related injuries and conditions (Cooksey 1960).

The World Health Organisation has made many significant contributions over the last 60 years including the development of a global policy for health development (Asvall 2006). However, it has also been heavily criticised for being excessively bureaucratic (Tollison and Wagner 1993); for not being sufficiently diverse in staff recruitment (Scruton 2000) and for becoming overly political, e.g. at the time the ICF was endorsed , the WHO Director General was the former Prime Minister of Norway, who brought with her former cabinet members into the organisation. Finally, the WHO has been criticised for proposing legislative measures when, as an unelected body, it does not have a democratic mandate to so do (Scruton 2000).

Some of the criticisms about the lack of diversity within the broader WHO can also be levied at the WHO Collaborating Centres for the family of classifications (WHO-FIC), the remit of which is to develop and implement the classifications including the ICF. For example, in 2005, eight out of the thirteen WHO-FIC collaborating centres were based in developed countries with a western bias (WHO-FIC 2008). However, recent additions to the network include India and Mexico, with further nominated candidates from Korea, Kuwait, South Africa and Thailand (WHO 2014a), so this criticism is being addressed. Furthermore, the initial revision process from the ICIDH to the ICF claimed a wider global audience with representation from Africa, India, the Middle East, South America and Asia and nongovernmental organisations, including representation from the Disabled Rights Movement (WHO 2001). Therefore, it could be argued that the ICF can claim inclusivity and diversity in its development process.

2.6.2 Introducing the ICF

The ICF is an attempt to integrate opposing models of disability and thus uses a biopsychosocial approach. (WHO 2001: 20) It is a framework (see Figure 2) and detailed classification system. This section will explore the historical developments leading to the endorsement of the ICF as well as the purpose and evidence to support its use in clinical practice.

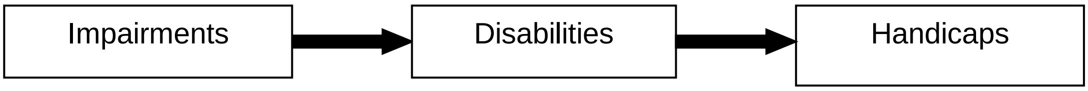
2.6.2.1 Historical developments

Prior to the 1970’s the WHO focused primarily on a model of health and disease that was akin to the medical model, i.e. concerned with body systems and aetiology; this included the formulation of the International Classification of Diseases (ICD) which was a code to classify specific illnesses (Hurst 2000). As previously mentioned, in section 2.2, the development of version eleven of the ICD is underway; but now it is part of a broader WHO family of classifications (WHO 2014b).

As a result of the ICD, rehabilitation professionals began to classify the outcome of disease but lacked a framework to support their findings. Therefore in 1973, Wood, Bury and Badley were commissioned by the WHO to develop an international tool to enable the classification of the *consequences* of disease (Bury 2003). The result was the International Classification of Impairments, Disability and Handicap (ICIDH) endorsed by the WHO in 1980, which included a framework (see Figure 1) and a classification system. However, whilst it was endorsed by the WHO, it was never officially approved by the World Health Assembly, unlike its successor, the ICF (Cieza and Stucki 2008), although the difference between endorsement and approval has not been clarified.

The ICIDH was seen as a positive step forward as it made the link between the effect of impairments at an activity and societal level and did not purely focus on the disease component (Bury 2003).

Figure 1: The International Classification of Impairments, Disabilities and Handicaps (WHO 1980)

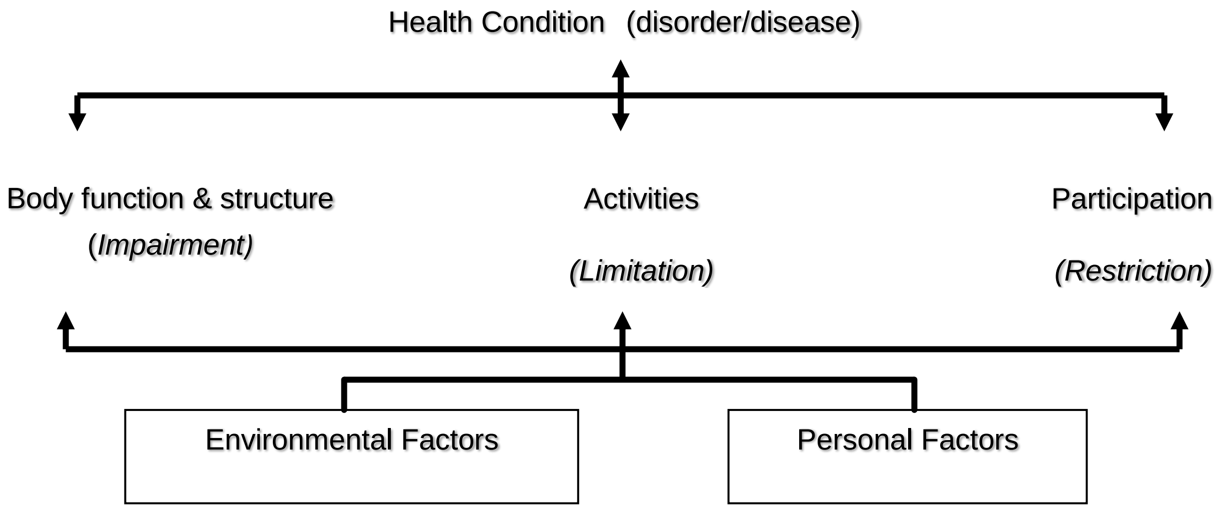


However, the ICIDH caused much debate and controversy, leading some disability theorists to call for it to be abolished, as it remained entrenched in the medical model by implying a causal relationship between impairments, disabilities and handicaps (Hurst 2000). Disability rights movements argued from the social model perspective, i.e. that disability was not a consequence of disease but was caused by the way society was organised, which prevented disabled people contributing to society. In addition, the negative terminology used within the framework perpetuated negative views of disabled people (Pfeiffer 2000).

The criticisms levied at the ICIDH have been disputed, albeit by one of the original authors, who argued that it made a positive difference by enabling health care professionals to consider and communicate the impact of disease, thus identifying priorities for people with ill health (Bury 2003). Ultimately, the same ICIDH author felt that the framework and classification were sunk by ideologically motivated criticisms of the semantics and language used within the framework (Bury 2003).

Therefore in the mid 1990's discussions began on how to revise the ICIDH and the debate commenced on the ICIDH-2. Subsequently, the ICIDH-2 was renamed the International Classification of Functioning, Disability and Health (ICF) to promote the use of the word 'functioning' (Bornman 2004). Whereas the purpose of the original ICIDH was to produce statistics on the consequence of disease, there was a fundamental shift in purpose for the revised framework. The overall aim of the ICF was to provide a unified, standard language and framework for the description of health and health related states (WHO 2001). Therefore the focus of the ICF is health (not illness) and it enables the articulation of the complex interactions between components in the framework, i.e. not a causal relationship between illness and function. Figure 2 illustrates the framework of the ICF.

Figure 2: The framework of the International Classification of Functioning, Disability and Health (ICF: WHO 2001)



The use of neutral language and an interrelationship between components in the ICF now encourages all healthcare professionals to acknowledge the impact of contextual factors (environmental and personal factors) on an individuals' functioning. It has moved away from the notion of disability as a consequence of disease. However, caution is given that in the quest for neutral language there is a real risk that the understanding of disablement may be lost (Bury 2003).

There is a detailed classification for body functions and structures, activities and participation and environmental factors, totalling 1424 items. For example, self-care (a construct within the activities component) is just one of nine constructs, including mobility, communication and domestic life. Within self-care, there are nine domains including toileting, dressing and eating. Some of these are classified in further detail, for example, dressing has separate categories for putting on clothes, taking off footwear and choosing appropriate clothes. However, a major challenge persists as the personal factors component remains unclassified. When assessing functional abilities, it is often issues of personal choice that determine performance; this currently cannot be demonstrated using the ICF and, therefore, there is an opportunity lost when describing the complex interplay of components on functional performance (McLaughlin Gray 2001). The ICF requires further adaptation to demonstrate the importance of the patient's perspective otherwise there is a risk that it will remain an impersonal and externally driven framework (Wade 2003). It has been acknowledged that the ICF will undergo updates (Cieza and Stucki 2008). It must be appreciated that it is in an infant stage, so there is an expectation that it will undergo further development and revision (Taylor and Geyh 2012).

It is not just in healthcare that the use of the ICF is advocated (Stucki and Cieza 2008); it has a role as a statistical tool for population studies, an outcome measurement research tool, a clinical tool throughout the rehabilitation process, a tool to aid curriculum design in education and for use in social policy (Cieza and Stucki 2008). Indeed, the ICF is used by a number of agencies including the United Nations social classifications and the International Labour Organisation (Cieza and Stucki 2008). The next section will explore the use and developments of the ICF specifically in healthcare with additional attention to stroke care.

2.6.2.2 The use and developments of the ICF in healthcare

Some commentators believe the approval of the framework and classification marks an exciting step in healthcare rehabilitation, as the ICF has the potential to be used within multidisciplinary team (MDT) assessment, goal planning, intervention and evaluation (Stucki et al. 2002). There is now an internationally agreed terminology, classification and framework that can be used within the MDT and also across agencies, to enhance communication.

However, given the level of detail in its original format (1424 categories), the ICF is impractical to use in clinical practice. Therefore the ICF Research branch was established in 2003, which signalled the start of the core sets project the aims of which are: 1) to produce minimal standards required for disease and site specific groups (Stucki and Grimby 2004); 2) to develop systematically practical sets of ICF categories for clinical practice (Stucki et al. 2008).

The ICF core sets development process involves a preparatory phase (including literature review and qualitative survey); followed by phase one which, using consensus conferences, cumulates in a draft core set which is subsequently tested and validated in phase two (ICF Research Branch 2014). The first draft of the core sets for stroke was developed by 39 experts at one consensus conference. However, 25 of the group were physicians and there were no representatives from the disability movements or stroke survivors. This has been acknowledged and extensive field-testing was undertaken including patient-led focus groups to gather wider opinions (Geyh et al. 2004). Nonetheless, the core sets project is a return to classification according to disease, which the original formulation of the ICF was so keen to avoid (McIntyre and Tempest 2007). A practical challenge remains as, given the wide ranging impact of the health condition, the comprehensive core set for stroke includes, an arguably impractical, 130 items. However, a brief core set for stroke, comprising 18 items, has also been developed by the ICF Research Branch (Geyh et al. 2004) although, given its brevity, it could be argued it is no longer holistic.

2.6.2.3 Emerging evidence for the process and outcome of implementing the ICF into clinical practice

The ICF (WHO 2001) has become a globally accepted framework to describe functioning from an integrative biopsychosocial perspective, for example, in rehabilitation (Jelsma 2009). It has been endorsed for use by multidisciplinary teams to aid communication within stroke care (ISWP 2004; ISWP 2012), to inform thinking in interprofessional rehabilitation (Dean and Ballinger 2012) and also by individual health care professions, e.g. occupational therapy (College of Occupational Therapists 2004). The use of the ICF could enhance communication both within the team as well as during the transfer of care. Yet, clinicians still need to be convinced of the worth of investing time and finances into adopting it into practice (Farrell et al. 2007). Furthermore, in order to implement it into practice, attention must be paid to the development of policy and service provision (Stucki et al. 2008) and creating appropriate ICF tools for clinical practice (Rauch et al. 2008). There is debate about the form of ICF tools. While electronic records are viewed by some to reduce the amount of time spent on documentation (Rauch et al. 2008), logistical challenges persist with introducing electronic records within the National Health Service in England.

The success of the ICF depends on its uptake in clinical practice (Geyh et al. 2004). A procedural manual and guide for standardised application of the ICF has been developed to assist practitioners (WHO 2013), but this process has identified problematic areas within the ICF; in particular, the overlap of some of the codes and qualifiers as well as difficulties distinguishing between activities and participation (Reed et al. 2005). It could be suggested that one standardised application for the first edition of the ICF may be too challenging.

Returning to the literature review in 2009, it concluded that the ICF was a globally accepted framework (Jelsma 2009), yet the focus of the majority of the articles in the review focused on explaining the conceptual framework or applying it to the management of data collection, rather than on any outcomes of using it in clinical practice with healthcare professions and multidisciplinary teams. In 2011, a systematic review also concluded the majority of the 670 ICF papers examined were conceptual in nature (Cerniauskaite et al. 2011). Nonetheless, 173 papers focused on using it in clinical practice, albeit mainly anecdotal reflections, or applying it in theory. The main conclusions from the clinically focused papers were that the ICF has the potential to improve team communication (Rentsch et al. 2003; Steiner et al. 2002); enhance inter-agency communication (Martinuzzi et al. 2008; Darzins et al. 2006); help clinicians construct a broader view of disability (O'Donovan et al. 2009; Rimmer 2006; Raggi et al. 2010) and clarify team roles (Tempest and McIntyre 2006; Mitchell 2008).

Empirical evidence regarding the process and outcome of implementing the ICF in practice is scarce (Verhoef et al. 2008). Explicit use of change management theory has been suggested (Appleby and Tempest 2006) and training programmes have been established, which are considered an effective way to teach health and social care professionals about the ICF (Francescutti et al. 2009; Bjorck-Akesson et al. 2010). The latter involves working with an external facilitator with expertise in the ICF. One study concluded that on completion of the training, health care professionals framed their understanding of interventions differently, with a greater focus on activities and the environment (Bjorck-Akesson et al. 2010). However, the challenge of understanding the benefits of training is that it remains unclear if the process of training, i.e. the greater emphasis on activities and the environment, subsequently transferred into the clinical setting (Francescutti et al. 2009). Moreover, the studies on the effectiveness of training programmes focus on measuring the "before" and "after" effects, so they provide no insight or guidance for other clinicians wanting to learn about the process of transferring the ICF, as a conceptual framework and classification, into clinical practice, or if indeed this has been achieved. Therefore, research is needed to analyse the implementation process.

There is also scarce empirical evidence on the outcome of implementing the ICF into clinical practice. However, a study of two multidisciplinary teams in rheumatology (Verhoef et al. 2008) concluded that health care professionals held mixed opinions on the benefit of the implementation of the ICF. While staff satisfaction with team conferences increased in a day-patient setting, this effect was absent with staff in an inpatient setting. This study offers an insight into staff perceptions on the use of the ICF in clinical practice, but as the data was quantitative in nature, it is not known why staff held these opinions. Furthermore, the opinions from patients, carers and those beyond the multidisciplinary teams were not sought and these could have enhanced a fuller understanding of the outcomes. The research team concluded that the outcome of introducing ICF-based tools should be studied at the level of individual teams, to gain a greater understanding of the effects of using it in practice (Verhoef et al. 2008).

A number of challenges to adopting the ICF into clinical practice have been postulated in recent literature. These reflections describe a need for teamwork, a culture change and managerial support (Reed et al. 2009), as well as a practical requirement to adapt existing artefacts, e.g. assessment documentation (Bjorck-Akesson et al. 2010). There are potential problems with the ICF language itself, for example, the negative connotations of the word ‘functioning’ when translated into German (Schuntermann 2005) and difficulties in understanding the ICF terminology for patients with low levels of education or concrete cognitive styles (Maini et al. 2008). In addition, it has been suggested that clinicians lack in-depth knowledge and experience in using the framework (Farrell et al. 2007; Heinen et al. 2005). These insights offer a hint as to some of the implementation challenges but do not systematically research the learning involved in, or help to inform, the implementation process.

Therefore, despite the general endorsement and acknowledgement of the potential use of the ICF in clinical practice (Cerniauskaite et al. 2011) there has been no systematic attempt to explain or evaluate the means by which it can be implemented. There has been only one paper (Verhoef et al. 2008), using quantitative data to measure the outcome of so doing, which sought to assess staff satisfaction with the ICF, however this was in the field of rheumatology and not stroke services.

2.7 Chapter summary

This chapter undertook an historical exploration of the key topics within the research environment. It has determined that the profile and reputation of stroke as a health condition has changed from being a passive one, where stroke was a consequence of old age, to viewing it as the medical emergency it is now known to be. However, further work is needed to promote and sustain this notion of stroke.

The provision of stroke services was, in part, negatively affected by the perception of the disease and has only recently been recognised as a medical specialism similar to that of coronary care. Post war England saw a rehabilitation focus on the consequences from war. This, coupled with an emphasis on rehabilitation to aid return to work, meant that stroke was not seen as a priority. Furthermore, a debate continued until the early 1990’s regarding the most effective way to deliver stroke care as it was questioned if there was a need for specialist services in a geographically defined space.

But by the end of the 1990's significant developments, in the way stroke research and data were organised, led to an evidence base that confirmed the need for coordinated and specialist multidisciplinary, although the composition of the teams and understanding the components that make them effective still remain unclear.

An historical evaluation of the WHO and the developments which led to the endorsement of ICF highlighted some concerns that the organisation itself was too political and overly bureaucratic. The previous classification and framework, the ICIDH, received heavy criticism for focusing on disability as the consequence of disease. In contrast, the ICF uses neutral terminology and portrays the biopsychosocial nature of health and health related states. The inclusivity in which it attempted its conception has partly contributed to it being widely accepted in various fields including social policy, data collection and healthcare.

The evidence on how to implement the ICF into healthcare, and the outcome of so doing, remains largely at an anecdotal level. In relation to stroke care, the National Clinical Guidelines for Stroke (ISWP 2004) was the first edition to recommend explicitly the use of the ICF to aid communication within the multidisciplinary stroke team. Therefore, the next chapter will review the literature to explore critically and understand the challenges to communication in healthcare teams which may have warranted the call for the use of the ICF, as an alternative to existing methods.

Chapter 3. Literature Review: Challenges to communication in healthcare teams

3.1 Background

Of the 2034 medical errors recorded in America's acute cardiovascular hospital services, during 2002-2005, communication breakdown was identified as the root cause of more than 60% of cases, of which 75% resulted in a patient's death (Woods 2006). There are also specific types of health care where communication is vital; for example, poor communication has been cited as a contributing factor to stillbirth and infant deaths (Rowe et al. 2001). Therefore, effective communication is essential in relation to patient care (Fernandez et al. 2010). It is one of the cornerstone components of team working (ISWP 2012).

Yet effective communication is hindered by a number of factors including: the stressful healthcare environment; the autonomous culture; health care professions working in isolation rather than as a team; hierarchical environments which impact on the willingness of staff to speak up; confusion over which member of the team is responsible for what; practical issues including illegible handwriting and traditional gender and power barriers, mainly between nurses and doctors (Friesen et al. 2007, Fernandez et al. 2010).

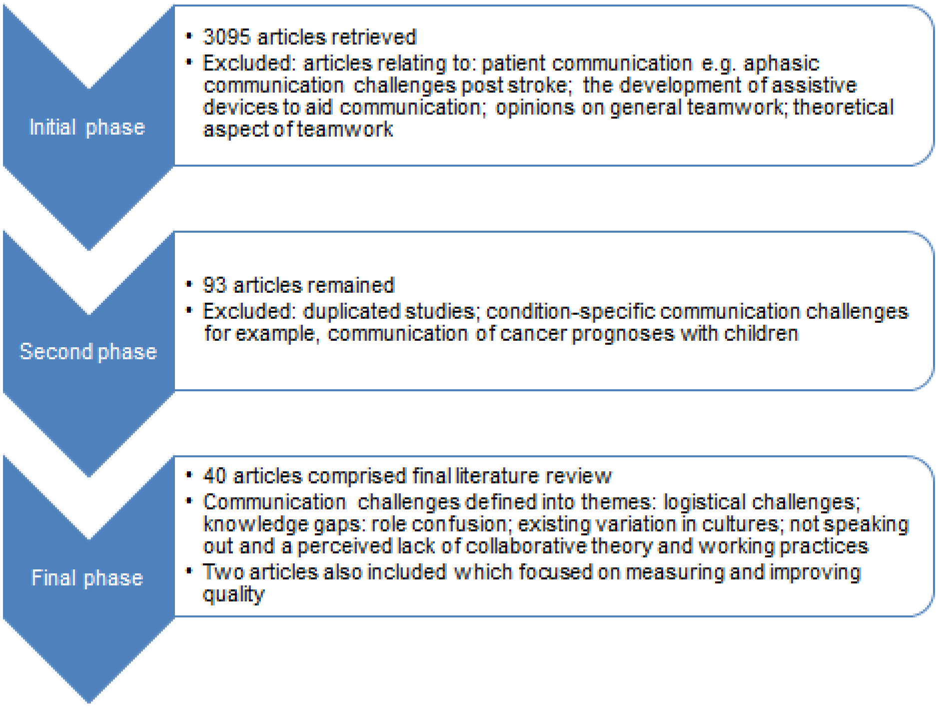
Communication is only one component of teamwork; it requires cooperation, coordination, mutual respect, leadership and shared responsibility (Derry et al. 2005). While acknowledging the entwined relationship of these components, this literature review will critically and specifically explore the challenges to effective communication within healthcare teams. The findings will be useful in order to understand the context which warrants the ISWP (2012) recommendation to adopt the ICF (WHO 2001), as a new theoretical framework, to aid multidisciplinary team communication in stroke care.

3.2 Search strategies

A literature search was undertaken using the following keywords: team, communication, challenges and health. Truncated terms *team, health* and communic* assisted in locating articles. The following databases were searched:

AMED, Cinahl Plus, Medline, PubMed Central and Scopus. Limits were imposed within the search to ensure articles were written in the English language and published between 2001 (when the ICF was first endorsed by the World Health Organisation) and 2013. Hand searching of reference lists and the following pertinent journals was also undertaken: Journal of Interprofessional Care; Journal of Multidisciplinary Healthcare; Journal of Qualitative Research; Journal of Healthcare Management; and the Health Service Journal. The outcome of the search strategy is outlined in Table 3.

Table 3: Outcome of the literature search strategy



Initial phase

- 3095 articles retrieved
- Excluded: articles relating to: patient communication e.g. aphasic communication challenges post stroke; the development of assistive devices to aid communication; opinions on general teamwork; theoretical aspect of teamwork

Second phase

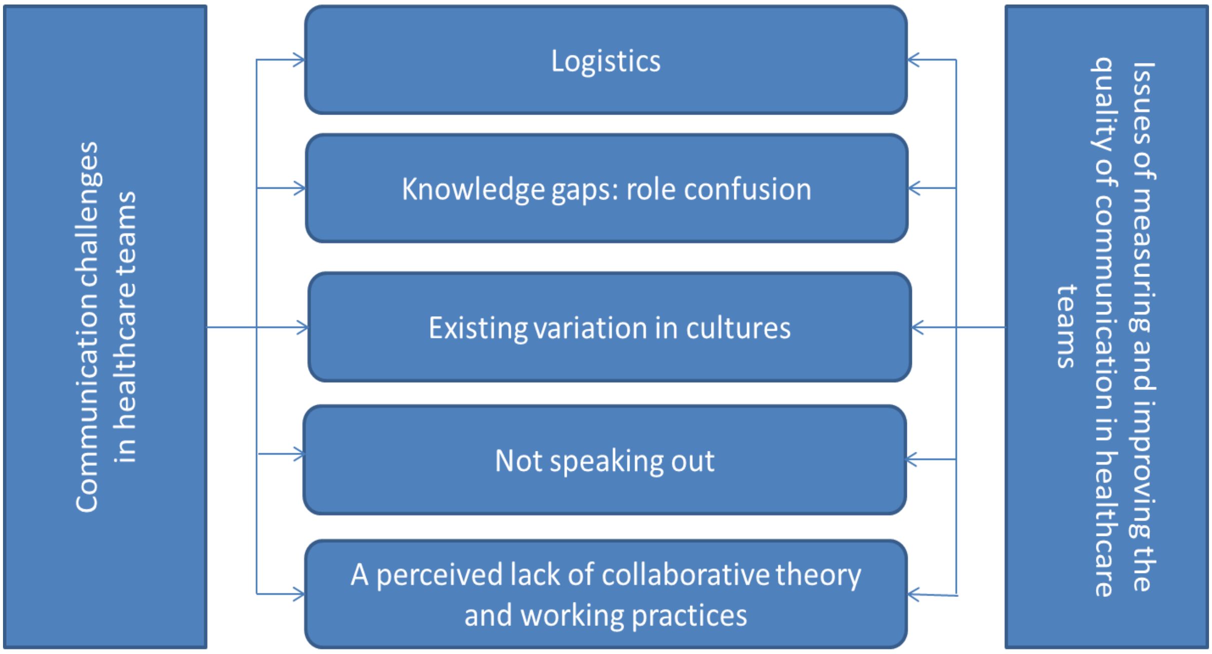
- 93 articles remained
- Excluded: duplicated studies; condition-specific communication challenges for example, communication of cancer prognoses with children

Final phase

- 40 articles comprised final literature review
- Communication challenges defined into themes: logistical challenges; knowledge gaps: role confusion; existing variation in cultures; not speaking out and a perceived lack of collaborative theory and working practices
- Two articles also included which focused on measuring and improving quality

The five defined themes for the literature review are presented as separate sub-themes, to aid reading of this complex topic, but their interdependent relationship has been explored (see Figure 3) and a number of papers are present in two or more sub-themes. Within the 40 articles there were two papers which did not fall neatly into one of the five themes. Yet their inclusion is justified because they focus on the issues of measuring and improving the quality of communication in health care teams outlined. A list of the reviewed articles as a research outcome from the literature search is provided in Appendix 2.

Figure 3: A conceptual framework of the inter-related factors impacting on communication within healthcare teams



3.3 Logistical challenges to communication in healthcare teams

Eight papers considered the following logistical challenges which will be explored in this subsection: the volume of communication events; the fast pace of medical events, illegible handwriting, lost information, staff turnover, part-time staff, inadequate technology including hospital email systems and electronic records, and finding communicative space.

In a small action research study with one primary care team in England, Arksey et al. (2007) found a range of reasons for communication challenges within the team including the number of part time workers, inadequate supporting technology (i.e. email systems) and gaps in knowledge about the full extent of individual roles within the MDT. The latter suggests therefore that communication challenges are also knowledge based rather than purely due to the organisation of the team. The participants (n=16 of the 24 available staff members) comprised doctors, nurses, counsellors and administrative staff who consented to one-to-one interviews. On identification of the problems, participants sought to make changes in their work routines including a review of working arrangements, a technology upgrade and an increase in out of hours socialising. However, the study does not report whether these changes occurred or the benefits of so doing. Arksey et al. (2007) also report an increased level of anxiety by participants about making such findings public, which may have been alleviated through the use of focus groups rather than one-to-one interviews; the latter reportedly left participants feeling anxious and vulnerable. Nonetheless, from the details that participants were prepared to share for publication, a number of logistical challenges were identified which have the potential to impact on effective communication.

Another logistical challenge is the volume of communication and the frequent interruptions faced by nurses in accident and emergency departments (A&E). A study by Woloshynowych et al. (2007) concluded that the nurse-in-charge dealt with, on average, 100 'communication events' per hour, 41% of which were synchronous, i.e. an interruption of an existing communication event or an example of multi-tasking, e.g. writing on the whiteboard while talking on the telephone. This led to the conclusion that effective communication could be under threat given the high number of interruptions experienced.

In contrast, a multidisciplinary team in an Australian neuro-oncology ward were able to find communicative space by setting up a weekly MDT meeting and, on evaluating the outcome of this with a survey, it was found that all respondents (n=16; response rate 100%) felt the main benefit of the meeting was the improvement in team communication and documentation (Field et al. 2010). Therefore this suggests that it is possible to overcome the challenges caused by a lack of communicative space by meeting as a team to discuss, plan and document. But whether this, in turn, could imply that the nurse-in-charge would be interrupted less often is questionable. Furthermore, the lack of transparency in this study renders these findings debatable. For example, Field et al. (2010) cite a 100% response rate from the clinicians who attend the team meeting, yet they did not invite all the clinicians who actually attended it: therapists, nurses and social workers were not invited to participate. While this is acknowledged as a limitation, there is no explanation as to why they were excluded. Therefore, it remains unclear whether or not the whole team did benefit from the newly created 'communicative space'.

Communication failures can occur at every step of the patient journey (Redfern et al. 2009). In an analysis of admissions to a London acute hospital via A&E, using the Failure Mode Effects Analysis (FMEA) technique, Redfern et al. (2009) concluded there were 21 communication steps involved from a patient presenting at A&E to their subsequent admission; identifying that all steps had at least one communication failure (with a maximum of 7 failures per step). For example, long-winded and unclear nursing entries caused delay in finding the salient information required for handover to the medical team. Therefore, the example cited also shows that, while the challenges can be due to logistics, there may also be problems caused by what is actually written as well.

It could be argued that these findings are unique to A&E, as it is the only part of the hospital without true boundaries, i.e. no limits to the number of admissions. And specific targets, such as the four hour maximum time limit for a patient to be in A&E, give rise to unique communication challenges. However, lost information and time wasting were the common themes that emerged as communication challenges (Redfern et al. 2009); these are not unique to A&E as they can occur across the whole pathway, e.g. the surgical pathway (Nagpal 2012).

But, there were a number of methodological flaws with the study by Redfern et al. (2009) which could undermine the conclusions. Firstly, the researchers assigned the FMEA scores taken from interview data, but it is not clear if these scores were validated or confirmed by the participating clinicians. Secondly, there was no transparency in the process undertaken by the researchers to define the emerging themes and, while the participants were from different backgrounds including doctors, nurses, receptionists and porters there was no representation from any therapists or social workers. Nonetheless, the conclusion that communication challenges existed at every point in the pathway and the recommendation to establish formal team processes to limit the risks, are findings that are supported elsewhere in the health service literature (Nagpal et al. 2012; Potheir et al. 2005; Manias et al. 2005). For example, in an analysis of ‘information flow vulnerabilities’ across eight medical-surgical units, Keenan et al. (2013) recommended that to minimise the risk of serious and undetectable errors throughout the patient journey, healthcare teams needed to: 1) standardise the wording and format of their documentation; and 2) test the use of electronic records to help the disconnected interdisciplinary team in communicating and understanding patient's needs. These issues will be explored further in the next subsection in relation to collaborative practice when considering knowledge gaps and role confusion.

Most of the literature on communication challenges within healthcare teams focuses on communication between, or within, the medical and nursing professions, predominantly in the hyper-acute (A&E; operating theatres) or acute hospital phases. However, Suddick and DeSouza (2007) conducted a small exploratory study interviewing occupational therapists (n=5) and physiotherapists (n=5), working in neurology across the acute and rehabilitation phases, in a broader analysis of positive and negative factors (termed 'critical happenings') impacting upon neurological teamwork. Communication factors comprised the largest proportion of events and four logistical sub-themes were identified which could challenge effective communication and therefore impact on teamwork: 1) whether effective communication occurred; 2) the timing and frequency; 3) who was involved; and 4) the type or format, e.g. meetings or referrals to other hospitals.

Yet, while these factors appear to focus on the logistical challenges surrounding communication, rather than the inter and intra personal factors, on closer examination, participants in this study also identified the need for team members to be open, supportive, willing to explore role overlap and understand roles. But these factors were defined as 'team events and team characteristics' rather than relating to communication per se. This highlights the complexity of teamwork and the significant overlap between factors that occur within this process; a point also acknowledged by the authors.

In an editorial, Gibson et al. (2010) outline the challenges with verbal communication in emergency care in two different situations. Firstly, during the handover phase from one shift to another, the comparison is drawn with fixing an engine that is still running. Communication is challenging given the fast pace at which medical events unfold in the emergency ward setting, the information is already old before it is told. Secondly, there are different challenges when communicating between settings, in this case emergency to acute wards, potentially caused by different expectations and needs in relation to what is being communicated. It is concluded that clinicians intuitively know the feel of a ‘good’ or ‘bad’ verbal handover but more research is needed to better understand the variations of communication, the associated outcomes using different approaches in relation to patient care and to design tools and procedures to enhance effective communication (Gibson et al. 2010). There are parallels that can be drawn from these findings with acute stroke care which also requires effective communication between team members from one shift to the next and when transferring patient care from the hospital into the community.

This section has focused on a number of logistical challenges including the volume of communication events, the fast pace of healthcare work, staffing issues and finding space to communicate. Yet, in so doing, it has also alluded to the need for healthcare professionals to be more willing to explore role overlap, have a greater understanding of roles and know what and how to communicate. This suggests there are knowledge gaps which also impact on communication and these will be critically explored next.

3.4 Knowledge gaps: Role confusion

This section will explore role confusion within and between teams and link this to clinical reasoning processes. Four papers were identified under this theme for critical exploration.

A study by Sada et al. (2011) identified a need to actively coordinate and communicate the clear delineation of roles in the cancer care journey. Interviewing ten patients with cancer, six primary care physicians and eight oncologists in one North American state, there was uncertainty about specific roles including who took the lead on support for psychological distress and behaviour modification. This suggests a lack of communication regarding role boundaries between the primary care physicians and the oncologists. A second practical challenge to communication was also identified between the medical participants; electronic health records facilitated communication between hospital staff but not in the transition of care between hospital and the community. The study was limited by the small sample size and the gender bias, as all the participants were male. But two conclusions were generated from this study regarding the need to communicate roles clearly and the logistical challenges posed by electronic health records in the transition of care.

Role confusion exists within teams as well as between groups of healthcare workers. In a study based in the acute hospital setting, using discharge planning as the focus from which to explore perceptions, Atwal et al. (2002) concluded that role confusion and competing priorities often challenged effective communication between occupational therapists, nurses and care managers. Furthermore, communication was also hampered by the physical location of different professions and the personalities of individual team members. While limited to views from one hospital site and just three professions within the multidisciplinary team, this study highlights that role confusion can be an underlying factor that challenges effective communication with members of the same team.

This was further supported by Widmark et al. (2012) who undertook an action research project with one multidisciplinary team in an oncology radiotherapy unit in Sweden. Five focus groups (n = 34) were undertaken in the initial project phase to identify the current perceptions of team communication. A number of communication challenges were identified by the participants including: blurred role boundaries; disrespect between different professional groups (doctors, nurses, engineers and physicists) and inadequate systems for transferring information. The authors concluded that nursing staff were becoming disenfranchised within the hospital which manifested itself in their passive resistance to change.

While action research projects do not lay claim to generalisability (Meyer 2006), there were also a number of design flaws which limits the conclusions drawn from the study by Widmark et al. (2012). It was concluded that role conflict and the communication associated with it was only encountered between the nurses and the physicists but not between any other professions. Yet, the nursing professionals were the only participants to be in a uni-professional focus group so may have felt greater freedom to express opinions. In contrast, the doctors, engineers and physicists were all in the same focus group. Two facilitators led the different focus groups but one was a novice, while the other was an experienced cancer researcher. The details of any training and support for the first facilitator were not presented.

Without such input, the novice researcher may have not been as skilful, as the experienced researcher, in eliciting the depth of information in a focus group situation which, in turn, could compromise the quality of the data gathered. Furthermore, the topic guide was adjusted following each focus group but there was no critical exploration of potential limitations caused by the alterations. Finally, the project was partly initiated by a need to explore communication challenges following a politically-initiated merger of two university hospitals. Extracts of the primary data hint at the different practices between the two hospital sites but the authors do not detail what prompted the politicians to merge them. If one was a failing hospital and the other required to merge with it, inherent in this process are many confounding and specific factors that could impact on communication.

When exploring the literature to identify knowledge gaps, it has been concluded that there is confusion about who does what within a team, who does what between teams and what actually needs to be communicated. One final challenge has been postulated by Seedhouse (2009) who suggested that the same communication challenges would be found if researchers studied intra-professional communication as much as inter-professional communication. In conclusion, Seedhouse (2009) suggested the way to address team communication difficulties, and the knowledge gaps that contribute to them, is by being transparent in the different reasoning processes that guide healthcare professionals to make their clinical decisions. But this may prove a challenging task, in part, due to the persisting cultures which operate within health care teams which will now be critically explored.

3.5 Existing variation in cultures

The literature in this section, comprising 18 articles, highlights a number of factors which can be defined as existing cultures that challenge effective communication within healthcare teams: the use of verbal handovers; gender barriers between doctors and nurses; note-writing; appreciating the importance of and the different styles of notes entries; the action focused / outcome driven culture; the prevailing dominance of the medic and the hierarchy within teams; too many managerial layers; a lack of respect for nurses leading to disenfranchisement of this profession; and prioritising the needs of the individual profession over those of the multidisciplinary team.

One, arguably basic challenge to effective written communication within the multidisciplinary team is the different methods used between therapists and nurses. Therapists use the SOAP format for notes, a system devised in the 1960s by Laurence Weed who was a medical doctor (Kibble et al. 2006); it stands for subjective, objective, assessment, plan; although not in a consistent fashion as clinical experience has highlighted different interpretations of the 'A' in SOAP including for analysis or achievable. In contrast, nursing teams are being encouraged to use SBAR communication: situation, background, assessment, recommendation but the uptake of this is not universal at present (Iacono 2009). As the therapeutic and nursing processes are different, it could be argued that it is not surprising that they use different documentation processes. However, the concern here is that there are potential problems when the different professions do not understand the acronyms and their clinical application.

It has been argued that a challenge to effective communication within health care teams is partly a result of a preference towards 'action-focused' communication styles, e.g. giving reports, writing reports, rather than prioritising collaborative discussion (Bokhour 2006). While limited to one acute dementia care ward and only focusing on the analysis of communication in the team meeting, Bokhour (2006) concluded that, even when space was found for shared dialogue, communication within the MDT was still problematic because of the different perspectives held by different professionals.

A substantial degree of the evidence suggests that, mainly due to poor communication within the multidisciplinary team, nurses feel under-valued (Farahani et al. 2011), or unable to speak out (e.g. Casey and Wallis 2011), are frequently interrupted (Friesen et al. 2007) and have to contend with a high volume of information (Woloshyrewych et al. 2007). At worst, it has been concluded that poor teamwork, of which ineffective communication is often cited, leaves nurses feeling disenfranchised and passively resistant to change (Widmark et al. 2012). Yet, nurses are pivotal to the effective working of collaborative health care teams in the unique way they share close proximity to patients and other MDT members (Propp et al.

2010). Furthermore, in their study of nurse-team communication practices, Propp et al. (2010) conclude that in order to improve patient outcomes, health care services must take proactive steps to improve communication and foster a culture of respect for nurses. This highlights there are many, inter-related factors that contribute to challenges with communication in healthcare teams, central to which are nursing related factors.

Challenges relating specifically to nurses are not just about how other professionals interact with this them. While effective communication is one of the nine Principles of Nursing Practice (Casey and Wallis 2011), it has also been argued that a culture change is needed within nursing to enable written notes to be viewed as valuable and useful, rather than an optional extra to be completed at the end of each shift (Casey and Wallis 2011).

There are also some factors that cannot be avoided, rather acknowledged as a limitation, that impact on communication. For example, surgeons need to be necessarily task focused at critical junctures in surgical procedures thus limiting communication opportunities (Gillespie et al. 2013). Yet, in the same study, an in-depth ethnographic study within one operating room (OR) in an Australian hospital, but across a number of clinical specialities, Gillespie et al. (2013) concluded that communication was difficult due to the implicit hierarchy and dominating nature within the OR. This negatively impacted on the confidence of relatively inexperienced professionals to communicate. In contrast, the same study found that familiarity with each other was a helpful factor to maximising the safety culture. In these instances verbal communication was not paramount as harmony within the team, enhanced by team members' knowledge of each other's skills and expertise, meant the operating room worked smoothly. A stable team membership is consequently important to maximise communication and safety. Yet, in some settings a high staff turnover is the norm, thus implying this makes its practices vulnerable to poor communication and presents potential risks to patient safety.

Gillespie et al. (2010) stated that there is strong support for the improvement of communication within interdisciplinary teams, yet progress to deliver these improvements has been hampered by numerous contextual and historical factors. Using a grounded theory approach with 16 participants, all healthcare professionals in an operating department, two key findings relevant to communication were: 1) communication was challenging when individuals prioritised their own professional identity and culture over the multidisciplinary team identity; 2) education changes culture and education improves communication yet clinical pressures meant a perceived lack of time for educational sessions. Gillespie et al. (2010) concluded that participants felt a palpable recognition of the critical role of communication in developing cohesive teams yet felt it needed to be addressed at the student education stage. It was probably too late, they concluded, to change entrenched behaviours of the current senior doctors, nurses and anaesthetists. This may partly explain why improvement in communication is slow.

The study by Gillespie et al. (2010) focused on challenges to team communication in operating theatres where the majority of the participants were nurses (n=12); findings will naturally be skewed towards nursing perceptions in a specific clinical setting as a consequence. However, it could be argued that enhancing professional identity and finding the time to educate colleagues are issues that transcend into the wider healthcare sphere, including acute multidisciplinary stroke care.

In discussion of their study, Gillespie et al. (2010) suggested that the use of a ‘shared mental model’ may have utility to organise and improve team communication by providing a structure to minimise the risk of omissions. In this instance, the research team subsequently undertook a study to implement and evaluate the use of structured pre-surgery briefings; they concluded that the use of the collaborative tool helped to communicate a shared understanding of the team plan, yet reported that pre-briefings in the operating room only happened 12.5% of time (Gillespie et al. 2013). This suggests there were challenges with knowledge translation and implementing new ideas and change into clinical practice.

Relationships between health care professionals may be a factor that makes difficult the attempts to introduce change related to team communication. For example, Barkley (2005) perceived two key challenges to communication between radiologists and doctors: 1) radiologists need to be more effective in their communication to referring clinicians, rather than use their own uniprofessional terminology which is neither clear nor helpful beyond the profession; 2) radiology reports are often ambiguous and unclear when presented to referring clinicians. No reasoning for the existence of these challenges was shared in this study although a statement, that radiologists were polarised from the rest of the medical community, suggests a division between the radiologists and the doctors that could impact on collaborative working.

Other challenges to effective communication beyond the culture of team dynamics also exist; for example, verbal handovers have been viewed as limited. Potheir et al. (2005) identified the need for a formal handover sheet to reduce errors and omissions in verbal handovers between nursing shifts. Following observation of handovers for 12 patients over five consecutive nursing shifts, they found only 31% of data was still present using the traditional note-taking style resulting in a significant amount of lost information which could negatively impact on patient care. While limited to one profession within the team, this is an example of an historical practice that continues to prevent effective communication within healthcare teams.

Reporting on their study, conducted in Iran, Farahani et al. (2011) acknowledged a range of issues impacting on effective communication including: the differences in status between doctors and nurses; cultural barriers caused by multiple languages and religions; and a wide variation in beliefs, rituals and customs within the 68 million population of the country. By interviewing 35 participants (nurses, doctors, patients and family members) regarding their perception of communication barriers three overall themes emerged: 1) a lack of collegiality and communication between nurses and physicians, partly due to a perceived lack of respect from the doctors towards the nurses; 2) problematic communication between the health care team, patients and their families attributed to, amongst other factors, the use of medical jargon and lack of empathy; 3) cultural challenges associated with discussing taboo topics, e.g. the impact of medication on sexual functioning.

In the clinical recommendations from the study, Farahani et al. (2011) concluded that issues pertaining to the development of effective communication need to be included in clinical guidelines to ensure quality improvement in patient care and the associated outcomes. In recommending the use of the ICF (WHO 2001) to aid communication within the stroke multidisciplinary team, it could be seen that the Intercollegiate Stroke Working Party (2012) have done just that.

There are a number of limitations in the study conducted by Farahani et al. (2011). All interviewers were nurses therefore this could have affected the responses given by the participants or influenced the way the researchers analysed the data; it was not clear how they managed their own professional, tacit thinking within the research process. In addition, by only including doctors and nurses, the voices of the therapists and other members of the healthcare team went unheard. The study was limited to Tehran, Iran thereby different cultural factors existing within Iran in comparison to the UK, question the transferability of the findings. But, Kilbride (2005), in a single case study in the UK, concluded that effective teamwork was built by valuing the central role of the nurse within stroke care; this is congruent with the findings of Farahani et al. (2011) that a lack of respect towards nurses was perceived as having a negative impact on the quality of care.

Furthermore, the issue of doctors as the dominant force in the team, has also been identified in Australia (Rowlands and Callen 2013). Twenty-two clinicians within a lung cancer MDT (including allied health professionals in addition to doctors and nurses) were interviewed for their perceptions on communication and the challenges that existed in one in-patient service. A single researcher interviewed all participants but four research assistants assisted with data analysis, using a grounded theory approach, to determine two main themes: 1) The role of the team member determines the direction of communication, with doctors' as the dominant force; 2) face-to-face communication is preferred; team meetings are medically dominated and the paper-based record is a failure as a medium for communication.

Encapsulated in the two broad themes defined by Rowlands and Callen (2013) are a number of individual sub-themes. With regards the first theme, participants reported that in order to break down the dominance of the medical staff, other staff needed to understand their own roles in greater detail and the roles of others. In the second theme, not all participants had access to the paper-based records, while different doctors, e.g. the respiratory physician, kept separate information in their offices. To this end, participants recommended using electronic records and developing multidisciplinary team paperwork.

The authors concluded that current clinical guidelines for multidisciplinary team cancer care are deficient, as they fail to address the need to change communication behaviours nor fully acknowledge the challenges faced when implementing a new way of working, i.e. a team focused way with the existing and dominant medical model. This study and therefore its findings are limited to one lung cancer multidisciplinary team in an Australian hospital. Nonetheless, Rowlands and Callen (2013) were able to engage with the wider clinical team as well as the doctors and the nurses. Furthermore, their findings have been supported elsewhere beyond cancer care in the southern hemisphere (for example Arksey et al. 2007; Sada et al. 2011; Gillespie et al. 2013). But, the voices of the patient and their families are absent so it is unclear of the impact caused by the communication challenges on the delivery of patient care.

Research has also explored challenges to communication between teams as well as within them. Dunn and Markoff (2009) suggested that inadequate communication between inpatient and outpatient physicians is the norm, rather than the exception, outlining examples of poor quality of information in discharge summaries and the timeliness in which they are sent. But they also raised the notion that the gains from effective communication have yet to be established in the research literature (Dunn and Markoff 2009). Conversely, as Gibson et al. (2010) pointed out, the lack of established research cannot paralyse clinicians in developing effective communication. Citing Smith and Pell (2003), they have drawn an analogy with jumping from an airplane without a parachute: just as it is unnecessary to try the latter to determine if it is unsafe, so it would be superfluous to conduct a randomised controlled trial to validate the importance of effective communication.

In an example of the impact of culture on efforts to improve communication, Dunn and Markoff (2009) postulated whether inpatient doctors feel there is limited value, therefore making it less of a priority, in communicating with their community colleagues. They concluded that more education on the consequences of inadequate information transfer needs to be undertaken with hospital doctors. While concluding that effective communication must become engrained in the behaviour and culture of hospital doctors, it is not clear how this can be addressed (Dunn and Markoff 2009). It has been acknowledged that optimal patient care not only requires expertise in the delivery of suitable interventions, but also needs a timely and accurate transfer of information when communicating between services. To this end a simple written template is recommended to improve communication between providers (Szary et al. 2010). Yet implementing a 'simple' template in itself may be a challenge as it has been perceived as unlikely that entrenched behaviours can be altered (Gillespie et al. 2010).

Under the heading of existing cultures, a number of inter-related factors have been highlighted from the literature including working practices (e.g. verbal handovers); interpersonal cultures (e.g. gender differences, relationships between different professions); the prevailing hierarchical culture which gives doctors more power; cultures which prioritise professional needs over team needs; and the outcome driven culture which limits space for collaborative discussion and education. One particular behavioural outcome which may arguably be symptomatic of these cultures, is not speaking out. To this end it is necessary to examine the evidence related to this specific phenomenon.

3.6 Not speaking out

Seven articles identified within the review debate the challenges to speaking out. In a study by Sutcliffe el at (2004), communication failures contributed to, or were associated with, 91% of 'medical mishaps' as perceived by junior doctors (n=26). When examining the reasons for these communication failures, they concluded that, rather than purely being due to faulty transfer of information, communication failures were insidious and caused by a complex interplay of factors including: 1) the pervasive hierarchy; 2) conflicting roles and role ambiguity; 3) interpersonal power and conflict. Specific examples included: participants feeling hesitant to speak out for fear of looking incompetent to the senior doctors; role confusion between private, community physicians and the hospital team; poor communication between medical specialities within the hospital and between the doctors and nurses. Therefore, there are specific personal and environmental factors which negatively impact on effective communication.

The study by Sutcliffe et al. (2004) was conducted in the United States therefore the private healthcare arrangements may have contributed to the role ambiguity played between the different doctors. This finding may not be relevant between an NHS GP and a hospital doctor in the UK due to the socialised healthcare system, although this may change with the introduction of GP-led clinical commissioning groups. However, actual causality cannot be concluded from this study, which relies on recollection of medical mishaps from one specific group of health care professionals, i.e. junior doctors. So the findings should be viewed as suggestions of the association between poor communication and adverse events. Nonetheless, the issues of hierarchy, an unwillingness to speak out, role demarcation and conflict are common themes in the literature on challenges to team communication in healthcare (e.g. Sada et al. 2011; Gillespie et al. 2013; Rutherford 2012).

When interviewing operating theatre assistants in Scotland, Rutherford et al. (2012) found that five of the 19 participants said they would not speak up even if they were concerned with a decision being made in theatre. The reasons for this were not fully explored in the study nor were they linked to the level of experience of the participants. But in an exploration of a critical incident, leading to the death of a patient, Walker (2008) quotes the subsequent conclusion, from the independent expert review, for the need to ensure an atmosphere of good communication so any staff member feels comfortable to make suggestions on treatment.

Garon (2012) conducted focus groups with 18 front line nurses to ascertain their perceptions of workplace communication. Three themes were identified which influenced their decision making process to speak out: their personal factors including upbringing and culture, the organisational culture, and the outcomes from speaking out. The most powerful determinant was the influence of the Nurse Manager. The use of focus groups may have limited the extent to which participants felt they could be truly open in front of their colleagues but nonetheless, this study highlights the multi-layered reasons that impact on decisions to speak out or not within the health care team including personal and environmental factors.

Furthermore, with regards verbal communication, a survey of over 5,000 members of the Royal College of Nursing (RCN) in the UK, in 2009, highlighted 57% of respondents would not be confident to communicate any concerns they had without thinking twice for fear of personal reprisal (Casey and Wallis 2011). It could be argued that the presence of an open and fair culture is a prerequisite for improving communication yet, studies continue to cite the prevailing hospital hierarchy as a negative influence on open communication (Garon et al. 2012, Gillespie et al. 2013). Indeed, the Francis Report from the Mid Staffordshire Public Inquiry called for a culture of 'openness, transparency and candour' (Francis 2013 pg. 75) and the need to strengthen the professional voice of the nurses (Francis 2013 pg. 77).

So far, this critical review of the literature concerning the challenges to communication in healthcare teams has identified a number of themes: logistical challenges, knowledge gaps, existing cultures and issues with not speaking out. The final theme, to be explored next, is the perceived lack of collaborative theory and working practices.

3.7 A perceived lack of collaborative theory and working practices

It has already been ascertained that it is a risk to effective communication when individual professions put their own needs ahead of the needs of the multidisciplinary team (Gillespie et al. 2010). It could be argued that implicit within this is the acknowledgement of a lack of team-working practices.

A qualitative exploration of communication within a community mental health team (CMHT: Donnison et al. 2009) concluded that a lack of shared ideology hampered team communication. Furthermore, the work of the CMHT was undermined by the absence of a theoretical model to underpin their practice. The impact of this for the CMHT participants (n=7 comprising social worker, psychiatrists, psychologists and nurses but no therapists) led to confusion over the aims of the team which, in turn, meant staff often felt vulnerable in the way the service was externally driven, i.e. pulled in many different directions by others outside of the team.

In the study by Donnison et al. (2009), communication was a challenge because clinicians did not have a common language to define their service nor a theoretical model from which to draw the language. The mandatory use of national standardised clinical terminology in the NHS (SNOMED: Systemised Nomenclature of Medicine), by April 2015, may prove sufficient to help healthcare teams develop a shared ideology. However, it could be argued that SNOMED is not a theoretical model to underpin practice, rather a list of standard words. On closer inspection of the sub-set of SNOMED standards words produced by one profession, occupational therapy, it is evident to see that SNOMED has incorporated the detail within the ICF classification (Austin 2014), thereby introducing a theoretical framework implicitly into the language of healthcare workers.

Formal methods for structuring and recording team information and decisions have been found to benefit team communication (Manias et al. 2005). This observational study, of 12 graduate nurses in an Australian teaching hospital, found participants were effective in communicating medication management to doctors, when initiating the dialogue, but they struggled with impromptu discussions and in the ward round. The introduction of a structured format for communication within the team, for use in the ward round setting (Manias et al. 2005) was recommended.

In a study by Parker et al. (2009), to identify projects to overcome communication challenges, participants' suggested centralised communication boards and hand-outs for use by all members of the multidisciplinary team. The authors concluded that of priority was the need to implement and evaluate integrated models of care in order to enhance communication and ensure dignity for patients, families and staff.

There are two main limitations to the study by Parker et al. (2009): first, the over-representation of the nurses' voice, although focus group participants included physiotherapists and dieticians; second, the production of a list of possible projects signalled the end of the project. Therefore it remains unclear whether or not the ideas were successfully implemented into practice, a gap often cited as an obstacle in the research translation process (Metcalfe et al. 2001).

Health care settings, power dynamics and the willingness of professionals to adopt a collaborative model of practice could also pose threats to effective communication (Marshall et al. 2011). This suggests that, while national clinical guidelines may recommend the use of a collaborative framework, i.e. the ICF (WHO 2001) to aid team communication, it is likely that environmental barriers may impact on the actual implementation of it into clinical practice. In their qualitative interviews of 10 participants from a range of healthcare professions, including doctors, nurses, pharmacists, physiotherapists and occupational therapists, Marshall et al. (2011) found that, to be more inclusive, healthcare teams needed to avoid the use of professional jargon to benefit collaborative working with each other and to foster a culture of collaborative working with their patients and their families.

There are a number of limitations to the study by Marshall et al. (2011). Firstly, the authors stipulate that data analysis focused on the meaning of the words ‘interprofessional’ and ‘collaboration’, yet the aims of the project were to explore barriers and challenges to collaborative working. This suggests: 1) a disconnect between the original aims of the research and the data analysis process; 2) a level of subjectivity in determining the findings, given the authors suggested beforehand their belief that there were differences in the level of engagement when either of the two terms were employed in practice. No limitations were acknowledged by the authors in the article.

However, other studies have also cited the lack of collaborative working practices and theory as challenges to communication within the healthcare team (Davison and Sloan 2003) because it can be challenging when: 1) different team members bring with them their own discipline-specific way of thinking and communicating which has the potential to cause conflict and; 2) the impact of high staff turnover coupled with the pace of the work means it is difficult to establish trust and personalise relationships within the team. While limited in its description of the methodology and data analysis, participants interviewed from palliative care teams by Davison and Sloan (2003), concluded that organisational artefacts were used as a substitute to build trust within the multidisciplinary team. In short, artefacts like team documentation or other such processes enable collaborative thinking and working, which in turn engenders trust in each other and improves patient care.

Davis et al. (2003) identified that poor team communication, especially written team plans, was the most extensively described factor that negatively impacted on the participants' own communication with their patients and families. In focus groups attended by 51 nurses, it was recommended that documentation needed to be more clearly defined, based on team discussions and monitored at a team level. This study highlights the impact of team communication on the relationships between health care professionals and their patients / their families, i.e. if the team communicates effectively among itself, then healthcare professionals can communicate better with their patients and family. This is of significance because, after issues with pain management, poor communication is cited as the second largest cause of distress for patients with cancer and their families (Davis et al. 2003). This study is limited to the nursing profession only and furthermore to those working in acute care of people with advanced cancer so, the findings may be specific to the clinical area.

However, placed within the larger body of evidence in this review, it is possible to see how the findings from Davis et al. (2003) could transcend oncology teams and the nursing profession. Nurses in the study recommended better team communication and more team discussions, but it may be hard to make this a clinical reality due to the following factors: a perceived lack of respect for nurses and their opinions (Farahani et al. 2011), junior doctors lacking confidence to speak out to facilitate change (Sutcliffe et al. 2004), a preference towards action over collaboration (Bokhour 2006), coupled with the logistical challenge of finding communicative space (Manias et al. 2005).

Nagpal et al. (2012) also concluded that communication processes need to be standardised, with systems developed across the pathway to improve patient care. This conclusion was reached in a qualitative study interviewing doctors and nurses only (n=18), across the surgical pathway. Nagpal et al. (2012) also acknowledged that, in order to improve the processes, there must be a greater understanding, first, of the current position and communication failures and, second, of the context specific challenges which lead to targeted interventions to improve communication.

Nagpal et al. (2012) outlined with great detail the methodological processes used in their study and how data saturation was achieved. Communication failures were identified across the whole surgical pathway and included examples such as a lack of process for handing information over from one team to the next. Many reasons were cited for the communication challenges and were grouped into four over-arching themes: 1) task factors (e.g. reliance on paper methods for transferring information); 2) team factors (e.g. nurses not empowered to take a leading role); 3) work environment factors (e.g. high staff turnover); 4) organisational factors (e.g. too many layers in the system). The perceived impact of these failures included patient delays / increased length of stays; unhappy / stressed staff and inefficient use of resources. Participants also gave suggestions on how to address the identified challenges including standardised handover procedures and increased interdisciplinary communication. However, the participants were not representative of the whole multidisciplinary team so the voices of the therapists and social workers were not heard; this may in part explain that, while data saturation was achieved, no participants raised issues pertaining to communication challenges at the point of discharge from hospital to community – a transition posing communication challenges that have been highlighted by other studies (Sada 2011; Dunn and Markoff 2009).

But in drawing to a close the critical debate on the themes emerging from a literature review on the challenges to effective communication in healthcare teams, the study by Nagpal et al. (2012) articulates some of the many inter-related factors, including the: tasks, team membership, work environment and organisational structures, that weave together to, arguably, pose a threat to the quality of patient care.

There is one final topic to explore, arising from the literature search for this chapter – issues in measuring and improving the quality of communication in health care teams. It is important to explore this issue briefly to demonstrate the two opposite schools of thought around how improved quality can be achieved.

3.8 Issues in measuring and improving the quality of communication in health care teams

Two papers from the search strategy yielded different views on how to improve the quality of communication in health care teams: namely, whether the focus should be on improving processes to achieve better outcomes or, whether they should focus on the people within the processes.

The first paper (Kavanagh and Cowan 2004) cites the more traditional view of quality improvement: enhancing communication by implementing clinical governance initiatives, i.e. a systematic, process driven and outcome focused approach. The authors, writing in a clinical governance journal and working for the Medical Protection Society, outlined ten processes for continued team improvement including: cross-checking systems and competence testing. They acknowledged the need to improve motivation and develop a greater understanding of others' roles but their focus remained on putting in place policies and processes to facilitate a quality service and measuring the outcomes. It could be argued that the National Clinical Guidelines for Stroke and linked Stroke Sentinel Audits follow this line.

In contrast, Colon-Emeric et al. (2006) advocate the use of complexity science to aid our understanding of and make improvements in the quality of care in nursing homes. They argued that quality can be enhanced through developing and measuring open communication channels between all healthcare professions, regardless of their status within the team, because this encourages information flow, cognitive diversity, innovations in care and improved self-organisation (Colon-Emeric et al. 2006). This is in comparison to a 'vertical chain of command' where a hierarchy in the team limits these characteristics.

While limited to an analysis of doctor-nurse communication patterns in two nursing homes in the USA, this in-depth, mixed-methods, qualitative study was conducted over a six month period using interviews, focus groups, focused observations and shadowing encounters with 119 nurses and seven doctors. It concluded that interventions, to improve the quality of care to nursing home patients, should focus on improving connections and communication between staff members rather than traditional programs of quality improvement initiatives. Furthermore, interventions such as this are likely to generate sustained change (Colon-Emeric et al. 2006).

However, a high staff turnover can make vulnerable the connections and communications made between members of healthcare teams, a point also acknowledged by Colon-Emeric et al. (2006). This suggests that the use of organisational artefacts to improve connections and communications could bridge the gap caused by staffing changes, in the same way that Davison and Sloan (2003) identified their potential to build trust within the constantly changing multidisciplinary team.

There are limitations to the study by Colon-Emeric et al. (2006). The driver, for one of the two nursing home multidisciplinary teams to open their channels of communication, was out of necessity because of frequent absences from the lead manager. So, greater transparency for team communication was rather out of necessity than having in place the most effective climate to develop initiatives to maximise patient care. Indeed, the study did not detail how, or if, the quality of care in this nursing home was higher than in the nursing home where the junior nurses reported to the senior nurse who liaised with the doctors, in a hierarchical, closed communication channel.

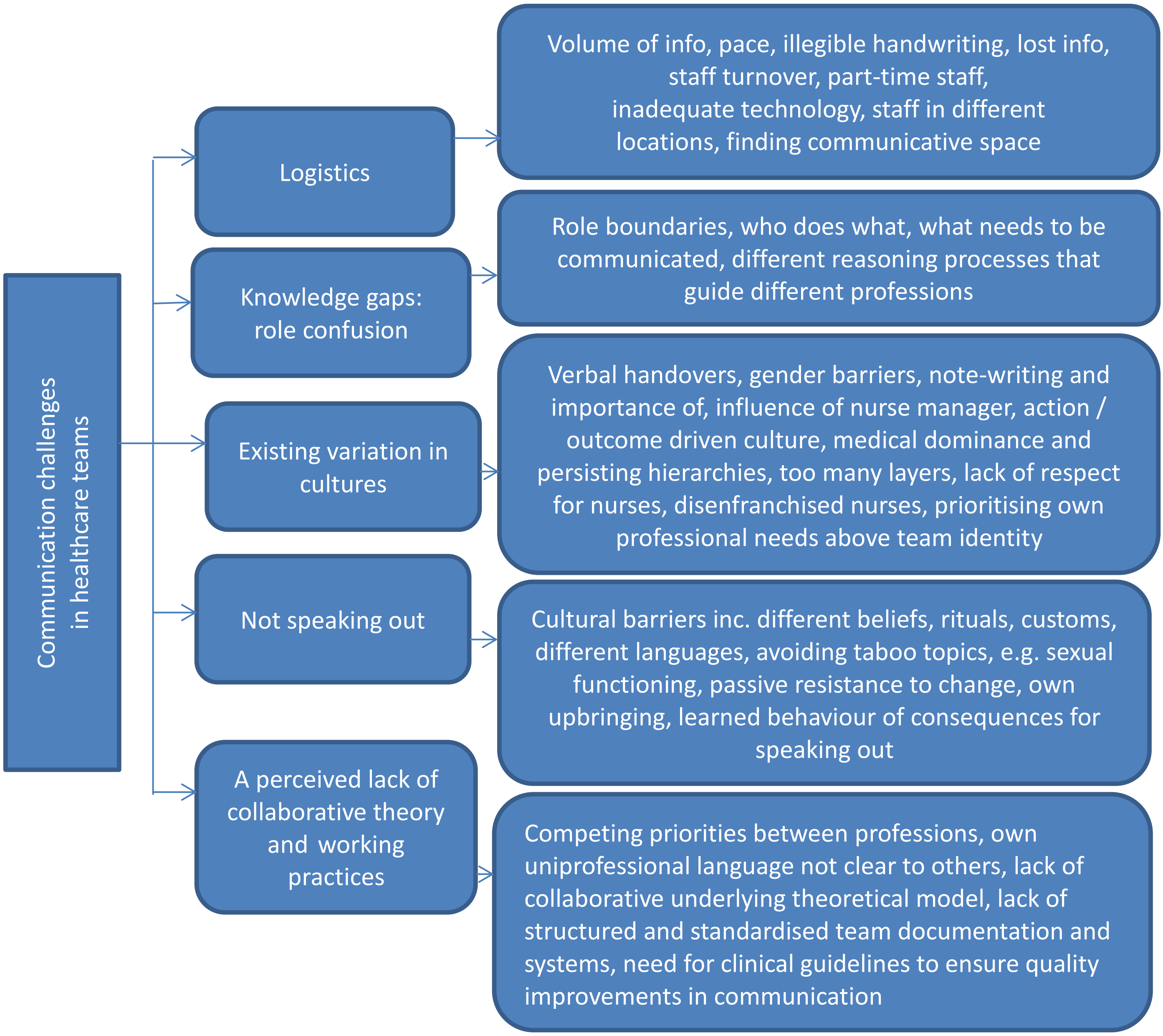
When considering the challenges to effective communication in healthcare teams the articles, by Kavanagh and Cowan (2004) and Colon-Emeric et al. (2006), also highlight the dichotomy presented, in the first instance, by different ontological perspectives on how to develop and measure communication and the quality of care.

3.9 Chapter summary

This chapter has explored the literature in relation to the current challenges to communication within healthcare teams. Five inter-related themes emerged, each with a number of topics within them (see Figure 4). Communication challenges are caused by: logistical factors, knowledge gaps such as role confusion, existing cultures, not speaking out and a perceived lack of collaborative theory and working practices. Furthermore, there is a debate concerning how communication and quality of care can be improved and measured.

In the literature, there has been much emphasis placed on communication challenges within two main areas: 1) within and between the nursing and medical professions; 2) in the hyper-acute and acute phases of care, i.e. accident and emergency and operating theatres. Only one study focused on communication challenges with therapists in neurology. Using these specific search terms, no studies were identified that a) were specific to stroke and / or b) sought to engage with all members of the multidisciplinary team, patients and their families / carers.

Figure 4: A conceptual framework of the inter-related factors, and topics within them, that impact on communication within healthcare teams



Content from the next two chapters (methods and findings) have been published, copies of the articles can be found in Appendix 21 and 22:

Tempest, S. Harries, P. Kilbride, C. and De Souza, L. (2013) ‘Enhanced clarity and holism: The outcome of implementing the ICF with an acute stroke multidisciplinary team in England’, *Disability and Rehabilitation* 35 (22) pp.1921-1925.

Tempest, S. Harries, P. Kilbride, C. and De Souza, L. (2012) ‘To adopt is to adapt: The process of implementing the ICF with an acute stroke multidisciplinary team in England’, *Disability and Rehabilitation* 34 (20) pp.1686-1694.

Chapter 4: Methods in theory and practice

This chapter will critically explore the selection of the methodological framework, the methods subsequently developed and used within this action research project, the methods of analysis, an outline of the participants and the different ways they chose to engage with the project.

4.1 Selecting the methodological framework

From the outset, the overall broad aim of this project was to evaluate the process and outcome of implementing the ICF with an acute stroke service. The drive behind this was the recommendation in the National Clinical Guidelines for Stroke (ISWP 2004; the 2nd edition in use at the time of planning the project) to use the ICF, but a recommendation based only on evidence level of expert opinion. Furthermore, no research had evaluated the process of attempting to implement the ICF or the outcome of so doing. As outlined in the introductory chapter, the project aim was presented, discussed and agreed upon with members of the Stroke Oversight Committee, most of whom would become participants, once the relevant ethical approvals were received. Therefore, central to the project was the need to address a problem arising from practice, to undertake action with and for clinicians and other stakeholders, and evaluate the key learning points from the process and the outcome.

The research aim did not fit with traditional methodologies. Both quantitative and qualitative methods conclude with findings where the onus is on the reader to implement them into practice; the difficulties of relying on clinicians for the transference of knowledge into practice has been recognised (Meyer 2006b).

Positivism, with its emphasis on statistical enquiry (Ritchie and Lewis 2006), the manipulation of an independent variable under controlled conditions, and making judgements against testable hypotheses (Polgar and Thomas 2001), would not enable the exploration of the implementation process. Nor was a stroke unit, in a busy metropolitan hospital, deemed a controlled environment. For example, and as outlined in the section 1.1, during the time frame of the project, the unit moved geographical locations three times and the remit of the service changed twice. In addition, the researcher's role would involve facilitating the change process with the participants and it would not be possible to remain purely objective in order to measure and record the outcome of the innovation.

In contrast to positivism, but still incongruent with the research aim, interpretivism places value on the context in which an investigation occurs. The central focus relates to an explanation of meaning rather than outcome (Ritchie and Lewis 2006). So, this approach had potential to aid the evaluation of what was learnt from the process and outcome of implementing the ICF, as it would allow participants the opportunity to describe their thoughts on the ICF. But, as this project also sought to bring about a service innovation and then evaluate the outcome, a traditional qualitative design would not enable the change component of the research.

A third way to conduct research has been discussed in the literature, re-emerging in the 1960's (Zubler-Skerrit and Fletcher 2007) namely participatory inquiry and action. Using this approach as the methodological framework would mean that traditional methods could be incorporated into the data collection. This is considered powerful as the qualitative data would contribute personal meaning to the technical data gathered through quantitative means (Polgar and Thomas 2001 pg. 97).

Within this third way, there are different types of participatory inquiry including co-operative inquiry, action inquiry and participatory action research (PAR) so participatory inquiry is not necessarily action research (Thesen and Kuzel 1999). In a debate on these particular three forms, Reason (1994) likened them to cousins in the same family but articulated their differences; these will now be briefly explored and related to considerations for this project.

Co-operative inquiry tends to be used with empowered groups who can self-determine projects (Reason 1994). It could be argued that a multidisciplinary stroke team is one such example of an empowered group. But, with its roots in humanist psychology and a tendency to focus on the psychology rather than the politics of action, co-operative inquiry may not be the most effective framework for a project which sought to introduce change into clinical practice, arguably a political process partly caused by implicit hierarchies within the setting.

The second form of participatory inquiry debated by Reason (1994) is action inquiry which focuses on the development of effective action to transform an organisation. But, from the outset, the aim of the project was to explore the process and outcome of implementing the ICF; a non-directional aim which did not and could not focus on effective transformation of the acute stroke service. In short, it was not possible to say if using the ICF would positively impact on the effectiveness of the service.

Finally, PAR has two main objectives: 1) to produce knowledge and action directly useful to a group of people and; 2) to empower people to challenge the status quo to produce their own knowledge, recognising the politics within the change context (Reason 1994). Therefore, this was congruent with the proposed project which sought to produce useful knowledge and action, in relation to a clinical guideline, and implement change within a clinical setting, one which from experience, the researcher knew was bound by healthcare politics.

However, the use of PAR has historically been used with oppressed groups (Reason 1994) and not with educated healthcare professionals; whereby a co-operative inquiry approach may be of greater benefit. Therefore, the use of PAR needed further exploration when considering the selection of the most appropriate methodological framework within the participatory inquiry family.

Further reading highlights that not only has PAR been recognised as useful to answer questions on health care delivery (Lingard et al. 2008), a systematic review on the use of PAR in nursing alone (between 2000-2005) identified sixty-two separate action research studies, already completed, half of which were undertaken in the hospital setting (Munn-Giddings et al. 2008). Furthermore, four UK-based action research studies have been published specifically within stroke (Mitchell et al. 2005, Hammel et al. 2006; Jones et al. 2008; Dewer et al. 2010; Kilbride et al. 2011), a summary of each is in Appendix 3 along with one from the USA (Hammel et al. 2006). Therefore, there is evidence to highlight that PAR is recognised as effective and is already used with healthcare professionals and specifically within stroke services.

Additionally, as action research is a cyclical process of reflection, planning, action, observation, reflection and replanning, it mirrors the steps within the rehabilitation process, i.e. assess, plan, implement, evaluate and replan. Therefore, while it may be packaged in different terminology, it is already a familiar process for doctors, nurses and therapists (Glasson et al. 2008).

There are also other advantages to using PAR as the methodological framework for this project because it emphasises societal change and can be used to explore process and outcome related research questions. PAR seeks to improve society rather than to prioritise the acquisition of knowledge (Waterman et al. 2007). As the National Clinical Guidelines for Stroke (Intercollegiate Stroke Working Party 2004) recommended using the language of the ICF to improve multidisciplinary team communication in stroke units, the planned project, using PAR, had the potential to improve a micro society, i.e. the acute stroke unit. PAR also systematically researches the change process and outcome of it, in relation to the literature (Meyer 2006). Therefore, this methodological framework had the potential to enable the evaluation of the process and the outcome of implementing the ICF into clinical practice; a topic of interest to the global ICF community.

Another essential component within PAR is that it is for and with people and not research on them (Meyer 2006); which also resonated with the planned research as the participants were going to shape the specific aims.

Therefore, there appeared to be components within PAR that suggested it was the methodological framework with the best fit for the overall research aim. However, in the literature, it is also clear there are debates on the definition of PAR, different types of action research, different methods and different elements to individual projects. Therefore, this justified and required further critical exploration of action research which will be addressed in the next section.

4.1.1 Action research theory: definitions; process; common elements and principles

Kurt Lewin has been widely credited as coining the term ‘action research’ in the 1940’s, viewing it as a way to generate knowledge about a social system whilst attempting to change it at the same time (Lewin 1945, cited Hart and Bond 1995 pg. 13).

Lewin outlined a process for undertaking action research (1948; cited in Drummond and Themessl-Huber (2007)):

1. *devising an initial plan around a general idea*;
2. *exploring the general idea to modify the plan*;
3. *executing the plan*;
4. *evaluating the action*;
5. *learning from the process to gather a new insight*.

It was possible to see that the overall aim of this research could be mapped to the process outlined by Lewin: 1) Devise an initial plan around the idea of implementing the ICF as recommended by the National Clinical Guidelines for Stroke (ISWP 2004); 2) explore specific ways the ICF could be useful with the acute stroke service; 3) develop and implement a clinical tool to operationalise the ICF theory; 4) evaluate the process and outcome of developing the clinical tool; and 5) relate the learning to the ICF literature.

While the process, outlined by Lewin, remains the same for most action research projects to this day, Drummond and Themessl-Huber (2007) suggest that the process does not begin with devising a plan, rather the process starts much earlier by developing a sense of a problem, or the idea of a problem. They do not see this in negative terms, as they outline that developing a sense of the problem is a form of knowledge in itself. In relation to this project, the problem focused on the fact that the National Clinical Guidelines for Stroke (ISWP 2004) recommended using the language of the ICF within stroke multidisciplinary teams, yet there was no literature on the process of actually implementing it into practice and only a small number of clinical commentaries (none in the acute setting or specifically in stroke services) that evaluated ways of so doing. Furthermore, on discussion with the clinicians in the stroke service at the research site, they did not feel they had sufficient knowledge on the ICF itself in order to think about implementing it.

So, there is debate on the starting point for action research but there remains a more fundamental topic which still lacks consensus. An unambiguous definition of action research remains elusive (Walsh et al. 2008), partly due to the influence of many different disciplines and backgrounds (Drummond and Themessl-Huber 2007) and this presents a challenge for action researchers particularly those who are new to the process. But, as a participant in a previous action research project (Kilbride 2005), the researcher would not be a complete novice to the experience.

Munn-Giddings et al. (2008) identified twenty-four different terms to describe the action research approach including collaborative action research; participatory research and emancipatory and enhancement action research. As there are different traditions within action research, a number of people have engaged in developing different taxonomies (Drummond and Themessl-Huber 2007); this has contributed to the number of different terms used within the literature as identified by Munn-Giddings et al. (2008).

However, there is also confusion within the literature concerning the basic nature of action research. Lingard et al. (2008), writing in the British Medical Journal, classified action research as a form of qualitative research. In the same journal, eight years previously, Meyer (2000) explained that, whilst action research drew upon qualitative methods, it was not synonymous with qualitative research and was more of an approach to research than a specific method in its own right. This has led to suggestions that action research should be seen more as a generic term that encompasses a number of action-based research approaches (Goduscheit et al. 2008).

But, in relation to the typologies, Meyer (2006) identified three types of action research although encouraged the use of typologies to explain the complexity of action research, rather than seek to provide distinct labels for individual projects:

1) technical scientific; where the researcher is seen as an expert and the project uses ‘traditional testing’ design methods;
2) mutual-collaborative; bringing people together to identify problems, try out solutions and monitor;
3) critical and emancipatory; challenging values and developing moral intent.

The notion that action research projects are not static entities and that they naturally evolve through different typologies has been reinforced elsewhere in the literature (Portillo 2007), thereby stressing the importance of combining different types and selecting the right one at the appropriate time within projects. In practice, the messiness of action research projects often means the process is much more complex than a well-defined typology is able to capture (Crow et al. 2006).

Therefore, when scrutinising the literature on the definition of action research, it was evident there was no consensus on its exact nature and that the projects could be messy. Nonetheless, as an outcome from a commissioned systematic review of action research, by the English Department of Health Technology Assessments Research and Development (R & D) programme, Waterman et al. (2001) offered the following:

> *"Action research is a period of inquiry, which describes, interprets and explains social situations while executing a change intervention aimed at improvement and involvement. It is problem-focused, context-specific and future orientated. Action research is a group activity with an explicit value basis and is founded on a partnership between action researchers and participants, all of whom are involved in the change process. The participatory process is educative and empowering, involving a dynamic approach in which problem identification, planning, action and evaluation are interlinked. Knowledge may be advanced through reflection and research, and qualitative and quantitative research methods may be employed to collect data. Different types of knowledge may be produced by action research, including practical and prepositional. Theory may be generated and refined, and general application explored through cycles of the action research process."*
>
> (Waterman et al. 2001 p.11)

The above definition highlights some of the common elements of all action research projects, i.e. the focus on action; participatory practice; and solutions for practical problems that also generate new knowledge (Meyer 2006, Drummond and

Themessl-Huber 2007). Action research is a cyclical process of reflection, planning, action, observation, reflection and replanning, which seeks to gain evidence to bring change into the workplace (Glasson et al. 2008).

There are three key characteristics to action research that occur within most definitions (regardless of type); it is participatory in nature, based on democratic impulse and contributes to social science and social change (Meyer 2006). These common elements would be appropriate to adopt with a research project that sought to work with participants from an acute stroke service to explore the process and outcome of implementing change, i.e. the ICF into clinical practice.

There are five fundamentals within all action research projects: 1) a cooperative process; 2) ownership of the project by the group; 3) focus on an issue of interest to the group; 4) reflection on and re-negotiation of aims, methods and the membership of the group; and 5) negotiation of coordinated action by the group aimed at an agreed improvement (Walsh et al. 2008). These five fundamentals are congruent with the characteristics proposed by Meyer (2006) and focus on overall characteristics, unlike Glasson et al. (2008) who suggested specific process components within the action research cycles.

There are three phases within an action research project; the exploratory, innovatory and reflective phases (Meyer 2006). Prior to the start of the exploratory phase there is also a period of pre-exploratory negotiation and induction whilst the team adjust to working together and establishing their roles. In the exploratory phase the issues and problems are defined prior to taking action. The innovatory phase involves action cycles to implement ways to address the problem areas and the reflective phase evaluates the actions and the processes that have been undertaken. The phases are common with all action research projects, although they often occur simultaneously. In the written format, they are presented as distinct phases to assist the readers' journey.

Within the different phases, there are action research spirals involving the planning, acting, observing, reflecting and re-planning aspects (McNiff 1988). Embedded into the cyclical process is the idea of 'trying out' new ideas in practice (Waterman et al. 2007). However, whilst the cyclical approach is one of the key characteristics, different traditions within AR use cycles of action in different phases of the research, although the rationale underpinning them (i.e. reflect, plan, act, observe, reflect and replan) remains the same (Drummond and Themessl-Huber 2007).

The fundamental core elements, the different phases of action research and the concept of the spirals resonated with the overall aim of the planned research. They also helped the researcher to appreciate why action research has been described as ‘messy’ (Crow et al. 2006), although these common elements at least provide a structure for the mess to occur within. The common principles are also congruent with the previous description of the planned research in relation to Lewin’s definition.

Critical reflection is another key feature of all action research projects (Winter and Munn-Giddings 2001) as it enables modification in thinking, behaviour and service organisation. Critical reflection enables research participants (including the researcher) to question their assumptions and habitual ways of thinking and working. Therefore, it can transform habitual tendencies by making new connections between ideas and problems in the change process (Drummond and Themessl-Huber 2007).

But, Kemmis (2006) stated that all action research projects intervene in many ‘contemporary crises’ by seeking to change the established order within a service. However, it could be argued that, rather than intervening, the action research process could cause the contemporary crisis by heightening awareness of an issue, which some could perceive as threatening. Some commentators have likened action research and researchers to bringing a Trojan Horse into an organisation (Goduscheit et al. 2008). This will be explored later, in 4.1.2, when considering conflict and politics.

Finally, another common aspect to all action research projects is the use of reciprocal feedback and dialogue, as participants learn by doing, rather than being detached from the process (Drummond and Themessl-Huber 2007).

By critically exploring the common elements within action research, it was possible to see the emerging justification for using it as the methodological framework for the planned research project. This included the focus on action; the participants as owners and shapers of the project; and the cyclical approach which could aid problem solving when challenges were presented, by trying out something new. The exploration of the theory also highlighted that practical challenges were almost guaranteed as part of the action research process, a selection of which, will be debated next.

4.1.2 Challenges with action research

This section will explore some of the challenges with action research including the ethical issues; the position of the researcher; the practical considerations; conflict and politics; and judging quality.

Research conducted in the UK healthcare setting requires ethical approval and / or research and development approval to protect the participants from harm. However, Meyer (2006b) argued that ethical approval alone was insufficient with action research projects due to their evolving nature; ground rules must also be agreed at the start of the project to enable researchers to work within an ethical framework at all times. Five ethical issues must also be addressed: mutual respect, honesty about own objectives, honesty about what is in it for the participants, clarity that the findings will be disseminated, and an ability to acknowledge that some of the expected changes cannot be guaranteed (Gibbon 2002).

Another ethical issue is the reputation of action research itself. While it is gaining recognition within the National Health Service, e.g. through the National Coordinating Centre for NHS Service Delivery and Organisation, Research and Development (Munn-Giddings et al. 2008), some people continue to view action research as risky and are sceptical of its value (Walsh et al. 2008). This may be because the process and the outcome are often difficult to predict at the onset of a project itself. While this is not a universally held opinion, those who are sceptical of the value of action research, are the same people who hold the majority of the resources for research and development within the National Health Service (Walsh et al. 2008).

Therefore, there are specific ethical issues relating to action research that are not relevant to traditional qualitative or quantitative methods. These relate to the unpredictable nature of the research itself; conducting action research in the healthcare setting; the differing opinions of its value and the impact of this on obtaining funding.

Furthermore, there are ethical concerns relating to the position of the researcher, the practical challenges; conflict and politics; and judging quality and these will be explored next along with other factors linked to these themes.

Both qualitative research and action research acknowledge the role of the researcher but the latter views the researcher as part of the research process itself, i.e. as a facilitator and co-researcher (Meyer 2006); there is a dynamic relationship between the researcher and the project, to the extent that Drummond and Themessl-Huber (2007) view the action researcher as a ‘friend’ to the research.

This unique relationship to the research requires a range of academic, inter and intrapersonal skills. Action researchers must be reflective, be able to define and understand their role (Herr and Anderson 2005), understand the historical context and culture of the service and be an accepted onlooker and/or a participant (Daniel pg. 10 1993). They must consider the duality of their role both as an observer and problem solver (Goduscheit et al. 2008).

The collaborative process can be further enhanced if the action researcher is already familiar with the setting, not only to gain access to the research site, but to aid clinical credibility (Meyer 2006b). So, some of the challenges were reduced for this project as the researcher had previous clinical experience working within the stroke service, thereby was already familiar with the setting and understood the context. But, this in itself could pose a risk of making assumptions based on prior knowledge. Furthermore, there are also practical things to consider including creating space for discourse, selecting the ‘right’ projects, time pressures and securing participation, all of which will now be explored.

Kemmis (2006) suggests that action research must evolve into a process for facilitating discourse between people and organisations in order to acknowledge that organisations do not work as ‘whole systems’. In the case of this research it could be difficult to create communicative space for discourse, as the current healthcare

setting is an inherently outcome focused, target driven environment; problems are often viewed as obstacles to overcome with quick solutions, with limited space for reflective learning (Crow et al. 2006).
Another practical challenge concerns the nature of the change projects themselves. Waterman et al. (2007) acknowledge that better outcomes are associated with projects that relate to the targets of the organisation, which makes diffusion of the innovation more likely to succeed. However, the definition of a 'better' outcome could be contested; more 'successful' projects may include producing knowledge and action, with a group of people, to illuminate reasons for perceived failures in implementing change.

Time factors also present a practical hurdle for participants, as it takes a long time to embed new ideas into practice (Meyer 2006b), as well as time to develop the changes. There would also be time factors for the researcher, who would be under pressure to 'deliver' the research within the time span allowed to complete the PhD qualification. To counteract this, Meyer (2006) acknowledged that it is common, when undertaking an action research project for a doctoral thesis, to see part of the project written as the thesis for the purpose of the academic qualification, thereby reducing the time pressure on the researcher.

The final practical challenge identified within the literature relates to securing participation (Waterman et al. 2007) especially within the demands of a clinical setting.

A number of practical topics have been raised including creating space for discussion; potential tensions between the participants and the wider organisation; time factors and securing participation. All of these factors have the potential to cause conflict and now will be explored.

Kemmis (2006) argued that at the core of action research is the desire to transform practice by working with participants; therefore it is a social but also a political process. Participation in an action research project can be empowering as it enables participants to influence change in their own practice (Glasson et al. 2008). However, conflict can also arise as the process of change may be seen as threatening to some people, especially within the healthcare setting where democratic practice may not be the norm (Meyer 2006), thus necessitating the researcher to have a range of abilities.

As action research requires different methodological standards to those that regulate traditional research methods, there is some scepticism within the academic community from those who see it as controversial (Drummond and Themessl-Huber 2007). It has been suggested that support for action research in higher education is lacking (Munn-Giddings et al. 2008). The impact of this, on a new researcher, is the potential need to seek additional learning support for participatory methods from outside the academic institution (Gibbon 2002).

Therefore, there could be potential for conflict both within the research / healthcare setting and the academic community; the conflict with the latter was mainly due to the different requirements for judging the quality of an action research project and thesis and these shall be explored in further detail.

Traditional research methods use the criteria of validity and reliability to measure the quality of the study but in action research, it is paramount to consider authenticity (Zubler-Skerrit and Fletcher 2007). The findings are only valid and reliable if they are authentic to the participants as part of the democratic, participatory process.

There is a debate about the different components that should be included when measuring the quality of an action research project. Lingard et al. (2008) suggested, when critically appraising action research articles, the reader must seek the following key features: the collaborative nature, the egalitarian approach to power, and the blend of scientific inquiry with social action. Seeking scientific inquiry within the articles would help to delineate action research from a practice evaluation focused on audit and service development.

Zubler-Skerrit and Fletcher (2007) defined a list that was synthesised with their own experience, as action researchers and examiners (see Table 4), and relates to the process of writing up action research theses rather than undertaking the actual action research fieldwork. But as the two are inherently inter-related, the quality markers could be of value when considering the project planning as well.

Table 4: Quality markers of action research theses (Zubler-Skerrit and Fletcher 2007)

1) Practice orientated (evidence of improving practice)
2) Participative, including in their research, all stakeholders and others who will be affected by the results of the research
3) Focussed on significant issues relevant not only to the researcher but also to the wider world
4) Using multiple perspective of knowing; triangulation of appropriate methods and theories; and connecting own judgements to the discussion in the current literature
5) Rigour in the action research methodology; creative and innovative; contributing something new to knowledge in theory and practice within and across systems
6) Explicit about assumptions so the readers and examiners may use appropriate criteria for judging the quality of the work
7) Reflective, critical, self-critical and ethical

This list of quality markers includes the factors previously outlined by Lingard et al. (2008), therefore could be an effective resource for the researcher. But there is another resource to consider when judging the quality of AR projects, a list of seven ‘choice points’ used by the Action Research Journal editorial board, (see Table 5) when judging the quality of submitted articles for publication. The editor in chief also gives a note of caution: it is exceptional to find a project that equally addresses all choice points, but quality is determined by the transparency of the author on their endeavour to address them (Bradbury Huang 2010).

Table 5: Quality choice points and definitions for an action research project (Bradbury Huang 2010)

1) Articulation of objectives	The extent to which authors explicitly address the objectives they believe relevant to their work and the choices they have made in meeting those
2) Partnership and participation	The extent to and means by which the project reflects or enacts participative values and concern for the relational component of research. The extent of participation means the continuum from consultation with stakeholders to stakeholders as full co-researchers
3) Contribution to action research theory and practice	The extent to which the project builds on (creates explicit links with) or contributes to a wider body of practice knowledge and or theory, that contributes to the action research literature
4) Methods and process	The extent to which the action research methods and process are articulated and clarified
5) Actionability	The extent to which the project provides new ideas that guide action in response to need
6) Reflexivity	The extent to which the authors explicitly locate themselves as change agents
7) Significance	The extent to which the insights in the manuscript are significant in content and process, i.e. have meaning and relevance beyond their immediate context in support of the flourishing of persons, communities, and the wider ecology

There are similarities between the measures of quality suggested by Zubler-Skerrit and Fletcher (2007) and Bradbury Huang (2010): both emphasise the need for practice orientated research that is participative in nature, findings that are significant to the wider world, a contribution of something new to theory and practice, and reflexivity and transparency in detailing the AR process.

But there are also some differences. The choice points seek explicit articulation of the research objectives and methods as well as demanding rigour; they also develop the notion of actionability so the new ideas generated guide further action. But, their intended use is for journal articles whereas the quality markers have been developed specifically for judging action research theses.

As the judgement of quality within an AR project is often undertaken within an academic environment, one which as previously discussed may not overtly support AR (Munn-Giddings et al. 2008), a set of evidence-based principles could assist the quality assessment process (Zubler-Skerrit and Fletcher 2007). So, when considering how to measure the quality of this action research project, the researcher has chosen to blend the quality markers and the choice points to form ten principles based on the work of Zubler-Skerrit and Fletcher (2007) and Bradbury Huang (2010), see Table 6.

Table 6: The ten principles to measure the quality of this action research project (based on Zubler-Skerrit and Fletcher (2007) and Bradbury Huang (2010))

Principle one: The action research project is practice orientated

Principal two: The action research project is participative in nature

Principal three: The action research project is significant to the wider world

Principal four: The action research project contributes something new to theory and practice *(i.e. the latter being the actionability component)*

Principal five: The researcher demonstrates reflective and critical thinking

Principle six: The researcher demonstrates an ethical stance

Principle seven: There is transparency in the assumptions made from the action research project

Principle eight: Rigour and reasoning are evident for the methods used in the action research project

Principle nine: Clear articulation of the action research process is evident, including the research objectives

Principle ten: The researcher connects judgements to the discussion in the current literature

This section has explored the concept of judging quality within action research and justified the blending of two resources to form ten principles to measure the quality of this project. Principle four refers to the development of new knowledge in theory and practice. Action research generates different types of knowledge and these will be considered next.

4.1.3 The development of learning and knowledge and generalising the findings

Action research generates two types of knowledge (Meyer 2006b). Firstly knowledge-in-practice refers to the learning generated through the action research cycles to inform subsequent phases. Secondly, the knowledge-in-theory findings refer to the development of new theoretical knowledge from the overall process (Meyer 2006b). This is further supported by Coughlan and Coghlan (2002) who encourage viewing the action research process as two distinct elements, i.e. the core project (the actual project involving the action) and the research project (the aspect which seeks to generate knowledge).

A substantial amount of data is generated which warrants a specific approach to its analysis, defined as ‘immersion and crystallisation’; and necessary when dealing with a multimethod approach (Borkan 1999). As implied by the phrase, the process involves immersion in all of the data sets together to crystallise the overall theoretical knowledge generated from the project.

Action research has been criticised for developing learning and knowledge that is specific to one setting, which cannot be generalised (Meyer 2006); this is likely to be one of the reasons why some people remain sceptical of its value. However, Meyer (2006) argues that findings can be generalised, albeit in a different way to traditional methods, i.e. the reader of an action research study must interpret the relevance of the findings to their own setting.

Furthermore, the process of action research embraces the tension between local solutions and transferable knowledge, therefore helping to bridge the gap to assist knowledge transfer (Lingard et al. 2008) However, there is insufficient evidence within the literature that considers this process, i.e. the role of action research in the diffusion of innovations, even though there are many examples of this achievement occurring in practice (Waterman et al. 2007).

Finally, the desire to seek generalisability has been challenged as a concept itself. Some action researchers are concerned that the endeavour to generalise essentially strips away the contingent variables for further experimental scrutiny (Greenhalgh et al. 2005). As action research favours a whole systems approach to generating learning and knowledge (i.e. one that focuses on multimethods and the interaction between components within a process) it does not and should not seek to elucidate individual components for further targeted research (Kemmis 2006).

This section of the methods chapter has critically explored action research including the definition of; comment elements within; and challenges when using it. While there is no consensus on the definition of action research, there is some agreement on the components within the process. Issues of measuring quality have been explored and a method for a quality assessment proposed for use within this thesis.

Through this critical exploration of the action research literature, it is possible to justify its appropriateness for use as the methodological framework for this research. This is because it enables the researcher to work with and for participants to facilitate action. There is an emphasis on a democratic process, not dissimilar from the rehabilitation process, to bring about social change. This allows the process and the outcome to be explored while, at the same time, seeking to overcome practical problems that arise. The fluid nature of the phases and cycles offer flexibility so the process can respond to the changing research environment (i.e. the healthcare setting). Furthermore, action research generates knowledge in practice and knowledge in theory, helping to translate theory (i.e. a clinical guideline and the ICF) into practice.

Therefore, with the appropriate methodological framework selected, the subsequent sections will explore the development of and the methods used for data collection specific to this project.

4.2 Development of and methods used for data collection

This subsection will begin by detailing all the aims which evolved throughout the project as participants shaped its direction. Following this, a second table will outline the methods used to address the aims; specific subsections will then evaluate how each method was developed and used within the project.

4.2.1 An overview of the specific aims for the three action research phases

Table 7 provides an overview of the project aims per action research phase. These aims differ from those outlined in the introduction chapter (Table 2) because Table 7 details the aims after they had been refined by the participants. They are all being presented here to enhance the understanding of the development of the subsequent data collection tools. However, it must be appreciated that, it was not until the end of the exploratory phase, that the participants decided to focus on a checklist and an MDT transfer of care report. Indeed, it was not until the innovatory phase was well underway, did the participants decide on the third innovation; an ICF based glossary. These topics will be returned to in the findings chapter.

Table 7: The refined aims per action research phase as decided upon by the participants

Research phase	**Project aims**
Exploratory phase (EP): Issues and problems are defined prior to taking action	*Aim 1(EP)*: Identify which of the ICF domains and categories from the Comprehensive ICF core set for stroke are already addressed within the service *Aim 2(EP)*: Identify the current challenges within the service which may benefit from the use of the ICF framework and classification to aid service organisation and patient care
Innovatory phase (IP): Ways to address the problem areas are implemented using action cycles	*Aim 3 (IP) / Action cycle 1:* Develop, pilot, implement and evaluate an ICF checklist for use by the multidisciplinary team (MDT) during the patients' admission on the acute stroke unit. *Aim 4 (IP) / Action cycle 2:* Develop, pilot, implement and evaluate an MDT transfer of care (TOC) report for use by the acute stroke MDT *Aim 5 (IP) / Action cycle 3:* Develop, pilot, implement and evaluate an ICF glossary to aid completion of the MDT transfer of care report
Reflective phase (RP): Actions and processes that have been undertaken are evaluated	*Aim 6 (RP):* Evaluate the outcomes from the project, i.e. the checklist, the transfer of care report and the ICF glossary *Aim 7 (RP):* Evaluate the process of developing, piloting and implementing a checklist, a transfer of care report and an ICF glossary with an acute stroke service

The aims for the exploratory phase were originally formulated by the researcher but, were discussed and agreed upon with some of the future participants, in their roles as committee members of the Stroke Oversight Committee. This occurred during the pre-project phase when applying for ethical approval. The aims needed to explore current practice first, rather than start with an ICF focus, because participants reported they did not feel fully informed or sufficiently knowledgeable about the ICF in the first instance. Therefore, the purpose of aim one and two was to demonstrate the potential the ICF had by identifying the challenges it could help overcome.

The means of collecting the data in this phase were also largely determined by the researcher but subsequent phases would become more participant-led, once ethical approval was given (see appendix 1) which meant the researcher had the relevant permissions to access the research site for greater collaborative workings.

Table 8 details the data collection methods that were used to meet the specific aims of the project. Again, the selection and develop of the methods were more researcher led in the exploratory phase but became defined by the participants as the project evolved. As evident in the table some of the data collected by tools for aim one were subsequently not used to address the project aims. The reasoning for this will be explored in the findings chapter to aid transparency of the action research project and to help illuminate some of the subsequent findings.

Table 8: Data collection methods used to meet specific project aims

Phase aims	**Data collection methods**
Aim 1 (Exploratory Phase): Identify which of the ICF domains and categories from the Comprehensive ICF core set for stroke are already addressed within the service	Documentation topic guides: a) for the analysis of the multidisciplinary team notes and; b) the medical notes to identify ICF categories currently documented by MDT (n=2086 discrete data points) Questionnaire to staff within stroke team: ICF categories currently addressed within the service
Aim 2 (Exploratory Phase): Identify the current challenges within the service which may benefit from the use of the ICF framework and classification to aid service organisation and patient care	Multidisciplinary team meeting observational tool: to identify ICF categories currently discussed by the MDT Interview topic guide with staff at the start of the project to discuss perceived communication challenges Focus group topic guide with staff at start of project to help identify their priority innovations (employing the Nominal Group Technique)
Aim 3 (Innovatory Phase) Action cycle 1: Develop, pilot, implement and evaluate an ICF checklist for use by the multidisciplinary team (MDT) during the patients' admission on the acute stroke unit. *Aim 4 (Innovatory Phase) Action cycle 2:* Develop, pilot, implement and evaluate an MDT transfer of care (TOC) report for use by the acute stroke MDT *Aim 5 (Innovatory Phase) Action cycle 3:* Develop, pilot, implement and evaluate an ICF glossary to aid completion of the MDT transfer of care report	Reflective diary, Field notes, documentation analysis (emails, STEP working party minutes) NB. used for all aims in all phases Questionnaires: a) To staff within the stroke team to gather opinions on version 6 of the TOC report b) To staff beyond the stroke team to gather opinions on version 6 of the TOC report c) To staff within the stroke team to gather opinions on version 12 of the TOC report NB: Glossary evaluated in reflective phase
Aim 6 (Reflective Phase): Evaluate the outcomes from the project, i.e. the checklist, the transfer of care report and the ICF glossary *Aim 7 (Reflective Phase):* Evaluate the process of developing, piloting and implementing a checklist, a transfer of care report and an ICF glossary with an acute stroke service	Questionnaires b) and c) Interview topic guide with staff at the end of the project to evaluate the process and outcome of the project Focus group topic guide with staff at the end of the project to evaluate the process and outcome (employed force field analysis)

4.2.2 The development of and methods used within the project

Each data collection tool for the exploratory phase was subjected to a piloting process, overseen by the researcher's supervisors and critical friend, using criteria to measure and demonstrate their effectiveness. Samples of the data collected by each tool were shared with the research participants, who were able to verify their authenticity; this process of member checking aided the transparency and trustworthiness of developing the tools (Polgar and Thomas 2001). By the end of the piloting process for the exploratory phase, not only were all the tools deemed fit for purpose but the researcher, new to qualitative data collection, had also gained experience in using them and in analysing qualitative data.

Tools for subsequent phases, prior to their use in the project, were also piloted and reviewed by experienced qualitative researchers, colleagues within the university with previous clinical experience working in multidisciplinary teams but, with one major difference. The content of, for example, the questionnaires and indeed the concept of using specific methods had been determined by the participants themselves.

Throughout the whole project, participant information sheets were provided in advance and consent was obtained for the formal data gathering procedures, i.e. the interviews and the focus groups, where a digital voice recorder was used. All data sets were transcribed verbatim. The researcher gained experience in transcribing interviews and focus groups. In the reflective phase, a professional transcriber was employed for the interview data; on receipt of the transcriptions the researcher checked each one against the relevant audio file and made corrections where regional accents and medical abbreviations had caused confusion. A copy of each transcript was sent to participants, as a form of member checking, to enhance the trustworthiness and transparency of the data collection process (Zubler-Skerritt and Fletcher 2007).

All interviews and both focus groups were conducted at the hospital, in private rooms, at a time identified as convenient to the participants. The interviews lasted between 30-90 minutes duration and the focus groups were approximately 125 minutes. At the end of each interview or focus group, once the participant had left, the researcher completed a self-reflective form (see Appendix 4) which captured the initial topics that had been shared and thoughts on the interview process. The subsequent data was used to reflect upon and refine the way the interviews and focus groups were conducted.

4.2.2.1 Topic guides for the team notes

Two topic guides were required to obtain the relevant data from the written documentation used by the acute stroke service; this was because the medical team had their own set of notes and all the other health and social care professionals wrote in the MDT files.

The purpose of the topic guides was to identify the patient related topics documented by each profession, which would subsequently be mapped, by the researcher, to the ICF categories contained within the ICF comprehensive core set for stroke (Geyh 2004).

The medical notes were written in chronological order and contained three different types of entry: 1) a collective entry, e.g. a summary from a family conference, in attendance by a number of the stroke MDT, written by one of the doctors; 2) a daily ward round entry written by one of the doctors and; 3) an entry from a health or social care professional to communicate directly to the medical team. The medical notes topic guide evolved through seven versions, the final of which is in Appendix 5.

The development of multidisciplinary team notes topic guide became more complicated because, at the same time as the exploratory phase began, the hospital Trust launched a new admissions document for use throughout each patients stay (not stroke specific). It comprised seven separate sections including admission information, assessment, functional goals, evaluation of care and discharge planning. A topic guide for each section was subsequently developed to effectively capture the relevant professions and topics documented in each section. The admissions booklet, negatively likened to a telephone directory for its size by one senior nurse, was not well received across the hospital Trust, the limitation of which will be considered in the findings. A sample of the topic guide sections is in Appendix 6.

4.2.2.2 Questionnaires

The first questionnaire (see Appendix 7) in the exploratory phase was structured on the ICF categories identified within the ICF core set for stroke (Geyh 2004), for example driving; washing and dressing; and religion and spirituality. Participants were asked to score each category for the level of involvement for each profession, on a five point scale, from always involved (score 5) to never involved (score 1). There were also options to code U (unsure) and N (not addressed within this service). It evolved through nine versions and was piloted with stroke clinicians, now working in higher education, from different professional backgrounds. The data were subsequently excluded from the project, the proactive reasons for which will be outlined in the findings chapter.

There were two other questionnaires (the same format with different introductions) used within the innovatory phase when evaluating draft versions of the TOC report: one to staff within the acute stroke multidisciplinary team and one to staff beyond the service. Both questionnaires comprised six belief statements against which respondents were asked to rate their level of agreement using the following statements: strongly agree, agree, neither agree nor disagree, disagree or strongly disagree. Four belief statements related to the content of the report: 1) the report contains relevant information; 2) I found it useful; 3) It is written in user friendly language; 4) it is easy to understand. Two belief statements asked for opinions on the report length and layout. Respondents were also invited to write additional comments if they wished. The belief statements were defined by the STEP team and the researcher (see Appendix 8 for a summary of the findings from the questionnaire sent to staff beyond the service).

Questionnaires were also used within the reflective phase: one to staff within the acute stroke multidisciplinary team and one to recipients' of the report including community colleagues, and for the first time in this project, to patients, their families and carers. The one to recipients' was the same as the questionnaires used in the innovatory phase to evaluate version six of the TOC report, but had also since been reviewed by the speech and language therapist who confirmed it was suitable in the original format for people with communication impairments post stroke. But there were minimal differences in the one to the team which was completed first; it also asked for opinions on any further changes to the report, before it was implemented into practice, i.e. sent to other clinicians, patients and relatives. This was part of the final stages of the innovatory phase where the report was being developed to a point that the acute stroke service participants wanted to pilot it in practice.

4.2.2.3 Multidisciplinary meeting (MDM) observational tool

The Multidisciplinary meeting (MDM) observational tool (see Appendix 9) was for use by the researcher, in the exploratory phase, and consisted of a column for each profession and blank spaces underneath, where the researcher would capture the verbatim topics that each professional reported on within the team meeting. This evolved through eight versions and was piloted at the hospital site. Subsequently, the plan was to map the topics discussed in the MDM to the categories within the ICF. But, later in the exploratory phase, these data were also excluded, the reasons for which will be debated and outlined in the findings chapter.

4.2.2.4 Interviews

The exploratory phase interviews (see Appendix 10 for topic guide final version number 10) asked participants for their opinions on the following topics of interest: written patient-related documentation (i.e. team notes, medical notes), formal patient-related verbal communication (i.e. team meetings, ward rounds), and informal patient-related communication (i.e. ad hoc opportunities on the unit such as during joint sessions). The interviews needed to focus on topics of interest rather than the ICF itself because, at this point in time, participants had reported they did not feel confident in their knowledge about the framework and classification. Therefore, the exploratory phase focused on topics identified as significant because they focused on communication, the aspect of team work identified in the National Clinical Guidelines for Stroke (ISWP 2002) where the ICF could be of benefit and was recommended for use.

The reflective phase interviews were different (see Appendix 11 for topic guide final version 2); some of the questions were defined from the outcome of the reflective phase focus group (see next subsection). It asked participants for their opinions on:

the pros and cons of the ICF; the outcomes of the project (i.e. the checklist, glossary and TOC report) and the factors that helped or hindered the process. As a warm down exercise, to aid reflection on the whole project and also featured in the reflective phase focus group, participants were also asked what tips they would give to other health care professionals wanting to consider implementing the ICF.

4.2.2.5 Focus groups

Towards the end of the exploratory phase (a period of approximately eight months), the nominal group technique was used as the structure for the focus group topic guide (see Appendix 12), which enabled the evaluation of individual and group strength of opinion (Steward 2001), thereby ensuring all voices were heard in the process. A single question was posed in the exploratory phase focus group, i.e. "In what ways do you think the ICF could be of benefit to the team?" On compiling a list of different ways, beginning with the list summarised from the documentation analysis, participants were then asked to award one of the following scores for each item:
0 = no, don't want to and can't do
1 = maybe, would like to and think we could
2 = yes, definitely, can do it and want to do it

The individual scores were then collated in order to gain an understanding on the collective strength of opinion.

The reflective phase focus group used a different topic guide (see Appendix 13 for final version 3) from the exploratory phase; it asked participants for their thoughts on the ICF itself, the process of developing the ICF based tools and their views on the tools themselves (the outcomes). It also incorporated a force field analysis task, i.e. asking participants to identify the forces they felt facilitated and hindered the process (Brager and Holloway 1992).

4.2.2.6 Documentation analysis, reflective diary and field notes

Throughout the fieldwork period, i.e. all the action research phases, field notes and reflections from the researcher were handwritten in A4 notebooks and amounted to five notebooks of contemporary data entries. Minutes from STEP working party meetings and all emails during this period were stored electronically. They were analysed at different stages of the project to address the different aims of the phases. Contemporary notes were taken during the STEP working party meetings and the minutes were also sent to the researcher after each meeting where the project was discussed, irrespective of attendance at the meeting.

Immediately after each interview or focus group, the researcher completed a self-evaluation form (see appendix four). After each STEP meeting or session at the hospital, the researcher reflected upon the learning in the reflective diary.

Section 4.2 has provided an overview of the aims and data collection tools developed as the project evolved. It has also been transparent in detailing how the tools were developed and acknowledged that some of the data were subsequently excluded. The next section will detail the participants and the different types of participation in this project.

4.3 Participants

As outlined in detail in the introduction chapter, the acute stroke service involved in this research project was established in November 2000. The service included the STEP team (‘Stroke Treatment for Every Person’); this was an initiative with representation from all the professions involved in local stroke care. The remit of the STEP team is to act as a working party on all service development issues, in line with the recommendations from the National Clinical Guidelines for Stroke (ISWP 2012).

There were many changes in participants during the life of the project. This was due to a high level of staff turnover, common in busy, metropolitan teaching hospitals and partly due to rotational posts. Only the consultants, the ward sister and one of the speech and language therapists (SLT) were the same people in their posts at the start and the end of the project. The ward sister and the SLT have since moved on, leaving the consultants as the only remaining staff since 2005. During the project, new staff joining the team were informed about it by the existing participants’ at the time.

Even though the STEP team was the driving force behind this project, they were not the only participants. All members of the wider acute stroke service were invited to participate and many were involved in different ways. In the reflective phase, participation was sought from recipients of the developed ICF-based transfer of care report and, to this end, participation was secured from former patients, their relatives and community therapists. Initially, the STEP team did not want to seek involvement from patients and carers until “they had got their own house in order” (field notes July 2007). Once the team were satisfied with version 12 of the ICF-based transfer of care report, the participants within the STEP team felt it was the right time to seek input from patients and their relatives. An amendment to the ethics approval was obtained to enable this to happen.

In addition, advice and input was sought from a number of people beyond the team including senior managers and information technology specialists. Creating an organisational climate, by engaging with senior managers and key stakeholders, is seen as effective to support and achieve change within stroke care (Kilbride et al. 2005).

Given the democratic nature of action research, the researcher was also a participant. A facilitative style of working was adopted, with the researcher drawing upon interpersonal skills, to enable other participants to share their own ideas and views, an approach which has been reported as effective elsewhere in health care action research studies (Bridges and Meyer 2007). Equally, it could be argued that the STEP team participants functioned as co-researchers (or co-applicants) because they owned the project and governed the direction it was undertaken.

Table 9 details the participants who chose to engage in the formal data gathering processes, e.g. consenting to interview. Other people chose informal routes of engagement throughout the project, e.g. conversations with the principal researcher, which were subsequently written in the field notes.

Table 9: Participants who engaged in the formal data collection procedures

Exploratory phase:
One-to-one semi-structured interviews (n=11) comprising: doctor, nurses (n=2), occupational therapists (n=2) , physiotherapists (n=2), speech and language therapist, clinical psychologist, carer and family support worker; social worker

One focus group (n=9) comprising: clinical psychologist; psychology assistant; speech and language therapist; dietician; occupational therapists (n=2); physiotherapists (n=3)

Innovatory phase:
Questionnaire to staff within the team (n=8) comprising: nurses (n=3); dietician (n=1); physiotherapist (n=1); occupational therapist (n=1); others, not identified (n=2)

Questionnaire to staff outside of the team (n=15) comprising: clinical psychologists (n= 7); physiotherapy (n=2); speech and language therapy (n=3); occupational therapy (n=1); others, not identified (n=2)

Reflective phase:
One focus group (n=4) comprising: dietician, speech and language therapists (n=2), physiotherapist

One-to-one interviews (n=3) comprising: clinical psychologist, occupational therapist, dietician (NB: the same dietician from the focus group who wished to expand upon some of the discussions from the focus group)

Questionnaire to staff within the team (n=8) comprising: nurses (n=3); stroke coordinator; dietician; physiotherapists (n=2); occupational therapist

Questionnaire to recipients of the report (n=9) comprising: former patients (n=3); relatives (n=3); physiotherapist; unknown (n=2)

Therefore, it is challenging to quantify the specific number of participants. Sixty-five different people consented to participate in the formal data collection procedures but, when considering the informal conversations captured in the field notes with members of the nursing team, advice and input sought and obtained from central hospital support teams, e.g. information technologists; and input from senior managers, the number of participants is closer to one hundred.

But the key issue is that, in keeping with the democratic and participatory nature of action research, all members of the acute stroke service and other stakeholders were invited to participate and individuals chose to do so as much, or as little, as they wished and in their preferred manner.

And in so doing, a substantial amount of data were gathered and the following two sections will outline the method delivery and the methods of analysis relating to the different data sets.

4.4 Methods of analysis

This subsection will explore the methods of analysis for the different types of data collected.

There were two levels of data analysis; the first was undertaken as the project evolved in order to generate knowledge-in-practice, which would inform subsequent phases (see Table 10). The second level of data analysis adopted a conceptual model of 'Immersion and Crystallisation' and was undertaken at the end of the project; this form of synthesis involves the researcher as a reflective participant who is immersed simultaneously in all of the data sets to crystallise overall findings (Borkan 1999). In this project, the researcher sought to crystallise the knowledge-in-theory, i.e. the overall theoretical and practical knowledge to evaluate the key action processes and learning points from the development of the ICF based clinical tools and the outcome of the implementation process.

While different approaches were used to analyse the knowledge-in-practice findings, the predominant form was qualitative and inductive, seeking to define emerging themes. Qualitative analysis seeks to provide knowledge and understanding of the phenomenon under study (Downe-Wamboldt 1992) and there are different approaches to undertaking it. In this project thematic analysis was the main method of choice because, its flexible and pragmatic approach (Braun and Clarke 2006) was congruent with the research aims and the nature of action research. In part this is because thematic analysis has a certain degree of epistemological freedom, i.e. it does not rely on an underlying theory such as feminism or neo-Marxism (Sandelowski 2000).

Table 10: Methods of analysis for different data sets used to inform subsequent phases (knowledge-in-practice)

Data collection method	**Type of analysis**
Key: EP = exploratory phase; IP = innovatory phase; RP = reflective phase	
Interview topic guide (EP)	Inductive, thematic analysis
Focus group topic guide, using the Nominal Group Technique (EP)	Inductive: to identify different ways the ICF could be used in the first instance Quantitative scoring to ascertain individual and group strength of opinion
Medical and therapy notes topic guide (EP)	Deductive, content analysis: 'testing' the content of the medical and therapy notes against the pre-determined categories of the ICF to quantify the content
Questionnaire to staff within the team (IP, RP)	Quantitative, descriptive stats to rate level of agreement *and* Qualitative, thematic analysis of open ended question
Questionnaire to other stakeholders beyond the team (IP, RP)	
One-to-one semi-structured interviews (RP)	Inductive, thematic analysis
Focus group using the force field analysis (RP)	Inductive, thematic analysis
Reflective diary (EP, IP, RP)	Inductive, thematic analysis
Participant based observational field notes(EP, IP, RP)	Inductive, thematic analysis
Documentation analysis: minutes from STEP working party meetings and email communications (EP, IP, RP)	Inductive, thematic analysis

In practice, data analysis was undertaken by hand, as the preferred method of the principal researcher when handling a large volume of data. Using the exploratory phase as an example, each data set (e.g. each interview transcript), was read through twice, and initial data were grouped into sub-themes. The initial sub-themes were then refined and grouped in overarching themes which became the first list of ways the ICF could be used within the service. Units of analysis (i.e. chunks of raw data from various sources) were identified from the data in relation to each overarching theme. Operational definitions were used to link each overarching theme and its associated sub-themes to the units of analysis (see Table 11).

Table 11: An example of data analysis in the exploratory phase

Overarching theme	Initial sub-themes	Operational definition	Sources (from exploratory phase data)
7. To use the ICF as a structure for a transfer of care report	7.1 All writing own reports	There is a joint occupational therapy and physiotherapy report but it is still time consuming and everyone else does their own reports. The nurse has to chase everyone in order to pull them all together before faxing them off and sometimes there is incongruent information on different reports which causes a delay.	Interview 7 pg. 4, 13, 14 Interview 9 pg. 10 Field notes pgs. 2, 38a, 38b, 92, 96, 134

The coding process, operational definitions, themes and audit trail were shared with experienced researchers to check the transparency of the process, which enhanced the trustworthiness of the data collection process (Spencer et al. 2006).

The quantitative data from the questionnaires were analysed using descriptive statistics, as deemed appropriate given the number of respondents and the intended use, i.e. to inform the overall themes.

As the project evolved and in keeping with the participatory nature of action research, the findings were shared with the participants, who confirmed their authenticity. But the researcher also shared various findings throughout the project with different audiences including an audience of experienced researchers within the Centre for Research in Rehabilitation at Brunel University, and members at a local meeting of the Action Research Network. The main purpose of sharing with the wider audiences was to aid the learning process for the novice action researcher through the articulation of the findings. The Action Research Network presentation also served to be the external support the researcher needed when considering the trustworthiness of some of the data.

4.5 Chapter summary

This chapter started with an exploration of research methods which concluded that action research was the most appropriate methodological framework to meet the aims of the proposed study. However, action research can be seen more as an approach to research, rather than a specific methodological framework, due to the varying definitions and different traditions within it. To this end, common elements were explored which confirmed it was the most appropriate approach to adopt for the proposed project, especially as evidence for its use in healthcare, including within stroke services, demonstrated its potential.

Challenges with action research were explored and these included ethical issues with an evolving project; the position of the researcher; practical challenges; managing conflict and politics and judging quality. To address the latter, ten principles were outlined that will be used for judging the quality of this project, devised from two existing sources (Zubler-Skerrit and Fletcher (2007) and Bradbury Huang (2010).

Finally, the chapter has explored the methods that were developed and used within this specific action research project and mapped these to the specific aims. The participants who engaged in the formal data collection procedures were detailed as well as a discussion on the different levels of participation. Given the democratic nature of the project, it is not possible to state exactly how many people were involved but every member of the team was given opportunities to engage at the level they wished. The final subsection summarised the methods of data analysis.

Chapter 5. Findings: knowledge-in-practice; knowledge-in-theory; theoretical generalisation

This chapter is divided into two main sets of findings. The first will outline the knowledge-in-practice findings that relate to specific aims as the different phases evolved during the action research project. The second set of findings report on the knowledge-in-theory where, using a model of crystallisation and immersion, the researcher sought to elicit the overall theoretical findings from the entire project. The chapter will close with findings and reflections in relation to the researcher.

5.1 Knowledge-in-practice findings: exploratory phase

Aim one sought to identify the ICF domains and categories which were already addressed within the service. There were four tools originally developed to meet aim one:

1) Documentation topic guide for the analysis of the multidisciplinary team notes
2) Documentation topic guide for the medical notes to identify ICF categories documented by MDT
3) Questionnaire A: asking participants to identify the ICF categories (from the core set for stroke) which they felt were currently addressed within the service
4) Observational tool for the multidisciplinary team meeting (MDM)

As outlined in chapter four, all of the tools been developed to the point they were deemed suitable but, it was not until the data collection process was underway, it became apparent that questionnaire A and the MDM observational tool were not fit for purpose. A proactive decision was made to exclude data from them. This finding will be briefly explored first because it occurred early on in the project and in order to enhance the transparency of the research process, by highlighting an example of critical thinking, reflexivity and rigour within the project.

5.1.1 Making the proactive decision to discard some data

The data from the exploratory phase questionnaire (see Appendix 7) were excluded because the response rate was very low (three from eighteen; a response rate of 16%) and so did not represent a wide range of opinions. In addition, only one of the three questionnaires was fully completed and a respondent from one of the incomplete questionnaires wrote on it that it was too long. Examples A1 and A2 in Dialogue box A outline further, data that supports the decision not to use the questionnaire data to inform the subsequent innovatory phase.

Dialogue box A: Deciding to discard the data from the questionnaire and the multidisciplinary meeting observational tool

A1) "Psychologist tells me "The questionnaire is a bit difficult, I must stop thinking about what people should do" (rather than what they actually do)." *2nd April 2007 Reflective diary*

A2) "Spoke to the social worker today who said the questionnaire was taking longer than the 30 mins advised. Need to discuss with supervisors, is there a wider problem here?" *30th April 2007 Reflective diary*

A3) "They (MDM) have been more concise recently but so long as everyone feels they are getting to say what they can say but I wonder if everyone does." *Interview one pg. 29*

A4) "…There are always issues and a lot of that is down to personality really – I may not feel as confident around one person, nothing to do with the service but more about the two individuals. I mean, it may be perceived that MDM in not confrontational you know, but I might feel like it is." *Interview two pg. 24*

A5) "I'm beginning to question the value of using MDM data for research aim to identify areas covered within the service. Discussion with psychologist today "In MDM we don't really feedback on everything – it's not a true reflection of what we do." *19th Feb 2007 Reflective diary*

While the decision to exclude the questionnaire data was relatively straightforward, the decision to exclude the data from the multidisciplinary team meetings (MDMs) was a challenging one. It was the original intention to use the data to map which members of the team verbally reported on individual domains within the ICF. However, in practice, it transpired that not every professional was able to attend every meeting, especially lone representatives of professions who worked part time, e.g. the part-time psychologist. Examples A3, A4 and A5 in Dialogue box A highlight other data which also led to the decision to discard the data from the MDM observations.

In short, there were issues around attendance at the meeting, the perceived inequality of time for each professional to present their views and the confidence of individuals which impacted on the verbal reporting in the MDM; these factors undermined the validity of collecting data for aim one. By this point in the exploratory phase, a substantial amount of data had been collected but, as a novice action researcher, there was concern about not using it.

This challenge was discussed in supervision and also taken to the local Action Research Group Meeting where a productive discussion ensued with experienced action researchers. They acknowledged the evolving nature of action research projects often meant that it was not possible, at the outset, to predict if all the data collection methods were going to be appropriate and this was one such example. It was recommended that the data should be excluded from the research while ensuring transparency about the reasons for so doing. Furthermore, one person commented that the process of data collecting in the MDMs may still prove valuable even if the findings were not.

In summary, there were limitations with the data actually collected by the exploratory phase questionnaire and the multidisciplinary meeting observational tool, which led to the pro-active decision to discard them. Nonetheless, the process of gathering the data could still evolve as a useful process within the action research project. The next subsection will explore the findings elicited from the two other exploratory phase tools that worked in practice, namely the multidisciplinary team documentation topic guide and the medical notes topic guide.

5.1.2 Most ICF categories were documented by the MDT but not in a systematic way per patient and some were missing

In the first instance, the researcher mapped the data from twenty sets of medical notes and twenty sets of multidisciplinary team notes to the relevant ICF domains. Table 12 highlights an example of the data mapping process. From this it is possible to see how one single entry from a professional comprises a number of data points; in the example, from one entry by the physiotherapist, there are four data points relating to three different ICF domains. On sharing this with the participants, they requested they would like to see the data mapped to the ICF category level as well.

Table 12 also shows how the same single entry from the physiotherapist subsequently contained four data points mapped to four different ICF categories, thus providing a greater level of detail for the participants, at their request. This early example of participants directing the work of the researcher suggests they were taking ownership of the project from early on in the exploratory phase.

In total, there were 2086 discrete data points. Where it was unclear about which ICF category to match a particular notes entry to, the definition was clarified using the ICF text (WHO 2001) and a record made of the decision, in order to enhance the trustworthiness and consistency within the data collection process. Clarification of any jargon or abbreviations that were unfamiliar to the researcher was sought from the relevant health care professional, but prior clinical experience in the setting proved helpful to understand local abbreviations.

Table 12: An example of the mapping process for aim one of the exploratory phase

<table>
<tr><th colspan="3">Raw data from MDT notes 10, section 2 by the physiotherapist:
<i>SOEOB with AO2. Used RZF + AO2. Mob 2m to toilet, improved gait</i>
<i>Codes: prefix ‘d’ = activities and participation; prefix ‘e’ environment as coded by WHO</i></th></tr>
<tr><th>Discrete data points within raw data</th><th>ICF domain</th><th>ICF category</th></tr>
<tr><td>SOEOB with AO2 (translates as ‘sat over edge of bed with the assistance of two people’)</td><td>Mobility</td><td>d415 Maintaining a body position</td></tr>
<tr><td>Used RZF + AO2 (translates as ‘used rollator zimmer frame with the assistance of two people’)</td><td>Products and technology</td><td>e120 Products and technology for personal indoor and outdoor mobility and transportation</td></tr>
<tr><td>Mob 2m to toilet (translates as ‘mobilised 2 metres to the toilet’)</td><td>Mobility</td><td>d450 Walking</td></tr>
<tr><td>Improved gait</td><td>Neuromusculoskeletal and movement related functions</td><td>d770 Gait pattern functions</td></tr>
</table>

Seventy two percent of the ICF categories were identified within the analysis of the notes. The findings were incorporated into a small summary booklet (see Appendix 14) and shared in a variety of ways to maximise the level of engagement including: feedback to the STEP team, informal ad hoc conversations on the ward, attending three nursing handovers and in-service teaching attended by most of the therapists. Copies of the booklet were also left on the unit, e.g. on the notice board.

Tables 13, 14 and 15 outline the findings of the documentation analysis, i.e. the details of which ICF categories were addressed or not addressed. Entries from the reflective diary and field notes are also used as findings, to illuminate some of the discussion points that were raised when sharing the information with the team. Appendix 14 provides the details of the individual ICF categories that were addressed in the service where the tables denote 'all addressed'.

Table 13: The outcome of the documentation analysis for Body Functions and Structures

ICF domains within the Body Functions and Structures component	ICF categories: number addressed or not addressed as determined by the documentation analysis
Mental functions	17/18 addressed Not addressed: 'Calculations'
Sensory functions and pain	All 9 addressed
Voice and speech functions	All 4 addressed
Functions of the cardiovascular, haematological, immunological and respiratory systems	All 8 addressed
Functions of the digestive, metabolic and endocrine systems	All 8 addressed
Genitourinary / reproductive functions	1/3 addressed Not addressed: 'Sensations associated with urinary functions'; 'Sexual functions'
Neuromusculoskeletal and movement-related functions	8/9 addressed Not addressed 'Stability of joints'
Functions of the skin	1/1 addressed

The reflective diary entries indicated that the participants were not surprised that the body level issues were well represented in the notes, as they felt the main focus of the acute stroke service was to stabilise and manage the initial impairments post stroke. However, when sharing this information with the acute stroke team, they acknowledged they were also not surprised that sexual functions was not covered, as they felt this was a grey area in terms of identifying which member of the team should deal with this delicate issue.

Table 14: The outcome of the documentation analysis for Activities and Participation

ICF domains within the Activities and Participation component	ICF categories: number addressed or not addressed as determined from the documentation analysis
Learning and applying knowledge	5/12 addressed Not addressed: Watching; Listening; Other purposeful sensing; Copying; Rehearsing; Acquiring skills; Calculating.
General tasks and demands	1/4 addressed Not addressed: Undertaking multiple tasks; Carrying out daily routine; Handling stress and other psychological demands.
Communication	All 8 addressed
Mobility	9/12 addressed Not addressed: Lifting and carrying objects; Fine hand use; Moving around using transportation.
Self-care	All 7 addressed
Domestic life	1/3 addressed Not addressed: Acquisition of goods and services; Doing housework.
Interpersonal interactions and relationships	3/4 addressed Not addressed: Intimate relationships.
Major life areas	None of the 6 categories addressed
Community, social and civic life	2/4 addressed Not addressed: Community life; Human Rights.

There were a number of activities and participation categories not covered within the notes analysis. The participants were not surprised by the lack of coverage regarding intimate relationships for the same reason as sexual functions was not represented.

However, sharing this table facilitated a discussion about ‘Learning and Applying Knowledge’, an ICF domain which some participants were surprised was not covered; this is also an example of how key learning was occurring in action. One participant felt the team always considered it implicitly, to establish rehabilitation potential, but probably did not communicate this in written documentation. So, the use of the ICF domain headings in practice could help make explicit communication. On this topic, this is an example of how the work in the exploratory phase also helped participants, unfamiliar with the ICF at the start of the project, to appreciate its potential for use in the future.

It was felt the lack of coverage for Major Life Areas reflected the nature of the service since it had become an acute stroke unit. Participants felt that it could still be useful to contribute information on this area to justify referring on, as part of recommendations for on-going rehabilitation.

Therefore, the process of sharing the findings for aim one began to facilitate discussions about the need for change. This would ultimately help inform aim two, i.e. to identify the current challenges within the service which could benefit from the use of the ICF and shape the innovations in the next phase.

The participants felt the areas not addressed within the Environmental component also reflected the ward based nature of their work, although it was raised that some of the language within this component felt unfamiliar. Indeed, as the project progressed, comments were raised about some of the other domain headings and this will be explored in section 5.2.1.

Table 15: The outcome of the documentation analysis for Environmental Factors

ICF domains within the Environmental Factors component	ICF categories: addressed and not addressed within as determined by the documentation analysis
Products and technology	2/5 completely addressed. 3/5 partially addressed but some missing. Not addressed: Products for transportation; Products for employment; Design of buildings for public use; Assets.
Natural environment	None of the 3 categories addressed
Support and relationships	5/10 addressed Not addressed: Support and relationships with: Acquaintances; Peers; Colleagues; Neighbours; Community members.
Attitudes	7/13 addressed Not addressed: Attitudes of: Acquaintances; Peers; Colleagues; Neighbours; Community members; Societal attitudes.
Services, systems and policies	4/9 addressed Not addressed: Services relating to: Architecture and Construction; Transportation; Legal system; Associations; Employment services.

At the end of sharing the findings at the STEP meeting, the participants confirmed they felt all three tables showed an accurate representation of their work remit and during the information sharing sessions for aim one, they began to reflect upon specific ways the ICF could be helpful as a structure within their service. For example:

> "*Sister said that it would have been useful to have the list (i.e. ICF domain headings) by the nurses' station yesterday. She took a telephone call and was caught off guard. X was calling from the inpatient rehabilitation unit, asking her why they had referred patient A; he was able to walk so they didn't understand why they needed inpatient treatment. Sister said "If we'd had that list, I would have rattled off, because he has problems with this, this, this and this! That would have told them!".* (Field notes 28th June 2007)

Discussions about the potential use for the ICF continued in subsequent STEP meetings. Field notes from a meeting in July 2007 captured one of the members stating: "*… this could become more about hijacking the ICF as a vehicle to drive through some changes! I think we just need to keep in touch."* (Field notes 6th July 2007). The significance of this comment would be realised upon full immersion in all of the data sets once the field work had finished. It will be returned to in the discussion chapter, in section 6.1.1.

The findings demonstrated that whilst 72% of the ICF categories were addressed within the notes, they were not considered in a systematic fashion, i.e. the data represented the appearance of the information on one or more occasion only.

To summarise, aim one sought to identify the ICF domains and categories which were already addressed within the service. After discarding the data from the exploratory phase questionnaire and the MDM observational tool, the aim was met through the analysis of the medical notes and multidisciplinary team notes and the discussion that ensued from sharing the information, captured in the field notes and reflective diary. Over 2000 data entries comprised the analysis which showed that 72% of the ICF categories were addressed within the service, albeit not systematically. The focus of the entries tended to be at the body functions and structures level. Presenting this data to the participants helped to facilitate dialogue on what they chose to document and also helped to raise awareness of the potential of using the ICF classification which relates to the findings for aim two, as outlined next.

5.1.3 Participants identified 14 ways the ICF could potentially benefit the service and chose to work on 3 of these

The following data collection tools were used to address aim two in the exploratory phase: the interview topic guide (the same guide as used for aim one); a focus group topic guide (using the nominal group technique); a reflective diary and participant based observational field notes.

The activity in the interview topic guide, where participants had to read verbatim entries from the notes and identify which profession wrote it (see Appendix 15), appeared to raise awareness of the challenges with the current method for documentation, as one physiotherapist commented:

> *"Oh, this must be written by a physio, it's full of abbreviations ... gosh, when you look at it like that it makes you realise just how undecipherable... notes can be!" (*Interview 11 pg. 7).

Furthermore, of the 11 interview participants, only the doctor could correctly identify the profession of each author and fully understand the content of each entry. Therefore, this activity highlighted a challenge with the current method of written communication; health care professionals did not fully understand the content of their colleagues written entries in the team documentation.

The researcher did not want to rely too heavily on interview data to address the exploratory aims; participants in the interviews would be a self-selecting group and only a small percentage of the whole team. A wider participatory approach was essential in order to enhance the democratic nature of the decision making process. Therefore, a flexible approach was required to attempt to engage with as many members of the acute stroke multidisciplinary team as possible.

The data from the interviews, the reflective diary and the participant based observational field notes collected at that point in time (i.e. when all the interviews had been conducted) were analysed in relation to aim two. Seven themes, as listed below, were defined as the current challenges to the service and were presented back to the team as ways the ICF could help (not in ranked order):

1) To help define which professionals take the lead in different areas of care to assist organising the patient journey.
2) To guide areas for care planning and goal setting.
3) To help define what the service is able to offer in its acute capacity.
4) To help make decisions about a patients rehabilitation needs, e.g. to communicate their rehab agenda when referring on.
5) To help describe the impact and complexity of stroke.
6) To use the terminology as a common language within the team and beyond.
7) To help structure note writing and meetings.

Table 16 outlines the themes and subthemes related to the two projects subsequently selected and refined for the innovatory phase by the participants, i.e. point six and seven from the list above.

Table 16: The themes and subthemes which relate to the subsequent innovatory phase projects

Overall emerging themes six and seven for aim two: ways the ICF could help within the service	The subthemes of issues raised within theme six and seven
Theme 6) Use as a common language	Other people's jargon is difficult to read; Abbreviations are not always clear.
Theme 7) Structure for notes and meetings	There is no set way to communicate; Not sure if the notes and MDMs are inclusive; Everyone has different styles of writing; We are all writing our own reports and don't always see each other's; There are different places to write and look for information and this can be time consuming; there is a lot of repetition; The structure of notes is not always clear.

Towards the end of the exploratory phase, participants were invited to a focus group employing the nominal group technique. Nine participants represented the following professions: psychology (n=2); dietetics (n=1); physiotherapy (n=3); occupational therapy (n=2). Nursing cover had been arranged on the unit to enable the nurse in charge to attend; however an emergency situation on the unit meant this did not happen. The junior doctors had rotated the previous week and relationships had not been formed with the new team, nor had they benefitted from the experiential learning to date. The consultants did not reply to the invitation to attend, or the reminder. This example shows that finding communicative space with the nurses and doctors remained a challenge throughout the exploratory phase.

The seven ways that the ICF could benefit the service were used as the starting point of the discussions and through the process of the group, another seven ways were identified. At the end of the nominal group process, participants were asked to vote on their preferences from the list of fourteen ways to use the ICF, using the following scale:

- 0 = no, don’t want to and can’t do;
- 1 = maybe, would like to and think we could;
- 2 = yes, definitely, can do it and want to do it.

Table 17 outlines the individual and group scores, which gave an indication of the weight placed upon each idea from the participants. The data is ranked in terms of preference as indicated by the highest group score.

Table 17: The outcome of the focus group, using the nominal group technique, to identify ways the ICF could benefit the service

Idea for use (in order of priority as scored by the participants from the discussion session)	**Individual scores 0, 1 or 2**	**Group total (max 18)**
Scores: **0** = no, don't want to and can't do; **1** = maybe, would like to and think we could; **2** = yes, definitely, can do it and want to do it.		
1. "To help define what the service is able to offer in its acute capacity"	1(n=3); 2(n=6)	15
2. "To communicate a patient's rehab agenda when referring on"	1(n=3); 2(n=6)	15
3. "To structure an MDT discharge report"	0(n=1); 1(n=2); 2 (n=6)	14
4. "To identify gaps in the current service provision and target areas for development either within the team or, to see who else can / does offer a particular service to meet a patient's needs"	1(n=5); 2 (n=4)	13
5. "To guide areas for care planning and goal setting"	1(n=5); 2 (n=4)	13
6. "As a flow chart to guide decision making when referring on"	1(n=6); 2 (n=3)	12
7. "To use in the multidisciplinary team meeting to enhance the structure and provide a written record"	0(n=1); 1(n=5); 2 (n=3)	11
8. "As a laminated prompt at the front of the MDT notes to use as a ready reference"	0(n=1);1(n=5); 2 (n=3)	11
9. "To use as language within the MDT notes"	0 (n=1);1(n=6); 2 (n=2)	10
10. "For structure in care booklets (as a checklist to see everything is covered), e.g. when a person is being transferred to a nursing home for long term care"	0(n=1); 1(n=7); 2 (n=1)	9
11. "To help define which professionals take the lead in different areas of care to assist organising the patient journey"	0 (n=1);1(n=8)	8
12. "As a 'one stop' record of the MDT plan"	0(n=2); 1 (n=7)	7
13. "To structure an induction booklet for new staff and students"	0(n=3); 1(n=6)	6
14. "As a pocket guide for staff to use as a ready reference"	0(n=6); 1 (n=3)	3

The outcome from the focus group was shared with the rest of the team via email, at a STEP meeting, through discussions on the unit and a poster display. Participants decided to work on the third and eighth most popular outcome, i.e. to use the ICF to structure an MDT discharge report (subsequently referred to as 'Transfer of care (TOC) report' or 'the report') and as a laminated checklist at the front of the MDT notes, the exact nature of which would evolve once in place. The reasoning for the report choice was captured in the minutes from the STEP meeting:

> *"The team felt that the best way to move forward would be to look at a discharge report. By focusing on this, the remit of the service and communicating rehab needs would also be addressed…given the move to electronic records... it would be very beneficial to have a template document to see contributions from other professions."* (STEP meeting minutes 14th September 2007).

However, the minutes did not record the reasoning behind the choice of the checklist, although the field notes indicated that participants thought there was potential for it to be used to structure the multidisciplinary meetings and for goal planning. The intention was to place the checklist at the front of the multidisciplinary team notes which were taken to MDM's and goal planning sessions, therefore would be an accessible resource in these meetings.

The researcher had planned to share the focus group findings and have further discussion with the STEP team in August 2007, but the meeting did not occur until mid-September. The reason for the change in date suggests the continued participant ownership of and enthusiasm for the project:

> *"Hi Steph, We realised in STEP meeting today that there won't be many people around next week when you were planning to come... everyone is really keen to be there so we wondered whether it would be better to postpone to a STEP when more people are around?"* (Email from STEP team member 3rd August 2007)

So, by the end of September 2007, the two projects had been selected and plans were in place to begin the innovatory phase. However, in reality, the exploratory phase continued beyond the parameters outlined in this section and later on in the research process, as will be described in the innovatory phase, the participants chose a third project, which was to produce an ICF glossary to aid completion of the transfer of care report.

In summary, aim two sought to identify the current challenges within the service which could benefit from using the ICF classification. The process of data gathering included formal methods (interviews and a focus group) as well as informal methods, e.g. conversations and contextual observations captured in the reflective diary and field notes, although creating the space for informal communication was sometimes difficult. By the end of the exploratory phase, fourteen ways to use the ICF were identified. Through a process of sharing and discussing the ways, the team identified two projects they wished to work on, i.e. to develop a multidisciplinary team transfer of care report and a laminated checklist to sit at the front of the MDT notes, the use of which was to evolve. Later on, a third innovation was added as the team also chose to develop an ICF glossary to aid completion of the transfer of care report. It will be debated if indeed this is a third innovation or, through engagement in the action research process, an evolution of the checklist.

5.2 Knowledge-in-practice findings: innovatory phase

Unlike the exploratory phase, there were no data excluded from this phase or the reflective phase. The likely explanation for this was the transfer of ownership of the project; the exploratory phase was researcher led, as part of demonstrating the need for change and how the ICF could help the service. However, the aims and projects within the innovatory phase had been chosen, therefore owned, by the participants, who also decided which data and tools were needed as part of the research process. In short, the STEP team had become co-researchers and the wider team were participants who provided feedback which their colleagues brought back to the STEP meetings.

The change in ownership was reflected by comments made by the participants during STEP meetings. For example, one clinician commented that it was "*nice for us to have you to do our donkey work as we don't have the time to change templates like you do!"* (Reflective diary entry: referring to the TOC report template).

The next section will explore the knowledge-in-practice findings relating to the innovations. It will begin with the TOC report, followed by the checklist and the glossary.

5.2.1 The ICF-based transfer of care (TOC) report evolved through 14 versions and was successfully implemented into practice, with the help of external feedback prompting honest discussion about concerns with some of the ICF language

To develop the content within the report, the STEP team met to examine the ICF itself first including the complete text and the ICF core sets for stroke; the latter had been developed to aid the clinical utility of the complete ICF classification (Geyh et al. 2004). However, the participants considered the twenty-two ICF domain headings within the complete ICF sufficient as the level of detail for their clinical use, rather than utilising all the categories within the ICF core sets for stroke (Geyh et al. 2004). Therefore, the core set for stroke was quickly dismissed, a point which will be explored in the discussion.

The process of developing the report evolved through fourteen different versions with a small pilot of version six in practice. Versions one, six and fourteen (final) are in appendices 16-18 respectively.

The report needed to have clinical utility and meet all contemporary guidelines so key documents were referred to for other headings and information that needed to be included in the report including: the Sentinel Audit Tools (RCP 2006); the National Clinical Guidelines for Stroke (2nd edition; ISWP 2004); and Profession Specific audit tools for stroke (ISWP 2007).

At the participants' request, the researcher produced a first draft template and a completed first version (using a fictitious in-patient). The wording used in the fictitious report mirrored the wording and terminology extracted from the notes analysis in the exploratory phase, to aid authenticity of the example draft report. Versions one and two were shared with the researchers' critical friend and supervisors who suggested alterations to the layout and the wording. Version three was e-mailed to the STEP team prior to the researcher attending the weekly meeting.

At the STEP meeting, the team shared their concerns about the challenge of making the report inclusive of all members of the MDT, as per the original intention. They had spoken to the Consultant who reported that he was not aware of the project and the rest of the team felt that he was not keen to be involved. They appeared despondent, but on discussion felt that, rather than abandon the project, they should proceed with the report as a joint nursing and therapy report rather than an inclusive MDT report.

Relevant changes were made to the template to reflect the lack of representation from the medical profession, who subsequently had no further input into the project. Interestingly, later on in the innovatory phase, it transpired that losing the input from the doctors was not necessarily due to the influence of the Consultant; the medical team had in fact been instructed to use a Trust-wide discharge report, to be used in part by the Finance department for costing. Therefore, it was likely there were a number of reasons for losing the doctors from the project, one being that contributing to an additional MDT discharge report would increase their workload, providing little incentive for them to use it.

Over the course of the next few months, changes were made to produce versions three to seven of the report. For example, following discussions it was decided to remove the name of the professions next to each ICF domain in version seven. Some clinicians worked part-time and did not see every patient on the ward, therefore they felt the inclusion of the professions next to each domain may raise expectations above the service level they were able to provide.

The STEP team decided that, at version five, they wished to share it with the wider acute stroke MDT, in order to engage the whole team and enhance ownership of this part of the process; this was done informally through discussions with their colleagues. The feedback from the informal discussions shaped further alterations and the participants decided to seek opinions from their colleagues outside of the acute stroke service on version six, using one of the developed questionnaires (see Appendix 8). The reasoning behind the desire to share widely at this stage was not fully understood by the principle researcher at the time.

In addition, an opportunity arose for the team to seek opinions from future recipients, at a meeting with therapists from one of the local rehabilitation hospitals. The questionnaire was also sent to colleagues within one of the community teams and line managers of the stroke team staff who did not carry a caseload within the acute stroke service. In total, thirty questionnaires were sent (with a cover letter and a stamped addressed envelope to the researcher). Nine replies were received (one psychology, two physiotherapists, three speech and language therapists, one occupational therapist and two unknown). The reply from psychology was a summary of a discussion from seven clinical psychologists, but treated as one response here; the findings from all responses are outlined in Table 18.

Table 18: Opinions from colleagues (n=9) outside of the stroke team on version six of the MDT transfer of care report

Statement	**Strongly agree**	**Agree**	**Neither agree or disagree**	**Disagree**	**Strongly disagree**
The report layout is easy to follow	0	4	2	3	0
It contains relevant information	2	6	0	1	0
I found it useful *NB: data missing x1*	1	3	4	0	0
It is written in user friendly language	0	3	1	5	0
It is an appropriate length	0	4	0	5	0
It is easy to understand	0	4	1	4	0

Colleagues from outside of the stroke team had mixed opinions on version six. While most agreed the information was relevant and the report was useful, opinions were divided on the nature of the language and its clarity. The qualitative statement *"Please write any additional comments about this report if you wish"* offered further insight (see Table 19). Whilst the respondents supported the concept of a multidisciplinary team report, they felt some of the terms were either overused or unclear.

Table 19: Comments from the free text question from colleagues (n= 9) outside of the stroke team on version six of the MDT transfer of care report

Positive:	***Negative:***	***Suggestions:***
Like the idea of a joint report A positive direction A very nice and holistic report All relevant information was included Concept is good Simple to understand	Very long (n=6) Overuse of the word 'functions' in the headings Functions of the skin = should be skin condition	Does 'cognitive functions' need a definition for the clients? May need to define 'Major life areas' Could the admission and discharge be combined under each section?

At the following STEP meeting, the researcher felt a growing sense of frustration with the project; the exact nature and reasons were difficult to elucidate until the mixed feedback from the colleagues outside of the service was shared. This appeared to have an enabling effect on the participants and led to a frank discussion on the actual terminology within the ICF.

Prior to this, only one participant, a part-time lone working therapist had explicitly raised concerns about the ICF language. It had led to changes in the wording of 'mental functions' in the abandoned checklist, but the change had not filtered through into the report template. But, following external feedback, more participants in the team raised the issue that, like some of the questionnaire respondents, they also felt uncomfortable with some of the ICF terms. A debate ensued, as other participants within the STEP team were unsure if it was appropriate to change language that had been set as an international standard by the World Health Organisation (WHO). However, the researcher suggested that if the ICF language did not feel suitable then consideration should be given to changing it; the team were reminded the WHO acknowledge the evolutionary nature of the ICF and also noted the success of it depended on its uptake in practice. Therefore, changes could aid revisions to the ICF in the future and could be seen as an interesting research finding in itself.

After further discussion, it was decided that any terminology which the participants were unhappy with should be changed and during the rest of the innovatory phase, it was changed a number of times. Versions six to the final version (version 14) of the report evolved quickly and Tables 20, 21 and 22 summarise the ICF domain headings, and the changes to the wording, according to the different component levels (body functions, activities and participation and environmental factors).

Table 20: The changes made to the ICF terminology by the participants on the TOC report: Body Functions component

ICF domain headings for Body Functions	Amended headings on final version of report
Mental functions	Cognition (thinking abilities)
	Alertness and motivation
	Mood and behaviour
Sensory functions and pain	Sensory systems and pain
Voice and speech functions	*Not included at body level: incorporated into activities and participation. Replaced by:* Swallowing
Functions of the cardiovascular, haematological, immunological and respiratory systems	Cardiovascular, haematological, immunological and respiratory systems
Functions of the digestive, metabolic and endocrine systems	Digestive, metabolic and endocrine systems
Genitourinary / reproductive functions	Genitourinary / reproductive systems
Neuromusculoskeletal and movement-related functions	Neuromusculoskeletal system and movement
Functions of the skin	Skin condition

The division of mental functions into three separate headings was deemed necessary to communicate the specific nature of any residual impairments. It also removed the word ‘mental’ from the report; one participant raised concerns that the term was misleading and could cause confusion for a person discharged from the ward following a stroke, i.e. they may think they were suffering with a mental illness as well. The other participants agreed and the term was changed. Some of the terms were also simplified which included removing the word ‘functions’. For example ‘Functions of the skin’ (four words) was renamed ‘Skin condition’ a move supported by the Speech and Language Therapist; fewer words to communicate the same topic would benefit receivers of the report with mild to moderate language difficulties following a stroke.

Table 21: The changes made to the ICF terminology by the participants to the TOC report: Activities and Participation components

ICF domain headings for Activities and Participation component	**Amended headings on final version of report**
Learning and applying knowledge	Learning and applying knowledge
General tasks and demands	Managing daily routine and structure
Communication	Communication (including voice and speech)
Mobility	Mobility
Self-care	Self-care (including medication management)
Domestic life	Domestic tasks
Interpersonal interactions and relationships	*Removed. Incorporated into Environmental factors*
Major life areas	Education and / or work needs
	Finance management
	Religion and spirituality
Community, social and civic life	Recreation and leisure

Major life areas was divided into three separate sections, all of which feature in the second level detail of the ICF. General tasks and demands was deemed unclear and replaced with ‘Managing daily routine and structure’, a heading which implied multi-tasking and also present in the second level detail of the ICF.

Table 22: The changes made to the ICF terminology by the participants to the TOC report: Environmental factors component

ICF domain headings for Environmental component	**Amended headings on final version of report**
Products and technology	Equipment
Natural environment	Home environment
Support and relationships	Support and relationships
Attitudes	*Removed. Team felt it was implicit within ‘support and relationships’*
Services, systems and policies	*Removed. Team felt it was not required as a separate heading as it was incorporated into the recommendations for on-going rehabilitation section later on in the report*

The Environmental factors component underwent significant changes and reduced to three headings which were felt to better reflect the focus of the acute stroke service. The use of the word ‘Equipment’ instead of ‘Products and Technology’ reduced the number of words but also adopted a word commonly used and understood within local practice. This is an example of how some existing words already had universal acceptance within practice therefore the participants felt it was of little value to change them.

In addition to gathering opinions on version six, a small pilot of the report was undertaken with two patients that were due for discharge from the stroke unit. Significant logistical problems were highlighted in addition to the difficulties understanding, therefore using, the ICF language. These will be considered next as the practical difficulties negatively impacted on the timespan in which the ICF was eventually implemented into clinical practice.

The logistical difficulties centred on the format of the report. Initially, version six was an electronic copy which was e-mailed around to different members of the team to add their sections. This was too time-consuming for the acute service staff and it was difficult to keep track of which version was the master copy. Version seven was a handwritten template and the Consultant's temporary secretary agreed to type it up on completion. Access to the handwritten report was difficult; many staff preferred to write the report away from the unit and the Consultant's permanent secretary, on return from leave, felt unable to take the additional workload of typing the report.

The participants felt that the imminent introduction of the new electronic records system (LC1) could help resolve the logistical issues; therefore a decision was made to continue to develop a report template that was fit for purpose for use in the future. Development work continued with various changes to layout and wording, as version six evolved through to version eleven.

A previous version of the report had been informally shared with the wider stroke MDT, but now the participants felt sufficiently content with version eleven and wished to gather opinions more formally using a questionnaire. The questionnaire differed slightly from the one previously used with version six to gather opinions from colleagues outside of the team with two changes: 1) The statement 'I found it useful' was replaced with 'If I was working in another team, I would find the report useful'; and 2) An additional belief statement was added 'If I was a patient or carer, I would find the report useful'. The participants decided on these two changes to reinforce the different purposes for the report to the wider team.

A copy of version eleven was sent to each member of staff with a cover letter and stamped addressed envelope (n=30) to be returned to the researcher. There were eight replies (three nurses, two other, one dietician, one physiotherapist and one occupational therapist). Table 23 shows their responses to the belief statements:

Table 23: Opinions from colleagues (n=8) within the stroke team on version eleven of the MDT transfer of care report

Statement	**Strongly agree**	**Agree**	**Neither agree or disagree**	**Disagree**	**Strongly disagree**
The report layout is easy to follow	5	1	1	1	0
It contains relevant headings	4	3	0	1	0
If I was working in another team, I would find the report useful	5	2	1	0	0
It is written in user friendly language	2	6	0	0	0
It is an appropriate length	4	3	1	0	0
It is easy to understand	3	5	0	0	0
If I was a patient or carer, I would find the report useful	5	2	1	0	0

Respondents this time felt the report was written in user-friendly language and easy to understand. Therefore, whilst gathering responses from a different group of people, it appeared the substantial changes to the wording had a positive impact.

The comments from the qualitative statement *"Please write any additional comments about this report if you wish"* shaped the changes to the final version and are outlined in Table 24:

Table 24: Comments from the free text question from colleagues (n=8) within the stroke team on version eleven of the report

Positive:	***Negative:***	***Suggestions:***
This looks easy to use as we can start it on admission Language much easier to understand – it will become more systematic once used in practice Structure looks clear Overall, I like it	It looks a bit long	I prefer 'domestic tasks' to 'domestic life' Need a box for 'managing daily routine and structure' Consider separating education and work with religion and spirituality

The changes recommended by the wider team were incorporated into version twelve and the team used this version for the large scale pilot. Versions thirteen and fourteen evolved after using the report for the pilot; the changes were aesthetic and completed by the Medical Illustrations team to comply with Trust rules on presentation and layout.

It was now March 2008 and the plan was to implement version twelve of the report into practice for a full-scale pilot. However, it was at this point, that another, unforeseen logistical problem occurred and ultimately took the piloting process of the report into the following calendar year.

As previously mentioned, the Trust had been selected as the pilot acute hospital for the launch of the NHS electronic records system (Brand name Cerner LC1, hereby known as LC1). The launch of LC1 had originally been scheduled for October 2007 but in practice it did not occur until April 2008; by coincidence around the same time that version twelve of the report was ready for the pilot.

The introduction of LC1 had always been considered during the evolution of the project, as it had been raised as a potential issue when seeking advice from the head of the Therapy Documentation Working Party. Advice had been sought from the LC1 development team who confirmed that the report template could be uploaded to the system and used as a ‘live’ document, i.e. individual team members could add their sections onto the report using the LC1 system. However, once the system was launched, it became apparent that the functionality of LC1 was not as sophisticated as had been led to believe; it could only cope with completed documents, not live templates. At the STEP meeting, the participants were extremely disappointed and felt that all their efforts to develop the report template had been wasted.

However, one of the senior managers, the Matron of Neurosciences, was also present at the STEP meeting. Previous engagement with Matron meant she was already aware of the project. She informed the rest of the team that there was a solution to the problem. The Neuroscience consultants had a confidential shared drive on the hospital intranet, which they used to complete their reports. Matron suggested the stroke multidisciplinary team could discuss this with the Information Technology (IT) team, who could set up a similar drive. The template of the report could be stored and treated as a live document from the drive and once completed, could be uploaded to LC1.

The rest of the STEP team were encouraged by this solution and over the next nine months, the stroke coordinator worked with the IT team to organise the confidential shared drive for the stroke multidisciplinary team. Once this was in place, version twelve of the report was piloted in practice, with aesthetic changes made on two occasions following completion of the pilot.

Finally, by September 2009 version fourteen was implemented into practice. But there was one final significant change. At the STEP meeting before the pilot of version twelve, the Ward Sister reported that, although the nursing team had been instrumental in the development of the report and were keen to use it, they were not going to be able to do so. The Trust had announced the introduction of a Nursing Discharge Report and, similarly to the report used by the Doctors, the Nurses within the acute stroke multidisciplinary team were expected to use the Trust wide documentation. Therefore the report became a therapy transfer of care report as the nursing staff also had to leave the project.

Version twelve of the report was evaluated using a survey to recipients. A questionnaire, cover letter and stamped addressed envelope was sent to the first thirty recipients including former patients, their carers and other health care professionals, e.g. when referring on to the community teams. There were nine respondents (two unknown; one physiotherapist; three relatives; and three former patients). The scores for each belief statement are in Table 25.

Table 25: Belief statement findings on the transfer of care report used in large scale pilot to recipients

Statement	**Number of responses per category (n = 9)**				
	Strongly Agree	**Agree**	**Neither agree nor disagree**	**Disagree**	**Strongly Disagree**
The report layout is easy to follow	8	1	0	0	0
It contains relevant information	8	1	0	0	0
I found it useful	6	3	0	0	0
I received it at an appropriate time	6	3	0	0	0
It is written in user friendly language	7	2	0	0	0
It is an appropriate length	7	2	0	0	0
It is easy to understand	7	2	0	0	0

Respondents indicated they were very satisfied with the new transfer of care report. Three respondents added additional comments as outlined below:

"I was delighted to receive this detailed and helpful report." (Physio).

"The only problem I found was that my husband's GP and religion were incorrect." (Relative).

"It was effective in showing us the health condition on admission and on discharge, thus able to see the progress made. The detail was of a good quality and was very informative." (Former patient).

The problem with the incorrect information, as commented by the relative, was caused by an administrative error on the original records and not a problem with the report per se. It could also be argued that the quality and detail within the report was more to do with the health care professionals completing the paperwork rather than the report itself. However, the exploratory phase analysis of the documentation had highlighted ICF domains that were not covered and the new report included them, therefore the structure of the report, i.e. based on the ICF domains and categories aided the quality and detail provided.

The final version (fourteen) of the report was formatted by the Medical Illustrations Team within the Trust to make the report template easier to type onto, with formatting of the box sizes and Trust logo. There were no further changes to the content or the language. By September 2009, the report was incorporated into clinical practice.

It took nearly two years from the decision to devise a joint report (i.e. the end of the exploratory phase) to successfully implementing it into clinical practice. Local policies meant the report was not inclusive of all team members. National initiatives (including the introduction of electronic records) meant the process took longer. Nonetheless, by the end of the action research cycles, all therapists were contributing to a single transfer of care report for the first time. They were writing in a language they all had learnt and redefined, so therefore understood. Most importantly, patients' were being given a copy of a report from all members of their therapy team; an aim which the team had long wished to achieve but was only accomplished through this research project.

Alongside later versions of the report, an ICF glossary was also developed, the process and findings of which will be discussed in section 5.2.3. Before that, the next subsection will return to the ICF checklist, implemented before the first version of the TOC report had been devised, which proved unsuccessful.

5.2.2 The ICF checklist was not successful; its use remained unclear and participants chose to abandon it

The checklist was devised with the STEP team and the participants decided it would sit at the front of the MDT notes, although let the exact purpose evolve once in place. It was developed within a short period of time (approximately one month) and the first of the three innovations to be completed. The checklist was a one page diagram; the person with a stroke was in the centre with arrows to and from the four ICF components (Body functions and structures, Activities and Participation, Environmental factors and Personal factors). The domains were listed under each component (see Appendix 19 for the final version number 3).

The STEP team were satisfied with version three and the final version included an alteration to the ICF terminology as the wording was changed to remove ‘mental functions’. As previously mentioned, this was the first suggestion that there could be problems with some of the ICF terminology, but a topic that did not resurface until reviewing version six of the TOC report which received mixed comments from colleagues outside of the service.

The ICF checklist was implemented in October 2007, with a laminated copy at the front of each MDT notes folder, but its use was sporadic. Participants reported they did not refer to it when note writing and it was not used in the MDT meeting. It was now December 2007 and the participants felt the checklist was not useful, as its role remained unclear, yet they did not wish to quantify it either. As it did not seem to have clinical utility, the participants decided to stop this part of the innovatory process.

At the time, the researcher postulated different reasons why the checklist had not been successful. Firstly, it was only trialed for two months before it was abandoned so its use may not have had time to cement into clinical practice. Secondly, because the participants had decided to let its use evolve rather than give it a defined purpose; this may have been its downfall. It was unclear how the checklist should be used to aid the multidisciplinary team in their clinical work. Therefore, in the busy reality of clinical practice, it was not a priority and may have been largely forgotten. The issue of the unfavourable ICF terminology was not raised but this could also have been the reason why the checklist did not work. At the time, the participants either did not want to say or had not fully formed their opinions on this matter.

Yet, through engaging in the action research process, the ICF checklist would return, or rather grow into something different with a defined purpose; the ICF glossary evolved and will be explored next. Therefore, it may be erroneous to consider the ICF checklist as unsuccessful because, it paved the way for another innovation and it may have helped participants to engage with and form their own opinions on the ICF.

5.2.3 The checklist reincarnated as an ICF glossary. After 4 versions it was successfully implemented into practice as an aide memoir for the TOC report

The piloting process of the TOC report, especially of version six, had facilitated an honest discussion with the STEP team who decided two changes were needed; 1) a reword of the ICF domain headings – the headings used within the report and 2) a list of prompts on the ICF categories within each ICF domain, for use by those completing the report. It was felt that the second change would aid consistency of the information written by the team, who were still learning the ICF framework and classification during the innovatory phase.

By this time, the original checklist (from aim three) had been abandoned but participants recognised there was a need to develop an ICF glossary with a specific purpose, i.e. to be used as an aide memoir to assist completion of the report, by prompting the writer which categories went under each domain heading / report heading.

Four versions of the glossary were produced and the final one is in Appendix 20. The changes to each version reflected the on-going changes that were made to the ICF language within different versions of the report, as previously outlined. Version four was considered the final version as it linked with version twelve of the report and was used as an aide memoir during the pilot. In practice, once the shared drive was established, a pdf version of the glossary was accessible to all; health care professionals could then print a copy of the glossary for use in their own office space when completing the report.

As discussed, it could be argued that the development of the ICF glossary was not a third and separate action research cycle as it was linked to aim three, i.e. developing a checklist but with a quantified purpose.

5.3 Knowledge-in-practice findings: reflective phase

Whilst the previous knowledge-in-practice subsections have outlined the findings from one aim then another, this subsection, for the reflective phase, will address both aims six and seven together. This is because, in this phase, participants reflected on the process and the outcome of implementing the ICF at the same time, so the data is naturally interwoven between the two.

This section will outline the following themes which, in combination, form the overall findings for this phase: the factors that facilitated and hindered the implementation process; reflections from participants for other clinical teams considering implementation of the ICF; and thoughts from the participants on the ICF-based tools. The latter incorporates participants who developed the tools as well as opinions from participants who were the recipients of the report.

5.3.1 Learning from the implementation process

The focus group data would inform some of the questions in the interview topic guide. Thematic analysis was employed to identify emergent themes and subthemes from the focus group. Collectively, three themes emerged from the data which became topics within the interview guide: 1) There are pros and cons with the ICF; 2) There are mixed thoughts on the outcomes; and 3) There is a need to reflect on the change process. On completion, the data from all the interviews were analysed and combined with the focus group data where appropriate. Table 26 summarises the themes and subthemes.

Table 26: The themes and subthemes from the focus group and interviews on what was learnt from the process of undertaking the project

Overall themes from reflective phase focus group and interviews	Subthemes from reflective phase focus group and interviews
There are pros and cons with the ICF	The language of the ICF is unfamiliar at the start
	The ICF helps communication within and beyond the team
	The ICF helps the clarity of written communication
	The ICF aids holistic thinking
	It is best to learn the ICF by applying it and adapting it into practice.
Reflections on the change process	The team need to own the change process
	The pace of change must be right
	Select projects that are priorities for the team
	A project facilitator is essential, with specific qualities, to help the change process
	Linking the changes to the bigger picture is helpful
	Include as many people as possible
	Feedback from others can have a positive or negative effect
	The medics have not been involved and this has impacted on the change process, but they may come on board later.
Mixed thoughts on the outcomes	The glossary is very useful The checklist did not work so well and its use was not clear Version 12 of the report is great

The participants acknowledged that the checklist did not work partly due to the timing of its introduction and also because it lacked clarity regarding its purpose. In contrast, the ICF glossary was deemed very useful; its purpose was identified from the start and the language had evolved to be acceptable to the participants. As previously discussed, it could be viewed that the ICF glossary was more of an extension of the original checklist once participants had fully formed their opinions on the ICF regarding its potential and their challenges with the language.

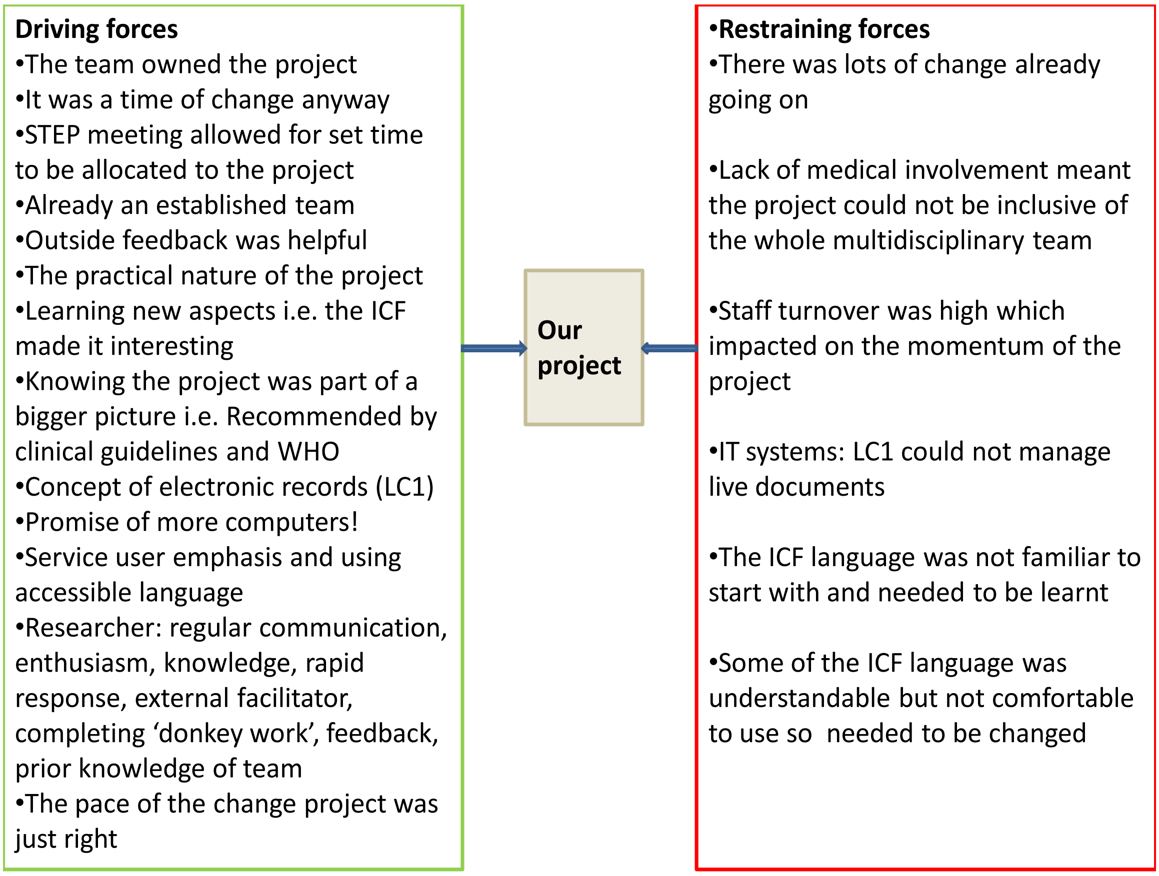
The process of fourteen cycles to produce a therapy transfer of care report appears to have been a worthwhile investment of time. Version twelve was discussed in the focus group (the changes to thirteen and fourteen were aesthetic only); it received positive endorsement from all participants in the focus group and the interviews. In addition, the feedback from the questionnaires to other staff within the team (as previously outlined) was also positive.

In short, the participants acknowledged the checklist did not work but were extremely happy with the transfer of care report and the associated glossary.

5.3.2 Reflecting on the driving and restraining forces

Participants in the focus group and interviews were also asked to undertake a force field analysis (Brager and Holloway 1992) to identify their thoughts on the driving and restraining forces which influenced the project. In practice, the focus group participants were given an A3 sheet of paper and post-it notes on which to write their ideas. A summary of their thoughts was subsequently given to interview participants to discuss and expand upon. The researcher later compiled a final list of forces by combining the original list, generated by the focus group participants, with those ideas added by the interview participants (see Table 27).

Table 27: The driving forces and restraining forces identified by the focus group and interview participants in the reflective phase



Driving forces

- The team owned the project
- It was a time of change anyway
- STEP meeting allowed for set time to be allocated to the project
- Already an established team
- Outside feedback was helpful
- The practical nature of the project
- Learning new aspects i.e. the ICF made it interesting
- Knowing the project was part of a bigger picture i.e. Recommended by clinical guidelines and WHO
- Concept of electronic records (LC1)
- Promise of more computers!
- Service user emphasis and using accessible language
- Researcher: regular communication, enthusiasm, knowledge, rapid response, external facilitator, completing ‘donkey work’, feedback, prior knowledge of team
- The pace of the change project was just right

Our project

•Restraining forces

- There was lots of change already going on
- Lack of medical involvement meant the project could not be inclusive of the whole multidisciplinary team
- Staff turnover was high which impacted on the momentum of the project
- IT systems: LC1 could not manage live documents
- The ICF language was not familiar to start with and needed to be learnt
- Some of the ICF language was understandable but not comfortable to use so needed to be changed

The forces identified by the interview and focus group participants resonated with the issues captured in the researcher’s reflective diary and field notes, thereby demonstrating triangulation of the key findings. But there was one notable exception: the researcher had not fully appreciated the positive impact of her working style as a facilitator and this will be reflected upon in section 5.5.

5.3.3 Recommendations for other clinicians

Part of the discussion in the reflective phase also included identifying a list of recommendations, which participants would suggest to other people, who wanted to think about using the ICF in their own clinical practice. There was some overlap with this question and the previous ones in the topic guide. However, the purpose of this question was to provide a final opportunity for participants to reflect upon the process and the outcomes of the project, in a manner which was grounded in a practical purpose. The list generated from the focus group was agreed upon by all participants and then used as a prompt to aid the interview discussion. Subsequent ideas were also generated from the interview participants and from the reflective diary entries. Table 28 outlines their recommendations.

Table 28: Recommendations for other people wanting to introduce the ICF into their own clinical setting from the reflective focus group and interviews

Be prepared to pilot, pilot, pilot!
Don't worry about just having a go – you can change things from doing this.
Pick projects that are practical and the majority of people would like to change in your team.
Have one person to facilitate the project, e.g. a stroke coordinator, although an external person is better as they avoid the day to day politics and often see something with fresh eyes.
Be prepared that the project will take time.
Share what you are doing with everyone in the team – even if they don't want a big role.
Share what you are doing with people outside of the team – external feedback is useful and can also be motivating and nice.
Expect peaks and troughs throughout the project.
Don't give up if you run into problems – find a way around them.
At the start, do a team analysis of the potential driving forces and restraining forces that may occur during the project – embrace the positives and think about ways to manage the negatives.

The recommendations all focused on practical issues and identified ways to potentially deal with them. None of the recommendations were specific to the ICF, to stroke care or to action research, thereby of interest to the broadest of audiences interested in implementing change into the clinical setting.

5.4 Knowledge-in-theory findings

There was one broad aim within this action research project with two subcomponents namely to evaluate the process and the outcome of implementing the ICF with an acute stroke service. Therefore, this subsection has combined the knowledge generated across all phases to identify the overall theoretical findings which will now be explored.

Five inter-related themes emerged from the process and outcome of implementing the ICF into practice, (see Table 29). The findings for each theme will be presented in turn but there is an interdependent, rather than hierarchical, relationship between them.

Table 29: The knowledge-in-theory findings on the process and outcome of implementing the ICF with an acute stroke service

Change was facilitated by:

1) adopting the ICF in ways that met local service needs;
2) and adapting the ICF language and format.

The outcome of which revealed that the use of the ICF:

3) fosters communication within and beyond the acute stroke service;
4) promotes holistic thinking;
5) and clarifies team roles.

5.4.1 Adopting the ICF in ways that met local service needs

One of the key factors that aided the adoption of the ICF into practice was for participants to use it to meet their own needs. This involved local ownership of the implementation process, supported by an external facilitator who had experience and knowledge of how to utilise the framework and classification.

Owning the change process motivated participants to implement the ICF, although the main driver was not to adopt the ICF per se, rather to use it as a vehicle to drive through changes already wanted by the participants, i.e. a new report. *"I think the team ownership is really important because, I think it motivates you ... if you are allowed to then work with it and try and make it fit with the needs of the team." (Interview 1 pg. 8).* Therefore, the ICF was successfully implemented because the participants used it as a subtext to meet their local needs rather than adoption on an explicit level.

It was felt there was a need for an external facilitator to enable successful implementation of the ICF. As the participants were not familiar with the ICF at the start, external support from someone with knowledge and experience of using it helped them to learn the fundamentals. *"It can take a lot of time and energy if you are learning something from scratch, all yourself but then if you are being facilitated by somebody, I mean it's ...taken the best bits for our learning and development" (Focus group pg. 14 participant 4).* In addition, it was identified that an external facilitator avoided the problem with the time and authority required from an internal person taking the lead on facilitating a multidisciplinary project:

> *Participant 3: "I think it is really hard for an actual therapist to do."*
> *Participant 4: "I mean, the amount of work that has gone into something like this, it is not something that any of us would have the time to do. This is such a big thing across all the professions that it would be hard for one speciality to take ownership."*
> *(Focus group discussion pg. 26)*

5.4.2 Adapting the ICF language and format

Participants needed to adapt some of the wording within the ICF. There were two main reasons for changing the ICF terminology: the first was the need to make it more familiar and user friendly for clinicians, as some of the terms felt separate to the terminology already in use within the service and were not automatically clear. *"It was almost like it was creating a separate language rather than making it easier to* *understand...these are words we do not use often....it was not automatically understandable." (Focus group pg. 4 participant 4).*

Secondly, some of the terms were changed to make them more acceptable and understandable for patients, their families and carers, as perceived by the participants. Some headings were shortened, e.g. 'Functions of the skin' became 'skin condition', the latter being in common use and, as two words, would be easier for a person who had residual communication impairments following their stroke to read and understand. There were also concerns that some of the ICF terminology could be misinterpreted by those receiving the report, e.g. the use of the word 'mental' may lead a person to think they had mental health problems in addition to their stroke. *"...things like global mental functions...I think we would perceive that a lot differently to someone who had had a stroke or family." (Interview 1 pg. 7).*

The participants also decided that the format of the ICF required adapting to meet their local needs. The ICF chapter headings from body functions, activities and participation, and environmental factors (once adapted by the participants) gave sufficient detail to structure the headings within the report.

The categories within the ICF core set for stroke (Geyh et al. 2004) were considered for use in the report, but even though there were fewer categories than in the ICF full text, participants felt the core set detail would still make the report unwieldy. However, the category level detail within the ICF core set for stroke was not completely abandoned by the participants; through the process of developing the report, they identified the need to clarify the meaning of each amended ICF chapter heading. Therefore, the categories were subsequently used to develop the ICF glossary, which acted as an aide memoir. The glossary helped the participants to learn the ICF and they felt it could aid consistency when completing the report in the future. *"It was generally felt that some terms* [i.e. adapted chapter headings] *needed further definition and it would be beneficial to produce a glossary of terms* [i.e. the categories for each chapter heading]*." (Minutes from STEP meeting 16th May 2008)*

5.4.3 Fosters communication within and also beyond the acute stroke multidisciplinary team

Participants within the team felt the ICF terminology resolved the issue of specialised uni-professional language and, while the potential for jargon remained, nonetheless it was felt the report would be clear to former patients. *"….at least if we all use the same language really, ok, it might be slightly jargon but if we are all using it… it looks now quite clearer…. And I think that as a patient you would at least have an idea about what each box is going to talk about (participant 3; focus group).*

The role of the ICF to aid communication between services was a strong theme, for example: *"When someone's in an acute stage….it's often back down to grass roots washing and dressing. It's not so much focussed on back to work. But this will allow you to maybe help the next group of professionals plan a bit more towards that." (Interview 2)*

5.4.4 Promotes holistic thinking

Participants felt the use of the ICF within a team report challenged them to think more holistically as individual clinicians *"You're not just thinking in your own area…it makes you think differently about a stroke or just makes you ...aware of all the different aspects that are affected." (Interview 1)*

Furthermore, citing the complexity of the framework, one participant suggested *"not one person can cover it all, so you have to work as a team don't you to be able to work holistically. So I guess it reinforces that doesn't it, just by the nature of what it is." (Interview 3).*

Therefore by implementing the ICF in a way previously identified and thereby owned by the participants, the framework and classification was able to change the thinking of clinicians and reinforce the requirement for collaborative working within stroke care.

5.4.5 Helps to clarify team roles

While participants acknowledged the ICF did help to clarify team roles, it was also clear there needed to be flexibility when considering this issue; participants preferred to consider which profession took the lead in particular areas for individual patients rather than be dogmatic and over-protective of specific domains*. "I feel there…should be scope for some flexibility in the report template e.g. the lead professionals could be interchanged where necessary, hence tailoring the report to each patient… it could be a nurse or dietician who acts with regard to products and technology." (Email 20/11/2007)*

By using the ICF within a joint report, participants felt they could learn in more detail, what other professions did in relation to patient care. *"You do know your own specialist bit much more, so I guess it does help to kind of learn what other people are doing as well…and what they contribute. So that's been really helpful." (Interview 3)*

These five inter-related themes highlight that the ICF enhanced clarity and holism but in order to adopt it into practice, it needed to be adapted. An external facilitator was part of the process and the last findings subsection will reflect on the researcher in this role.

5.5 Reflection of the researcher

There are three components to this section: the first will explore the adaptation process from occupational therapist to researcher which sometimes proved challenging; the second will critically analyse the happenings that led to the researcher feeling like an insider / outsider researcher; and the third will outline some of the interactions undertaken by the researcher to develop effective relationships with the participants during the exploratory phase.

As a relatively new academic and a novice action researcher, the process of establishing a new role as a researcher within the team was a challenge. The performance skills relating to the research process, e.g. conducting interviews, remaining objective with observation and developing topic guides, had been undertaken during the pre-project phase with experienced researchers, thereby giving the researcher confidence in the activities within the actual research process.

However, it was very difficult to make the personal and emotional transition from clinician to researcher within the healthcare environment. The researcher felt nervous and self-conscious (see B1 and B2) and expressed wishes to be back working in the NHS, in familiar roles and environment (see B3 and B4).

Dialogue box B: The challenging personal transition from clinician to researcher

B1): “I feel very nervous and I don’t want to intrude on clinical time. I’m also ++ nervous about my own researcher role but must not downplay or make excuses for not being a clinician. I’m not surprised this is a struggle, as I still find it hard to let go of my clinical self to make the transition into being an academic.” *First reflective diary entry from pre-project phase 16th June 2006*

B2): “Sister’s office feels like a safe haven as I’m ++ nervous on the ward. It’s nice to be back in the NHS but my shoes are a bit noisy and I’m worried they give off the wrong signal, i.e. “Here I am!” This could be misinterpreted.” *Reflective diary 16th October 2006*

B3): “I wished I was back here but I must remain focused on my PhD and research. It doesn’t always feel like ‘proper’ work even though I know it is. I must ensure these feelings do not affect the standard of my data collection and work.” *Reflective diary 26th February 2007*

B4):“A difficult day for me – it seems like it is left to a minority of people to fight for the patients’ right to be referred to rehabilitation and I can’t say anything or do anything.”

To overcome this, supervision sessions were used effectively and during the exploratory phase the transition from clinician to researcher slowly occurred:

*“Very good day – feeling more confident and settled….. Had good supervision last week and shared my frustrations (*about the minority of people left to fight for rehabilitation referrals: see dialogue box B4*) but now I know that whilst the team will have their ups and downs, ultimately they will be fine and of course can manage fine without me as an OT!”* Reflective diary entry 23rd April 2007

Furthermore, attending the Action Research Group (ARG) seminars also helped to establish internal confidence:

"ARG meeting was fantastic. At last I'm 100% sure inside that I am an action researcher!" Reflective diary 8th May 2007

The exploratory phase was to last over a year and it could be argued this was beneficial to the researcher and the project itself, by allowing space for the role transition to occur. During this time, there was also a transition in the nature of the role which meant that at times the researcher felt like a complete insider, other times like an outsider, or often fluctuated between the two. The insider and outsider components will now be explored.

Initially, the researcher sought to define the nature of the researcher role from academic sources, but on discussion at an ARG meeting, one action researcher commented that it depended on how an individual felt they were treated, rather than text book definitions. In the exploratory phase, the researcher fluctuated between both; dialogue box C contains extracts which highlight how sometimes the researcher felt like an insider (examples C1 and C2) and other times felt like an outsider (examples C3 and C4).

The feelings of being an outsider coincided with periods of tension within the clinical team. The context behind the tension referred to example C3 was never to be understood by the researcher, which further confirmed the outsider status. However, the context behind the situation whereby the clinical specialist occupational therapist was the new chair of STEP (example C4), was one which the researcher subsequently gained insider knowledge, through a personal friendship with the senior physiotherapist, thereby utilising insider resources.

Dialogue box C: Feeling like an insider / outsider researcher

C1):"I have been added to the STEP team email list without even asking. I feel like a true insider!" *Field notes 8th May 2007*

C2):"My previous work here is a great advantage, I understand all the local abbreviations and experience of working on the unit provides opportunities to start conversations too." *Reflective diary 20th November 2006*

C3): "I retreated to sister's office today to write some notes as I felt uncomfortable on the ward. There is clearly some tension in the team and I know I can't give my opinion or seen to be taking sides." *Reflective diary 19th February 2007*

C4):"The clinical specialist occupational therapist chaired STEP meeting today but not sure why as she doesn't have a caseload on the unit and has not been involved before. When it was my turn to speak, she said to the rest of the STEP team "Welcome to our guest." I wasn't sure how to take this, as it sounds a bit sarcastic, plus I've been feeling like part of the team until today." *Field notes 18th May 2007*

Thereby it is possible to see that, even when feeling like an outsider, the researcher was able to operate as an insider by drawing upon other personal relationships to understand the service context. Therefore, for the majority of time whilst undertaking the field work, the researcher felt like an insider.

Finally when exploring the nature of the researcher's role, this section will outline some of the interactions undertaken by the researcher to develop effective relationships with the participants. It will use one time frame, July 2007, as an example. This time signalled the beginning of sharing the findings and developing the ideas for the innovatory phase. It was also the time, as felt by the researcher, which had the potential to cause the most distress, i.e. when starting to talk about implementing change.

The researcher was aware that encouraging participants to think about tangible changes for the innovatory phase, may cause some concern for them, especially as their recent experiences of change had mainly been negative. Dialogue box D outlines some of the data captured in the reflective diary at the time. The first two examples show how the researcher's attempts to allay perceived concerns about implementing change. The third example indicates the effectiveness of the efforts made by the researcher to engage with nursing staff.

Dialogue box D: Examples of ways the researcher attempted to develop effective relationships

D1): "I felt I did a good job of responding to their feelings today, as they needed lots of reassurance that I wasn't going to enforce change. I guess this is what they're used to. I said things like "Don't worry, it's not for me to march in here and tell you what to do" and "This is something for us to go away and think about; we can catch up in a couple of weeks." *Reflective diary entry 7th July 2007 after the in-service teaching*

D2): "I made sure that I reinforced the fact that the success of my PhD was not reliant upon successful implementation of the ICF. I said my role was to monitor / research what happens when trying to put a clinical guideline into practice. I don't want them to feel under pressure to make this a success for me." *Reflective diary entry 6th July 2007 after meeting with STEP team*

D3): "One of the health care assistants said to me today that it was a good idea to come to the handovers; as it was nice that they got to really see me and get to know me." *Field notes 16th July 2007 after attending three nursing handovers*

From the outset of developing the project, the researcher had always been aware of the importance of developing and maintaining effective relationships with participants. This awareness had partly been in response to the positive experience as an action research participant in the past. So, even though the researcher had intrapersonal challenges making the role transition, participant feedback, as previously outlined in Table 27, identified the researcher, her specific skills and attributes as factors that facilitated the project.

5.6 Chapter summary and initial conclusions

The findings chapter has outlined the two different, yet inter-related, types of findings from this project. The knowledge-in-practice findings showed how participants, with facilitation from the researcher, identified challenges in their service where the ICF could be of benefit. From the list of 14 different ways, participants chose to develop three innovations: a checklist, a transfer of care report and, later on in the innovatory phase, a glossary. The first innovation did not succeed or rather it could be argued that, through engaging in the action research process, it was later refined with an exact purpose, to succeed as a glossary. The transfer of care report was successfully implemented with the impact of external feedback, regarding some of the ICF language, deemed significant to its implementation.

There were five overall themes that formed the knowledge-in-theory findings. Change was facilitated by: 1) adopting the ICF in ways that met local service needs; and 2) adapting the ICF language and format. The outcome of which revealed that the use of the ICF: 3) fosters communication within and also beyond the acute stroke service; 4) promotes holistic thinking; and 5) clarifies team roles. The five themes will be the basis for the next chapter, the discussion. But initial consideration of the findings demonstrates there is now empirical evidence, to support the stroke clinical guideline, that the ICF does indeed enhance communication within the team (ISWP 2004). These findings go a step further by showing that communication can be enhanced between teams and also afford therapists a broader, more holistic, view of their patients' needs. However, these notable outcomes were only achieved because, through engaging in an action research approach, participants owned the change process.

Finally, this chapter also explored findings in relation to the researcher both from a personal perspective and using feedback from the participants. The discussion chapter will critically consider and reflect upon being an insider/outsider researcher alongside a discussion on the quality and limitations of the overall project.

Chapter 6: Discussion and conclusions

This is the first project of its kind to explore the process and outcome of implementing the International Classification of Functioning, Disability and Health (ICF: WHO 2001), with an acute stroke service, which enabled the theoretical framework and classification to become a clinical reality. In using a phrase from one of the participants, the findings demonstrate that members of an acute stroke service “hijacked the ICF” to meet local needs and, in so doing, enhanced communication within and beyond their team, promoted holistic thinking and clarified team roles. In reflecting on the use of the word ‘hijack’, by a participant in this study, this discussion will argue that it encapsulates what happened during the research, albeit in relation to a specific definition which will be subsequently explored.

There are two types of findings that arise from this research: *knowledge-in-practice* findings and *knowledge-in-theory* findings. The *knowledge-in-practice* findings from this project demonstrate that participants prioritised using the ICF to develop a team transfer of care report and, during the development process of this, a glossary was also produced as an aide memoir to complete the report. Both were successfully developed and implemented into clinical practice. They remain in use five years on, demonstrating the achievement of sustained change. The *knowledge-in-theory* findings show that in order to successfully implement the ICF into practice, participants needed to adopt it to meet their own needs and adapt some of the language and format. But, once implemented the ICF enhances communication within and beyond the stroke service, promotes holistic thinking and helps to clarify team roles. The *theoretical generalisation* from this project focuses on the benefits of using the ICF to overcome the following specific communication challenges within healthcare teams: logistical challenges; knowledge gaps and role confusion; existing cultures; enabling clinicians to speak out; and providing a collaborative theory to enhance working practice. Both sets of findings, and the theoretical generalisations from them, are new and unique contributions to the ICF literature and the literature on communication challenges in healthcare teams.

In this chapter, the contribution of the *knowledge-in-theory* findings will be critically explored in relation to two bodies of knowledge: 1) the ICF literature (as outlined in chapter two) and 2) the broader debate on communication challenges within healthcare teams (as outlined in chapter three). Both bodies of knowledge will be placed specifically into the stroke context, the development of which was detailed in chapter two, to critically explore the *theoretical generalisations* from the project.

As previously outlined the ICF has been endorsed by the World Health Organisation (2001) and within the National Clinical Guidelines for Stroke, for particular use by stroke multidisciplinary teams, to aid communication (ISWP 2012). But no empirical studies had previously explored the process or the outcome of using the ICF in stroke care and only a small number of papers existed beyond stroke specific care, mainly comprising clinical commentaries rather than empirical data.

The researcher, in setting the initial parameters for this project, did not intentionally set out to explore communication per se, rather to work with participants in the stroke service in order for them to shape the innovations they desired. This is in keeping with the democratic nature of action research. Nonetheless, as part of the remit of the STEP team was to instigate changes endorsed by the clinical guidelines, which recommended the use of the ICF to enhance communication (ISWP 2004), it could be argued that it was not altogether surprising that the project became one which focused on communication. The key point here is that, through the action research process, it was the participants who subsequently chose to use the ICF to develop a transfer of care report thereby choosing to focus on enhancing a form of communication within a specific part of the care pathway.

This chapter will begin with a critical discussion of the findings in relation to the literature. It will then reflect on the methodological approach including the strengths and limitations of this specific action research project and the position of the researcher within the process. It will finish with a summary of the empirical and theoretical findings alongside identifying future research needs.

6.1 A critical exploration of the project findings

6.1.1 “Hijacking the ICF”

The means by which the ICF was adopted was reflected in the empowerment experienced in the team. The potential capacity “to hijack the ICF”, as a vehicle to drive through changes, was sensed and brought to fruition. On initial consideration, it could be argued the use of the term ‘hijack’ as a verb, in this context, is inappropriate – it is suggestive of an aggressive attempt to seize control which was certainly not the case. However, a specific definition of hijacking – in social partner dancing - shows parallels that can encapsulate the essence of what happened in this project.

Partner dancing involves two people with clearly demarcated roles; one partner is the lead and the other is the follower. The lead partner does as the name suggests, predominantly male, he selects the tune that the couple will dance to and the moves they will perform. He also takes the lead to ensure the movements are performed smoothly. In the context of this project, consider the lead within three different parameters: the global lead is the World Health Organisation who endorse the ICF; the national lead is the Intercollegiate Stroke Working Party (ISWP: authors of the National Clinical Guidelines for Stroke) who recommend using the ICF. The local lead is shared between the two consultants at the top of the implicit hierarchy within the team, both of whom had not previously prioritised developing a joint transfer of care report.

Hijacking, in partner dancing, involves the follower taking temporary charge and is also known as 'stealing the lead'. There is no aggressive intent, indeed, the lead partner is aware and understands what is going to happen. Hijacking requires skill and experience to execute smoothly (Knowlegerush Encyclopaedia 2014). Driven by the skill and experience of the STEP team, it could be argued that participants in this project were 'followers' who by engaging in action research, were able to steal the lead, from the WHO, the ISWP and the two consultants, to drive through a change they had long desired, that is, a combined transfer of care report. So, while the tune, i.e. the ICF remained the same, participants performed their own moves with it, to adapt it in order to develop a transfer of care report. This will be explored further in relation to the literature on the ICF itself and the literature on communication challenges within healthcare professional teams.

6.1.2 Adopting the ICF by first identifying, with participants, the current challenges in their service

This project showed how raising awareness, learning about the ICF and implementing it into practice could be successfully combined. Participants learnt about the ICF by focusing on doing, that is, by being involved in a participatory action research process, to provide solutions for practical problems that generated new knowledge. These are key action research principles (Meyer 2006). An action research approach was also an effective method of “convincing” clinicians of the worth of the framework and classification, a point of concern which has also been raised within the literature (Farrell et al. 2007). Later, section 6.2 will critically appraise the methodology but this section intends to explore the implementation process in relation to the ICF literature.

It has been acknowledged that the first challenge for ICF implementation is the need for clinicians to learn about the framework and classification (Farrell et al. 2007, Heinen et al. 2005). ICF training programmes have been devised, at a national level, for example in Italy where over 7000 people have participated in 150 training events (Francescutti et al. 2009). Yet little is known about the direct influence of these training events, if any, on implementing the ICF into clinical practice. At the start of this project, the ICF was not overly familiar to the participants but, rather than take part in training programmes, through a process of taking action, they learnt about the ICF and implemented it simultaneously.

Even with knowledge of the ICF as a theoretical framework, clinicians have struggled to think of ways it could be used (Reed et al. 2009). In our project, participants were asked to identify the current challenges within their service, which were collated by the researcher and shared back as potential areas where the ICF could be of benefit. The team had no difficulty in producing a list of fourteen different ways. It was not clear how the information was sought from participants in the project by Reed et al. (2009) but, their paper suggests that participants, all of whom worked in an inpatient psychiatric hospital, were asked to focus their thoughts on the ICF itself which proved difficult. In contrast participants in this project were asked to focus on identifying the real challenges in their day to day practice rather than a potentially abstract theory. Most centred on the topic of specific communication challenges. Our approach may have proved to be more effective in eliciting ideas for ICF implementation; it is known that a greater understanding of context specific challenges can lead effectively to the identification of targeted interventions to improve communication (Nagpal et al. 2012).

Furthermore because the National Clinical Guidelines for Stroke (Intercollegiate Stroke Working Party 2004) recommended the use of the ICF, to aid team communication, this may have proved an effective external driver when thinking about why and how to adopt it into acute stroke multidisciplinary practice. Change in practice is likely to be more successful when there is congruence between national and local targets (Bridges and Meyer 2007).

Ways to implement the ICF have been highlighted in the literature, including its use to: enhance communication from one service to another, to define the rehabilitation stages (Martinuzzi et al. 2008), to describe the remit of physiotherapy services (Mitchell 2008), to use it as a common language (ISWP 2008) and to use a common theory to structure the cultural artefacts with which multidisciplinary teams identify and protect themselves (Parkin 2009). These ideas were also identified by participants in this project who, by prioritising the development of a transfer of care report, identified the potential importance of three means of using the ICF: in moving patient care from one service to another (Martinuzzi et al. 2008), as a common language (ISWP 2008) and as a structure for their cultural artefacts (Parkin 2009).

Previous research has also advocated the use of the ICF to communicate the remit of a uniprofessional team (Mitchell 2008). While this project did not seek to do this at the conceptual level, participants did note the ICF had the potential to outline the remit of not just one profession, but the whole multidisciplinary team by clarifying team roles through the process of completing the transfer of care report.

The ICF has also been advocated to describe the rehabilitation stages (Martinuzzi et al. 2008) and findings from this project support this idea. When selecting the project for the innovatory phase, participants reasoned that, by choosing to focus on developing a transfer of care report, it could consequently highlight and outline what their acute service could offer a person with stroke. At the same time, it could identify and specify subsequent ICF domains for future rehabilitation stages. This project did not seek to measure a before and after practice effect so it must be appreciated that the findings are the participants views and not a representation of what has actually happened in practice with this finding. Future research will be required to ascertain whether using the ICF-based tools can actually enable participants to define their team roles and clarify the remit of acute stroke rehabilitation.

The WHO has released, initially for consultation, guidelines and support materials to assist people in implementing the ICF (WHO 2013). Yet using a “top-down” approach to develop materials (Degeling et al. 2003) may not help people to own the change process, which was found to be key to successful implementation in this research project. However, the WHO is also developing a database for ICF implementation including a section for comments on learning from the process. If this is an interactive forum whereby learning can occur from sharing experiences of identifying ways to adopt the ICF, it could provide a way to enhance the ownership of the change process for clinicians.

More studies are needed that focus on ways to implement the ICF, to inform the most effective ways of adopting it into clinical practice (Maini et al. 2008). The importance of publishing evidence on the practical and meaningful applications of the ICF, by those already using it in practice, has also been stressed (Farrell et al. 2007). The empirical findings from this project show that, rather than running training programmes to learn about the ICF or explicitly focusing on the theoretical framework itself, it was more effective to work with participants to identify the current challenges within their service which could benefit from the adoption of the ICF. In so doing, the participants were then able to learn about the ICF through its practical and locally relevant application to practice.

6.1.3 Adopting the ICF by adapting it to meet local service needs

In this project, it was not just some of the ICF language that needed adapting. The ICF core set for stroke, condensed from the original ICF text to promote clinical utility in stroke (Geyh et al. 2004), did not fulfil its intention. Participants still thought the ICF core set for stroke was too complex (with over 130 categories) and chose to use their locally adapted ICF chapter headings to structure the transfer of care report.

Participants were not alone in finding the core set format to be difficult to use; it has previously been acknowledged as problematic due to the fact that it does not have the flexibility to be tailored to individual needs and is time consuming to administer (Maini et al. 2008). In this project, a solution was sought whereby the detail of the ICF core set was used as an aide memoir, i.e. the glossary to the (adapted) chapter headings. It would be interesting to see if other clinicians, already using the ICF, have experienced similar difficulties when using the core set format and to learn how they have sought to overcome any challenges.

Authors from within the WHO network have acknowledged that the success of the ICF depends on its uptake in clinical practice (Geyh et al. 2004), suggesting there is a need for research efforts to focus on adoption studies in order to ensure effective implementation. However, on reviewing the publications from the ICF Research Branch, over the last decade, the focus remains on developing new, or validating existing, core sets with little research effort towards exploring the process of implementing the core sets into practice.

Participants also had two main concerns about some of the actual terms within the ICF itself. Firstly, some of the headings used an unnecessary number of words and shortened replacements for existing phrases were identified, e.g. 'functions of the skin' became 'skin condition'. The shortened phrases were considered easier to understand; this is of particular relevance in stroke services given the prevalence of post stroke communication impairments. Secondly, participants felt, the term 'mental functions' was open to misinterpretation by family members or people with stroke, on a transfer of care report, by potentially suggesting they also had mental health problems. Previous literature has supported the idea that some of the ICF categories are not easy to understand for people with low educational levels and concrete cognitive styles (Maini et al. 2008); understanding by people with communication difficulties following stroke, as perceived by the clinicians participating in the project, can be added to this list. Our findings also identified the need to adapt the terminology for clinicians, thus adding new knowledge to the debate on the user friendliness of the ICF language (Schuntermann 2005, Maini et al. 2008).

However, as the project focused on the opinions from one multidisciplinary stroke team, further research is required to ascertain if the ICF language itself is a potential barrier for implementation in clinical practice, or if it does indeed fulfil its original promise of solving the problems caused by professionals using their own technical language (Martinuzzi et al. 2008).

There have been calls for the WHO to seek proprietary rights for the ICF format and terminology (Jelsma 2009), to prevent it being adapted in clinical practice. However, in order to adopt the ICF with the acute stroke service, the findings from this project demonstrated the need for it to be adapted. Therefore, if proprietary rights were approved this in itself could present a barrier to adopting the ICF into practice and thus undermine one of the original aims, i.e. to establish a common language in clinical practice.

By adapting the ICF language and format for local acceptability in this project, it is questionable whether the language now remains a common and universal one. The issue of moving away from the ICF language was debated at length by participants. They concluded that any language needs to undergo some form of adaptation process to be used at a local level, just as the English language has a number of regional dialects within the United Kingdom. Furthermore, the Functioning and Disability Reference Group (FDRG), who advise the WHO on improvements to the classification, proposed work to develop an ICF update platform to gather and process proposals for updates to the ICF (WHO-Family of International Classifications: WHO-FIC FDRG 2009); this was launched in 2010. This suggests that there is a forward thinking and a flexible approach being taken by the WHO-FIC FDRG to gather information about the need to adapt the ICF; therefore findings from projects such as this could inform discussions about updating the classification and framework.

However, the process by which an update proposal is considered appears overly hierarchical and bureaucratic. It involves creating an online account with the WHO; digesting a 24-page user guide (WHO-FIC 2013) ; completing a 10 point proposal; checking its completion against a 16 point checklist; and a five layered discussion process to consider approval, one of which is closed for members of the update revisions committee. Proposed updates are taken through this process, on an annual basis, at the WHO-FIC Network meeting cumulating in either rejection or agreed updates. The agreed updates are in the public domain as subsequently they are published on the WHO website:

(http://www.who.int/classifications/icfupdates/en/index.html).

Yet, it has been acknowledged that the ICF is an evolving language and on-going dialogue and discussion about its application in practice and the development of its theory is necessary (Conti-Becker 2009). So, in theory, research findings such as those from this project, could help inform subsequent revisions to enhance the ICF and its uptake in the clinical setting. In practice, it remains to be seen if the process to propose changes is an environmental barrier that hampers dialogue about future developments of the classification.

Finally, there are also philosophical reasons for adapting the ICF in order to encourage a more client-centred approach, i.e. to enable people to describe their conditions in their own language (Conti-Becker 2009). Clinicians, therefore, have a responsibility to adapt frameworks, like the ICF, and clinical tools to facilitate and learn from the narratives of those living with stroke.

6.1.4 The ICF enhances clarity and holism in stroke services

Over the past 13 years since its endorsement, anecdotal reflections (e.g. Rentsch et al. 2003, Steiner et al. 2002) and expert opinion (e.g. ISWP 2004) have supported the use of the ICF to aid communication within clinical practice and this project provides empirical evidence to substantiate this belief. In so doing, it highlights specific improved areas, as perceived by the participants, namely: enhanced communication within the stroke service and beyond; promotion of holistic thinking within the team; and clarification of team roles.

6.1.4.1 Enhanced communication within the team

In adopting the ICF in the manner they chose, participants overcame a number of logistical challenges to effective communication. The use of a shared common language removed the communication challenge caused by different writing styles (Keenan et al. 2013); a single electronic transfer of care report, accessed through a shared drive, removed the inefficiency and inaccessibility of a paper-based system (Rowlands and Callen 2013) and was congruent with the vision for a paperless NHS (Illman 2013); typed information reduced the risks associated with illegible handwriting (Fernandez et al. 2010); information was less likely to get lost (Redfern et al. 2009) and communicative space was found, albeit virtual, to enhance communication between staff with different shifts or working patterns concerning the full extent of their role (Arksey et al. 2007). However, the role of the methodological framework in overcoming these challenges must not be overlooked as, it could be argued that, it was a combination of the holistic ICF framework and classification implemented using action research that enabled specific logistical challenges in communication to be overcome.

Furthermore, enhanced team communication may have improved because, on a practical level, the team developed a centralised report they could all access rather than it being based on the ICF. Other centralised, non-ICF methods for team communication have been highlighted as successful in the literature including: a pre-operative team briefing checklist (Lingard et al. 2006); and the use of a whiteboard for all team members (Parker et al. 2009). Lingard et al. (2006) concluded that the checklist increased team knowledge and identified additional patient related problems warranting extra decision making, thus improving patient safety. However, Parker et al. (2009) concluded that while the whiteboard was useful in enhancing team communication, an integrated model of care would also be of benefit, thus suggesting the importance of using the ICF to this end.

Returning to this project, it must be remembered that the ICF required some adaptation. Therefore caution must be applied when drawing the conclusion that the use of the ICF, in its current format, enhances team communication. In developing the ICF-based report, not only did the participants need to adapt it but they only chose to use the ICF wording rather than develop a report that also included the originally proposed numerical qualifiers; the latter was deemed too complicated to incorporate at that time. Nonetheless, the ICF-based report provided a common language for use within the team and also facilitated communication of the patients' needs when referring on to other services. This is an issue previously raised within the literature (Martinuzzi el at 2008, Darzins et al. 2006) and one which will now be explored.

6.1.4.2 Enhanced communication beyond the team

Services lacking in a shared theoretical base and ideology are at risk of being externally driven, which in turn can lead to poor communication and disenfranchised staff (Donnison et al. 2009). In adopting the ICF within a transfer of care report, participants in the stroke service were able to articulate their remit thereby enhancing within team communication. They also were able to articulate on-going patient needs in order to justify referrals to community colleagues. Therefore, the use of the ICF-based transfer of care report also enhanced communication of the patient’s on-going needs with those outside the immediate team.

Perhaps of greater importance, the use of the ICF-based transfer of care report enhanced communication to the people living their lives with stroke: the individual, their family and the carers. Poor communication has been cited as a major cause of distress for patients and their families (Davis et al. 2003) so this report reduces that burden. One participant in this project, a former patient, commented that the report was useful in showing the progress made to date, thus supporting hopefulness post stroke which has been identified, by stroke survivors, as a key lesson for health care professionals (Blijlevens et al. 2009).

6.1.4.3 Promotes holistic thinking

It has been argued that there are two key factors in effective rehabilitation: (1) understanding the complexity of the process, and (2) the multiple factors associated with participating in it (Rimmer 2006). Communication of this complex and multifactorial process is hampered when there is a perceived lack of collaborative theory and working practices (Donnison et al. 2009). By using the ICF as a structure for a team report, participants in this project had access to information which highlighted the complexity of the patients’ needs following a stroke; thus demonstrating the need to work holistically to address the many problems caused by this complex neurological health condition. In short, using the ICF as a collaborative theory to underpin the stroke service promoted holistic thinking and team working practices.

Previous research has also concluded that the use of an ICF-based tool provides a more holistic view of disability (O’Donovan et al. 2009), although the focus of that study was more the tool than the perceptions of the people using or receiving it. Furthermore, a journal editorial hypothesised the use of the ICF to aid holistic thinking by encouraging health professionals to consider function and context in addition to the body level impact of, for example, stroke (Raggi et al. 2010). Therefore the ICF, by promoting a biopsychosocial perspective on the impact of stroke, encourages clinicians to consider a wider range of issues that may be difficult for a person post stroke. For example, by assessing the social and attitudinal environment (context), a therapist may determine the wife of a patient has a fatalistic attitude towards stroke and, therefore, her husband's prognosis; an education based intervention working with her could, in turn, mean she is more likely to encourage her husband to achieve greater independence in activities, potentially leading to better outcomes for him.

However, as the purpose of the report was for transfer of care, i.e. at the end of the episode of care, it could be questioned whether the team report was able to aid holistic working during the acute in-patient admission. But, as the report contained sections for completion on admission, as well as discharge, staff were already completing parts of the report during the admission of individual patients. In addition, this project demonstrated how thinking in general, about patient needs, became more holistic and was not just limited to when the patient was being discharged. Therefore, implementing the ICF in one part of the patient pathway has changed the way clinicians think across the pathway and enabled a deeper level of learning that will remain even when the artefacts, which facilitated the change, have been superseded (Parkin 2009).

Nonetheless, these particular artefacts, the transfer of care report and the glossary, are still in use five years on. This is testimony to the value of the tools: in that time a significant number of staff have rotated through, or just left the service, as is common in large metropolitan teaching hospitals. The ICF based tools and other shared organisational artefacts, such as the STEP team, have remained constant when many other aspects of the working practices have been lost, e.g. the Hospital admissions booklet imposed by the Trust. Infrastructure, like the ICF report and a dedicated weekly slot for the STEP team meetings, work as substitutes to build trust between the team members, in the absence of a stable team who know how to work with each other. In turn, these artefacts improve patient care (Davison and Sloan 2003) in part by maintaining the collaborative ideology of the team (Donnison et al. 2009). The sustained quality of the service is demonstrated in the results of the newly formed Sentinel Stroke National Audit Programme (SSNAP 2012), the successor to the Sentinel audit results, which shows that, despite the major re-structuring of the stroke service research site within the last five years, it remains in the upper quartile for stroke service provision in England and Wales (Royal College of Physicians 2012a).

6.1.4.4 Clarifies team roles

Team members need to be open, supportive, and willing to explore role overlap and understand roles (Suddick and DeSouza 2007). This project has provided an opportunity, albeit not explicitly, to explore role overlap and individual roles but, by focusing on the ICF domains and categories, it has done so in a way that is arguably less confrontational and emotive.

The clarification of team roles was, in part, achieved by changing existing cultures within the team, some of which can often present as barriers to effective communication, e.g. when writing in uniprofessional language, within a culture, becomes entrenched (Gillespie et al. 2010). In the past, therapy staff at the research site service had written their own reports (with the exception of the joint occupational and physiotherapist report) which were not shared with other members of the team. Establishing a joint ICF-based transfer of care report, centrally accessible to all, meant that individual therapists for the first time could see the input from their colleagues for a specific patient. The different roles and reasoning processes were evident and articulated in a common language thus reducing the risk of knowledge gaps impacting on patient care (Sada et al. 2011).

Furthermore, poor role demarcation has been linked to an unwillingness to speak out within healthcare teams (Sutcliffe et al. 2004) potentially causing a negative impact on patient care. A joint transfer of care report, communicated in an electronic, virtual space provides a safe space for continued learning, by health care professionals, on the roles of others in their team. As outlined in the introduction to this thesis, experience working within this specific stroke service had shown it was not always easy to seek clarity of staff roles. Now this report provides a platform for learning to occur.

Building on from the above, it could also be argued that if there is a link between clarifying team roles and speaking out, other challenges could also benefit: a greater understanding of the nurses' roles could mean their value is better appreciated, thus reducing the likelihood of nurses feeling disenfranchised, resistant to change (Widmark et al. 2012) and disrespected (Propp et al. 2010). However in a study with front line nurses (n=18) Garon et al. (2012) concluded that upbringing and culture played a significant part in influencing participants to speak out. Therefore, the potential for the ICF may be of limited value in this instance.

When scoping the initial ideas for this project, clinicians working in the broader field of neurorehabilitation felt, in theory, that the ICF had the potential to clarify team roles (Tempest and McIntyre 2006). So this project adds empirical evidence in support of that supposition. However, the authenticity and trustworthiness of this finding could be questioned, i.e. the level to which it was predetermined by the researcher's previous published outputs and clinical experience, in implementing the ICF framework, with the occupational therapy department. To this end, the researcher employed many strategies to maintain the quality and integrity of the data, including the use of member checking, the skills of reflexivity, and utilising support from a critical friend and two research supervisors. This was effective in mitigating against the effects of prior knowledge and experience with the ICF and allowed the researcher to focus on the opinions from the participants, most of whom were new to the framework and classification.

Other studies have also concluded the valued use of the ICF in clarifying team roles (Martinuzzi et al. 2008) or for that of an individual profession, i.e. physiotherapy (Mitchell 2008). However, participants in this project were keen to stress the need for flexibility in the demarcation of roles, an opinion supported elsewhere in the way the ICF can communicate new trends in practice, i.e. a shift in focus towards activity level interventions (Mitchell 2008).

6.1.5 Summary of the discussion points in relation to the project findings

In these first sections of the discussion, the findings of this project have been critically explored in relation to the literature on the use of the ICF and on the communication challenges within healthcare teams. The overall research aim was: to evaluate the process and outcome of implementing the International Classification of Functioning, Disability and Health (ICF) with an acute stroke service. The outcome was that in order to adopt the ICF participants, from an acute stroke service, adapted it to meet their local needs and in so doing enhanced communication, within and beyond the service, promoted holistic thinking and clarified team roles.

However, the success of the project cannot be solely attributed to the ICF as an inclusive theoretical framework and classification. Attention also needs to be paid to the manner in which it was implemented. At a conceptual level both the ICF and the use of action research were active ingredients which made for successful implementation and must not be viewed in isolation. Therefore, the next section will critically explore the use of action research, as the methodological approach, within the specific context of this project.

6.2 Reflections on the methodological approach

In the methods chapter Table 6 outlined the ten principles to measure the quality of action research projects, based on the work of Zubler-Skerrit and Fletcher (2007) and Bradbury Huang (2010). Some of the principles were critically explored in other sections of the thesis: rigour and reasoning for the methods used (principle 8) and clear articulation of the process (principle 9) were addressed in chapter four; and judgements linked to the discussion of the literature (principle 10) were debated in previous sections of this current chapter.

The remaining principles will be incorporated into the next two sub-sections, most of which focus on the nature of the project itself to critically explore the level to which it: is practice orientated (principle one); is participative in nature (principle two); is significant to the wider world (principal three); contributes something new to theory and practice (principal four); and is transparent in the assumptions made from it (principle seven). The remaining principles focus on the researcher in: demonstrating reflective and critical thinking (principle five); and an ethical stance (principle six).

There has been a call for greater collaboration between researchers and clinicians for the development of evidence based practice, to ensure that research studies have clinical meaning (Demers and Poissant 2009) and findings are grounded in clinical settings. This project did just that; it was practice orientated as the detail of the project was defined within the clinical domain, drawing upon recommendations from clinical guidelines (ISWP 2004) and set within the acute stroke service. It was participative in nature as the clinicians themselves engaged to identify a specific project, i.e. to develop a transfer of care report and glossary, then develop, implement and evaluate the process and outcome of so doing. Therefore, working within an action research framework, they brought about sustained change.

A number of factors influence the change process within the healthcare setting including: the history of the team; the influence of culture; the threats to roles and the politics of power. The use of processes such as action research can help overcome challenges presented by these factors in order to promote improved and sustained change (Parkin 2009). Other methodological frameworks, where the emphasis is not on learning from doing while undertaking action would, arguably, not have been able to incorporate practical change management solutions. Rather, learning would be left until completion of the fieldwork thus causing a potential time lag when transferring theory into practice. The use of action research facilitated change and, on a practical level, meant that local challenges to the implementation process could be defined and overcome. For example, when the functionality of the electronic records system proved ineffective, working together, the solution of setting up a shared drive on the intranet was found to overcome the problem.

So, for example, the qualitative study by Parker et al. (2009) ended by producing a list of suggestions to help overcome the communication challenges. But it was not clear if the suggestions subsequently turned into actions and benefitted service delivery. The use of action research in this project and the researcher doing the 'donkey work' (as described by one participant in the reflective phase) meant that challenges were identified, solutions were implemented, evaluated and revised and ultimately improvements were made for the benefit of patient care.

Therefore, this project contributed something new to theory and practice. On a practical level, the team now have a joint ICF-based transfer of care report and glossary which, as previously discussed, remains in use five years on. Theoretical findings, highlighting the benefits of implementing the ICF in stroke care, add to the literature on the outcome of using the framework and classification. New to the ICF evidence is an in-depth, detailed case study showing the process of how the theory was made a clinical reality within stroke services.

Yet there were other factors which may have contributed to the success of this project some of which are not as powerful today. This project was undertaken between 2006-2009 an era, as outlined in chapter two, when stroke service development was high on the political agenda. The launch of the National Stroke Strategy (Department of Health 2007), one year into this project, was indicative of a time when service development changes, for the benefit of patient care, were actively encouraged. In addition, the research site stroke service had previously participated in an action research study, the outcome of which resulted in the establishment of a community of practice (Kilbride et al. 2005). Therefore, the national and local landscapes were rich for service development initiatives; there was fertile soil, some of which has since lost its nutrition. This is because, as described in chapter two, the stroke service has undergone many enforced changes including the closure of its hyper acute stroke unit from a failed bid to acquire specialist unit status. It would be interesting to see if, in the current cycle of the NHS culture, a project such as this could yield the same success. On a positive note, at a national level, there is a recommendation for service development changes to be driven at a local level (Department of Health 2008), so there remains the theoretical opportunity for local clinicians to continue to 'steal the lead'. At a local level, the STEP team, as an artefact from the first action research project, continues to this day, with a remit for local service development; this is despite a high staff turnover which means only the medical consultants remain the same people in post today from the start of this project in 2006.

The use of action research as a methodological framework has its strengths but also limitations. A strength of this approach lies in the democratic and participatory nature of it which, in this case, was a key factor that contributed to the success of the ICF implementation process because participants valued owning the change process. However, it was a challenge to engage participation with all professions within the multidisciplinary team as, while all professions were involved in the development of the report to a greater or lesser extent, the hospital management subsequently introduced individual medical and nursing discharge reports, for funding purposes, which meant the final report became a therapy transfer of care report. This highlights an example of the difficulties of implementing change in practice when the local needs of, for example, a stroke service, are incongruent with a wider agenda, i.e. the hospital level requirements (Bridges and Meyer 2007).

It must also be acknowledged that a limitation of action research is there can be no claim to generalisability, in the traditional sense. Indeed this is a project that focused on the experiences of a single, established and successful clinical team (as defined by results from the national stroke sentinel audits). As such, individuals must judge the findings in a different way from traditional methods, by considering the relevance and potential impact of the findings within the context of their own clinical settings (Meyer 2006). Indeed, as the project progressed, other services became aware of it. The researcher was asked to present to a local community trust and, from this, one of the clinicians in that team subsequently registered for a PhD to explore the process and outcome of implementing the ICF within that very different clinical setting. This shows the significance of the findings and the methodological approach in terms of their value to the wider world. There has been a call for ICF-based implementation studies to be at the level of individual teams in order to gain a greater depth of understanding on the effect of using it in clinical practice (Verhoef et al. 2008).

A further and important challenge to the use of action research in this project is the substantial amount of human resources required in using it to implement the ICF into practice. The duration of the project was three years: the exploratory phase started in September 2006 and the transfer of care report and glossary were officially ready for use within the team by September 2009 (NB this includes the time taken to set up the shared drive which took a number of months). However, the investment in the process to implement the ICF has brought about sustained change in clinical practice, extending beyond the three years taken to implement it. Therefore, the use of action research was time efficient because, as previously discussed, this approach enabled participants to learn about the ICF and implement it at the same time. Nonetheless, further research is needed to explore the effectiveness of different implementation strategies.

Yet within action research, there are ‘different’ typologies therefore, future research may also need to explore the use of different participative action research approaches. However, this project did not explicitly start with a particular typology as a structure although, initially, it could be argued that it had characteristics of the technical scientific approach and the mutual-collaborative approach as outlined by Meyer (2006). The researcher was the initial expert in the ICF (bringing experience and technical knowledge of the framework and classification) and the project also incorporated elements of a mutual collaboration approach, as the multidisciplinary team were facilitated by the researcher to identify the challenges within the service and then decide upon the developments they wanted to focus upon. However, as the project evolved, it became evident that there was an emancipatory element to the project, as the team began to challenge the historical medically-led culture to facilitate the changes. Furthermore, as will be debated in the next subsection, there may have been an element of emancipation for the researcher. However, in returning to the original ‘hijacking’ analogy, it could be considered that there was limited emancipation of the non-medical participants who temporarily stole the lead before returning to their follower roles.

This subsection has focused on action research as the methodological framework. It has articulated the practice orientated nature of the project, one which was originally defined by the researcher, based on the clinical guidelines (ISWP 2004), but subsequently refined and driven by the participants. The findings were significant to other clinical teams who interfaced with the stroke service, to the point that a clinician from another team subsequently used the same aims and action research framework within the community setting. The findings are also of value to the ICF community, where a call for in-depth case studies had been made. Furthermore, these findings also show how specific communication challenges within healthcare teams can be overcome with the use of the ICF. The next subsection will critically explore the role of the insider-outsider researcher.

6.3 Reflections on my role as an insider-outsider researcher

As I am the focus of this subsection and, in congruence with the introduction chapter, I will be writing in the first person, to communicate and locate my position effectively within the context of this project. I will explore topics relating to my previous experience and knowledge of the team; managing the potential for bias in the analysis; the challenges in making the transition from a clinician to a researcher; the impact of my work ethic on the project outcome; and the gradual withdrawal process when ‘ending’ the project. I will also offer some reflections on what I would do differently if I had my time again.

It was of benefit to this project that I had prior experience and knowledge about the history of the team; I knew and had felt at first hand the prevailing hierarchy that existed within the team. I understood that attempts to develop a team report had been unsuccessful in the past, which participants attributed to factors such as the challenge of working in a target driven culture; identifying who takes the lead on a team project; and finding someone who has the time to drive such a big change through. However, I also knew it was a project that was not deemed a priority by the medical team so the politics of power were also potentially at play. Nonetheless, I knew that the infrastructure was already in place, especially the STEP team, to influence a change in culture within the team, with the support of an action researcher, to take on some of the workload and help them to challenge those at the top of the hierarchy, to bring about desired change.

There were also shortcomings to having an insider/outsider action researcher. The potential for bias in the analysis of data must not be ignored and to this end, I utilised member checking and the skills of reflexivity and self-awareness, both in supervision and with a critical friend, to limit the potential impact.

In addition, there were challenges caused specifically by me as the insider/outsider researcher. Not only was I new to being an action researcher but I assumed this role while early on in my academic career when I was struggling to let go of being an NHS employee. At the time I was unsure of the decision I had made to move from healthcare into academia. In short, during the exploratory phase, I felt I was in the way of the important clinical work. I was also aware how anxious I felt at pushing forward my own agenda (as I perceived it); a deep rooted personality trait which I always knew was going to be a challenge. In the early phase of the project, I found it very difficult being on the acute stroke unit as a researcher rather than a clinician.

My critical friend and supervisors helped me develop my confidence and skills as a novice researcher. My reflective diary and supervision sessions centred on the problems I felt with establishing my new role and in appreciating its worth. A useful analogy to describe how I felt was that it was like learning to fly while designing the plane. But, once the plane was designed, i.e. the participants had decided they wanted to devise a transfer of care report and a glossary, I was back within my comfort zone, working collaboratively on a practice based project, with the potential to benefit patient care. On reflection, the participants, by engaging and owning the innovatory phase in the way they did, may have emancipated me from my identity challenge and helped my transition from clinician to researcher.

Through experiencing the action research process, with the participants, I learnt to appreciate and understand my role and worth. As the innovatory phase progressed, I became more confident in my researcher role but, it is likely that the exploratory phase took longer because I needed to, first, adapt myself. Nonetheless, during the reflective phase, participants defined my work ethic as an active ingredient contributing to the project's success including, my efforts to keep momentum going and the fast pace in which I responded to their requests to update the various drafts of the report.

Before reflecting back on what I would do differently if I had my time again, the final theme to explore, in relation to my role, was the process which led to 'ending' the project. From the start, I was acutely aware that I did not want the participants to feel like 'lab rats' or there purely for the purposes of helping me in my selfish quest to achieve a PhD qualification. From the prior reading I had done about action research, I was also aware that leaving and ending a project could be a challenge.

The extent of my presence on the unit during the exploratory phase was self-determined (one day per week) while gathering data to identify the challenges within the service. Once the participants had selected their projects and the innovatory phase was underway, my role became more remote, as the STEP team began to take the lead on developing the tools. I was given an open invitation to attend their weekly meeting which I did every four to six weeks. At the end of each meeting, we agreed an action plan which I would take forward, e.g. update the latest version of the report. I would send my 'homework' back to the stroke coordinator who would circulate it to the rest of the STEP team; following which the participants would provide comments, directly back to me, via email. Alternatively, the stroke coordinator would email me a summary from a STEP meeting, where the report had been discussed, with an update and my next instructions. So even though I was not at the research site every week, I was still integral to the project.

There reached a point where the report was ready for a final pilot but, at a STEP meeting I was attending, it was established that setting up the shared drive was going to take a few months. With the project essentially in limbo, it became apparent that my role was coming to an end. This was November 2008; I was also due to go on maternity leave in February 2009. However, to me, as a completer-finisher by nature, this was not the ending for which I had hoped. Nor did I feel prepared, after nearly two and a half years together, for the ending to essentially come out of the blue. As a team, we spoke about the final stages and how we could finish our work. I was also honest about how I felt and said I would like to continue, in a remote manner, to finish the work we had started while on maternity leave. We agreed that, once the shared drive was ready, the team would pilot the report, sending out questionnaires to the first 30 recipients. The return address for the questionnaires would be my work address and the administrator at work would then collate all of them and forward to my home address. I subsequently analysed the data from the questionnaires thus completing the process. I visited the research site for a final time, while on maternity leave, with the final data set to share with the participants but, just as important for me, with knowledge and a feeling of preparedness to close the project. The gradual withdrawal from the project was of mutual benefit; participants received the, very positive, feedback from the questionnaire recipients which I had analysed for them and I was able to finish the work I had started and close the project in a way that felt right to me.

Reflecting back on the project, I feel I could have done more to engage with the medical consultants, from the pre-project phase right through to the end. I had kept in touch with the Stroke Co-ordinator and the Chair of the Stroke Oversight Committee (both senior physiotherapists) but if I had been able to engage with the Consultants more at the planning stage, to get them on board with the project before it started then, during it, I might have been able to maintain a greater level of inclusivity. But, my past clinical experience, of being in an implicit subordinate position to the medical leads, coupled with natural disquiet to push forward my own agenda, meant this was a stone left unturned. Yet, had I achieved a greater level of engagement with the consultants, it could have reduced some of the rather aggressive questioning about the project, during one particular STEP meeting, where I was challenged about the number of randomised controlled trials undertaken on the ICF, a session which I felt I did not perform to the best of my ability. On reflection, as a researcher, I continued to feel intimidated by those at the top of the hierarchy and this may have impacted on their involvement in the project. Yet, on sharing the abstract, of our knowledge-in-practice findings, at a STEP meeting, I was congratulated on its clarity by one of the Consultants; I felt at that point, over three years later, he finally understood what we had been trying to do. This was hugely satisfying for me.

I worked hard to be inclusive with all the other members of the multidisciplinary team; I was particularly aware of the need to engage with the nursing staff in ways that suited them, especially as they were not able to block time in their diaries for meetings in the same way as the therapists. Furthermore, I felt I understood the roles of the allied health professionals in greater detail, from my clinical background, but was more superficial in my understanding of the demands upon the nursing profession in acute stroke care. In attending their morning handovers, I was able to gain some insight into their roles and responsibilities. If I had my time again, before commencing on the ward as a researcher, I would explore the opportunities to volunteer as a healthcare assistant, to enable a greater understanding of the nursing role.

With hindsight, there are many things I would have done differently but I know that it was only through experiencing them, did I learn and develop my skills as an action researcher. While it is a labour intensive methodological framework in terms of time, for me, it held greater emotional and psychological intensity. I was not fully prepared for this but, my previous clinical background and the experience this had afforded me in terms of using supervision effectively, meant I was able to reflect in action and ensure I had appropriate support when needed.

6.4 Conclusion

The use of action research, as the methodological framework for this project, shows that sustained change in clinical practice is possible. Change has occurred at many levels: with individual participants, who now think more holistically; within the team, who now have a clearer understanding of each other’s roles and; at the transition of care point, where information is clear to patients, carers, family members and clinicians beyond the team. Furthermore, the report remains in use five years after it was implemented despite the fact that most of the participants who were involved it the implementation process have left the service.

The action research approach has benefitted both research and clinical practice. There is now empirical evidence to support the expert-opinion level evidence, in the National Clinical Guidelines for Stroke (ISWP 2012), which recommends the use of the ICF within stroke care to aid communication. With regards clinical practice, members of the acute stroke multidisciplinary team now have a joint transfer of care report, something they had tried, but failed, to bring into their service on a number of prior occasions. They achieved this by engaging in a democratic action research process to hijack the theoretical framework and classification from the international, national and local leads, in order to perform their own moves with it to suit their own needs.

To further support the clinical relevance of this work, the project has subsequently been taken forward by another clinical colleague within a community neurorehabilitation team.

6.4.1 Empirical contributions

The empirical contributions from this project, to the ICF literature, are many in number. Fourteen different ways that the ICF could be of benefit to an acute stroke team have been identified; there is a rich, thick description of the implementation process which concludes that to adopt the ICF is to adapt it. The beneficial outcomes of using the ICF within an acute stroke service have been established; it enhances communication, aids holistic thinking and clarifies team roles.

6.4.2 Theoretical contributions

The theoretical generalisations from this project relate to using the ICF to overcome specific communication challenges within healthcare teams. An electronic team report, using a common language and collaborative theory base to underpin practice, reduces a number of logistical challenges: it marks an end to illegible handwriting, reduces the risk of losing or being unable to access information and it provides virtual communicative space to articulate patient needs. It also helps to promote understanding of profession specific knowledge by clarifying who does what within the team, in one accessible language. It helps to define the remit of one service, while simultaneously articulating unmet needs which warrant further rehabilitation.

Using the ICF in conjunction with action research, to implement the theoretical framework and classification, through the medium of a transfer of care report, also challenged and changed the existing cultures. Therapists were able to introduce a report they had long desired, even though the medical consultants did not deem it a priority. Therapists are now able to see the contributions of their team members with individual patients and can learn about the specific interventions undertaken by each other.

6.4.3 Future research needs

There are three main elements to identifying the future research needs: 1) within the clinical context of stroke care; 2) with the ICF; 3) with action research as the methodological framework.

At a local stroke service level, it would be of value to research the use of the transfer of care report, over the past five years, with the current staff on the acute stroke unit to explore: if the report is still used in conjunction with the glossary; and if the ICF language is consistently used in the free text boxes or if clinicians, new to the team, find the language itself presents too much of a barrier. Further work could also explore the potential of using the numerical qualifiers as an outcome measure, within the transfer of care report, which was a component deemed too complex to undertake alongside learning the new language at the time of this project. Participants in this project also rejected the use of the ICF core sets for stroke to structure their documentation and a review of this, with new members of staff, in an arguably more target driven culture, would be useful. Other research topics could include using the ICF in stroke care to address the remaining 13 items on the original list of identified challenges, e.g. to structure multidisciplinary team meetings or for care planning and goal setting.

Future research also needs to explore the process and outcome of implementing the ICF within different clinical settings to increase our understanding of the knowledge translation process. As there have been calls for ICF implementation studies to remain at the individual team level (Verhoef et al. 2008), the process and outcome from one community team is a useful start but insufficient on its own. A number of studies, all using the same overall aim and methodological framework as this one would enable a meta-synthesis of the findings to build a more robust body of evidence. In contrast, additional research is required on the effectiveness of other change management approaches or implementation strategies for the ICF in addition to action research.

When undertaking the data collection and analysis for this research, there was a lack of evidence to guide these processes. Advice was sought from colleagues who had written action research theses; some of the authors, in their participation in the Action Research Group (ARG), were crucial in sharing their experiences of the complexities of the data collection and analysis processes and in offering advice on 'managing the mess'. For example, as discussed in the findings chapter, the observational data collected from the interactions within 20 multidisciplinary team meetings, were discarded after taking the issue to discuss at a local ARG meeting. Further research could engage with action researchers within the healthcare setting to determine consensus advice for undertaking data collection and analysis of action research projects in the clinical setting.

Finally, this project has used a democratic approach to implement a collaborative theory to underpin multidisciplinary team working in stroke care. Working practice has been improved and this has the potential to enhance the quality of patient care. Future research could involve greater engagement and collaboration with those living their lives after stroke, to best identify areas across the whole stroke pathway which may benefit from the use of the ICF.

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Volume Two: Appendices

Appendix 1: Ethical approvals

Brunel
UNIVERSITY
WEST LONDON

School of Health Sciences and Social Care

School of Health Sciences and
Social Care
Brunel University, Osterley Campus
Borough Road, Isleworth,

20 February 2006

<u>Proposer</u>: Stephanie Tempest

<u>Title:</u> **Promoting Multi Disciplinary Teamwork Within a Stroke Service: Evaluating the Use of the International Classification of Functioning, Disability and Health**

The School Research Ethics Committee has considered the amendments recently submitted by you in response to the Committee's earlier review of the above application.

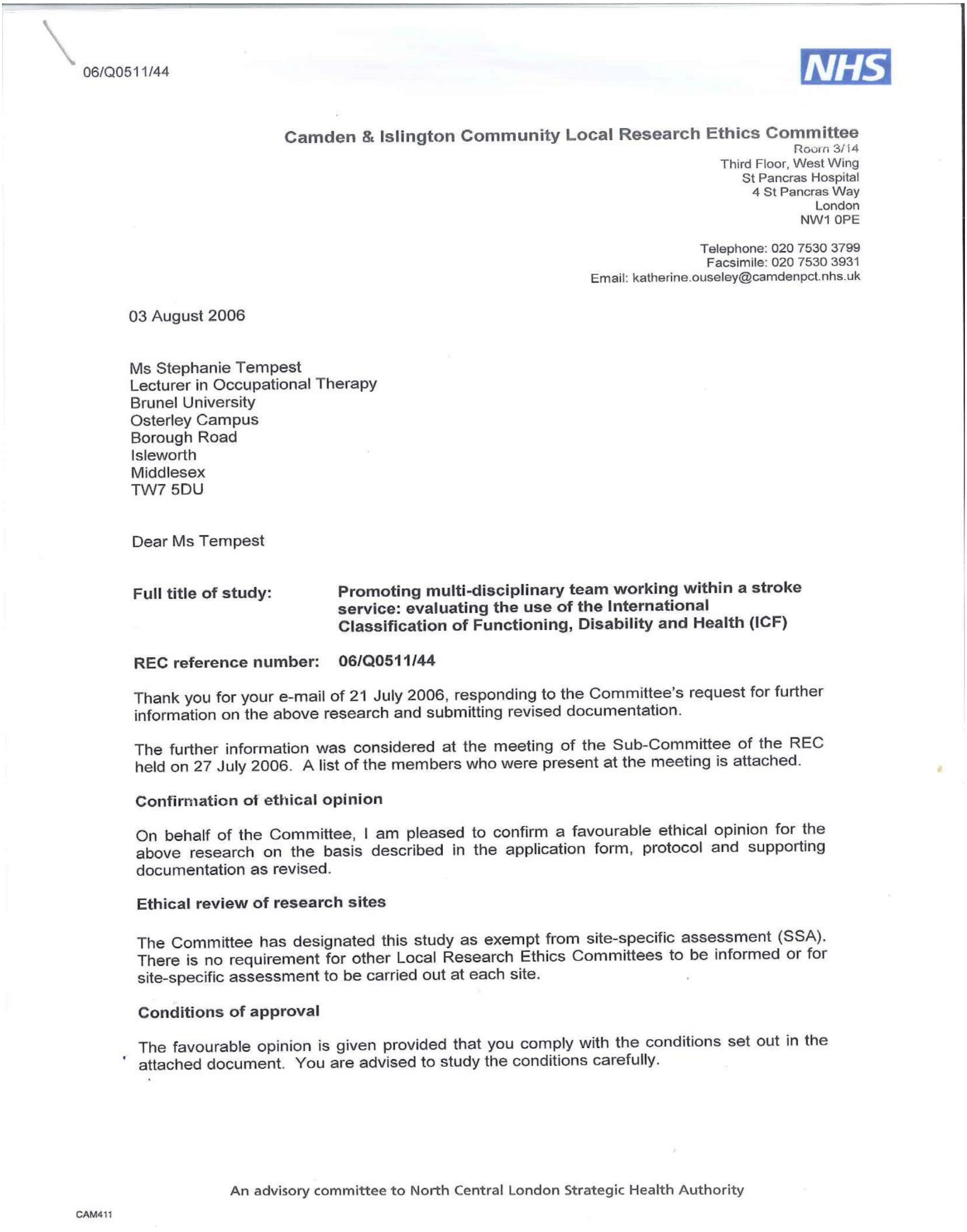
The Chair, acting under delegated authority, is satisfied that the amendments accord with the decision of the Committee and has agreed that there is no objection on ethical grounds to the proposed study. Approval is given on the understanding that the conditions of approval set out below are followed:

- *Question A6 plus A39: The researcher is reminded that approval to proceed will need to be obtained before the COREC application can be successful before the LREC.*
- *Question A10: For the School records, please provide any relevant "flyer" and Information Sheet to be used to invite Brunel staff to participate.*
- *Questions A14 and A16: The researcher should be aware that the LREC might suggest that absolute confidentiality cannot be assured should a public interest matter, e.g. in relation to the competence of staff members, arise.*
- *Question A45-2: It is suggested that there is an explicit statement that "statistical review was deemed inappropriate because this is predominantly a qualitative study".*
- *Question A48: Typo "frequency"*
- *Question A50/51: It is suggested that an explicit statement be included that "formal sample size calculations are not appropriate, as this is a qualitative study."*
- *It is assumed that the sentinel audit data that the researcher hopes to have access to will be anonymous. It is suggested that, again, this should be stated explicitly, as this means that that part does not actually need ethical approval.*
- *The "no detriment clause" contained in the Information Sheet still requires further amendment. At present, it only refers to no detriment in the event of withdrawal. The clause needs also to cover no detriment in the event of deciding, for any or no reason, not to take part at all in the study.*
- *The agreed protocol must be followed. Any changes to the protocol will require prior approval from the Committee.*

NB: Approval to proceed with the study is granted subject to receipt by the Committee of satisfactory responses to any conditions that may appear above, in addition to any subsequent changes to the protocol.

David Anderson-Ford
Chair, Research Ethics Committee
School of Health Sciences and Social Care

Ethical Approval from National Health Service (extract)



06/Q0511/44

NHS

Camden & Islington Community Local Research Ethics Committee
Room 3/14
Third Floor, West Wing
St Pancras Hospital
4 St Pancras Way
London
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03 August 2006

Ms Stephanie Tempest
Lecturer in Occupational Therapy
Brunel University
Osterley Campus
Borough Road
Isleworth
Middlesex
TW7 5DU

Dear Ms Tempest

Full title of study: **Promoting multi-disciplinary team working within a stroke service: evaluating the use of the International Classification of Functioning, Disability and Health (ICF)**

REC reference number: **06/Q0511/44**

Thank you for your e-mail of 21 July 2006, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information was considered at the meeting of the Sub-Committee of the REC held on 27 July 2006. A list of the members who were present at the meeting is attached.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised.

Ethical review of research sites

The Committee has designated this study as exempt from site-specific assessment (SSA). There is no requirement for other Local Research Ethics Committees to be informed or for site-specific assessment to be carried out at each site.

Conditions of approval

The favourable opinion is given provided that you comply with the conditions set out in the attached document. You are advised to study the conditions carefully.

An advisory committee to North Central London Strategic Health Authority

CAM411

Appendix 2: A reference list of the retrieved articles comprising the literature review (n= 40)

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Appendix 3: Summary of the action research studies within stroke care

Reference	Project aims	Project drivers	Level of engagement	Type of action researchers	Time frame for project	Sustainability of changes
Mitchell et al 2005`	To facilitate nurses to take ownership of their moving and handling practices on a stroke unit	A critical incident on ward and first author studying for academic qualification	Clinical nurse manager was kept informed only, focus was nurses	Insider action researchers	At least 2.5 years from dates in article but not specifically quantified	Change was sustained with individual nurses who took ownership of their practices
Hammel et al 2006	To identify community participation goals, barriers, and supports with people who have experienced stroke	US based study – responding to disability legislation – but local project drivers not clearly stated	Participants were all people living with stroke and family	Outsider researchers	Unclear – part of a broader and ongoing PAR project	Not stated
Jones et al 2008	To identify the key areas for stroke service development based on experiences of stroke survivors and their families	'The National Service Framework (NSF) for Older People provides a clear impetus for the involvement of patients in the development of stroke services in the UK' pg 1271	Voice of the service users and families at the centre	Outsider action researchers	Not stated	Not stated
Dewar et al 2009	To examine concept of compassionate care in hospital settings and to develop processes to facilitate embedding it in practice and education.	Bringing an idea to the participants; to demonstrate the potential of using emotional touchpoints to enhance compassionate care in clinical setting.	Staff, patients and their families	Outsider action researchers	Not stated	Acknowledge that more 'day-to-day' work is required to establish the method as part of everyday practice
Kilbride et al 2011	To seek to improve stroke care provision and identify key learning points from the implementation process	Long standing dissatisfaction from local health care professionals re organisation of the stroke care	MDT staff & senior management	Insider researcher	Two years	Provided examples of changes that occurred as a result of the project beyond the formal time parameters

Appendix 4: Copy of the self-reflective form completed at the end of each exploratory phase interview

Self-evaluation form (to be completed by the researcher only)
Focus Groups and Semi-Structured interviews

Focus Group number: **Or** **Interview number:**	
Profession of participant(s):	
Date of Focus Group / Interview:	

What story did the group comments tell in relation to:

Their opinion of who is in the MDT:

Their opinion of their role within the MDT:

Their understanding of others roles within the MDT:

Their opinion on the effectiveness of written communication:

Their opinion on the effectiveness of ward round communication:

Their opinion of how the service currently runs:

Anything else:

Appendix 5: The medical notes topic guide used in the exploratory phase (version 7)

Content analysis for medical notes in-patient history

Date of analysis:

Id tag:

Collective entry: describe type, date and who is documenting	List components of entry

Physician		Physician		Physician		Physician	

Other e.g. nurse specialist, opinion from specialist physician		Dietician		SLT		PT	

OT		Psychologist		Nurse		SW	

Appendix 6: The multidisciplinary team notes topic guide used in the exploratory phase (version 8: NBa new MDT documentation was introduced during the piloting phase which warranted an additional revision. NBb no data collected for section one as demographic / admin info only)

Content analysis for multidisciplinary notes

Section two personal details

Date of analysis:

Id tag:

Patient status: Acute or Rehab (circle)

Nurse		**Nurse**	

Name of profession and themes of entries		**Name of profession and themes of entries**	
		Additional notes	

Content analysis for multidisciplinary notes

Section three assessment forms

Date of analysis:

Nurse		**Nurse**	

Name of profession and themes of entries		**Name of profession and themes of entries**	
		Additional notes	

Content analysis for multidisciplinary notes

Section four discharge planning

Date of analysis:

Id tag:

Nurse		**Nurse**	

Name of profession and themes of entries		**Name of profession and themes of entries**	
		Additional notes	

Content analysis for multidisciplinary notes *section five new doc*

Date of analysis:

Id tag:

Add in grey box, the profession involved in goal setting if identified. Indicate if not sure within the grey box

Theme of goal	Planned interventions

Content analysis for multidisciplinary notes for *section six new doc*.

Date of analysis:

Id tag:

Nurse		**Nurse**	

		Additional notes	

Content analysis for section seven MDT notes

Date of analysis:

Id tag:

Collective entry: describe type, date and who is documenting	List components of entry

OT		PT		SLT		Other (add name of profession)	

Appendix 7: The ICF based questionnaire, subsequently discarded from the analysis, used in the exploratory phase with members of the acute stroke service. *NB Formatting has been changed (landscape to portrait and font reduced) to include in appendices*

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Researcher: Stephanie Tempest stephanie.tempest@brunel.ac.uk
Telephone number: 01895 268 689
Supervisors: Dr Priscilla Harries and Professor Lorraine DeSouza

Questionnaire

Professional roles in stroke care

I am interested in exploring the different roles that each profession has within the multi-disciplinary team, when working with a person who has had a stroke. As there are no right or wrong answers, I would value your experience from working within this service. The information from this questionnaire will enhance our understanding of who does what in the team and forms part of a larger research project.

This questionnaire has been designed to gather your experiences and it uses terminology defined by the World Health Organisation in the International Classification of Functioning, Disability and Health (ICF). The following guidelines are here to help you complete the questionnaire and it should take approximately 20 minutes.

Scoring:

Score *each* profession for *each* category; every space in the grid will need a score from you. Please score what each profession actually does within your service and not what you think they should do. You can award the same score for different professions in each category. If you think another profession is involved in a category, please award a score in the 'other' box and write the name of the profession. You may think a category is not addressed within your service therefore please put an X in the first box as you feel appropriate.

5 = Always involved
4 = Often involved
3 = Sometimes involved
2 = Occasionally involved
1 = Never involved
U = Unsure if a specific profession is involved in a category
X = Not addressed within this service

N.B. The questionnaire does not want you to think about the roles of other agencies e.g. wheelchair services or the roles undertaken by the carers or patients themselves.

Thank you for taking time to complete this questionnaire, it is much appreciated. Please return it in the pre-paid envelope to …..

Please circle your profession:

Dietician **Physician (Dr)** **Nurse** **Healthcare Assistant** **Clinical Psychologist**

Occupational Therapist (OT) **OT Assistant / Technician (OTA)** **Physiotherapist**

Physiotherapy Assistant / Technician **Speech and Language Therapist (SLT)** **Social Worker**

Other (please state) ……………………………………..

Body functions and structures

Category	**Not addressed within this service**	**Dietician**	**Dr**	**Nurse**	**OT**	**Physio**	**Clinical Psychologist**	**SLT**	**Social Worker**	**Other: please specify job and score**
Functions of the cardiovascular system *e.g. heart functions and blood pressure*										
Immunological system *i.e. protection against infection*										
Respiration functions *e.g. inhaling and exhaling*										
Additional respiratory functions *e.g. coughing, whistling, blowing*										
Exercise tolerance functions *i.e. capacity for enduring physical exertion*										
Ingestion functions *e.g. chewing, biting and sucking*										
Digestive functions *e.g. transporting food through body system or food tolerance*										
Seeing and related functions *i.e. vision*										
Hearing functions *i.e. sound*										
Vestibular functions *i.e. balance*										
Voice and speech functions e.g. *articulation*										
Category	**Not addressed within this**	**Dietician**	**Dr**	**Nurse**	**OT**	**Physio**	**Clinical Psychologist**	**SLT**	**Social Worker**	**Other: please specify job**

	service									and score
Additional sensory functions *i.e. touch*										
Pain *e.g. pain in head / back*										
Sexual functions										
Defecation and Urination functions										
Weight maintenance functions *i.e. maintaining appropriate body weight*										
Global mental functions *e.g. consciousness, energy and drive*										
Specific mental functions *e.g. memory, attention and perceptual functions*										
Mobility and stability of joints										
Muscle functions *e.g. power and tone*										
Movement functions *e.g. gait pattern*										
Functions of the skin *e.g. skin integrity*										
Haematological functions *e.g. metabolic functions or clotting*										
Sensations associated with the digestive system *e.g. nausea, cramp*										
Functions related to metabolism										

Activities and participation

Category	Not addressed within this service	Dietician	Dr	Nurse	OT	Physio	Clinical Psychologist	SLT	Social Worker	Other: please specify job and score
Learning and applying knowledge *e.g. making decisions and solving problems*										
General tasks and demands *e.g. undertaking tasks, carrying out daily routine*										
Handling stress *i.e. controlling emotions when carrying out tasks*										
Communication *e.g. spoken messages and written messages*										
Changing body positions *e.g. transferring oneself, sitting and standing*										
Carrying, moving and handling objects *i.e. hand and arm use*										
Walking and moving										
Using transportation *e.g. being driven in a car or catching the bus*										
Driving										
Washing and dressing										
Toileting *i.e. carrying out whole process including cleaning oneself*										
Eating and drinking *e.g. using cutlery*										
Looking after one’s health										
Domestic life *e.g. preparing meals, doing housework*										
Economic life *e.g. basic transactions, having command of finances*										
Community life *e.g. engaging in social organisations*										
Category	**Not addressed within this service**	**Dietician**	**Dr**	**Nurse**	**OT**	**Physio**	**Clinical Psychologist**	**SLT**	**Social Worker**	**Other: please specify job and score**
Interpersonal										

interactions and relationships *e.g. family relationships and intimate relationships*										
Work and employment										
Recreation and leisure										
Religion and spirituality										
Human Rights e.g. equal opportunities for disabled people										

Environment

Category	**Not addressed within this service**	**Dietician**	**Dr**	**Nurse**	**OT**	**Physio**	**Clinical Psychologist**	**SLT**	**Social Worker**	**Other: please specify job and score**
Products and technology for communication *e.g. communication boards*										
Products and technology for personal use in daily living *e.g. raised toilet seat*										
Products and technology for indoor and outdoor mobility										
Products or substances for personal consumption *e.g. access to medicinal drugs*										
Products and technology for employment *e.g. adapted office equipment*										
Design, construction and building products *e.g. adaptations for private or public buildings*										
Assets *e.g. financial assets*										
Natural and human made changes to the environment *e.g. light and sound*										

Category	**Not addressed within this service**	**Dietician**	**Dr**	**Nurse**	**OT**	**Physio**	**Clinical Psychologist**	**SLT**	**Social Worker**	**Other: please specify job and score**
Support and relationships *e.g. immediate family and*										

friends										
Attitudes of others *e.g. attitude of family or friends*										
Housing services and systems *e.g. Housing Association*										
Services, systems and policies *e.g. social security, access to legal system*										

Please return the questionnaire in the envelope provided to Stephanie Tempest, School of Health Sciences and Social Care, Mary Seacole Building,
Brunel University, Uxbridge, UB8 3PH.

Thank you for taking the time to complete this questionnaire.

Stephanie

Appendix 8: Copy of questionnaire, sent to staff beyond the service, during the innovatory phase, when evaluating draft 6 of the TOC report

Questionnaire on the nursing and therapy transfer of care report

We are looking at how we share information from the stroke service. Please find enclosed a new nursing and therapy report which we are developing. We would appreciate your views on this report. Many thanks for considering this request.

Are you (please circle):

Health/Social Care Professional
If yes, please state profession and your service:

Other (please state):

Please tick your level of agreement with the following statements:

Statement	**Strongly Agree**	**Agree**	**Neither agree nor disagree**	**Disagree**	**Strongly Disagree**
The report layout is easy to follow					
It contains relevant information					
I found it useful					
It is written in user friendly language					
It is an appropriate length					
It is easy to understand					

Please write any additional comments about this report if you wish:

Thank you for taking the time to complete this questionnaire.

Please return in the stamped addressed envelope to: Stephanie Tempest, Researcher, Mary Seacole Building, Brunel University, Uxbridge, UB8 3PH

Appendix 9: The Multi-disciplinary meeting (MDM) observational tool, subsequently discarded from the data analysis, in the exploratory phase

Content analysis for MDM

Date: Number of outliers (not included in analysis): Other factors of note:

Length of meeting: Acute pts numbers:

Number of patients involved in analysis: Rehab pts numbers:

Circle professions not in attendance.

Patient no.

Physician	Nurse	OT	PT	Psychologist	SLT	SW	Overspill for any profession (+ id)	Other

Appendix 10: The exploratory phase interview topic guide final version (v 10)

Topic guide: Interviews
Version 10 (for use by the researcher only)

Date:

Time:

Profession and grade of participant:

Introduction

Introduce self and role as researcher.

Consent form and confidentiality – tape recorded, names of individuals will be omitted at transcription and anything you say will not be attributed to you.

Explain purpose: no right or wrong answers, the aim is to gather opinions around following topic areas:

- what different team members do,
- your opinions on the written and verbal communication
- your thoughts on the organisation of the service.

I'd like to send you a copy of the transcription afterwards in case there is anything you would like to change, is this ok? E-mail / post?

Rapport building (straightforward questions)

The first topic is: Who is in the MDT and what do you do within the MDT? This is just to get you thinking, don't feel guilty if you forget, not a test, scrap paper if you want

- I'd like to start by asking you to run through the professions that make up the multi-disciplinary team in this service

Profession	Number order, write P if said after prompt.	Any other professions mentioned?
Doctor		
Nurse		
OT		
PT		
SLT		
SW		
Psychologist		
Dietician		

Quantifier: Think about who attends MDM or who you see on the ward.
Is there a … in the team?

- Let's take each one in turn and can you tell me what you think their core skills are in relation to patient care?

Quantifier: Think of an individual patient and what 'profession' did with them.

Ask	Dr	Nurse	OT	PT	SLT	Dietician	Psych	SW
Them								
You								

In-depth questions

The second topic is: Written communication

- I've got some statements from different professions and I'd like you to read them and talk me through which profession you think wrote it and why. This is about sharing your thoughts as we go along more than getting the answers right. Please feel free to scribble on the paper.

- I'm aware that there are different places that you write information:
    - Which places do you tend to write in the most?
    - Are there any places you look to gather information but do not necessarily write in?
    - Can you always find the information you are looking for written down?

The third topic is: Verbal communication

- On an informal, ad hoc basis, which members of the team do you tend to talk to the most and why?

I have sat in on the MDM meeting and observed one of the formal ways the team communicates verbally. (Confirm participant attends if not sure.)

- I'd like to know what you think the main purpose of this meeting is?
  Quantifier: "What sort of information are you looking for in this meeting?"

- What to you find most helpful about this meeting?

- What do you find least helpful about this meeting?

Our final topic is: Service organisation

- We've talked about what you all do within the team and have explored written and verbal communication. Finally, I'd like to ask your general opinion on the way the service is organised.
  Quantifier: What helps or hinders the service?

Hand out questionnaire with sae and explain

Closure

- Thank participant and please feel free to contact me if you feel something has been left out.
- I' d like to summarise the main issued I think that I have heard from you:
    - Who is in the team and what they do
    - Written communication
    - Verbal communication
    - Service organisation
- Clarify and confirm the summary

Appendix 11: The reflective phase interview topic guide (final version 2)

Interview topic guide for reflective phase

Pre-amble
Welcome and thank you
Explain aims of interview:

- To add more depth to the findings of the focus group on the outcome and process of introducing the ICF into practice.
- To explore what tips you might give other people who wanted to introduce the ICF into practice

Consent form

Warm up
We officially started this project in September 2006 and there have been many changes (including staff) during that time. Can you confirm when you started on the stroke unit and joined our project?

Main questions
Pros and cons of the ICF
In the focus group, there were a number of pros and cons identified with the ICF and I'd like to ask your thoughts on those.

- Pros of the ICF: to help communicate with other teams, to aid clarity of written communication within the MDT, to aid holistic thinking and to help written communication. Any examples?

- Cons with the ICF: Unfamiliar language, need to adapt for practice. Any examples?

The change process
I'd like to ask you about the change process next. The focus group identified the following things that helped and hindered. I'd like to ask you how important you feel these factors have been:

- Helped the process: Team ownership, getting the pace right, identifying priority projects, having an external facilitator, positive feedback from within and beyond the team, linking the change to the bigger picture
- Hindered the process: Not all involved, negative feedback from within and beyond the team

Outcome:
I would like to ask your thoughts on the things we have developed including the checklist which didn't work i.e. the checklist, the discharge template and the glossary.

- What are your thoughts on the checklist / discharge template / glossary as it is at the moment? Qualifiers: likes, dislikes, remain unsures

Warm down
In a few minutes, I'd like to summarise what I think I have heard from you. But before that I would like to ask a couple of final questions. The focus group came up with this list of tips they would give other teams who wanted to introduce the ICF into their practice.

- Which ones do you think are the most important?
- Are there any other tips you would add?

Close: Summarise around each question, ask for confirmation. Any further comments?
Thank you and close.

Appendix 12: The exploratory phase focus group topic guide, employing the nominal group technique

Focus group topic guide using the nominal group technique

Aim of session: to discuss and decide upon ways the ICF language could be introduced into the service to enhance the existing structures.

Outline of session plan using a nominal group technique

1) **Group formation (10 mins)**
   Welcome and outline of session

   Review of our research: ICF core set outline

   Explain nominal group technique

   Present a summary of the suggestions for potential use of the ICF language to date

2) **Silent phase (5 mins)**
   Ask participants to write down any other potential uses

3) **Item generation phase (10 mins)**
   Go around the group asking for additional suggestions until all are written down on the whiteboard

4) **Discussion and clarification phase (15 mins)**
   Take each suggestion in turn; discuss and clarify. Amalgamate any that are similar until there is an agreed upon list of potential uses

5) **Voting phase (5 mins)**
   Participants score each item:

Score 2: yes, definitely, can do it and want to do it.

Score 1: maybe, would like to and think we could.

Score 0: no, don’t want to and can’t do.

Individual scores are recorded and then collated to a group score to show the most and least favoured suggestions

6) **Final plenary phase (10 mins)**
   Discuss what the team would like to do next: not just about taking the top suggestion, more excluding the least favoured

   Gather e-mail addresses for those interested in commenting on draft work

   Thanks and close

Appendix 13: The reflective phase focus group topic guide (final version 3)

Focus group topic guide reflective phase

Pre-amble

Welcome and thank you

Not looking for consensus, interested in all of your thoughts. Mix of discussion and small activity so you can pick lunch as you go along!

Explain aims of focus group:
1) To explore your thoughts about the process we have undertaken so we can learn from what we did well and what we could have done differently.
2) To explore your thoughts on the outcomes of the process i.e. the things we have developed (dch rep, checklist, glossary)
3) To identify key topics about the ICF, the process we have been on and the outcome to date. This is to help inform the development of interview questions to explore specific things in more detail.

Consent forms

Warm up

- We all came to this project with different levels of knowledge and thoughts on the ICF. So, firstly I would like to ask you how familiar you now feel with the ICF in comparison to the start of the project?

- I'd also like to ask you about your opinions on the ICF now we have used it within the project?
  Qualifiers: likes, dislikes, remain unsure

Main questions

I'd also like to ask for your thoughts on the outcome to date and what has helped / hindered.

Outcome:
During the project, we've developed different things: dch rep, checklist, glossary and I'm interested in your thoughts on each of these.
- What are your thoughts on the dch rep/ checklist / glossary as it is at the moment?
  Qualifiers: likes, dislikes, remain unsure

Time for an activity!: sticky notes, driving forces and restraining forces, on board.
Process:
- What do you think were the driving forces that helped the process?
  Qualifiers: people, policies, culture
- What do you think were the restraining forces that hindered the process?
  Qualifiers: people, policies, culture

Warm down

In a few minutes, I'd like to summarise what I think I have heard from you. But before that I would like to ask one final question:

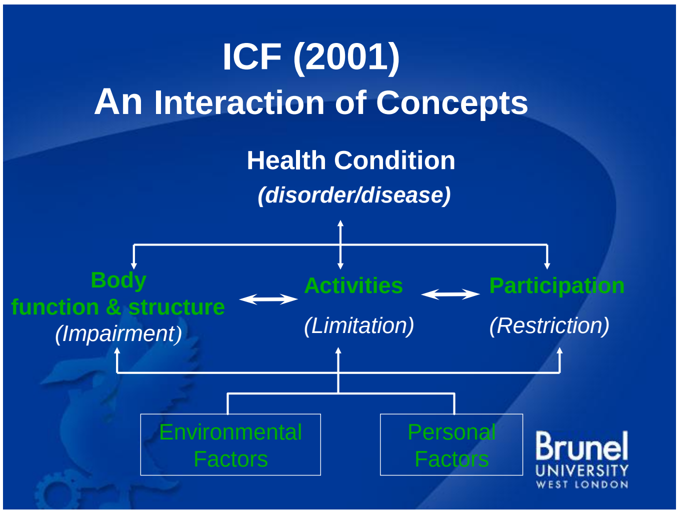
- What advice would you give to another MDT who wanted to introduce the ICF into their practice?
  Qualifiers: do again the same, do differently

Close
Summarise around each question, ask for confirmation. Any further comments?
Thank you and close.

Appendix 14: A copy of the small findings summary booklet in the exploratory phase

Front page:

Potential ways to use the International Classification of Functioning, Disability and Health (ICF) on the acute stroke unit.



ICF (2001)

An Interaction of Concepts

Health Condition

(disorder/disease)

Body function & structure

(Impairment)

Activities

(Limitation)

Participation

(Restriction)

Environmental Factors

Personal Factors

Brunel UNIVERSITY WEST LONDON

World Health Organisation (WHO: 2001)

"A common language…in assessment, rehabilitation and outcome evaluation"
(WHO 2001)

"One of the major factors impeding good stroke care is a lack of any widely accepted, easily understood framework, which may adversely affect communication. It is strongly recommended that the ICF terminology should be used."
(National Clinical Guidelines for Stroke 2nd edition 2004)

Page 1:

What is the ICF and why do we need to think about it?

The ICF is a framework (see the front cover) and also a detailed classification endorsed by the World Health Organisation (WHO). A research team working with the WHO has taken the detailed classification and condensed it to a list (or core set) of all the factors that may be affected if the health condition is a stroke. The affects can be seen at different levels:

- *body functions* = affecting the body
- *activities and participation* = affecting a person's routine
- *environmental factors* = affecting a person's physical and social world

The WHO and the National Clinical Guidelines for Stroke strongly recommend we use the ICF to communicate as a team but they do not tell us how to do this, nor is there much evidence to tell us the best way.

I have been gathering information with the team since October 2006; this booklet is part of phase one of a research project outlined on the next page. It is a summary of some of the findings so far. The findings are not 'results' or 'facts'; the aim is to use them to promote discussion. If you would like to share your thoughts with me, I am on the ward on Mondays and some other days too or stephanie.tempest@brunel.ac.uk

Thank you for taking time to read this booklet, Stephanie

Page 2:

Overview of the research

There are three phases to this research as outlined below:

Phase	**Aims**	**How**
Phase one: exploration	Explore how the service currently runs	Analysis of MDT and medical notes, observations including MDM meeting, interviews, questionnaires, field notes.
Phase two: intervention	Think about ways the ICF may help. Plan and implement into the service	Working with the team, feedback and field notes
Phase three: evaluation	Review the implementation	As per phase one

The next few pages list all the different categories in the ICF core set for stroke. Those in **bold** are ones which I have seen written or spoken about within the service. It does not mean this is purely what the service offers, more the things I have observed so far. You may wish to jot your thoughts down by the categories.

The final pages of this booklet offer some suggestions about how this information may be useful. It invites you to think about any other suggestions. There is also a list of useful references and websites if you would like more information.

Page 3:

Body functions that may be affected by stroke (problems are called impairments)

ICF domain	**Categories included**
Mental functions	**Consciousness, orientation, intellect, personality, energy, sleep, attention, memory, psychomotor, emotions, perception, thinking, higher level cognition, mental functions of language,** calculations, **mental functions for sequencing movement, experience of self and time.**
Sensory functions and pain	**Seeing, functions adjoining the eye, hearing, vestibular functions, sensations associated with hearing and vestibular functions, proprioception, touch, senses related to temperature and other stimuli, pain.**
Voice and speech functions	**Voice, articulation, fluency and rhythm, alternative vocalization**
Functions of the cardiovascular, haematological, immunological	**Heart functions, blood vessel functions, blood pressure, haematological system, immunological system, respiration, additional respiratory functions,**

and respiratory systems	**exercise tolerance.**
Functions of the digestive, metabolic and endocrine systems	**Ingestion, digestive functions, defecation functions, weight maintenance functions, sensations associated with the digestive system, general metabolic functions, water / mineral / electrolyte balance, thermoregulatory functions.**

Page 4:

Body functions (problems in these areas are called impairments) continued …

ICF domain	**Categories included**
Genitourinary / reproductive functions	**Urination**, sensations associated with urinary functions, sexual functions.
Neuromusculoskeletal and movement-related functions	**Mobility of joints**, stability of joints, **muscle power, muscle tone, muscle endurance, motor reflex, involuntary movement, control of voluntary movement, gait pattern.**
Functions of the skin	**Protective functions of the skin.**

Words in **bold** are the categories I have seen written or spoken about in this service so far. Some are referred to a lot and others I have seen mentioned once or twice. You may wish to circle any that are not in bold if you feel the service does address them or write any thoughts here.

Page 5:

Activities and Participation that may be affected by stroke (problems in these areas are called activity limitations or participation restrictions).

ICF domain	**Categories included**
Learning and applying knowledge	Watching, listening, other purposeful sensing, copying, rehearsing, acquiring skills, **focusing attention, reading, writing,** calculating, **solving problems, making decisions.**
General tasks and demands	**Undertaking a single task**, undertaking multiple tasks, carrying out daily routine, handling stress and other psychological demands.
Communication	**Spoken messages, non verbal messages, receiving written messages, speaking, producing non verbal messages, writing messages, conversation, using communication devices and techniques.**
Mobility	**Changing basic body positions, maintaining a body position, transferring oneself,** lifting and carrying objects, fine hand use, **hand and arm use,**

	walking, moving around, moving around in different locations, moving around using equipment, moving around using transportation, **driving.**
Self-care	**Washing oneself, caring for body parts, toileting, dressing, eating, drinking, looking after one's health**
Domestic life	Acquisition of goods and services, **preparing meals**, doing housework.

Page 6:

Activities and Participation that may be affected by stroke (problems in these areas are called activity limitations or participation restrictions) continued …

ICF domains	Categories included
Interpersonal interactions and relationships	**Basic interpersonal interactions, informal social relationships, family relationships**, intimate relationships
Major life areas	Acquiring, keeping and terminating a job, remunerative employment, non-remunerative employment, basic economic transactions, economic self-sufficiency
Community, social and civic life	Community life, **recreation and leisure, religion and spirituality**, human rights.

Words in **bold** are the categories I have seen written or spoken about in this service so far. Some are referred to a lot and others I have seen mentioned once or twice. You may wish to circle any that are not in bold if you feel the service does address them or write any thoughts here.

Page 7:

Environmental factors that may be affected by stroke (problems in this area are called environmental barriers) continued…

ICF domain	Categories included
Products and technology	**Products for personal consumption, daily life, personal indoor and outdoor mobility** and transportation. **Products for communication** and for employment. **Design of buildings for private use** and public, assets.
Natural environment	Physical geography, light, sound.
Support and relationships	**Immediate family, extended family, friends,** acquaintances, peers, colleagues, **neighbours** and community members. **Personal care providers, health professionals, health-related professionals.**

Attitudes	**Attitudes of immediate family members, extended family, friends,** acquaintances, peers, colleagues, neighbours and community members. **Attitudes of personal care providers, health professionals, health-related professionals,** societal attitudes, **social norms, practices and ideologies**

Page 8:

Environmental factors that may be affected by stroke (problems in this area are called environmental barriers).

ICF domain	Categories included
Services, systems and policies	Services relating to architecture and constructions, **housing, communication**, transportation, legal system, associations, **social security, social support, health services** and employment services.

Words in **bold** are the categories I have seen written or spoken about in this service so far. Some are referred to a lot and others I have seen mentioned once or twice. You may wish to circle any that are not in bold if you feel the service does address them or write any thoughts here.

Page 9:

How could the ICF core set for stroke help?

Here are a few suggestions for us to think about. They have arisen from discussions with some of you, my observations on the ward and also some suggestions from the literature on the potential uses for the ICF. You may think there are other uses too.

1) To help define which professionals take the lead in different areas of care to assist organising the patient journey.
2) To guide you in areas for care planning and goal setting.
3) To help define what the service is able to offer in its acute capacity.
4) To help you make decisions about a patients rehabilitation needs e.g. to communicate their rehab agenda when referring on.
5) To help describe the impact and complexity of stroke.
6) To use the terminology as a common language within the team and beyond.
7) To help structure note writing and meetings.

Is there anything else you think would be useful? (You may wish to jot something down)

Page 10:

What happens next?

If you would like to share your ideas with me, I am on the ward on Mondays and some other days too. I may ask you if you have any ideas but if you are too busy then please say and that is fine.

Alternatively, you can e-mail me your thoughts stephanie.tempest@brunel.ac.uk or leave your booklet with the notes you have written in the Sisters office in the envelope provided. There are spare copies of this booklet too should you wish to take one.

I will also be distributing a questionnaire which uses the different ICF categories, should you wish to share your thoughts this way. It is entirely voluntary to complete.

Over the next month or so, we can then think about how we can use the ICF core set for stroke and take it from there.

Many thanks for taking the time to read this booklet.

Stephanie

Back page:

Some useful websites and references:

World Health Organisation ICF homepage: www3.who.int/icf/icftemplate.cfm

Clinical guidelines for stroke 2nd edition:
http://www.rcplondon.ac.uk/pubs/books/stroke/

National Clinical Guidelines for Stroke (2nd ed.) Intercollegiate Stroke Working Party. Clinical Effectiveness and Evaluation Unit. London. Royal College of Physicians. 2004.

Geyh S, Cieza A, Schouten J, Dickson H, Formmelt P, Omar Z, Kostanjsek N, Ring H, Stucki G (2004) ICF Core Sets for Stroke. Journal of Rehabilitation Medicine Supplement 44 135-141

Stucki G, Ewert T, Cieza A (2002) Value and application of the ICF in rehabilitation medicine. Disability and Rehabilitation 24 (17) 932-938

Tempest S, McIntyre A (2006) Using the ICF to clarify team roles and demonstrate clinical reasoning within stroke rehabilitation. Disability and Rehabilitation 28 (10) 663-667

Appendix 15: The exercise in the exploratory phase interview: reading current notes entries

1 to 8 are taken from written documentation held on the ward. 9 and 10 are extracts taken from the multi-disciplinary team meeting

1.
Neurologically stable and unchanged. Meds given as prescribed c/o pain this morning in shoulder. Analgesia given. Mobilising to toilet with assistance. Slept well.

2.
S Pt ISQ. Sat out by N/S this am. Feels exhausted + keen to t/f back to bed.
O Obs stable
Rx sit – stand x2 A2 max
Step – round t/f to bed A2 max
A Pt initiating mvts with (L) UL today. Pt generally tired. Fatigued rapidly - Rx limited.
P Cont as able

3.
Offer a few tsps of yoghurt and sips of H2O when sat up. Re-insert NG (pt agrees) P) Will review 2/7

4.
Improving
Chest getting better
Obs stable
Plan: D/C Monday
Cont Warfarin

5.
R/V
Noted request re K+
Last K+ on 22/12 5 days ago
N) range up to 5.3. Pt 5.5 mmol
Requirement for K+ 89 mmol (RNI 50-90mmol)
Feed currently provides 66 mmol
Pt not even meeting K+ requirements via feed
K+ only 0.2 mmol above N) range
↓sing feed would compromise pt nutritionally
P) Cont on the same feed. Will R/V Friday

6.
S Patient asleep in bed on oxygen, woke upon being called
O Personal care assessment for functional rehab, washing face and arms, patient dipping in and out of sleep, drowsy, able to follow simple instructions but reduced arousal and neglect impairs her ability to participate
A Neglect on rt side, automatic movements observed in rt arm but no voluntary movements, positioned rt arm, retrograde massage for rt hand oedema
P Discuss with MDT, continue personal care

7.
- All care given. Sat out by physioT for 2 hours
- Remains neurologically stable

- NG feed in progress
- Danaparoid sodium infusion I progress at 3.3 rate per hour
- X1 episode of loose bowels
- Mouth care given

8.

The following guidelines aim to facilitate communication.

- Ensure quiet surroundings if possible
- Be patient
- Allow plenty of time for a reply
- Repeat what you have understood
- Never pretend to understand

9.

The patient has the capacity to make a decision but the risks of going home must be made clear. A referral to the Stroke Association may also be helpful.

10.

The family have been given the contact number for the nursing home and Jewish care have the reports. Panel have deferred on a decision and Continuing Care are concerned about the NG tube. The panel meet again this Friday.

Appendix 16: Version one of the Transfer of Care report

Logo

Stroke multi-disciplinary team report for transfer of care

Patients name		**Date of birth**	
Hospital number		**Patients address**	
Date of admission			
Anticipated discharge date		**Diagnosis**	
Barthel score on admission		**Barthel score on discharge**	
GP name and address		**Team transfer recommendation e.g. inpatient rehab, ICT**	

Summary of health condition and personal factors Diagnosis, age, gender, coping styles, past medical history, social background, lifestyle, profession and education.

Body functions	**On admission**	**At time of report**
Mental functions Consciousness, orientation, intellect, personality, energy, sleep, attention, memory, psychomotor, emotions, perception, thinking, higher level cognition, mental functions of language, calculations, mental functions for sequencing movement, experience of self and time.		
Sensory functions and pain Seeing, functions adjoining the eye, hearing, vestibular functions, sensations associated with hearing and vestibular functions, proprioception, touch, senses related to temperature and other stimuli, pain.		
Voice and speech functions Voice, articulation, fluency and rhythm, alternative vocalization		
Functions of the cardiovascular, haematological, immunological and respiratory systems Heart functions, blood vessel functions, blood pressure, haematological system, immunological system, respiration, additional respiratory functions, exercise tolerance.		
Functions of the digestive, metabolic and endocrine systems Ingestion, digestive functions, defecation functions, weight maintenance functions, sensations associated with the digestive system, general metabolic functions, water / mineral / electrolyte balance, thermoregulatory functions.		
Genitourinary / reproductive functions Urination, sensations associated with urinary functions, sexual functions.		
Neuromusculoskeletal and movement-related functions Mobility of joints, stability of joints, muscle power, muscle tone, muscle endurance, motor reflex, involuntary movement, control of		

voluntary movement, gait pattern.		
Functions of the skin Protective functions of the skin.		

Activities and Participation	**On admission**	**At time of report**
Learning and applying knowledge Watching, listening, other purposeful sensing, copying, rehearsing, acquiring skills, focusing attention, reading, writing, calculating, solving problems, making decisions.		
General tasks and demands Undertaking a single task, undertaking multiple tasks, carrying out daily routine, handling stress and other psychological demands.		
Communication Spoken messages, non verbal messages, receiving written messages, speaking, producing non verbal messages, writing messages, conversation, using communication devices and techniques.		
Mobility Changing basic body positions, maintaining a body position, transferring oneself, lifting and carrying objects, fine hand use, hand and arm use, walking, moving around, moving around in different locations, moving around using equipment, moving around using transportation, driving.		
Self-care Washing oneself, caring for body parts, toileting, dressing, eating, drinking, looking after one’s health		
Domestic life Acquisition of goods and services, preparing meals, doing housework.		
Interpersonal interactions and relationships Basic interpersonal interactions, informal social relationships, family relationships, intimate relationships		

Major life areas Acquiring, keeping and terminating a job, remunerative employment, non-remunerative employment, basic economic transactions, economic self-sufficiency		
Community, social and civic life Community life, recreation and leisure, religion and spirituality, human rights.		

Environmental factors	**On admission**	**At time of report**
Products and technology Products for personal consumption, daily life, personal indoor and outdoor mobility and transportation. Products for communication and for employment. Design of buildings for private use and public, assets.		
Natural environment Physical geography, light, sound.		
Support and relationships Immediate family, extended family, friends, acquaintances, peers, colleagues, neighbours and community members. Personal care providers, health professionals, health-related professionals.		
Attitudes Attitudes of immediate family members, extended family, friends, acquaintances, peers, colleagues, neighbours and community members. Attitudes of personal care providers, health professionals, health-related professionals, societal attitudes, social norms, practices and ideologies		
Services, systems and policies Services relating to architecture and constructions, housing, communication, transportation, legal system, associations, social security, social support, health		

services and employment services.		

Summary and recommendations

Appendix 17: Version six of the Transfer of Care report

Stroke service Nursing and Therapy report for transfer of care

Date report completed:

Patients name		**Date of birth**	
Hospital number		**Patients address and Borough**	
Date of admission			
Anticipated discharge date		**Health condition**	
Barthel score on admission		**Barthel score on discharge**	
GP name and address		**Team transfer recommendation e.g. inpatient rehab, ICT**	

Summary of health condition and personal factors May include: diagnosis, age, gender, coping styles, past medical history, social background, lifestyle, profession and education.(completed by case co-ordinator)

On admission

Body functions on admission
1. Cognitive functions(Psychologist, OT, Nurse, Physio, SLT)
2. Consciousness, Energy, Drive and Sleep functions (Psychologist, OT, Nurse, Physio, SLT)
3. Emotion and mood functions (Psychologist, OT, Nurse, Physio, SLT)
4. Sensory functions and pain (Physio, Nurse, OT, SLT)
5. Voice and speech functions(SLT, Physio, Nurse)
6. Functions of the cardiovascular, haematological, immunological and respiratory systems (Nurse, SLT, Physio) .
7. Functions of the digestive, metabolic and endocrine systems (Dietician, SLT, Nurse, OT, Physio)
8. Genitourinary / reproductive functions (Nurse, OT)

9. Neuromusculoskeletal and movement-related functions (Physio, OT, Nurse, SLT)
10. Functions of the skin (Nurse, OT, Physio, SLT)
Activities and Participation on admission
11. Learning and applying knowledge (OT, SLT, Physio, Nurse)
12. General tasks and demands (OT)
13. Communication (SLT, Nurse, Physio, OT)
14. Mobility (Physio, OT, Nurse, SLT)
15. Self-care (OT, Nurse, SLT, Physio)
16. Domestic life (OT, Physio, Nurse)
17. Interpersonal interactions and relationships (OT, Nurse)
18. Major life areas (OT, Nurse)
19. Community, social and civic life (Nurse, OT)
Environmental factors on admission
20. Products and technology(Dietician, Nurse, OT, Physio, SLT)
21. Natural environment (OT, Physio)
22. Support and relationships (Psychologist, OT, Nurse, Physio, SLT)
23. Attitudes (OT,SLT, Physio, Nurse)
24. Services, systems and policies (OT, Dietician, Nurse, Physio, SLT)

Summary of goals, intervention and progress during admission:
Key: GA = Goal Achieved, GNA = Goal not achieved

Goal	Outcome (GA or GNA) and date comment on intervention and progress if appropriate	Profession

On discharge

Body functions on discharge
1. Cognitive functions(Psychologist, OT, Nurse, Physio, SLT)
2. Consciousness, Energy, Drive and Sleep functions (Psychologist, OT, Nurse, Physio, SLT)
3. Emotion and mood functions (Psychologist, OT, Nurse, Physio, SLT)
4. Sensory functions and pain (Physio, Nurse, OT, SLT)
5. Voice and speech functions (SLT, Physio, Nurse)
6. Functions of the cardiovascular, haematological, immunological and respiratory systems (Nurse, SLT, Physio)
7. Functions of the digestive, metabolic and endocrine systems (Dietician, SLT, Nurse, OT, Physio)
8. Genitourinary / reproductive functions (Nurse, OT)
9. Neuromusculoskeletal and movement-related functions (Physio, OT, Nurse, SLT)
10. Functions of the skin (Nurse, OT, Physio, SLT)
Activities and Participation on discharge
11.. Learning and applying knowledge (OT, SLT, Physio, Nurse)
12. General tasks and demands (OT)
13. Communication (SLT, Nurse, Physio, OT)
14. Mobility (Physio, OT, Nurse, SLT)
15. Self-care (OT, Nurse, SLT, Physio)
16. Domestic life (OT, Physio, Nurse)
17. Interpersonal interactions and relationships (OT, Nurse)
18. Major life areas (OT, Nurse)
19. Community, social and civic life (Nurse, OT, Physio)
Environmental factors on discharge
20. Products and technology (Dietician, Nurse, OT, Physio, SLT)
21. Natural environment (OT, Physio)
22. Support and relationships (Psychologist, OT, Nurse, Physio, SLT)
23. Attitudes (OT, SLT, Physio, Nurse)
24. Services, systems and policies (OT, Dietician, Nurse, Physio, SLT)

Information and equipment given to patient and relatives / carers:

E.g. moving and handling, transfers, equipment, contact details for local statutory and voluntary agencies, dietary advice, communication guidelines, other advice sheets, plans for review

Patients / carer / family perspective of progress:
Completed by:

Recommendations and on-going plans:

Copy of report given to:

Profession	Name	Signature	Date

Appendix 18: Version fourteen (final) of the Transfer of Care report

Stroke Therapy Transfer of Care Report

Date report completed:		**Date report reviewed:**	

Patient's name		**Date of birth**	
Hospital number		**Patient's address and Borough**	
Date of admission			
Anticipated discharge date		**Health condition**	
Barthel* score on admission		**Barthel score at time of report**	
GP name and address		**Team transfer recommendation e.g. inpatient rehab, community rehab**	

*The Barthel score measures the level of performance in day to day activities

Summary of health condition and personal factors ***On admission***	**Summary of health condition and personal factors** ***On discharge***

Patient’s name		**Hospital number**	

Body functions	**On admission**	**On discharge**
Cognition (thinking abilities)		
Alertness and motivation		
Mood and behaviour		
Sensory systems and pain		
Cardiovascular, haematological, immunological and respiratory systems		
Digestive, metabolic and endocrine systems		
Swallowing		
Genitourinary / reproductive systems		
Neuromusculoskeletal system and movement		
Skin condition		

Patient's name		**Hospital number**	

Activities and Participation	On admission	On discharge
Learning and applying knowledge		
Communication (including voice and speech)		
Mobility		
Self-care including medication management		
Managing daily routine and structure		
Domestic tasks		
Education and / or work needs		
Finance management		
Religion and spirituality		
Recreation and leisure		

Environmental factors	On admission	On discharge
Equipment		
Home environment		
Support and relationships		

Patient's name		**Hospital number**	

Information and equipment given to patient and relatives / carers: *E.g. moving and handling, transfers, equipment, contact details for local statutory and voluntary agencies, dietary advice, communication guidelines, other advice sheets, plans for review*

Patient's / carer / family perspective of progress: **Completed by:**

Summary of goals, intervention and progress during admission:

Goal	**Outcome (GA or GNA) ***	**Profession(s)**	**Comments**	**GAS****

Key: *******GA = Goal Achieved, GNA = Goal not achieved*

*** GAS = Goal Attainment Scale (+2 much better than expected; +1 better than expected; 0 expected/achievable goal; -1 current level; -2 less than current level)*

Outcome Measures	**On Admission**	**On Discharge**	**Comments**

Recommendations and on-going plans:

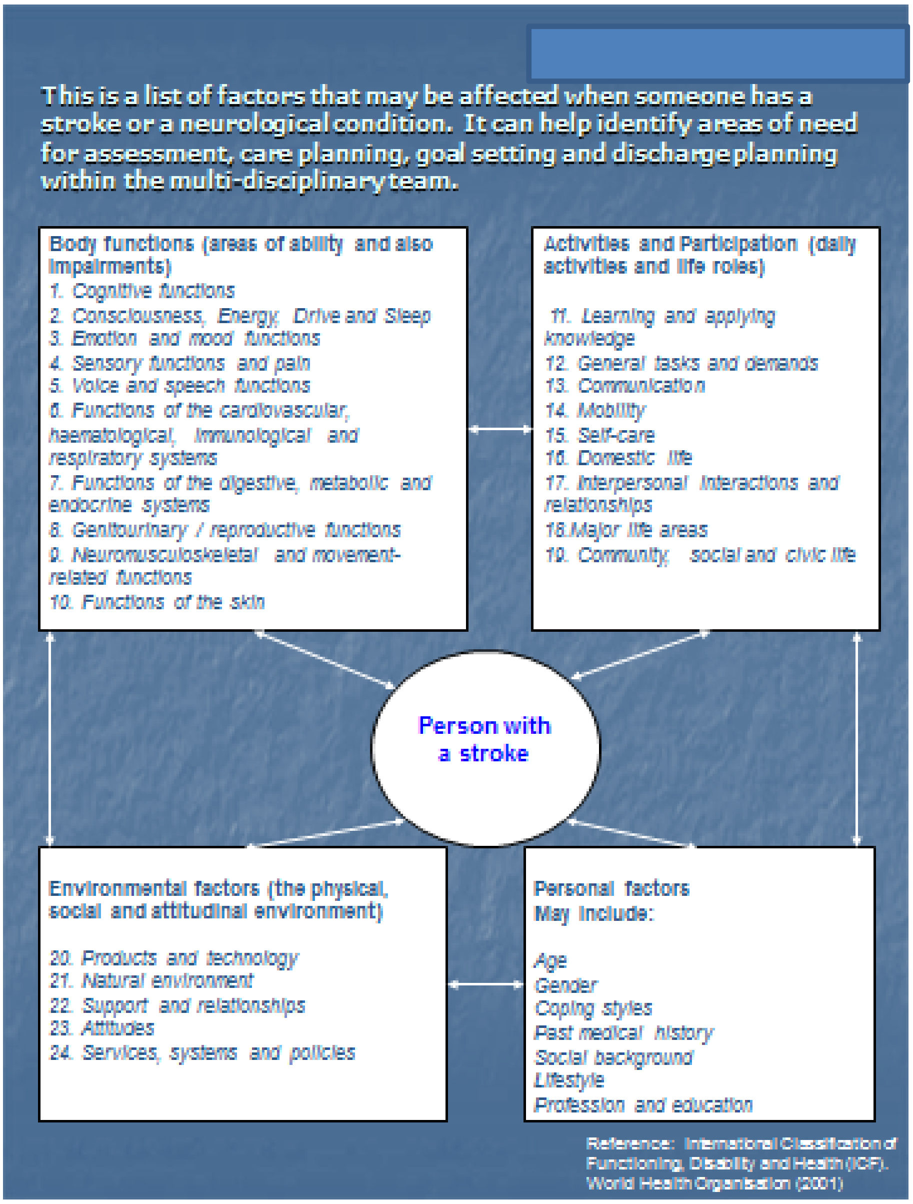
Family consulted about discharge plans? YES / NO **Comments:**

Report completed by:

Name	**Profession**	**Contact details**	**Signature**	**Date**

Copy of report given to:	

Appendix 19: The ICF checklist (version three) that proved unsuccessful



This is a list of factors that may be affected when someone has a stroke or a neurological condition. It can help identify areas of need for assessment, care planning, goal setting and discharge planning within the multi-disciplinary team.

Body functions (areas of ability and also impairments)

1. *Cognitive functions*
2. *Consciousness, Energy, Drive and Sleep*
3. *Emotion and mood functions*
4. *Sensory functions and pain*
5. *Voice and speech functions*
6. *Functions of the cardiovascular, haematological, immunological and respiratory systems*
7. *Functions of the digestive, metabolic and endocrine systems*
8. *Genitourinary / reproductive functions*
9. *Neuromusculoskeletal and movement-related functions*
10. *Functions of the skin*

Activities and Participation (daily activities and life roles)

11. *Learning and applying knowledge*
12. *General tasks and demands*
13. *Communication*
14. *Mobility*
15. *Self-care*
16. *Domestic life*
17. *Interpersonal interactions and relationships*
18. *Major life areas*
19. *Community, social and civic life*

Person with a stroke

Environmental factors (the physical, social and attitudinal environment)

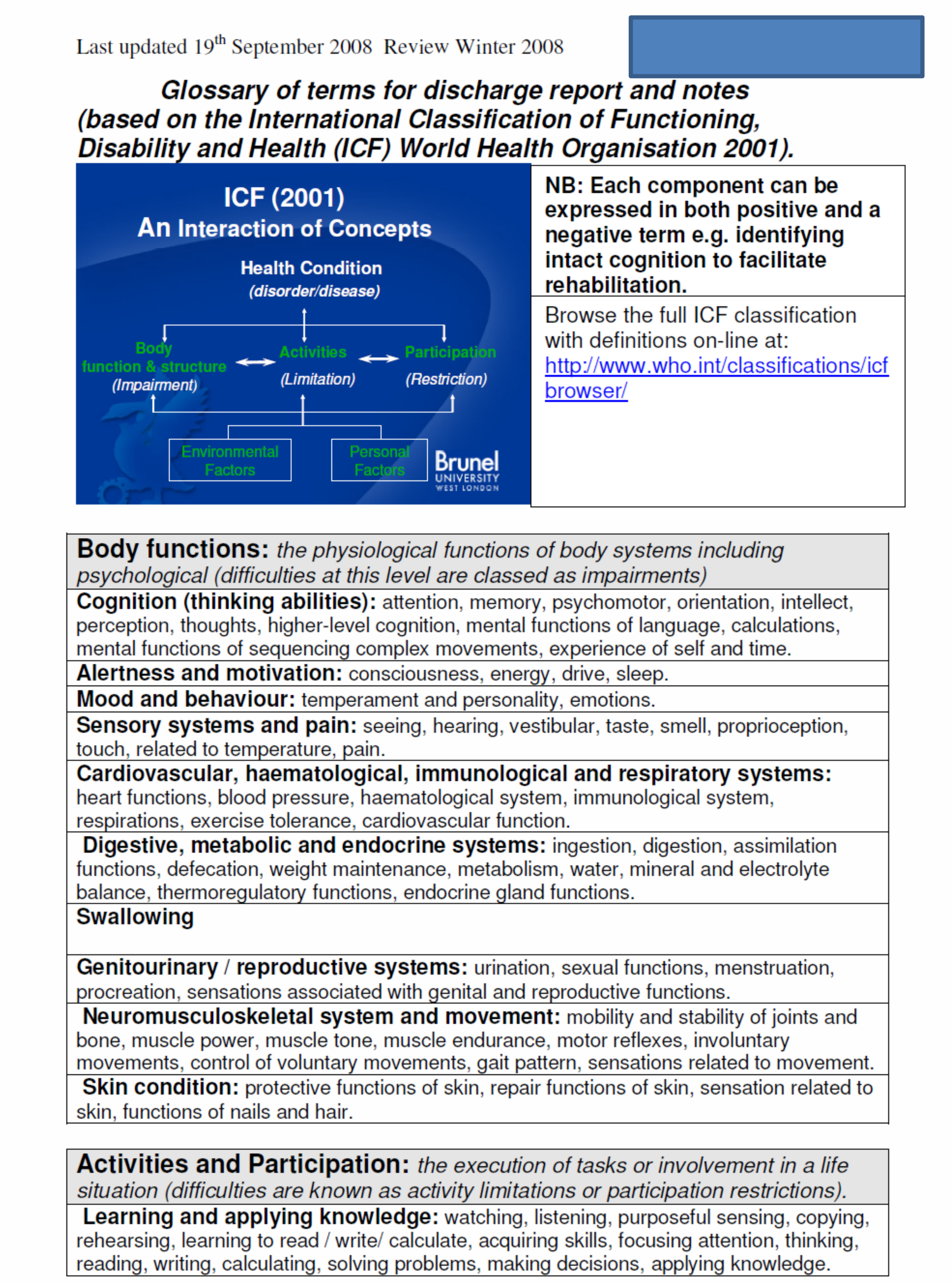
20. *Products and technology*
21. *Natural environment*
22. *Support and relationships*
23. *Attitudes*
24. *Services, systems and policies*

Personal factors May include:

Age
Gender
Coping styles
Past medical history
Social background
Lifestyle
Profession and education

Reference: International Classification of Functioning, Disability and Health (ICF). World Health Organisation (2001)

Appendix 20: The ICF glossary (final) used as an aide memoir with the TOC report



Last updated 19th September 2008 Review Winter 2008

Glossary of terms for discharge report and notes (based on the International Classification of Functioning, Disability and Health (ICF) World Health Organisation 2001).

NB: Each component can be expressed in both positive and a negative term e.g. identifying intact cognition to facilitate rehabilitation.

Browse the full ICF classification with definitions on-line at: http://www.who.int/classifications/icfbrowser/

Body functions: *the physiological functions of body systems including psychological (difficulties at this level are classed as impairments)*

Cognition (thinking abilities): attention, memory, psychomotor, orientation, intellect, perception, thoughts, higher-level cognition, mental functions of language, calculations, mental functions of sequencing complex movements, experience of self and time.

Alertness and motivation: consciousness, energy, drive, sleep.

Mood and behaviour: temperament and personality, emotions.

Sensory systems and pain: seeing, hearing, vestibular, taste, smell, proprioception, touch, related to temperature, pain.

Cardiovascular, haematological, immunological and respiratory systems: heart functions, blood pressure, haematological system, immunological system, respirations, exercise tolerance, cardiovascular function.

Digestive, metabolic and endocrine systems: ingestion, digestion, assimilation functions, defecation, weight maintenance, metabolism, water, mineral and electrolyte balance, thermoregulatory functions, endocrine gland functions.

Swallowing

Genitourinary / reproductive systems: urination, sexual functions, menstruation, procreation, sensations associated with genital and reproductive functions.

Neuromusculoskeletal system and movement: mobility and stability of joints and bone, muscle power, muscle tone, muscle endurance, motor reflexes, involuntary movements, control of voluntary movements, gait pattern, sensations related to movement.

Skin condition: protective functions of skin, repair functions of skin, sensation related to skin, functions of nails and hair.

Activities and Participation: *the execution of tasks or involvement in a life situation (difficulties are known as activity limitations or participation restrictions).*

Learning and applying knowledge: watching, listening, purposeful sensing, copying, rehearsing, learning to read / write/ calculate, acquiring skills, focusing attention, thinking, reading, writing, calculating, solving problems, making decisions, applying knowledge.

Last updated 19th September 2008 Review Winter 2008

Communication (including voice and speech): voice functions, articulation, fluency and rhythm, alternative vocalisation, communicating *receiving* and / or *producing* spoken messages, nonverbal messages, formal sign language messages, written messages, speaking, conversation, discussion, using communication devices.
Mobility: changing basic body positions, maintaining body positions, transferring, lifting and carrying objects, moving objects with lower extremities, find hand use, hand and arm use, walking, moving around including different locations, using equipment, using transportation, driving, riding animals for transportation.
Self-care: washing oneself, caring for body parts, toileting, dressing, eating, drinking, looking after one's health.
Managing daily routine and structure: able to organise self and daily routine
Domestic life: acquiring a place to live, acquisition of goods and services, preparing meals, doing housework, caring for household objects, assisting others.
Education and/or work needs: education, work and employment,
Finance management: basic economic transactions, complex economic transactions, economic self-sufficiency.
Religion, Spirituality: religion and spirituality including doing activities related to organised religion
Recreation and Leisure: community life, recreation and leisure, human rights, political life and citizenship.
Environmental factors: *the physical, social and attitudinal environment (difficulties are called environmental barriers, positives are called environmental facilitators).*
Equipment: for personal consumption, personal use in daily living, for indoor and outdoor mobility and transportation, for communication, education, employment, culture, recreation and sport, for the practice of religion and spirituality, design and construction of public and private buildings.
Home environment: physical environment, social environment, attitudes within the cultural environment.
Support and relationships: from immediate family, extended family, friends, colleagues, neighbours, community members, people in positions of authority, personal care providers and assistants, health professionals, strangers.

Personal factors:

To date, personal factors have not been fully classified by the World Health Organisation but include:

Particular background of an individual
Gender, Race, Age
Other health conditions, Fitness, Lifestyle, Habits
Upbringing, Coping styles
Social background, Education, Profession
Past and current experiences, overall behaviour pattern and character style

Appendix 21: Published article 1. Tempest, S., Harries, P., Kilbride, C. and De Souza, L., (2013) Enhanced clarity and holism: The outcome of implementing the ICF with an acute stroke multidisciplinary team in England, Disability and Rehabilitation 35 (22): 1921-1925

Appendix 22: Published article 2. Tempest, S., Harries, P., Kilbride, C. and De Souza, L., (2012) To adopt is to adapt: The process of implementing the ICF with an acute stroke multidisciplinary team in England, Disability and Rehabilitation 34 (20): 1686-1694

See BURA