

The PARTNERS Programme

An Evaluation Report



PARTNERS

Participatory Action Research To develop Nursing Electronic health Records

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This is a good case for you to seesaid the nurse he requires a lot of care across the different services. He's the type of case that when you meet him for the first time you wonder why the other people involved in his care could leave him like this and then it occurs to you that you have other similar cases on your books.... you do your best for them but you also need to respect where they are at.

A clean unremarkable tidy housing estate tucked away in a cul de sac in Dublin suburbia on a sunny June afternoon. The nurse comments to me as we cut across the road and garden oh he has the door open as she approaches and knocks whilst calling his name I enter behind her. It hits me like a wall this over whelming smell a mix of urine and stale food and tobacco ... but mostly its urine. I introduce myself and shake hands with a pale slightly jaundiced man in a chair in the corner of a living room. He appears happy to see us his expression is expectant and lively as he speaks to us in thick country accent. Then I start to take in the visual cues as they drop into place in front of me. He looks well nourished his clothes are not old nor un kept but his trousers shows signs of well formed stains from food from the past few meals and he has wet trousers which looks like a problem with urinary incontinence. He is unshaven and has marks on his chin we think its bruising but when we ask him about it he explains to us that its beetroot. The surrounding fire hearth, furniture and floor are filthy with dried food stains and layers of dirt on the grey tiles it looks like some of it has been there for a long time. On the uppermost layer of this dirt is the evidence of today's lunch some of which is scattered across the floor. This makes the floor damp and wet in parts with beetroot juice as well as cigarette ends which are also scattered around the floor. Moving around the room the rest of the kitchen come dining room looks reasonably clean and tidy. The dirt is isolated to this one area of the room. I find that hard to understand. The nurse is asking him some questions and then introduces me I shake hands with him and start to explain the study but before I have explained to him what it is he is saying to me Yes I'll do it ... I'll do it for you no problem.

I start to struggle concentrating I am upset and unsettled....more visual cues I notice a bottle of laxatives on his shelves in the corner the bottle appears sticky with laxative spilt on it. The nurse starts to talk to him again this time about his breathing. I have to give them up ... I have given them up he says referring to the cigarettes and points to some nicorette gum he has on the table. The nurse asks what happened to your chin did you fall? No.... its beetroot is it on my chin, he asks and he laughs. My phone rings it's one of the team from the research project the funding is under review and we discuss the ethical problems gaining access to one of the services which is ongoing What we can do we will do my familiar up beat Gandhi expression just doesn't seem to fit well today. I go back in to the room and ask permission to return next week just to give him time to consider the study and if he is still interested we can proceed. We say good bye and leave in the car we clean down our hands with alcohol rub. It's good he had the door open to day the nurse says the smell yesterday with the heat in the room was over bearing.

Excerpt from Diary 9th June 2.30pm Case 1

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Foreword

The focus of this project is inter- agency communication. This report evaluates how formal terminology underpinned by health informatics standards can assist health care providers to communicate patient centred information across traditional service boundaries more efficiently and effectively. It provides evidence on how nurses work between different environments across different settings. The tool devised for shared care by the project team may serve as a starting point for those individuals who are engaged in the development of discharge or transfer of patient centric care documentation e.g. the newly established clinical directorates. The participants in this project who are primarily nurses recognise that formal communication processes involving interagency communication between the primary care, continuing care, and acute care sectors is currently dependent on informal communication processes such as the telephone or fax machine. The process of approaching formal communication using health informatics standards and adopting formalised concepts and terms facilitates shared meaning between health care parties which the group maintain could enhance existing inter agency communication. In the longer term such initiatives may directly impact upon patient safety. This report is an evaluation of phase one of a pilot study project entitled PARTNERS, which is an acronym for Participatory Action Research To develop Nursing Electronic RecordS. The PARTNERS project identified two key objectives, firstly to educate and train nurses in health informatics, specifically in relation to a health informatics standard developed internationally to guide nursing records development on nursing diagnosis and interventions (ISO 18104). Secondly, to identify formalised concepts and reference terminologies for future inclusion in nursing documentation practices. The identified set of concepts and terms in this report, whilst crude, may inform future interagency communication on discharge planning or transfer of care, not only for nurses but also other members of the multidisciplinary team. To demonstrate these objectives in action a purpose built assessment form using a set of design restrictions in the form of an archetype was devised.

The archetype is designed in accordance with a health informatics standard entitled EHRcom (EN13606) and is defined as follows “*an agreed, formal and interoperable specification of the data and their inter-relationships that must or may be logically*

persisted within an electronic health record for documenting a particular clinical observation, evaluation, instruction or action” (Kalra 2004).

These two objectives were made possible by liaising with the Dublin Institute of Technology on a research programme entitled EHRland. The EHRland project supported by the Health Information and Quality Authority (HIQA) is a research programme which is testing the health informatics standard EN13606. The standard EN13606 is the European standard for the electronic health care record. The PARTNERS group defined the requirements, concepts and terms for the archetype and the EHRland group designed the archetype and created a database for use for the duration of the pilot study.

The information presented in this evaluation will draw from both of the PARTNERS and EHRland projects. This is made possible as the author is the Principal Investigator of the PARTNERS project and is a member of the EHRland project team. Whilst the focus of the project was the development of an archetype to enhance interagency communication the EHRland group also devised a prototype information system to collect and store patient centred outcomes as defined by Almost et al (2003). The PARTNERS group were keen to collect patient data which could minimally present patient centred outcomes, and involve the patient in the decision making processes relating to their care. For example did the patients like the idea of having access to and keeping their own record? Because of the size and resources associated with the project, the project team opted to complete a small pilot study and evaluate the overall effectiveness on a group of over 65 year olds and on those practitioners who sought to pilot the tool (practitioners n = 14, Cases n = 16 Settings = 6). Initial thoughts suggested that this evaluation would focus on whether the PARTNERS assessment form was effective or indeed ineffective, simply stated putting into practice the 3 W’s which are if the prototype archetype/s (assessment form) *worked* for *whom* and under *what* circumstances. Over time it became apparent that the evaluation required a more inclusive focus. This evaluation therefore focuses on exploring both the mechanisms (processes) and outcomes relating to the assessment form and also seeks to identify those mechanisms which will impact on the overall sustainability of such practice development initiatives in the future. In this way the PARTNERS group can offer the reader an honest account of the lessons learnt by practitioners, patients and the evaluator’s overall experience.

Executive Summary

Words reflect and collectively create meaning between people, and more often than not are associated with a view within a particular context and time. Words form the basis of a language which has the capacity to evolve and change thus altering the actual meaning of the vocabulary. The workflow of the role of nursing could be described as peripatetic; nurses often practice in several different settings which can span service boundaries. Often whilst performing nursing interventions their practice is interrupted due to unplanned events and information is often recorded retrospectively. Future health care systems will need to be able to address such events and from a quality and safety perspective facilitate capturing the language of nursing to reflect the local patient context detail and time. It is therefore important that nurses in Ireland initiate the process of adopting formalised concepts and terms whilst documenting shared patient care across service boundaries. This is of particular relevance to the profession of nursing as health care leaders focus more intently on measuring cost efficiency, and based on these results, redesign existing processes to be more effective, particularly from the patient perspective. In the summer of 2009 a national principles based framework was established to create clinical directorates within Ireland. The primary purpose of creating clinical directorates is to achieve the best clinical outcome and experience for patients with the best available resources (O'Shea, 2009, p.107). Such developments would suggest that objective data is increasingly becoming the yardstick to inform newly integrated programmes of care, enlighten clinical judgment and decision making and allocate already scant resources to care pathways. Within this particular report a care pathway could be described as locally agreed, multidisciplinary practice based on guidelines and evidence for a specific client group, it forms part of the clinical record documents the care given, and facilitates the evaluation of outcomes for continuous quality improvement Middleton and Roberts (2000).

The task of educating, training, and implementing formal language within nursing documentation has and will continue to be a complex process (Hoy et al, 2008). In addition, the anecdotal evidence within Ireland suggests that integrated programmes of care will be difficult to effectively deliver without first laying a strong foundation stone in the form of education and training (O'Shea, 2009). Education therefore must be viewed as an integral part of the transformational programme for change. In particular educational programmes which support electronic healthcare record development will need to include an introduction to the process of labeling and adopting formalised language in patient care records. One example of a repository to access formalised reference language relating to the profession of nursing is the International Classification of Nursing Practice. Further information is available from <http://icnp.clinicaltemplates.org/info/v2/>. It is important to state that this perspective is not solely related to nursing but extends to the entire multidisciplinary team. The profession of nursing as the largest stakeholder group involved in the co-ordination of care however will be required to engage as a priority (O'Shea, 2009). To do less may have serious ramifications for nurse resourcing and patient safety in future health care service provision (Aiken 2002, Aiken et al 2002, MacNeela et al 2006 Needleman et al 2002). A first step in delivering an archetype and collecting data to review the nursing contribution to patient care is to create a system in the form of a simple database and basic user interface application. Key principles guiding this development are that the system is clinically pragmatic, reflects the reality of nursing practice, captures patient centred outcomes, whilst including the preferred formal language and terms that are relevant and used frequently by the profession (Hannah et al, 2009). By "cross checking" or mapping the language of nursing into the existing formal reference terminologies objective data can be identified for inclusion in future EHR. Some authors advise that establishing a database can be a complex and indeed lengthy process and should not be entered into lightly (Hegyvary, 1991; Jones, 1993) and this is represented well in the following quote from Pringle and Doran (2003)

In order for databases that house information relevant to nursing to be established for a region or a health care system, there must be consensus among nurses as to a) what inputs processes and outcomes to include, b) how to define and measure them and c) agreement on the timing of their measurement recording and abstraction

Pringle and Doran, 2003 p. 8

System developers engaged in database development must therefore understand as a priority that such systems cannot and do not operate in isolation. Nurse researchers interested in developing such databases which will support information systems must recognise that such systems will inform part of a larger enterprise wide development centred on the patient journey through the continuum of healthcare –namely the Electronic Healthcare Record (EHR). For this reason the project identified in this evaluation has been designed in accordance with key European health information standards namely ISO 18104, the reference terminology for nursing diagnosis and interventions, and EN 13606 the European standard for the Electronic Healthcare Record (ISO: 2003, EN: 2008).

The format of this report is as follows: the main body of the report includes part one, PARTNERS as an vehicle for change, which offers a brief summary of the motivations for this particular project, the theory under investigation and the short and long term objectives of the project. Part 2 describes the evaluation methods adopted and briefly outlines evaluation principles as defined by Pawson and Tilley in their book *Realistic Evaluation* (Pawson and Tilley, 1997). This section also introduces the individual groups who participated in the evaluation process. Part 3 of the report is a presentation of the findings and is divided into separate sections according to the individual stakeholder groups. The findings are presented as follows

- a) Section 3.1 offers an introduction to the findings in this report and the manner in which they are presented.
- b) Section 3.2 offers an overview of the individual service provider's views.
- c) Section 3.3 offers an overview of the service providers collective views
- d) Section 3.4 offers statistical data report of the data collected in the patient assessment tool.
- e) Section 3.5 Statistical report of the data collected on individual patients.

Section 3.3 demonstrates the key concepts identified in the study by the nursing groups from the acute primary and continuing care sectors. The figures created can be viewed in conjunction with full transcripts of discussions in Appendix 3. The statistical data presented in section 3.4 is completed by a member of the PARTNERS group Ms Mary Sharp lecturer in Health Informatics in Trinity College Dublin. Included within section 3.5 is one patient case from each of the service providers who participated in the study. Broadly speaking there are four participant groups identified in this study, namely health care practitioners, patient participants, policy makers, and the researcher who completed the research programme and report. A total of 18 patients were recruited into the study between June and October 2009. Two of these cases did not participate for the duration of the study; the data reported upon in section 3.4 is therefore based on 16 cases.

The recruitment process involved selecting patients who were both well and chronically ill and who were aged 65 and over. The patients invited to participate in the study were from the primary continuing care and acute care sectors. Presentation of the data acquired from the use of assessment tool (Appendix 2) is supported by additional background information on each particular case collected during the study by the author in the form of a reflective diary. Part 4 of the report offers a summary and includes some general findings which have arisen from the evaluation process. Part 5 of the report offers a brief conclusion. Key requirements emanating from this study is the need for nurses, from the acute, primary and continuing care sector to access information on current, future and past health and social care initiatives undertaken with their patients by multidisciplinary teams. There is an urgent need for nurses to have access to medication regimes particularly post transfer from and to different health service providers, and also to have access to what transpires to patients during outpatient activity. The nurses who engaged within this study view the development and implementation of archetypes as a positive experience. The patients involved in this study liked the idea of having access to and holding their own record and in some cases articulated their interest in being involved in similar projects in the future. The bond of trust that was evident between the patients and nurses was tangible and the significance and vulnerability of this bond should not be underestimated particularly as we move forward within the health reform programme. Key recommendations from this evaluation are presented in the following section.

Key Recommendations

1. The International Standards Organisation (ISO) 18104 Nursing Diagnosis and Interventions standard¹ meets the requirements for nursing documentation in the acute primary and continuing care sector and nursing leaders may wish to consider this standard in future practice development initiatives within Ireland.
2. The introduction of scales (rather than tick boxes) in nursing documentation practices using outcome data sets such as C.HOBIC assist in making evident change or maintenance of patient outcomes status during assessment over sequential time intervals.
3. Integrated care programmes will require an educational and training budget and will require local management for effective implementation. Nurses who participated in the study but who were not members of the PARTNERS group tended to focus solely on practice interventions with their clients. This is perhaps best described as a task orientated service delivery of care. This particular focus hampers the individual nurse's ability to have dedicated mental time to engage with, reason through or indeed understand the implications of appropriate data collection for use across traditional service boundaries.
4. The evidence base suggests that patient outcomes collection should adopt a theory led model approach. From a health informatics standards perspective this theory led model should include strong linkage with an evolving information model underpinned by health information standards such as EN13606. It is anticipated that the context mechanism and outcome configurations identified in this study may offer a useful resource to inform future research work in this area.
5. Patients involved in this study liked the idea of having accessing to and contributing to their own health record. This is a feature that will need to be considered further in future EHR development.

¹ At the time of writing this report ISO 18104 is under review the new title for this standard is Categorical Structures for Representation of Nursing Diagnosis and Nursing Actions in Terminological Systems

6. Models designed for future patient outcome data collection will need to include an element for social care particularly in regard to social circumstances impacting on self care ability and education in relation to medication management.
7. The degree of reform needed is significant and should not be underestimated. This evaluation encountered nurses who are already practicing in a dynamic environment with existing fiscal constraints; one could perhaps describe these practitioners as “battle weary”. The project team would therefore suggest that the local leaders who possess skills and tacit knowledge of what will work under particular circumstances need to be nurtured and given the appropriate support as and where necessary.

1. PARTNERS as a Vehicle for Change

The current environment in which Irish health care professionals operate within could be described as complex, dynamic and often pressured. This may in part contribute to the limited enthusiasm that nurses possess to adopt and implement formal reference terminologies into existing documentation practices. It is however only in completing such methods that the profession of nursing can assist in making evident the impact of nursing care, and identify key concepts and terms for consideration in future EHR development within Ireland. This report evaluates a programme jointly funded by the National Council of Nursing and Midwifery and the Health Information and Quality Authority EHRLand research programme. The programme entitled PARTNERS is an acronym for Participatory Action Research To develop Nursing Electronic Records. An overview of the PARTNERS group and their work is available to view at www.PARTNERSCT.com. This reports main preoccupation is to focus on the evaluation of PARTNERS programme over the past two years. Briefly the report views information from four perspectives, namely the participant's perspective (the patient), the practitioner's perspective (the nurse), the policy maker's perspective and the author's perspective. By drawing information and opinions about the programme from these four sources this evaluation will endeavour to demonstrate the local operational processes of nurses to define contextual and information requirements across different settings. This approach the author would maintain can present to the reader a practical overview of what works for whom and under what circumstances. The theory defined by the PARTNERS group for evaluating in the programme is *Do archetypes have the capacity to support the creation and analysis of high quality data that can be shown statistically to be responsive to healthcare interventions across different settings and in different environments?*

2. Evaluation Methods

2.1 The Evaluation Process

The term *Realistic Evaluation* initially identified by Pawson and Tilley has been promoted extensively in social research programmes since its publication in 1997 (Dickenson, 2008). The central thesis of this particular evaluation approach is that social programmes do not operate in isolation; they therefore must be evaluated across the spectrum of contexts in which they would wish to operate. Pawson and Tilley (1997) suggest that programmes comprise of context mechanisms and outcomes and the best approach to evaluating social programmes is to identify the theory associated with the programme, and then to test whether this theory works, or does not work under different circumstances with different people in different contexts. In order to complete a realistic evaluation it is therefore necessary to evaluate the theory using a stratified approach for each group of participants involved in the programme, for example population versus specialists, client need versus task related interventions. They describe the research process as follows: *What are the mechanisms for change triggered by a programme and how do they counteract the existing social processes? It is not the programmes that work but the programmes ability to break into existing chains of resources and reasoning in specific contexts.* Pawson and Tilley 1997, p.15

From an ontological perspective Pawson and Tilley argue that a post-empiricist view is required as this approach focuses on a process of explanation, and is therefore not a technique which is solely driven by method and measurement. Research programmes which are practice orientated can often offer a more extensive role for theory or the generation of theory. By adopting a realist approach to the programme which informs the research method one is not completing research solely for the benefit of science, but rather a research method to inform the thinking of policy makers, practitioners, programme participants and the public in general (Pawson and Tilley, 1997, p158). Assuming Pawson and Tilley's viewpoint this research team is examining the effectiveness of one particular theory by testing a health and social care programme entitled PARTNERS. The focal point of this particular theory relates to interventions devised to enhance inter agency communication (shared care) whilst collecting data on

patient centred outcomes. The evaluation searches for new knowledge where evident and will make recommendations to inform future EHR development.

2.2 Participants and Tools used in the evaluation

This evaluation uses a stratified framework to present the findings of the PARTNERS programme. To assist in overall comprehension of the report the information will be presented in the following order a) domain viewpoint A – service provider’s individual b) domain viewpoint B service providers collective viewpoint and in the final section c) patients data summative and individual. The PARTNERS group opted to present both summative data and individualised patient data. However only one anonymous patient case from each service provider perspective is presented; this information is provided in section 3.4. All patient data is available to review on request from the PARTNER group. The sample cases n = 18 (16 completed the study) were recruited in association with the respective service providers. A table introducing these summary figures of data is outlined below for ease of reading

<i>DOMAIN</i>	<i>ACUTE</i>		<i>PRIMARY CARE</i>		<i>CONTINUING CARE</i>		
	A S. 1	A.S.2	PCS.1	PCS.2	C.C.S.1	C.C.S.2	C.C.S.3
Service provider Cases	4	1	4	4	2	2	1
Participants	3	2	5	3	2	2	1

Table 1 : Service Type

The PARTNERS programme used the text *Nursing Sensitive Outcomes State of the Science* as a core text to underpin the project and supported the notion that research relating to outcomes measurement where possible should be theory led (Pringle and Doran 2003).

It is recognised in the literature base that there is an increasing interest in collecting and researching outcomes (Mitchell et al, 1998). Using the international evidence base (Doran et al, 2002), the PARTNERS group have commenced work on devising an outcomes based model to test the theory of the PARTNERS programme.

In considering the various methods that could be used to complete this work the group opted to use a visual framework in the form of a conceptual map to represent the core concepts under consideration. By adopting this approach each of the service requirements to facilitate shared care were identified in order to enable inter agency communication to occur. Yamashita et al (2009) suggest concept mapping is an effective method to incorporate contextual information in the development of software engineering constructs. By using expert judgment in the conceptual mapping process to identify different attributes and dimensions expert knowledge can provide more realistic interpretations of the technical requirements and properties of a system. Concept mapping is a method commonly used in social research to plan and evaluate programmes overall effectiveness (Pawson and Tilley, 2007; Rossi et al, 2004). A second advantage of adopting this particular approach will be to use the articulated conceptual models for training and education of nurses in future initiatives. The process of creating a conceptual model includes asking participants to evaluate a programme with the author adopting a teacher learner approach. Pawson and Tilley (1997) reject the notion of pre determined questions arguing that this leads to limited understanding of theory under investigation. Rather they suggest that a relationship between the evaluator and the informant must develop in which the teacher explains the theory using a model and the informant assists the evaluator to refine the model in such a manner as the evaluator learns the informants view of the theory from an insiders perspective of the programme. The authors offer a model which they describe as a context mechanism outcome configuration (CMO configuration) as the following quotes explains:

In order to develop transferable and cumulative lessons from research, evaluators need to orientate their thinking to context- mechanism – outcome pattern configurations (CMO configurations). The CMO configuration is the starting point from which to start an evaluation and the refined CMO configuration is the finding of an evaluation.

Pawson and Tilley 1997, p.21

A CMO configuration for each group of participants who engaged with the study has been completed in this evaluation. The first CMO configuration is presented here from the perspective of the service providers as Pawson and Tilley (1997) have suggested the CMO configuration should be presented in a linear textual framework; however this table is subsequently followed in the text with an adapted CMO configuration in the form of a concept map for each participant group. As is evident from Table 1, each service has a set of associated individual cases recruited into the study from each of the participant groups. A significant proportion of the data collected in this evaluation is case related. In the proceeding sections there are three distinct sections

- 2.2.1 Service provider and policy maker CMO configuration in section 3.2 evaluation data on the PARTNERS programme as a process and a review of whether the draft archetype met the objectives of individual practitioners is presented.
- 2.2.2 Participant CMO models (conceptual maps) are presented in section 3.3 by service provider , the full transcript of the discussions with the CMO models are available in Appendix 3;
- 2.2.3 Section 3.4 offers a summary of the data collected by the PARTNER assessment tool. As the number of cases was small (n=16) only mean average data is presented using a similar framework as Canadian Health Outcomes for Better Information and Care(C.HOBIC). Future projects collecting data on a larger sample may wish to consider rank correlation. The key purpose of completing this statistical data was to present a framework to inform larger studies in the future.
- 2.2.4 A representation of case data from the patients who participated in the study n= 6 from a total of 18 cases. This data is included for transparency and completeness only as not all of the patients reported upon gave informal feedback. This is primarily due to the sample under review. In situations where cognitive ability was an issue, the evaluator made a decision not to overburden the individual case. The remainder of this Section 3.5 presents the patient centred outcomes from the assessment tool and where appropriate

additional supporting patient information from the evaluators diary based on conversations with the patients and practitioners is include as appropriate.

The CMO process (concept map) explained

Each stakeholder group completed the evaluation process in the following manner.

1. The proposed theory as defined by the PARTNERS programme participants which are under evaluation are circulated reviewed and discussed.
2. The identified draft CMO models are shown to each stakeholder group and the evaluator discusses them in detail.
3. The draft theory models initially defined by the researcher are given to the participants and edited by each stakeholder group to reflect their individual perspective on the programme.
4. The draft theory model as defined by the relevant stakeholder group is edited as the stakeholders see fit.
5. The draft matrices which identify to what extent the project achieved its objectives and proved the theory correct or incorrect is completed.

Four core groups were considered important to evaluate the PARTNERS programme.

The core groups are:

1. Practitioners – those nursing groups engaged in completing the PARTNERS tool during the pilot programme
2. The participants - those patients who agreed to participate in the PARTNERS programme and who were deemed suitable to participate in the evaluation (n= 18 total group of participant with n= 5 as appropriate participants to complete matrix).
3. Policy Makers - a series of meetings were held with key policy makers on nursing development initiatives within Ireland n=3 and a decision was made to update the policy makers on the project and seek advice and counsel on how best to progress. However the detail of these discussions is not included in this evaluation. This is primarily due to timing of the evaluation report. A Nursing and Midwifery Bill is currently awaited and scheduled to be enacted early in 2010. This bill will restructure the way in which nursing policy is operationalised in Ireland. In the midst of this changeover and restructuring

existing work is already underway and the author did not consider that the timing was congruent to complete a CMO model from the policy maker's perspective. For this reason policy maker views and opinions have been merged into the CMO configurations and are included in some of the recommendations of this report. In addition key members of the PARTNERS group who did not engage in data collection process have contributed to the study by creating a CMO configuration on population health. This configuration offers a macro view of the PARTNERS study and is included in the following section as the population health perspective for use with the population health information tool as designed by Ms Anne McDonald.

4. The researcher – as it was deemed appropriate the evaluator offers reflections on the programme from a diary that was kept over the six month duration. Excerpts from the diary are included as an additional data source particularly on individual patient outcomes.

3. Presentation of Findings

In this section the findings of the study are presented under a number of heading as follows

- a) Section 3.1 Introduction to service provider and CMO configurations
- b) Section 3.2 Service provider's views from an individual practitioner perspective.
- c) Section 3.3 Service providers collective views
- d) Section 3.4 Statistical report of the data collected in the patient assessment tool.
- e) Section 3.5 Statistical report of the data collected on individual patients.

3.1 Introduction Service Provider and CMO configurations

CMO models have been used to generate discussion on the evaluation of the PARTNERS programme. The findings from these discussions are presented in the format as suggested by Pawson and Tilley (1997). Figure 1 is a view of the participating services and case numbers recruited in the study from June to October 2009. Table 2 offers an overview of the service provider’s aims for participating in the study.

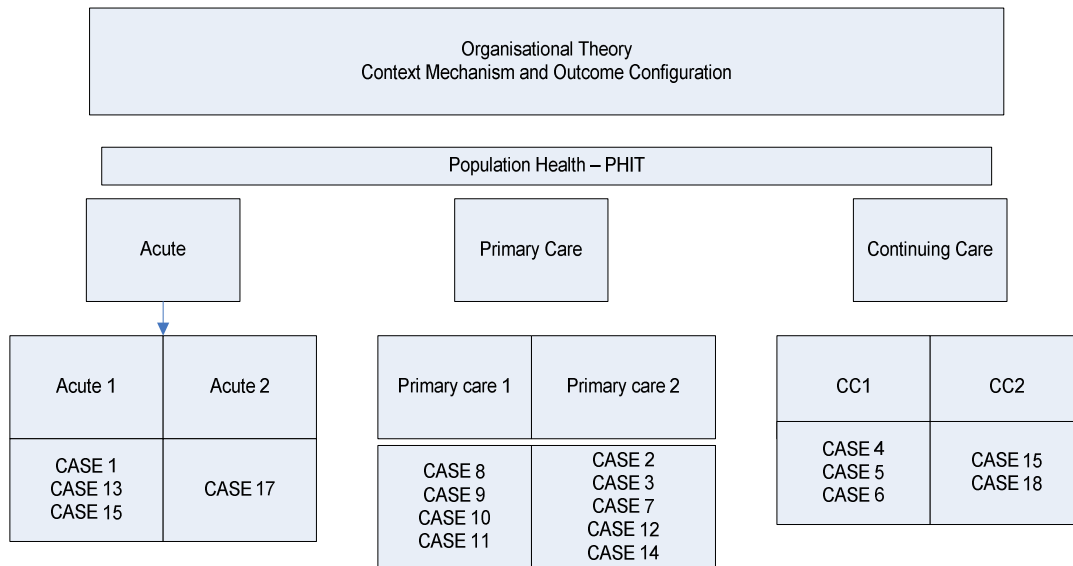


Figure 1 : Site Map CMO Configuration

Table 2 : CMO configuration by service provider

<u>CONTEXT</u>	<u>MECHANISM</u>	<u>OUTCOME</u>
<p>Acute Care</p> <p>Migration To Integrated Care Models Between The Acute And Primary Care Setting</p> <p>Engage In Project To Inform Health Services Executive Discharge Planning Programme</p>	<p>Enhance Interagency Communication Across Service Providers</p> <p>Enhance Existing Discharge Planning Processes</p>	<p>Sustainable Practice Development In Line With Transformational Programme From Paper Based Record Development To Electronic Health Care Record Development²</p> <p>Integration Of Health Informatics Standards</p> <p>Reduce Rate Of Readmissions To Accident And Emergency Or As An Inpatient</p>
<p>Primary Care</p> <p>Embed the acute care within a primary care model</p>	<p>Make visible the primary care model especially those patients who are maintained in the home environment</p> <p>Ensure case management is evident in future health care records</p>	<p>Role recognition</p> <p>Integration of health informatics standards</p> <p>Links to Population Health Information tool</p>
<p>Continuing Care</p> <p>Promote best practice using evidence base and self care as much as possible</p>	<p>Enhance existing documentation practices to make evident medium to long term improvements in patients ability to self care</p>	<p>Improves continuity of care</p> <p>Integration of health informatics standards</p> <p>Increase job autonomy</p>
<p>Underpinning the CMO Configuration for ALL stakeholders is Professionalism of Nursing and Patient Safety Regulation (An Bord Altranais)</p>		

² Note patient held record will be replaced with access to summarised data via personal health record portal.

The original CMO configuration created by the author and presented to each of the participant groups is identified in Table 3. A decision was made by the author however to alter the presentation to a conceptual map using color and form Figure 2. This decision was based on the premise that conceptual maps using color are a more effective method to use not only in this particular evaluation but also in defining future system requirements (Yamashita et al 2009).

PRACTITIONER CMO CONFIGURATION – CREATE CLINICALLY APPROPRIATE ARCHETYPE_TEMPLATE***				
Context		Mechanism		Outcome
Role		Enhanced interagency communication formal archetype		Sustainable (EHRcom)
Autonomy /flexibility		Enhanced interagency communication informal multimedia package		Efficiency Understanding Enhanced quality of record entry
Time		Access to record detail Right to perform interventions		Health informatics standards

Table 3 : CMO Configuration for Practitioner

*** Note the term Archetype is used within the report, however in practice it will be a suite of templates that could be produced from a core archetype developed by the EHRland project team.

The above CMO configuration in Table 3 was adapted to create a working theoretical model for practitioner's which is displayed below as a conceptual figure 2. This approach is then used to identify a series of revised theoretical models based on individual practitioner group's view of the context in which they practice. The revised theoretical models are based on conversations with each group of nurses who participated in the study. In Figure 2 and the proceeding figures presented in Section 3.3, the models can be read by the readers left to right. Lines and arrows with associated text form natural associations between the individual concepts defined by the practitioners. The author opted to create this method to present the data as it presented information in a clear manner and practitioners could start to consider their role and practice from a structure process output perspective. The theoretical models presented by the nurses also can be used in future discussion with the EHRland team and are similar in presentation to Universal Modelling Language (UML). Only the models are presented in the proceeding sections, the full transcripts with associated models are presented in Appendix 3.

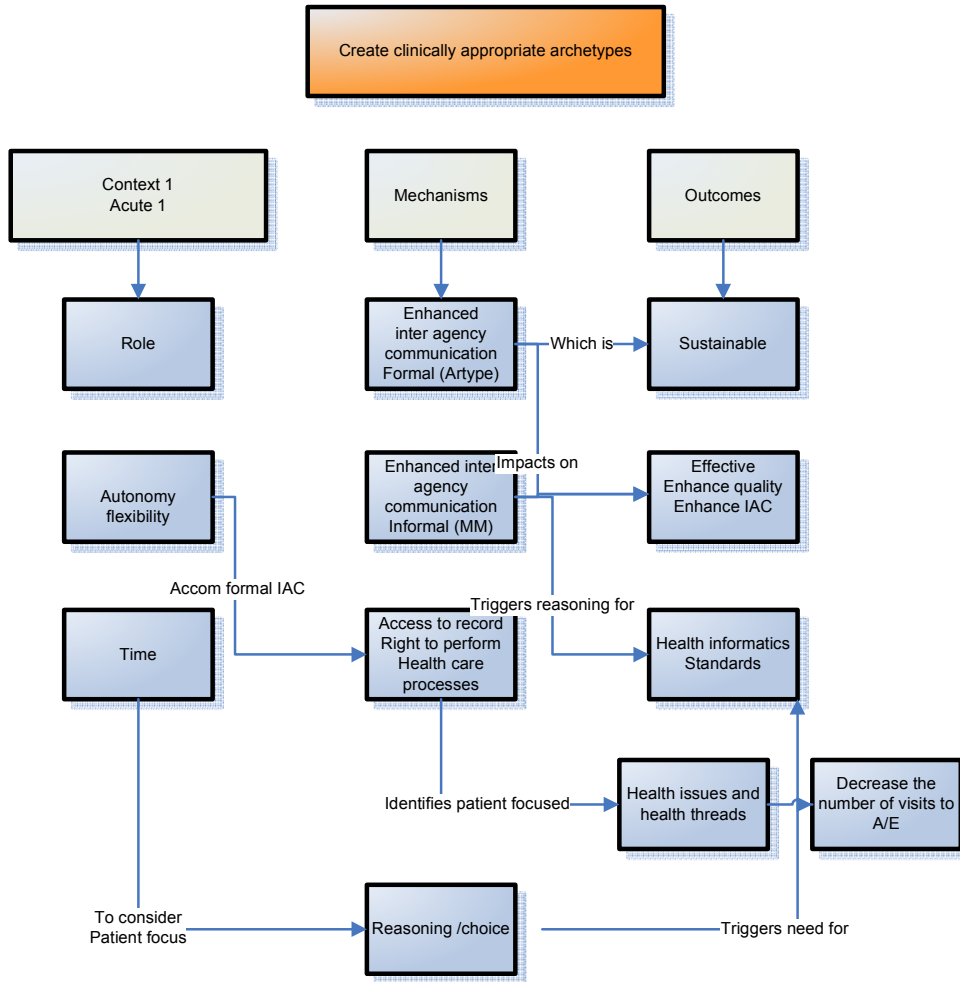


Figure 2 : Initial CMO in Discussion Model

Practitioners were then asked to review and discuss the model and rank the following statements in order of importance. The matrix and findings from the matrix are presented in Section 3.3 as domain viewpoint B – service provider’s collective viewpoint. The domain viewpoint A Individual viewpoint is now presented in Section 3.2.

3.2 Service Providers Viewpoint – Individual

<i>PARTNERS MATRICE</i>				
The PARTNERS Archetype	To a Considerable Extent	To a Moderate Extent	To a Slight Extent	Not at all
Captures patient centred outcomes				
Improves patient care processes (care planning)				
Helps Formal Interagency communication (Documentation)				
Helps Informal Interagency communication				
Helps Access Information previously not easily available				
Increases focus during assessment to the individual patients requirements to maintain independence				
PARTNERS as a process				
Helps to trigger practitioners understanding of health information standards in context				
Helps to provide a basis for practitioners to make an informed choice on concepts and terms for selection in EHR				
Helps produce records which I can use to demonstrate the impact of the care I have given to both other practitioners and the patient				
Assists me in identifying the right to access to perform interventions that are key to the individual patients health state				

Table 4 : PARTNERS Matrix Practitioners

Table 4 above is a view of the matrix used with individual practitioners n=14 who acted as participants with the PARTNERS study. Findings from this evaluation process are presented in the following section statistically where participants offered additional comments they are included.

Statistics

		Captures Patient Centred Outcomes	Helps formal interagency communication	Helps informal interagency communication	Helps access information not easily available
N	Valid	14	14	14	14
	Missing	0	0	0	0
Mean		3.7143	3.5714	3.2857	3.2143
Median		4.0000	4.0000	3.5000	3.5000
Mode		4.00	4.00	4.00	4.00
Std. Deviation		.46881	.64621	.91387	.97496

Table 5 : Evaluation of project objectives 1

Captures Patient Centred Outcomes

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	To a moderate extent	4	28.6	28.6	28.6
	To a considerable extent	10	71.4	71.4	100.0
Total		14	100.0	100.0	

Table 6 : Captures patient centred outcomes

Helps formal interagency communication

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	To a slight extent	1	7.1	7.1	7.1
	To a moderate extent	4	28.6	28.6	35.7
	To a considerable extent	9	64.3	64.3	100.0
Total		14	100.0	100.0	

Table 7 : Helps formal interagency communication

Helps informal interagency communication

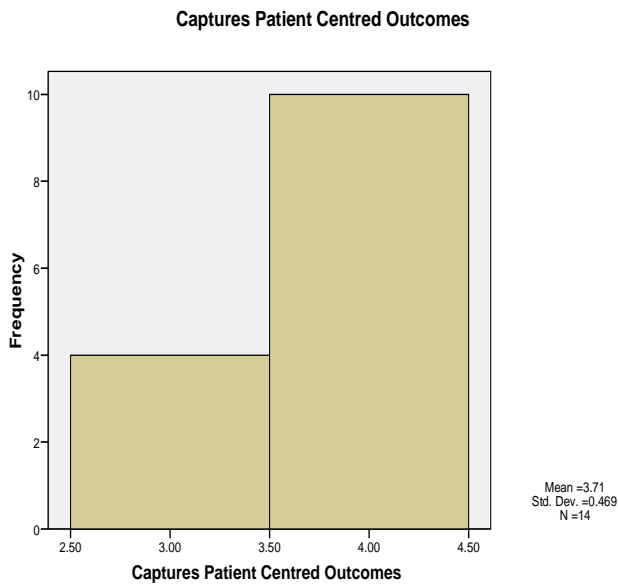
	Frequency	Percent	Valid Percent	Cumulative Percent
Valid Not at all	1	7.1	7.1	7.1
To a slight extent	1	7.1	7.1	14.3
To a moderate extent	5	35.7	35.7	50.0
To a considerable extent	7	50.0	50.0	100.0
Total	14	100.0	100.0	

Table 8 : Helps with informal communication

Helps access information not easily available

	Frequency	Percent	Valid Percent	Cumulative Percent
Valid Not at all	1	7.1	7.1	7.1
To a slight extent	2	14.3	14.3	21.4
To a moderate extent	4	28.6	28.6	50.0
To a considerable extent	7	50.0	50.0	100.0
Total	14	100.0	100.0	

Table 9 : Helps access information not easily available to me



Discussions with fellow colleagues highlighted the need for improved constant feedback on patients - resulting in improved discharge records to PHN.
Respondent 1

Figure 3 : Captures patient centred outcomes

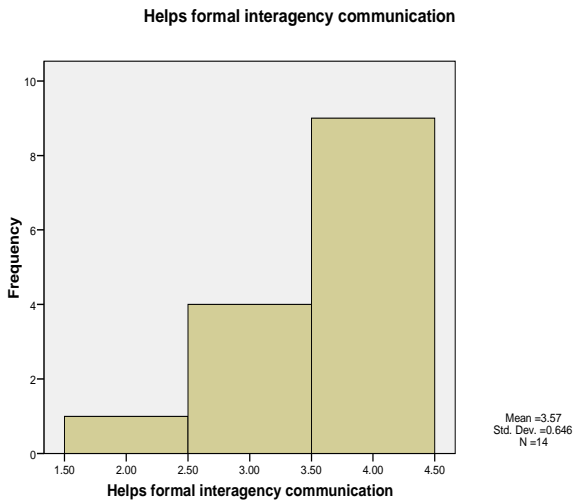


Figure 4 : Helps formal interagency communication

Helps formal interagency communication - although neither of my patients had a hospital admission I feel if they did it would provide them with a good insight of the patient at home
Respondent 4

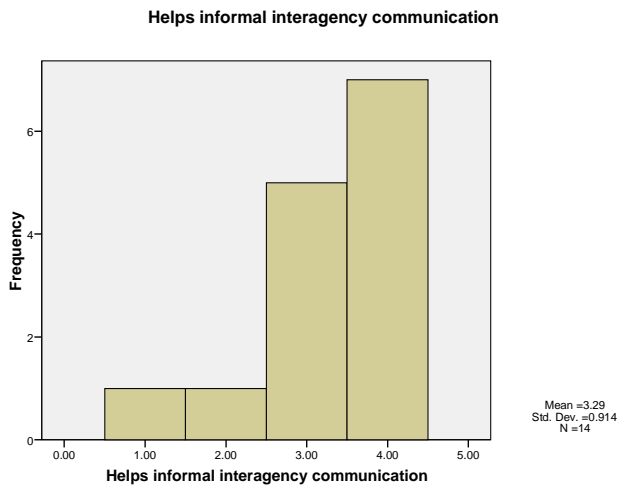
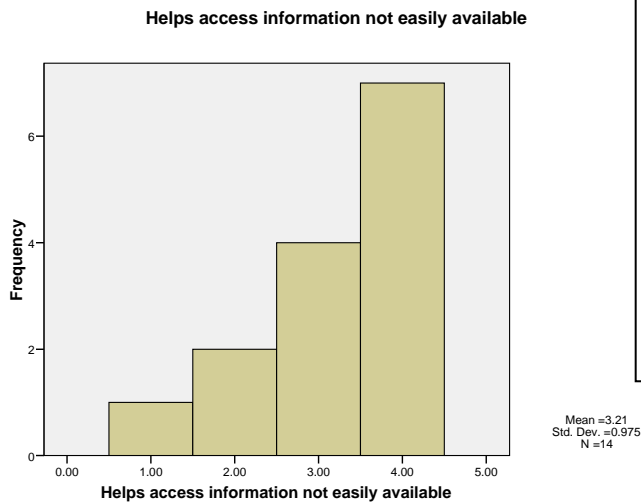


Figure 5 : Helps informal interagency communication



Accessing information not previously available did not occur there was poor contact and communication with PHN
 Respondent 2
Helps access information not easily available - yes I agree strongly spend a lot of time trying to speak to hospital doctors re a patients care
 Respondent 4
This will be more evident when it is part of an EHR
 Respondent 7

Figure 6 : Helps access information not easily available

Statistics

		Assists me to identify right to access and perform interventions key to patient	Helps produce records that I can use to demonstrate impact of contribution	Helps form a basis for choice of concepts and terms	PARTNERS as a Proces helps understandi ng of HIS
N	Valid	13	14	14	14
	Missing	1	0	0	0
Mean		3.5385	3.6429	3.7857	3.5714
Median		4.0000	4.0000	4.0000	4.0000
Mode		4.00	4.00	4.00	4.00
Std. Deviation		.66023	.63332	.42582	.51355

Table 10 : Evaluation of project objectives 2

Assists me to identify right to access and perform interventions key to patient

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	To a slight extent	1	7.1	7.7	7.7
	To a moderate extent	4	28.6	30.8	38.5
	To a considerable extent	8	57.1	61.5	100.0
	Total	13	92.9	100.0	
Missing	99.00	1	7.1		
Total		14	100.0		

Table 11 : Assists right to access and perform interventions

Helps produce records that I can use to demonstrate impact of contribution

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	To a slight extent	1	7.1	7.1	7.1
	To a moderate extent	3	21.4	21.4	28.6
	To a considerable extent	10	71.4	71.4	100.0
	Total	14	100.0	100.0	

Table 12 : Helps produce records to demonstrate contribution

Helps form a basis for choice of concepts and terms

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	To a moderate extent	3	21.4	21.4	21.4
	To a considerable extent	11	78.6	78.6	100.0
	Total	14	100.0	100.0	

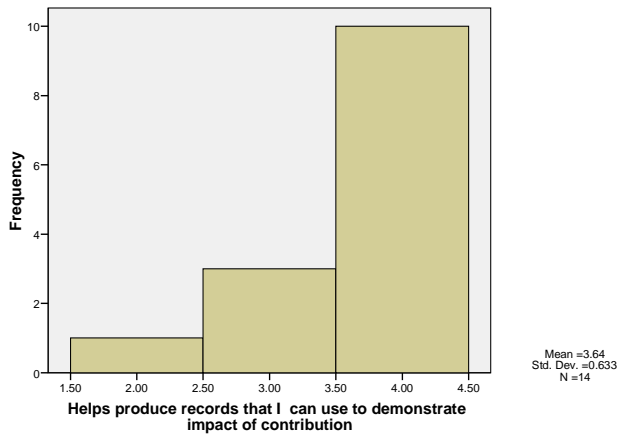
Table 13 : Helps choice of concepts and terms

PARTNERS as a Proces helps understanding of HIS

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	To a moderate extent	6	42.9	42.9	42.9
	To a considerable extent	8	57.1	57.1	100.0
	Total	14	100.0	100.0	

Table 14 : PARTNERS helps me understand health informatics standards

Helps produce records that I can use to demonstrate impact of contribution



Some parts of the tool were not user friendly but the concept is very good
Respondent 8

Figure 7 : Helps produce records to demonstrate contribution

Assists me to identify right to access and perform interventions key to patient

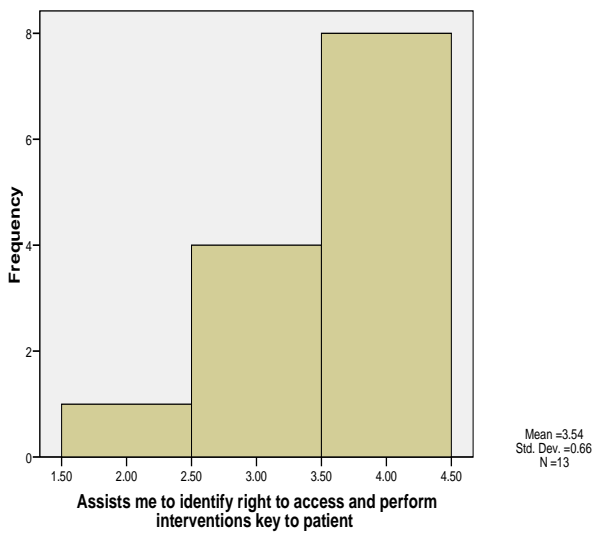
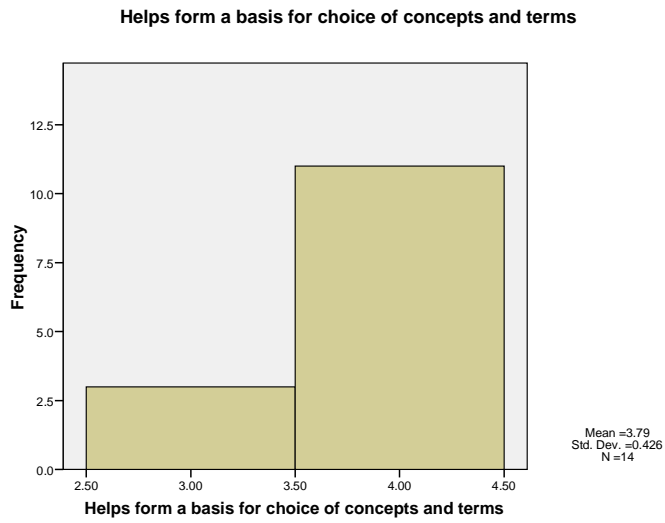


Figure 8 : Assists right to access and perform key interventions



I am able to decide if some parts of the assessment are ambiguous or non applicable to my practice.
Respondent 4

Figure 9 : Helps choice of concepts and terms

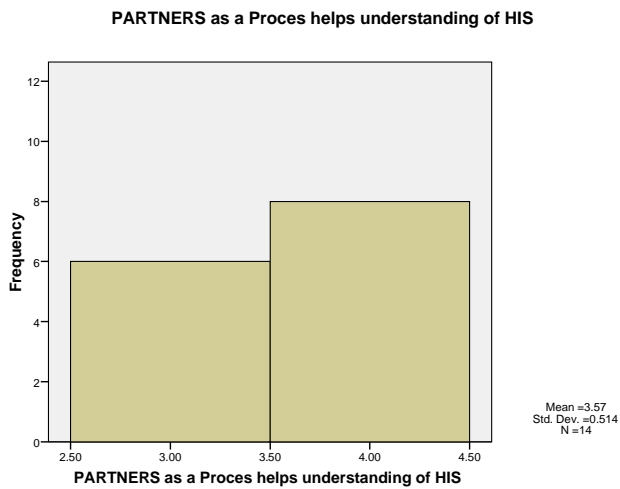


Figure 10 : Helps to understand health information standards

3.3 Participants CMO Configuration, Models & Transcripts

3.2.1 Population Health / Generalist View 03/11/2009

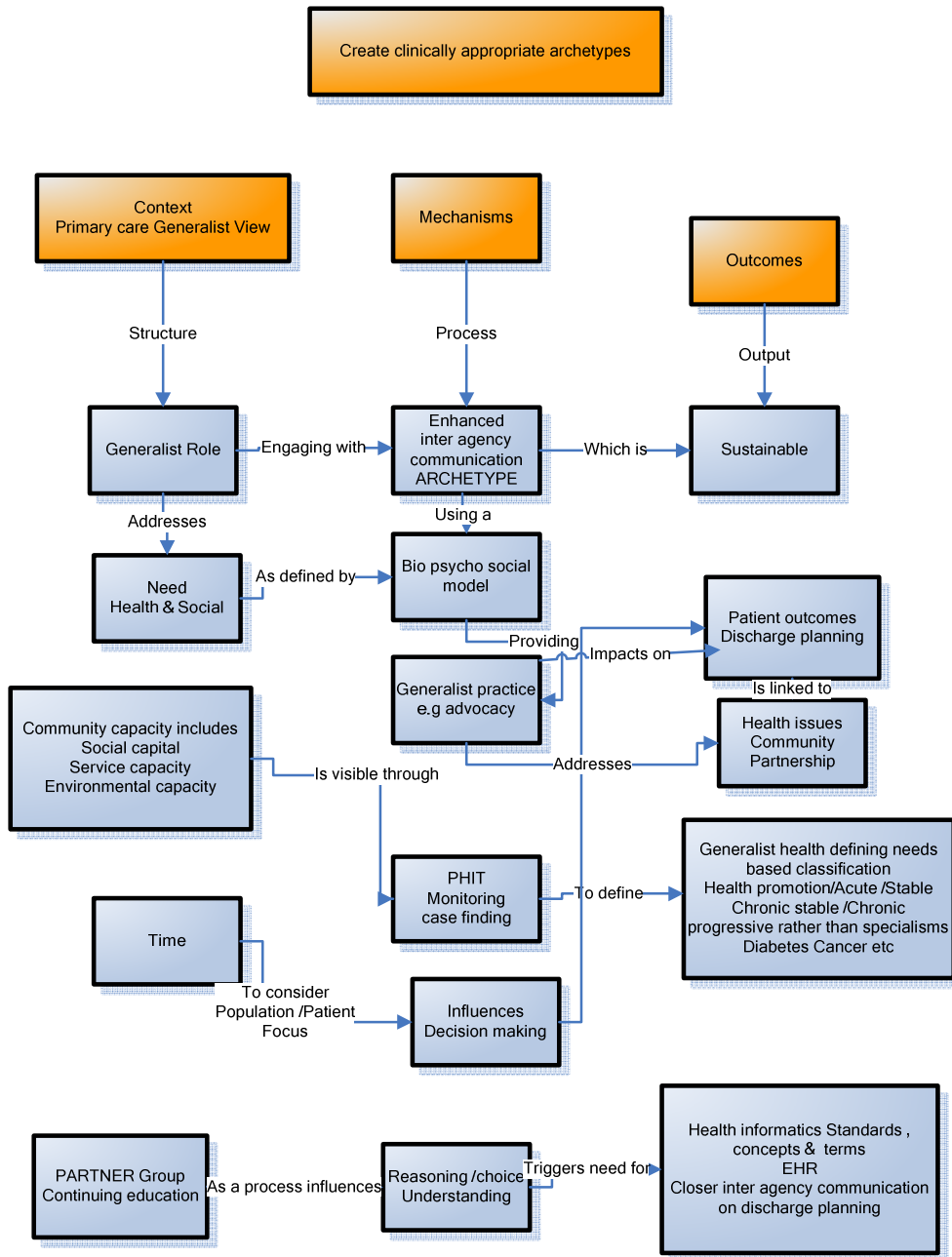


Figure 11 : Generalist population view

3.3.3 Primary care 1 16/10/09

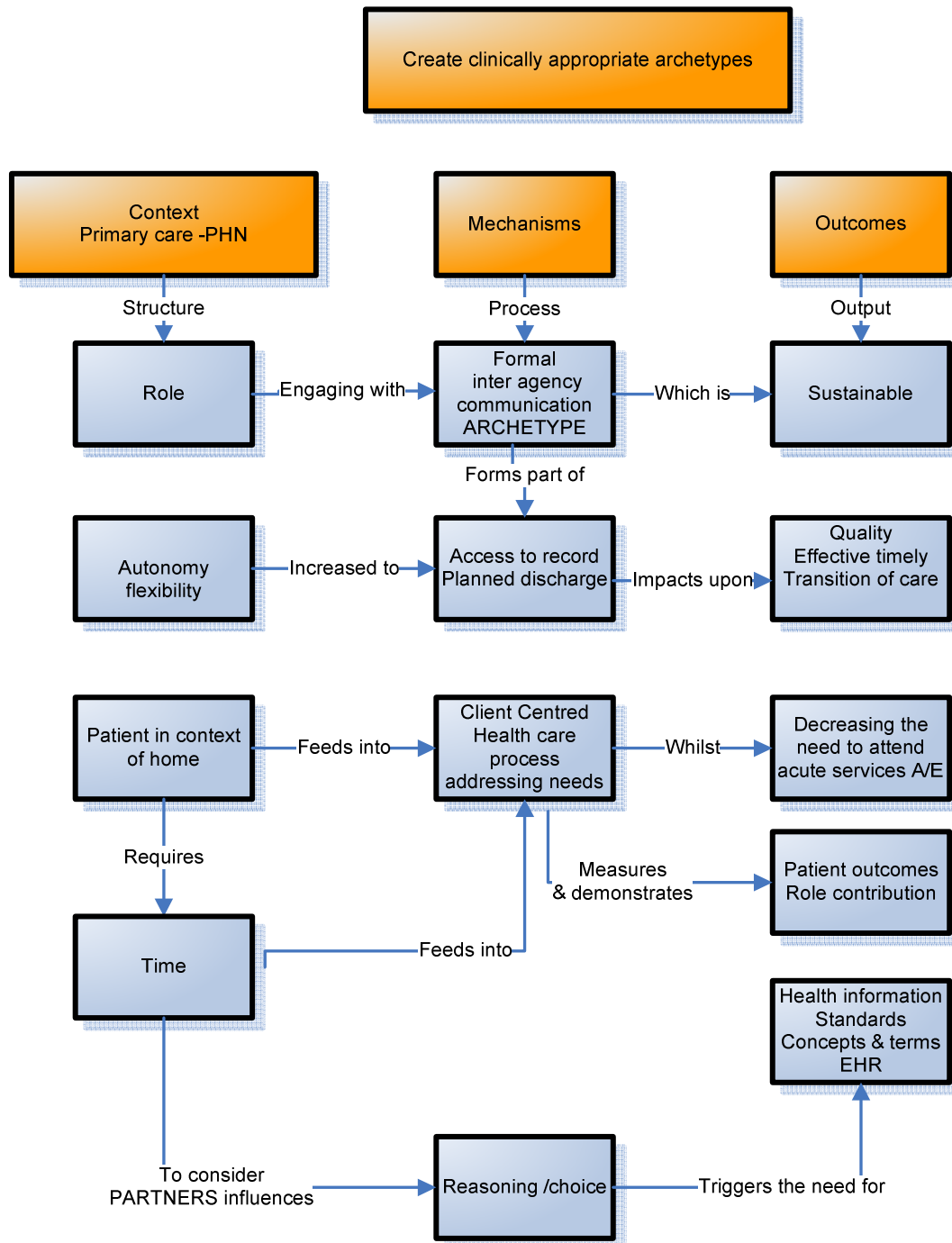


Figure 12 : Primary care 1 View

3.2.3 Primary care 2 21/10/09

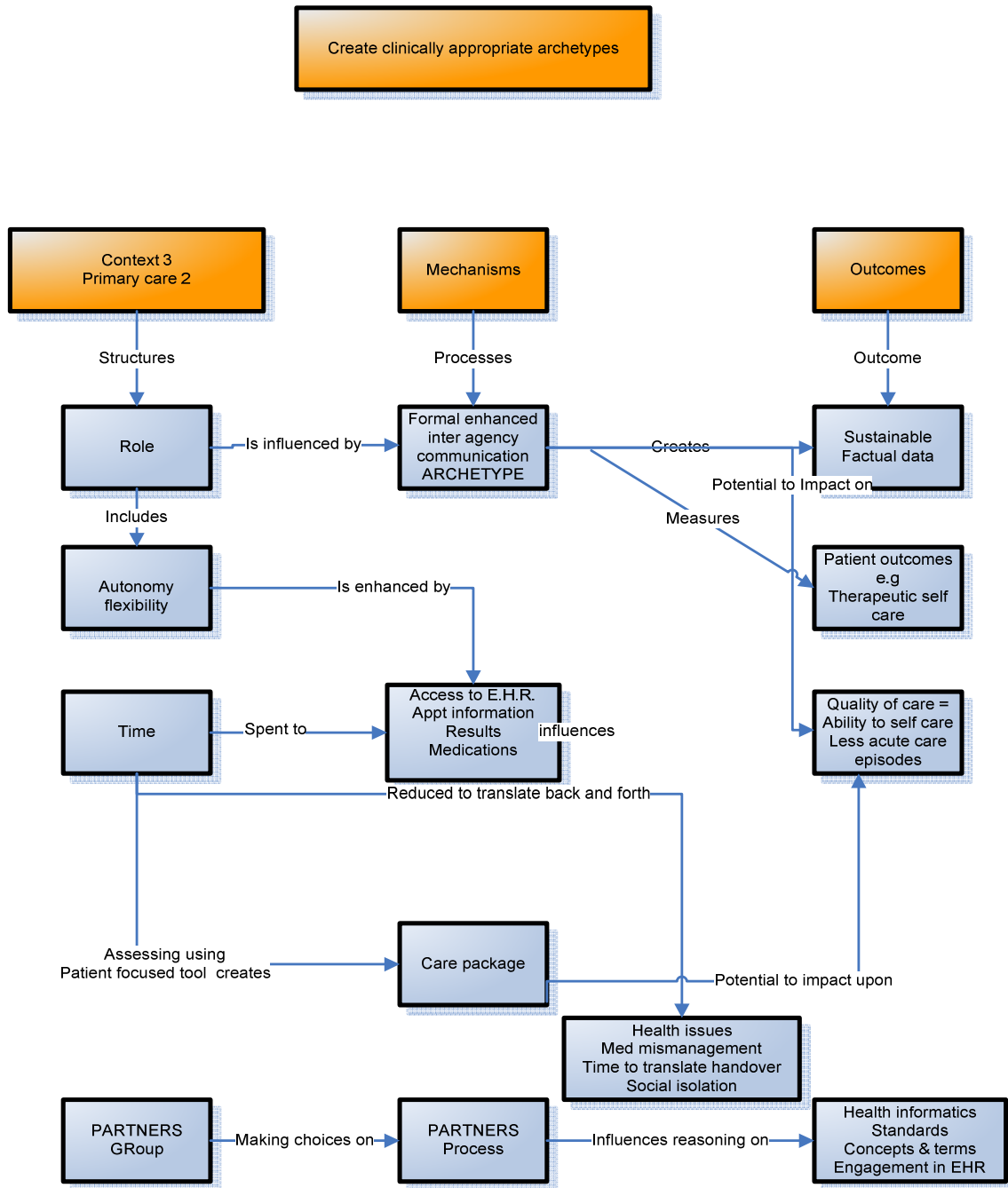


Figure 13 : Community rehabilitation team view

3.2.4 Continuing care 1 15/10/09

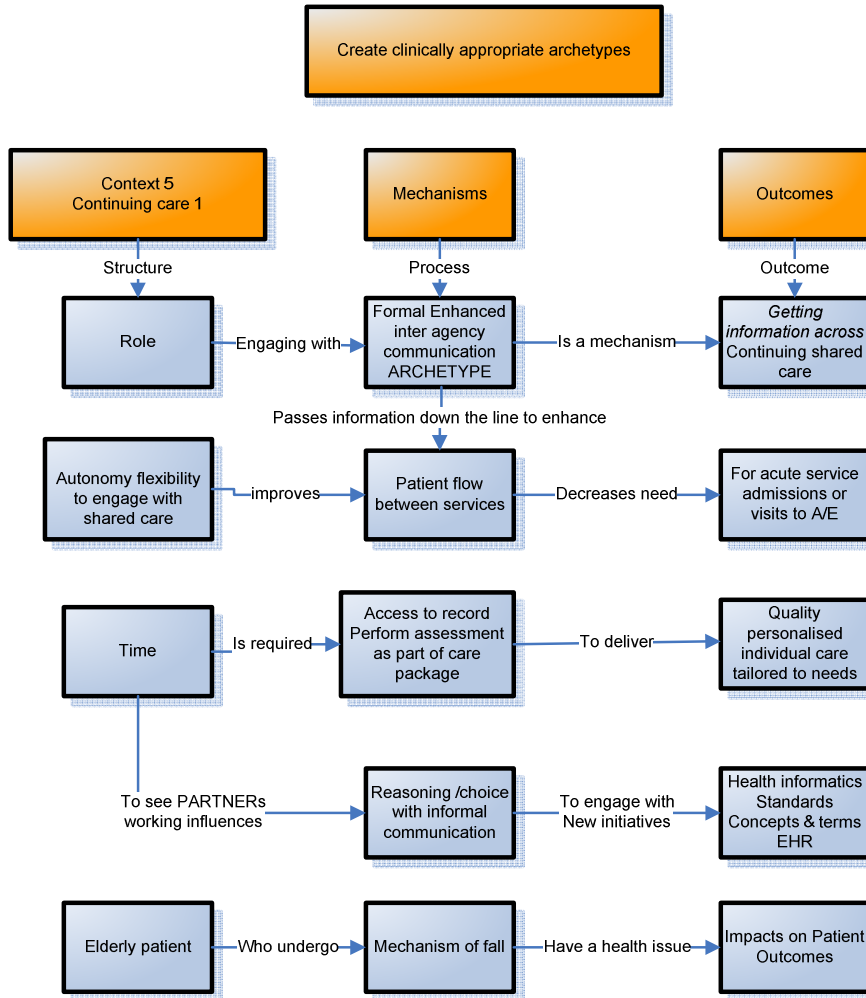


Figure 14 : Continuing care 1

3.2.5 Continuing care 2 02/11/09

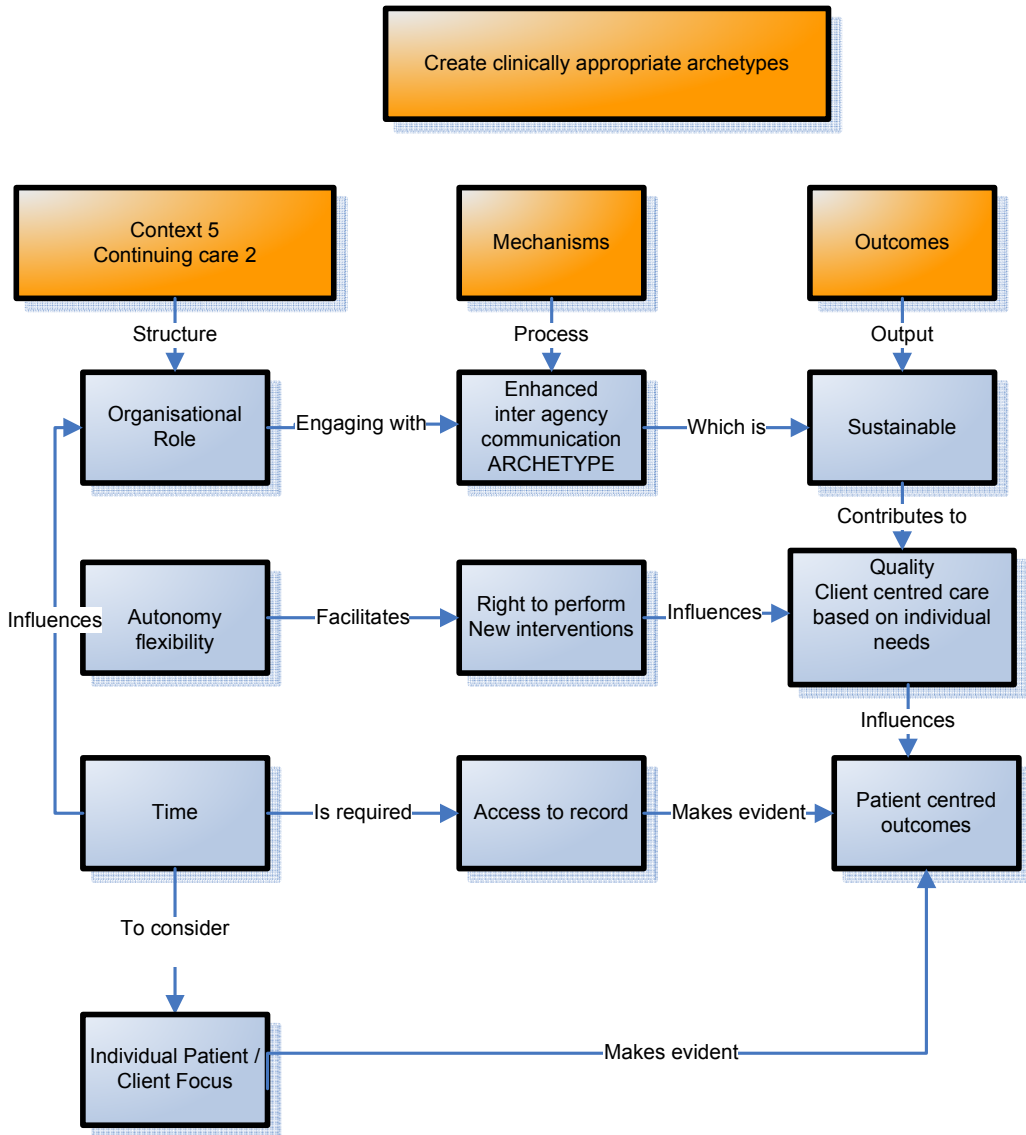


Figure 15 : Continuing care 2

3.2.6 Acute Services 1 30-10-2009

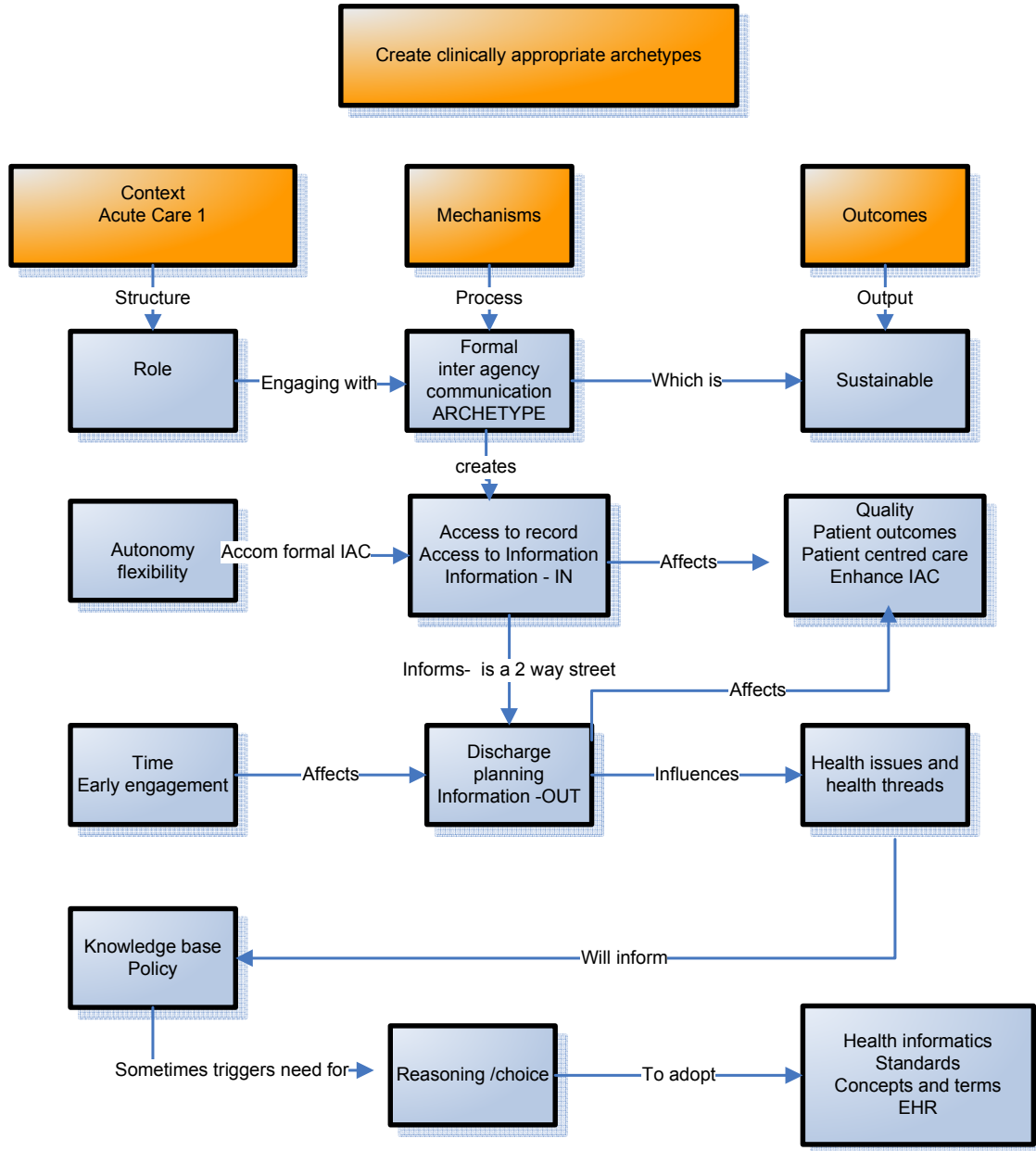


Figure 16 : Acute care 1 (Informatics) view

3.2.7 Acute Care 2 21/10/2009

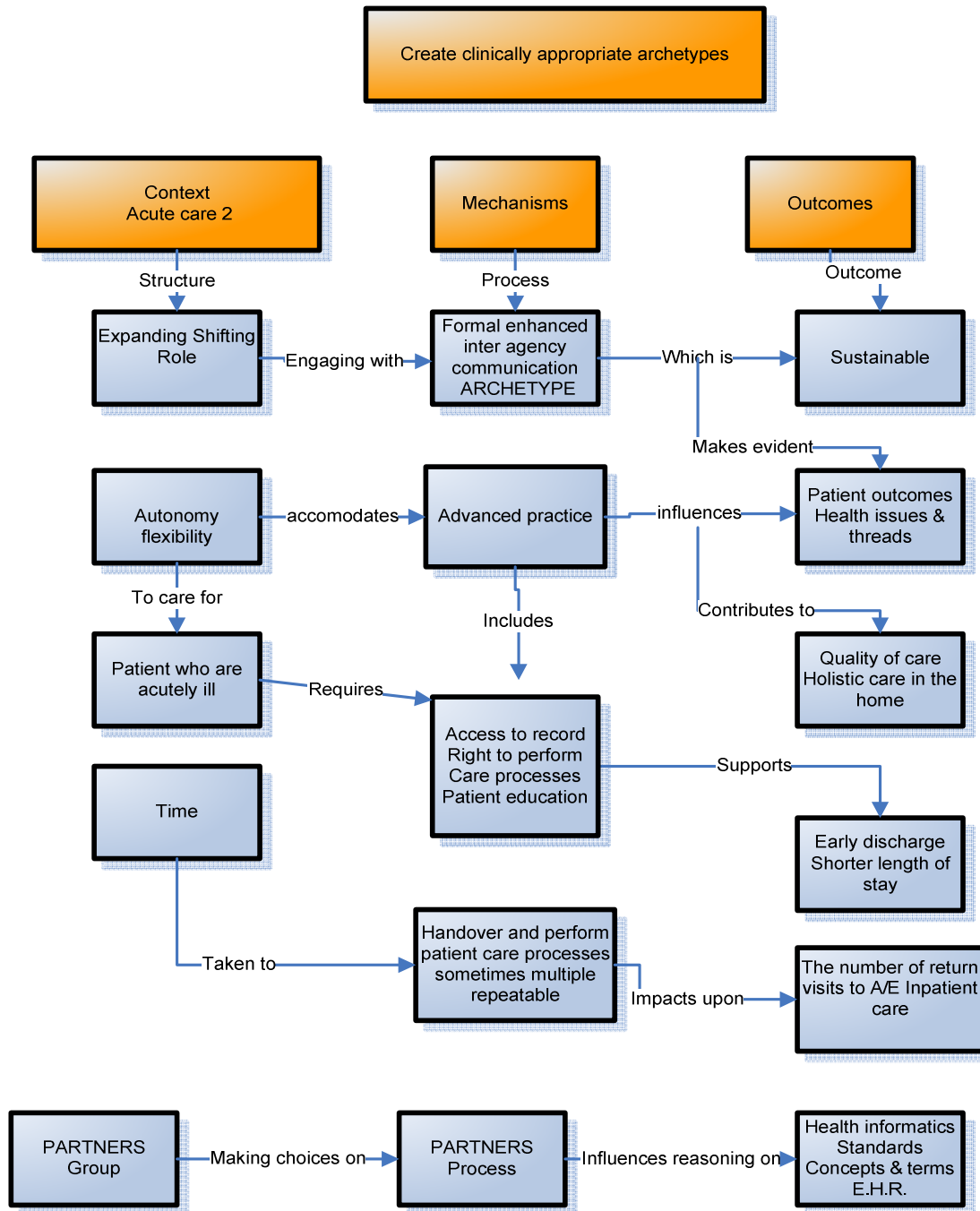


Figure 17 : Acute care 2 view

3.4 Summary of Quantitative Data Analysis Patient Assessment

Section 3.4 is a summary of the quantitative data analysed from the patient assessment tool. This work has been completed by Ms Mary Sharp, School of Computer Science Trinity College Dublin. The data shows the average assessment score and outcome for each measure within the specified episode range. An individual patient must have two completed assessments within the same time frame for their information to be included. The report will identify several comparable outcomes.

The information is listed below under a number of different headings – Ability to perform main tasks of everyday living, falls occurrence and the risk of falling, Pressure Ulcers and Skin Integrity. To view this data in context a general overview of the observational data is included as follows. The observation data collected by the author noted that there were six patients that showed a general improvement, six patients that showed a general deterioration and four patients that maintained their existing health status particularly in relation to outcome measurements within the study.

Ability to perform main tasks of everyday living

The first group of task to be compared were the ability to perform the main tasks of everyday living in the area of hygiene and movement. The abilities covered were those to perform hygiene, dress, groom, bath, mobilise, walk, transfer from a chair to a bed, walk in a room, walk in a corridor, toilet and feed. There were 16 patients in the group and the following Table 15 shows the mean based on functional status where functional status was measured on a scale of 0 to 4 where 0 was Independent, 1 minimally dependent, 2 partially dependent, 3 extensive dependency and 4 totally dependent. Therefore an increase between episodes indicated deterioration in the Functional Status.

Functional Status	Episode 1	Episode 2
Ability to perform hygiene	0.875	0.8125
Ability to dress	0.625	0.6875
Ability to groom oneself	0.625	0.625
Ability to bath	1.625	1.6875
Ability to mobilise	1	1.25
Ability to walk	0.875	1.125
Ability to transfer chair or bed	0.6875	0.625
Ability to walk in room	0.625	0.8125
Ability to walk in corridor	0.75	0.9375
Ability to toilet oneself	0.625	0.5
Ability to feed self	0.25	0.25

Table 15 : Functional status

Using a t-test to compare the overall averages for the abilities did not show a significant difference at $p = 0.118$ for a two tail test. A two tail test was chosen as some of the Functional status measures increased and others decreased. It was then decided to break

the Functional Status into those that improved, scores decreased Table 16, and those that disimproved, scores increased Table 17. The following tables show this division. The Functional Status that did not change was omitted.

Functional Status	Episode 1	Episode 2
Ability to perform hygiene	0.875	0.8125
Ability to transfer chair or bed	0.6875	0.625
Ability to toilet oneself	0.625	0.5

Table 16 : Functional status scores decreased showing improvement

A t-test was carried out based on the Functional Status scores that showed a decrease, therefore an improvement, this showed a statistically significant difference at $p = 0.018$.

Functional Status	Episode 1	Episode 2
Ability to dress	0.625	0.6875
Ability to bath	1.625	1.6875
Ability to mobilise	1	1.25
Ability to walk	0.875	1.125
Ability to walk in room	0.625	0.8125
Ability to walk in corridor	0.75	0.9375

Table 17 : Functional status scores increased showing disimprovement

A t-test was carried out based on the Functional Status scores that showed an increase, therefore a disimprovement, this showed a statistically significant difference at $p = 0.002$.

Ability to perform main tasks of everyday living combined with those for Falls, Symptom Management, Nutrition, Fluid Balance and Pain.

Combining the figures for Ability to perform the main tasks of everyday living, Falls and risk of falling, Pressure Ulcers and Skin Integrity, Breathing & Dyspnoea, Weakness and Fatigue and Nausea, Fluid Balance and Pain frequency and Intensity.

When all of the figures were combined for the different criteria as in the following Table 18 carrying out a t-test gave a significant difference of $p = 0.03$ for a two tailed test.

Functional Status	Episode 1	Episode 2
Ability to perform hygiene	0.875	0.8125
Ability to dress	0.625	0.6875
Ability to groom oneself	0.625	0.625
Ability to bath	1.625	1.6875
Ability to mobilise	1	1.25
Ability to walk	0.875	1.125
Ability to transfer chair or bed	0.6875	0.625
Ability to walk in room	0.625	0.8125
Ability to walk in corridor	0.75	0.9375
Ability to toilet oneself	0.625	0.5
Ability to feed self	0.25	0.25
Falls Frequency	0.5	0.5
Falls Risk	1.5625	4.5625
Pressure Ulcer & Skin Integrity	3.875	3.6875
Breathing & Dyspnoea	0.6875	0.875
Weakness & Fatigue	1.3125	1.5
Nausea	0.125	0.1875
Fluid Balance	0.125	0.25
Pain Frequency	0.625	0.625
Pain Intensity	0.3125	0.5

Table 18 : Functional status and other criteria combined

Again these were broken down into two groups those that improved and those that disimproved.

Falls and Risk of Falling

The numbers of falls in each episode were counted as being in one of three categories, Never, Rarely and Frequently. In both of the episodes the number in each category were identical at eight in each of the Never and Rarely categories while no one fell into the Frequently category. The figures for Risk of Falling were also similar in nature using the same categories of Low, Medium and High they were the same for each of episodes 1 and 2 with seven in the Low range and 9 in the medium range while no one was considered to be of a High risk of falling.

Pressure Ulcers and Skin Integrity

Twelve of the patients were divided, with six each, in the None and At Risk groups while of the remaining four two had stage 1 and one each with stage 2 and 4 Pressure Ulcers in

episode. This deteriorated somewhat in the second episode with ten of the patients divided, five each, in the None and At Risk groups and three in stage 1, two in stage 2 and one in stage 3 Pressure Ulcer groups. However the changes were statistically insignificant.

Breathing & Dyspnoea, Weakness & Fatigue and Nausea (Nutrition)

Type of Measurement	Episode 1	Episode 2
Breathing & Dyspnoea	0.6875	0.875
Weakness & Fatigue	1.3125	1.5
Nausea	0.125	0.1875

Table 19 : Nutrition measurements

All the factors involved in the Nutrition group deteriorated and a t-test gave a statistically significant result with $p = 0.036$.

Fluid Balance

The average of Fluid Balance deteriorated two fold between the two episodes going from 0.125 to 0.25.

Pain – Frequency and Intensity

The frequency of pain showed no change between episodes but the intensity deteriorated marginally from 0.3125 to 0.5

Overall change for Functional Status

The overall means, 8.5625 for Episode 1 and 9.3125 for Episode 2, were compared and graphed and are shown in the following Figure 18.

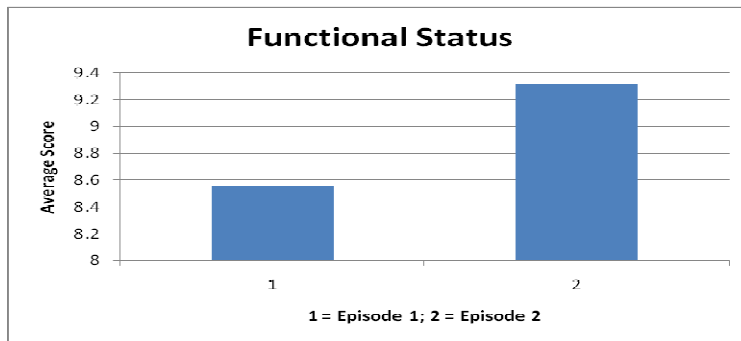


Figure 18 : Overall change in functional status

3.5 Individual Case Data

An edited version of the matrix was also created for use with the patients who participated in this study. A limited number of the participants only were in a position to complete the matrices. Reasons for this included comprehension of what was being asked of them, and in some instances patients were unable to complete this process due to medical or health related reasons. Whilst the data is limited due to the number of respondents, it is included in the following table for transparency and inclusiveness purposes. The remainder of this section presents the data collected in the patient assessment tool and presents it from an individual patient view.

	Case 12	Case 14	Case 3	Case 4	Case 16
Captures information on my health needs	4	4	3	4	4
Helps me understand my plan of care	2	4	4	3	3
Helps with communication between services taking care of me	4	3	4	4	3
Helps me see if my health state is improving or not	4	4	3	4	4
Helps me access information previously not easily available to me	4	2	4	3	3
The assessment is more focused on me and my needs to maintain independence	4	4	3	2	3
I liked the idea of holding my own record	4	4	4	4	4
Legend 4= To a considerable extent 3= To a moderate extent 2= To a slight extent 1= Not at all					

Figure 19 : Patient matrix on project

A total of 18 cases were recruited into the study 16 of these cases were completed over a six month period in the study. Six of the eighteen cases are presented in this section as a representative sample of the patients who participated in the study.

The individual case data is presented using a set of scales which are captured over a number of time intervals. These include a dependency scale, an independence scale and a number of symptom management scales. For ease of reading the author has not included individual legends in the body of the text but the scales are included in Appendix 1 and are also available to view in the pilot prototype form in Appendix 2 of this report.

3.3.1 Primary Care

3.3.1.1 Primary care 2

Case Number	Age	Greatest Need	Degree to which met
2	83	To be able to walk independently	Achieved she can now climb stairs and mobilise around her home

Background Information from Diary

This case was referred to the primary care unit 2 on discharge from the acute care area 2 for treatment of a neurological condition. Her sister who has recently moved into the house is the primary carer for case 2. This arrangement has been in place since her discharge from the acute services. The house is well maintained and case 2 has had a hospital bed moved into the living room. This initially presented with some issues with her sleeping pattern, but case 2 indicates *she has got used to it*. Case two patient centred outcomes relate to primarily functional status and medication management which is included in readiness for discharge based on Sidani and Doran self care tool (2003) For case 2 the data is as follows;

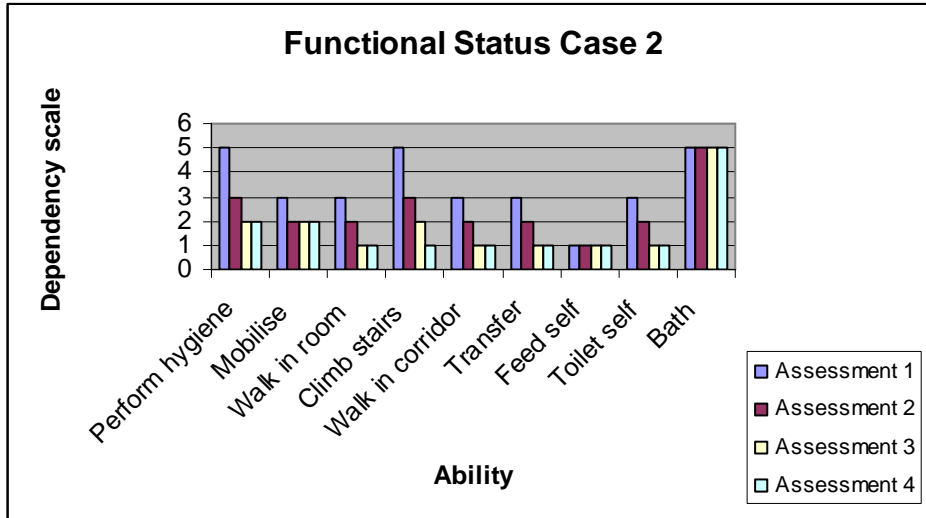


Figure 20 : Case 2 Functional status

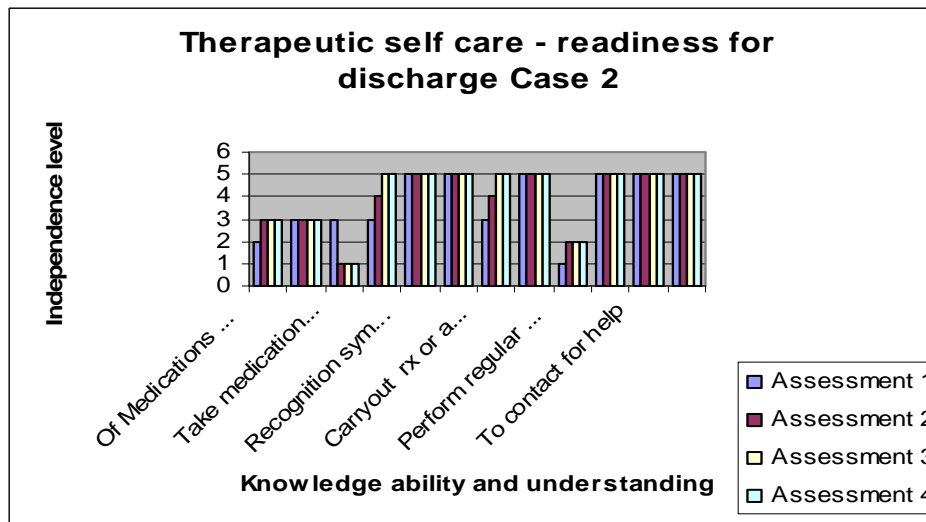


Figure 21 : Therapeutic self care / Readiness for discharge case 2

3.3.1.2 Primary care area 1

Case Number	Age	Greatest Need	Degree to which met
8	77	To give up cigarettes and sort out breathing problems	Enrolled in smoking cessation programme, general health has deteriorated recently diagnosed with diabetes also suffers with resting dyspnoea

Background 08/07/09

Case 8 lives in a small housing estate, is currently on home oxygen treatment and has a machine beside his chair. The home is well maintained and well organised and he explains that he lives with his daughter. His expressed greatest need is

“To get the breathing sorted and maybe stop my legs being so tired all the time”.

The nurse explains that he is on a waiting list to be seen by the vascular medicine team. Discussion with the nurse on subsequent visits noted that case 8 had deteriorated over a six week period. He was diagnosed with type two diabetes and his respiratory distress problems was more prevalent. Final report notes that he has a home care package in place suffers with resting dyspnoea and was admitted to hospital for a number of days.

Case 8 Patient Centred Outcomes are

Key patient outcomes noted were self care psychological, functional status relating to mobility particularly in regard to steps and stairs and a dependency on medical devices such as oxygen and nebulizers.

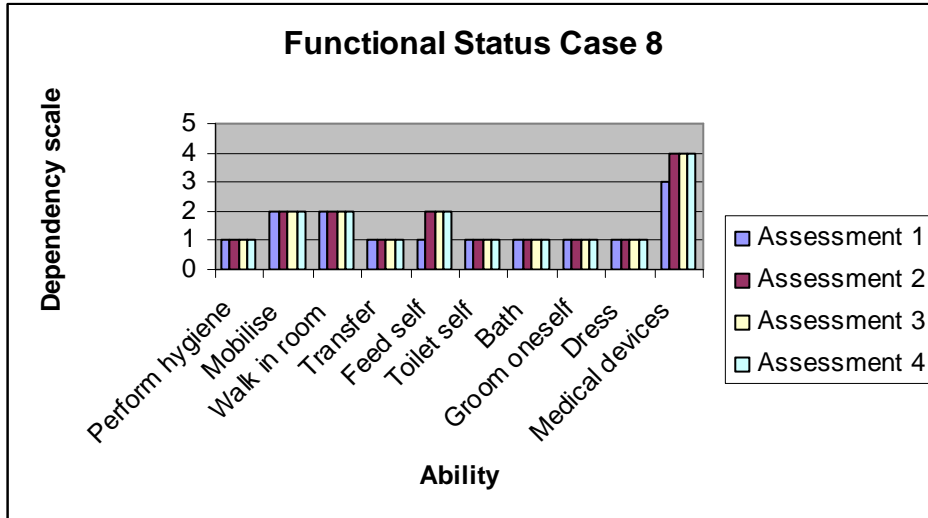


Figure 22 : Functional status case 8

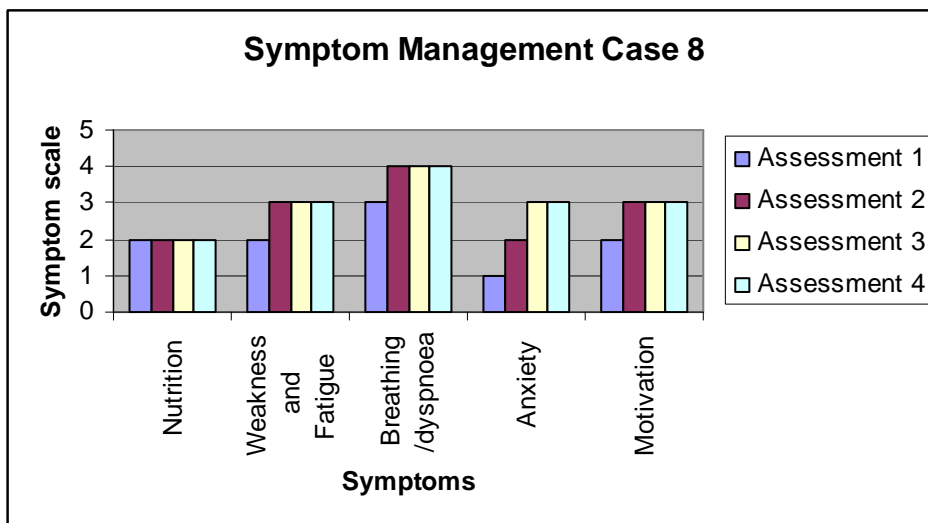


Figure 23 : Symptom management case 8

3.3.2 Continuing Care

3.3.2.1 Continuing care 1

Background Case 6

Case six is also recruited from the day hospital in continuing care area 1, she is more mobile than case 5 and lives alone. She tells me that she has nieces and nephews but doesn't see them often enough. She has good friends though. Case 6 attends the day hospital monthly and is seen by the multidisciplinary team for neck and back pain. "*It's the stiffness in my neck*" she says "*it's getting worse*". Her speech is slow and deliberate and as we chat she tells me about her concerns with living alone. She discusses how on one particular occasion she fell and was glad that she had the panic button as she was able to contact her nephew who came to help her. Over the course of the study case 6 struggled over time to maintain her independence. She experienced significant pain in her left ankle and had a series of interventions to assess and assist with her mobility. These included physiotherapy sessions on fall prevention and the fitting of a pair of Jodin shoes. The nursing notes document her complaining of increasing stiffness and joint pain which directly impacted upon her ability to perform regular activities such as visiting friends and going out. What is interesting to note in the functional status outcomes is that despite her ongoing problems her functional status is maintained on assessment

Case 6 Patient Centred Outcomes are

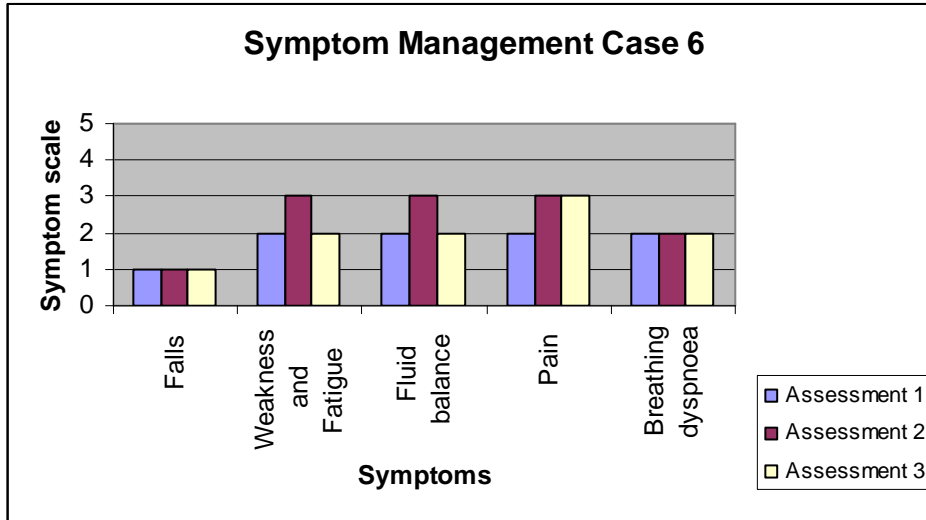


Figure 24 : Symptom management Case 6

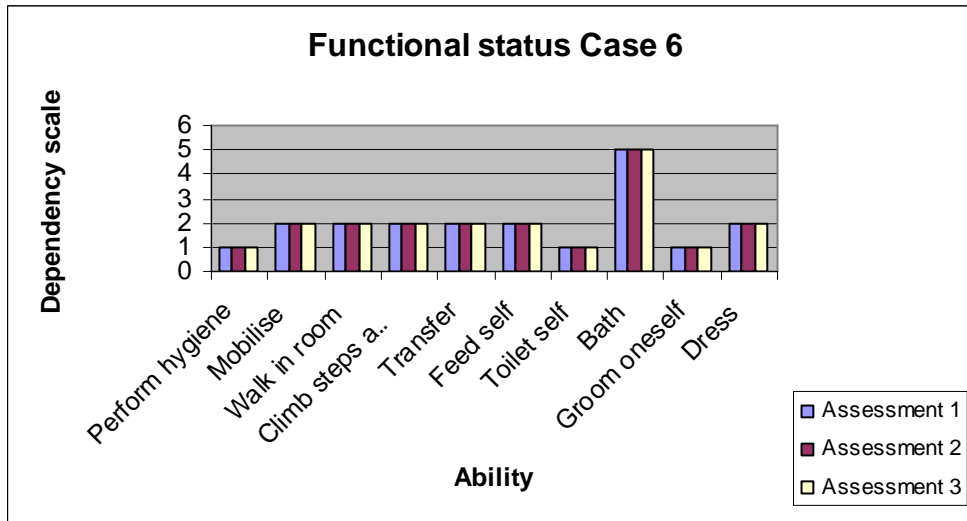


Figure 25 : Functional status case 6

3.3.2.2 Continuing care area 2

Case Number	Age	Greatest Need	Degree to which met
16		Back pain relief	Pain has subsided

Background

Case 16 is a pale quiet but confident lady who is tall in stature and walks with the assistance of a stick. She indicates that she is happy to participate. *Anything to help with my health I am happy to do she says anything to get rid of this pain.* Case 16 has significant chronic pain issues as the following excerpt from the diary demonstrates

“if people ask me about how the pain is now I just say its fine there is no point in always complaining. I have had an injection into the spine and it hasn’t worked, I am disappointed in this but I will see the entire set of injections through before I pass my final judgement. But nurse xx here in the centre gave me a massage a few weeks ago and I couldn’t believe how well I was after it you know I had no pain for two days after it.”

Excerpt from Diary September 2009

Case 16’s greatest expressed need is to address her back pain, she explains to me that she has already had two operations and she tells me that they want to do a third operation. However she says *“I don’t know if that’s such a good idea.”* Case 16 is under the care of the dietician for abnormal nutritional state for the duration of the study. Her body mass index is now within normal parameters following a course of nutritional supplements. Over the course of the study she maintained a fall which had a significant impact on her overall psychological state. Case 16 became quite lethargic this impacted upon her overall motivation. Her primary problem - chronic back pain improved following a series of treatments with the consultant for management of the pain. She also was receiving holistic massage and aromatherapy treatments in the day centre on her final assessment.

Case 16 Patient Centred Outcomes are as follows

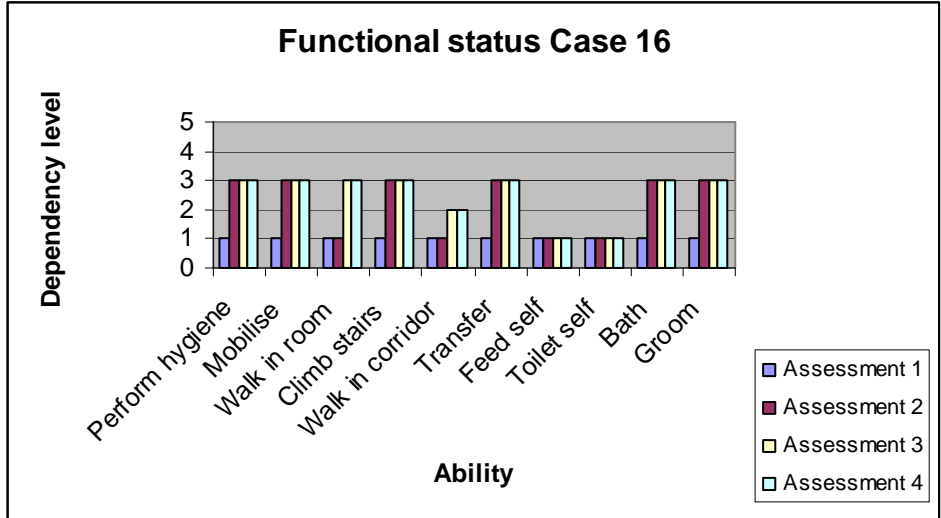


Figure 26 : Functional status case 16

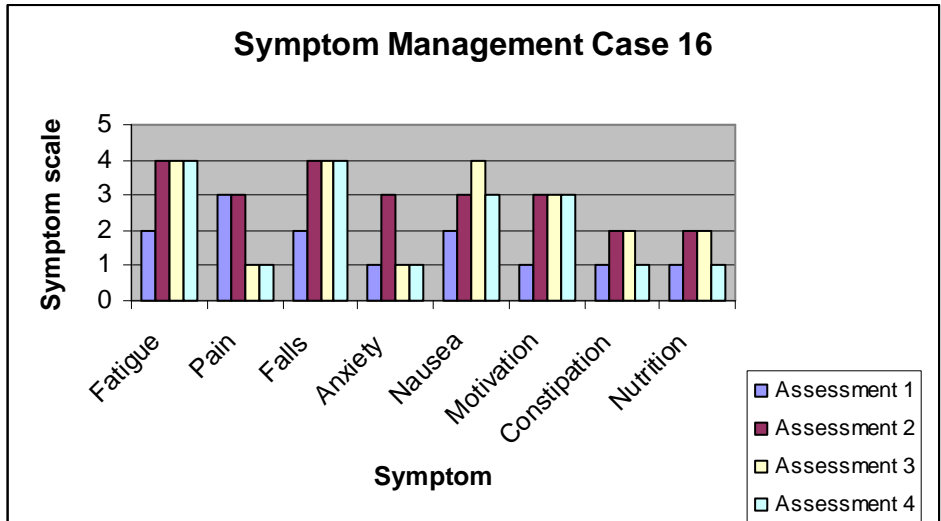


Figure 27 : Symptom management case 16

3.3.3 Acute care

3.3.3.1 Acute care area 1

Five cases were identified for inclusion in the PARTNERS study by acute care area 1 however only two actually enlisted. This was due to the fact that the acute care area 1 cases were linked to the acute care area 2, the other acute service involved in the study. Whilst a significant amount of time was invested on the part of the acute care area 2 staff ethical approval was delayed and granted later in the study in September 2009. During this timeframe three other cases had been admitted to the acute care area 2 but could not progress. Outlined below are the findings from 1 case enlisted by the acute care area 1.

Case Number	Age	Greatest Need	Degree to which met
1	76	To give up cigarette	To be completed

Case 1 is a very interesting patient; this is why some of the detail from the diary forms part of the introduction to this report. Case 1 has required a number of admissions to hospital on a regular basis due to an unstable INR and dyspnoea. He has a care package established in his home, and is well known to the public health nurse, social services and is also a regular referral to the community intervention team. Over the course of the study a number of calls and a visit to the health centre was arranged to discuss case 1. However only one face to face meeting was arranged in the local health care centre with the public health nurse subsequent scheduled meetings to assess case 1 in his home did not occur. This was due to competing workload for the assigned public health nurse who contacted me to cancel the meetings nearer the scheduled date and time. As a key focus of this study is to explore interagency communication, a decision to include all of the events as they transpired was made for this particular case. The diary excerpts are outlined in the following section.

Meeting one 8th June 12-1pm

This is a good case for you to seesaid the nurse he requires a lot of care across the different services. A clean unremarkable tidy housing estate tucked away in a cul de sac in Dublin suburbia on a sunny afternoon. The nurse comments to me as we cut across the road and garden oh he has the door open as she approaches and knocks whilst calling his name I enter behind her. The over whelming smell meets me head on a mix of urine and stale food and tobacco ... but mostly its urine. I introduce myself and shake hands with a pale slightly jaundiced man in a chair in the corner of a living room. He appears happy to see us his expression is expectant and lively as he speaks to us in thick country accent. The nurse starts to talk to him again *"I have to give them up ... I have given them up he says referring to the cigarettes"*. The nurse asks what happened to your chin did you fall? *"No... its beetroot is it on my chin?"* "I ask permission to return next week just to give him time to consider the project and if he is still interested we can sign a consent form We say good bye and leave in the car we clean down our hands with alcohol rub. It's good he had the door open to day the nurse says the smell yesterday in the room was over bearing.

Meeting two 16th June 12-2pm

Entering the home for a second time was not as traumatic for me as it had been the first week. Case 1 greeted us and mentioned that he felt better and was now off the cigarettes one week, *"I am on the nicorette"* he said *"and the HSE has sent me out all this information"* as he pointed to information leaflets on the table .

Following a brief period of formalities about the weather and how his colour had improved I launched into a summary of the form its purpose and what we hoped to achieve from the study. I was conscious that I was selling the idea to him and wished to reassure him that he could refuse to take part if he wanted. He nodded in the right places and indicated that he wanted to proceed. The nurse started to complete the assessment process by asking him specific questions from the form

During this assessment process the nurse noticed the nebulizer on the floor and asked him why he was not using it. He said *"it's broken"*. We plugged it in and it appeared to work fine. We searched with case 1 for some nebulizer solution and noted that he had none.

The nurse opted to request a prescription from the GP for nebulizer solution. We spent about 80 minutes with case 1 on this visit.

Meeting 3 22nd June

We arrive to complete and INR blood test and to ask case 1 if he is happy to sign a consent form to participate in the study. As I enter the house the now familiar smell becomes apparent as usual he is delighted to see us. I shake hands with him he remembers me and I ask him has he read over the material I left with him from last week. He says he hasn't had a chance but is happy to sign the forms. He has just finished eating the usual beetroot stains are on his chin on the table and all over the floor and a half eaten slice of bread sits on a dirty table beside what appears to be a bowl with remnants of weetabix in it. It's a hot day and I notice there are a lot of flies about the room I cast my eye over to the kitchen sink and see a plate with some left over potatoes and some meat. Beside it the remainder of a joint of lamb or a shank of lamb is exposed to the heat and the flies. I am unsure as to whether I should suggest putting the meat in the fridge or indeed tidy up as case 1 may be offended and ask me to leave. I decide to clean the floor up with the toilet roll that is beside him on the coffee table and I notice that he is not happy about this and tells me to leave it. I ask him do you want a cup of tea perhaps I can clean up the kitchen when I am making tea he declines but offers me one, I also decline. The nurse who is with me takes case one's INR, the reading is low so she repeats it and the reading is the same. She rings the outreach team to organise a prescription for him. I notice the nebuliser on the table across the room and ask him has he been using it he says no he hasn't, he is waiting to get his inhalers and nebuliser solution. He comments he has a problem with his water tablets also and has been on to the hospital to sort out a new drug for this. I sit down beside him and he looks at me as I explain the consent form after which we both sign it. He says he will read all the information later that evening and I tell him I will visit again next week. We leave and as we walk to the car I ask the nurse does not being able to address all of the patient's needs bother her ... she says it does I ask her for the number of the PHN who is looking after case 1 and make a decision to contact her during the week to discuss this case further. On a personal, professional and ethical level I am finding the role of researcher in this case difficult. I make a decision to talk to the research team about this case at our next meeting whilst it may be beyond the scope of

the research and politically inappropriate I need to seek advice on the matter from the main PARTNER group.

06/07/09 10 Morning

I have rang the public health nurse (PHN) this am and have got no answer I am now questioning whether I have the right number or not therefore I have rang a second number for the Health Centre and left a message for her to contact me when she can. I also contact the community interventions team (CIT) and left a message explaining that I haven't been successful in contacting the PHN.

06/07/09 Lunch time

Acute services 1 rang me to say that the PHN is on leave until Wednesday we agreed that I will pick up the communication with this PHN regarding the home care package. It would be good if we can get the assessment completed by the two nursing groups simultaneously and if the PHN considers it appropriate to increase this cases home package.

08/07/2009

I have tried to contact the public health nurse over the past couple of days to discuss case 1. Today one of the PHN's rang me to explain that the PHN who is allocated case 1 has been off sick and will be returning to work tomorrow. An initial review of the existing PHN records on case 1 would appear that the PHN records on case 1 were not up to date, last record indicated that he was admitted to the acute teaching hospital. Although the actual home care package was still in progress i.e. home help etc this would partly explain the lack of home visits by the PHN. I explained to the nurse what the actual study was about and asked that she mention to the delegated PHN to contact me on her return from sick leave. She agreed to update the PHN and request that she give me a ring over the next few days.

13/07/2009

I spoke to the acute services 1 staff today regarding case 1 the care package has increased by 5 hours a week approx. He is now on nebulisers although they have noticed there is a problem with his medication compliance / INR is not settling, the carer said he is not taking them in the morning – query there is a memory issue.

Final Entry

I eventually spoke with the PHN who cares for case 1, she requests that I come to the health centre to meet with the Director of Public Health Nursing (DoPHN) and explain the study after which she may be able to meet me to discuss case 1 further. I schedule a visit to the health centre and gave a brief overview to the DoPHN and the PHN.

The PHN agrees to meet me in the next week or so to assess case 1 from a PHN perspective. Following on from this a meeting was scheduled and subsequently cancelled by the PHN. The reason for cancellation was limited time due to additional workload.

This particular case was discussed with the PARTNERS team and one key lesson learnt from my perspective was the fact that acute and primary care nurses view patient care in very different manners and priorities are often somewhat different. I was very much looking at case 1 through the eyes of a nurse who is working in an acute service. My focus in the diary is very much on addressing to his hygiene and dietary needs whilst the primary care nurses interventions focused primarily on maintaining independence whilst living alone. This dichotomy of perspectives between acute and primary care nurses may be worthy of closer scrutiny in future studies.

Case 1 Patient Centred Outcomes are

Case one patient centred outcomes relate to primarily functional status and medication management which is included in readiness for discharge based on Sidani and Doran's Therapeutic self care tool and symptom management . What is interesting to note in case one is that there is no change in the patient outcome status. This case requires a significant amount of health care interventions and has a number of practitioners attending to his care in the home. He has also had a number of admissions to accident and emergency with an escalating INR as this patient is on warfarin. Key challenges for the service providers are to maintain effective medication management. For case 1 the data is as follows

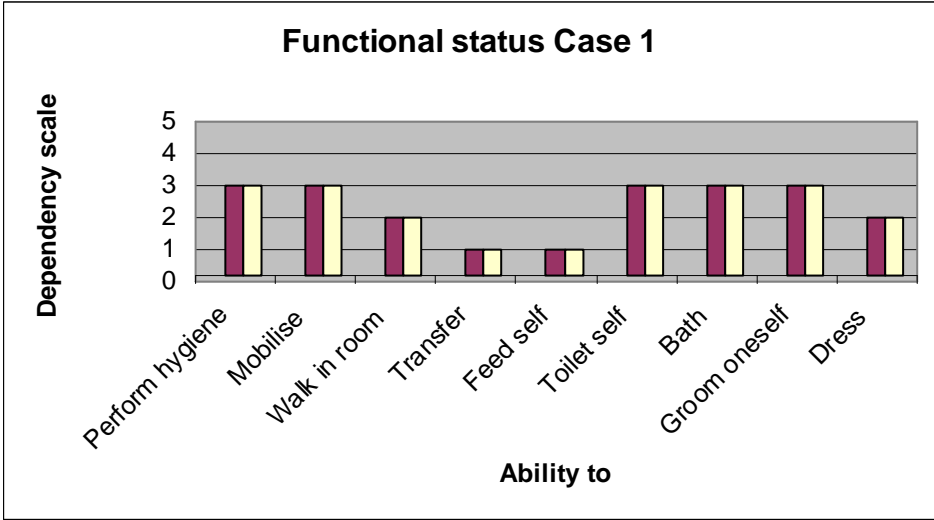


Figure 28 : Functional status case 1

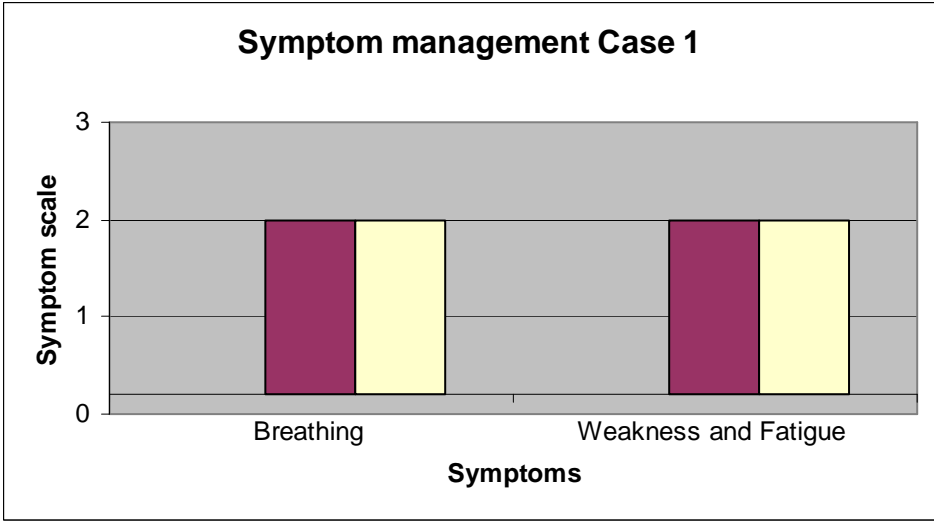


Figure 29 : Symptom management case 1

3.3.2.3 Acute care area 2

Case Number	Age	Greatest Need	Degree to which met
17	83	To go home	Transfer to care of the CRT and now residing at home as a carer for his wife with home care package in place.

Case 17

This 83 year old gentleman was recruited as an inpatient in acute care area 2 prior to discharge to the care of primary care area 2. He has recently had an above knee amputation and as a consequence of this surgery has bilateral amputations with reduced mobility and uses a wheel chair to mobilise. He is the main carer for his wife who has mental health problems and his expressed greatest need is to return home. He was recruited into the services by staff in acute care area 2 and followed up in the community by primary care area 2. When I visited him in his home he had made good progress in functional status and was striving to be independent in all of his activities of daily living. He is very articulate gentleman and speaks slowly and quietly about his experiences over the past few months. He explained to me that he had recently mastered the art of transferring to and from the bed with the wheelchair, and this has given him a great deal more independence. He had over the course of the past 6 months had the house renovated for wheel chair access and also had an extension added on to his home so he could sleep downstairs. He also explained that he was now in a position to reduce the home care package that he had been given initially on discharge to his home. Key elements in the care package that he now has relate to availing of meals on wheels and daily visits by two carers who call at different times of the day for him and his wife. He explained that he goes to bed at about 2am most nights as he likes to write and read, so he was keen to be able to resume to his normal routine, and being able to transfer independently into his bed makes this possible. *"Today is a good day"* he explains to me as he was contacted earlier in the morning to say that a shower chair was to be delivered to his home in the afternoon, this means *"I will be able to have a shower"* he says. Whilst I was there his

wife slept in the armchair for the duration of my visit. He explains that she found renovating the house difficult and doesn't think that she is in her old home. She is repeatedly asking visitors to take her home. He finds this particular issue hard but he is trying to maintain both of their independence as best he can and he doesn't allow himself to get depressed about this.

Case 17's patient centred outcomes relate to functional status, self care social and psychological and symptom management. Over the timeframe his social circumstances impacting on care were addressed particularly in regard to heating and safety, and meals on wheels which are now delivered daily to him and his wife except on Sundays when his daughter provides them with a meal.

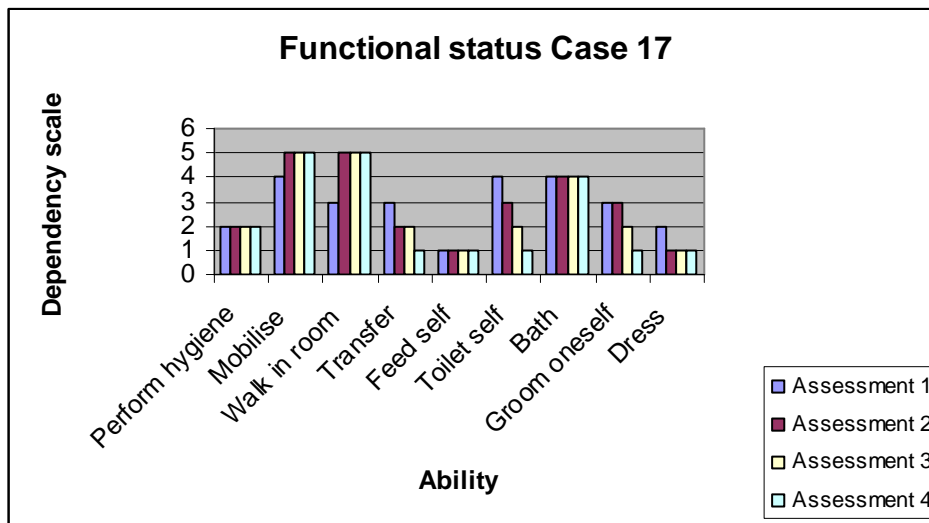


Figure 30 : Functional status case 17

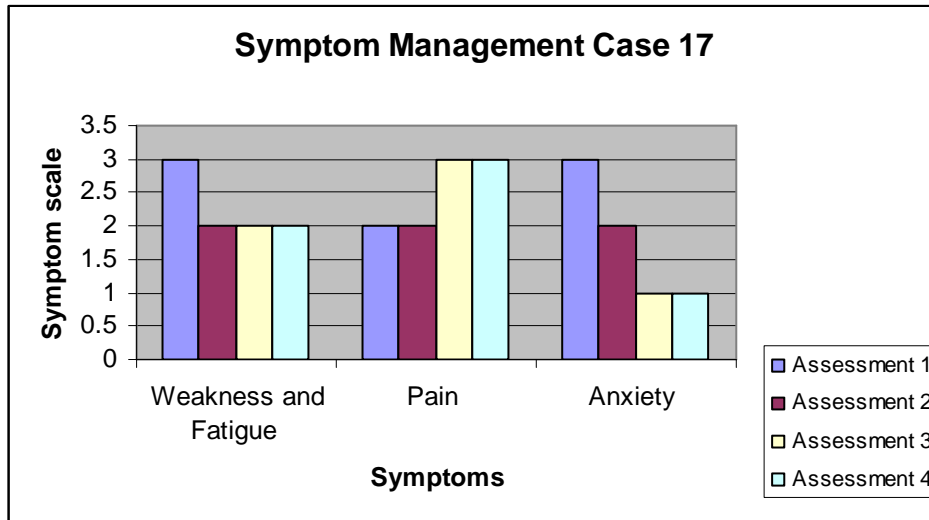


Figure 31 : Symptom management case 17

4 Summary

This evaluation was completed to test the following theory

Do archetypes have the capacity to support the creation and analysis of high quality data that can be shown statistically to be responsive to healthcare interventions across different settings and in different environments?

On completion of this pilot study the PARTNERS group have gained a greater clarity and understanding of what is now required to develop clinically appropriate archetypes and associated templates to support shared care across different service settings. Whilst the data collected is small and cannot be said to be statistically significant, the data demonstrates a purposeful selection of patients in context and the existing nursing expertise that is applied in this particular setting. Only a portion of the data collected on the PARTNERS form for the duration of the study has been included in this evaluation report. It is anticipated that additional data analysis will be reported upon by the EHRland team and further development on this particular archetype will be tested for statistical significance in the future. For the evaluation of this pilot study the following short and long term objectives were identified.

The archetypes will improve the patients experience during contact with health service providers by enhancing interagency communication across service boundaries.

A total of 3 out of a potential 18 patients successfully managed interagency communication across and between service providers. Also where cases moved beyond the boundaries of the catchment area where the study was planned to occur and where patients were recruited outside of catchment area, participation by nurses did not always occur. This is demonstrated in Figure 32.

Long term objective one which focused on collecting;

Data which would be statistically sensitive to making evident the nursing contribution to patient centred outcomes measured during assessment over extended time intervals

The statistical analysis on the data will be completed as part of a PhD study in TCD and for this reason this process is not yet complete. Interventions which are most evident from the study related to medication management, functional status and symptom management this included supporting patients with medical devices such as oxygen and or nebulizers. Although the sample is small and is not generalisable there is evidence of change in

functional status particularly with the patients recruited by the primary care 2 area (Case 2 and 14). Whilst in the continuing care and primary care one area, the cases recruited are chronically ill and although many of the cases are deteriorating the outcomes are maintained at a constant level, with one case being admitted to the acute services for additional care (Case 9 and 10 and 11). In the acute care sector, acute care area 1 identified and initiated a recruitment process on a number of patient n = 4. Identification of cases from the acute care area 1 was difficult due to the over 65 year old inclusion criteria, and also identification of patients within the specific catchment area was also problematic. Also the acute care area 1 group had a tendency to see patients from the entire north side of Dublin crossing existing service boundaries and the age profile of patients is broad in scope. Other issues which impacted on acute care area 1 recruitment process included a delay in access to the acute care area 2 services as previously mentioned.

In case 1 where a number of services were involved in a care package the researcher failed to recruit the public health nurse directly involved in his care, this was due to workload. In the author's opinion the primary care area 2 group were most effective in using the prototype form; this may be due to the timeframes that they care for patients over and the existing relationships which are well established with the public health nurses and acute services. Excellent working relationships were also evident between the public health nurses and the home help services in Dublin North East and this directly impacted on maintaining patient outcomes at a particular level with appropriate use of environmental resources tailored to current patient needs.

The third and final long term objective acted upon the process of PARTNERS and sought to consider whether *the process of developing archetypes assists nurses to understand health information standards and reference terminology and concepts*

This would appear to have been achieved particularly for those individuals who have participated and remained in the PARTNERS programme for the two year timeframe. However it is difficult to ascertain whether it was the process of engagement or the personalities which has had a direct bearing on this particular objective.

As the matrices evaluated this objective from nurses both who were participants and not active participants from the core PARTNERS group, the final judgement will note that

with the sample n=14 When asked did the process of PARTNERS help them understand health information standards 57.1% indicated that the process of partners helped them to a considerable extent with 42.9% indicating to a moderate extent. Likewise, 78.6% indicated that the PARTNERS process helped them to a considerable extent to form basis for selection of concepts and terms in future documentary practices with 21.4% assisted to a moderate extent. The data collected in this study on the individual patients and participants is crude and is limited in its statistical significance for either generalisability or validity. However this was never the focus for this particular thesis. The overall practice orientated focus of collecting individual patient centred outcomes on patients to demonstrate to the nursing community the individual contribution that nursing interventions were having on patients is evident. The pilot study also sought to ascertain if formal interagency communication between nurses could be enhanced by adopting a shared discharge form for use across and between agencies. This information could then contribute to future work of the EHRland project that is testing the European standard for electronic healthcare record exchange. It was disappointing that the PARTNERS group did not expand to include members of the multidisciplinary team although invitations to join the group were extended none were accepted. The design method adopted within the study on a vulnerable sample of patients carries with it a degree of risk particularly in relation to indemnity. Similar projects in the future will need to be cognisant of this fact, and accommodate additional time into the project plan. Likewise recruiting patients into a study across service boundaries can be problematic. In the final analysis only 3 patients were successful in achieving interagency communication this is presented in the following Figure 32. Additional information collected over the course of the pilot study and worthy of mentioning is identified from the diary notes of the author in the following section 4.1.

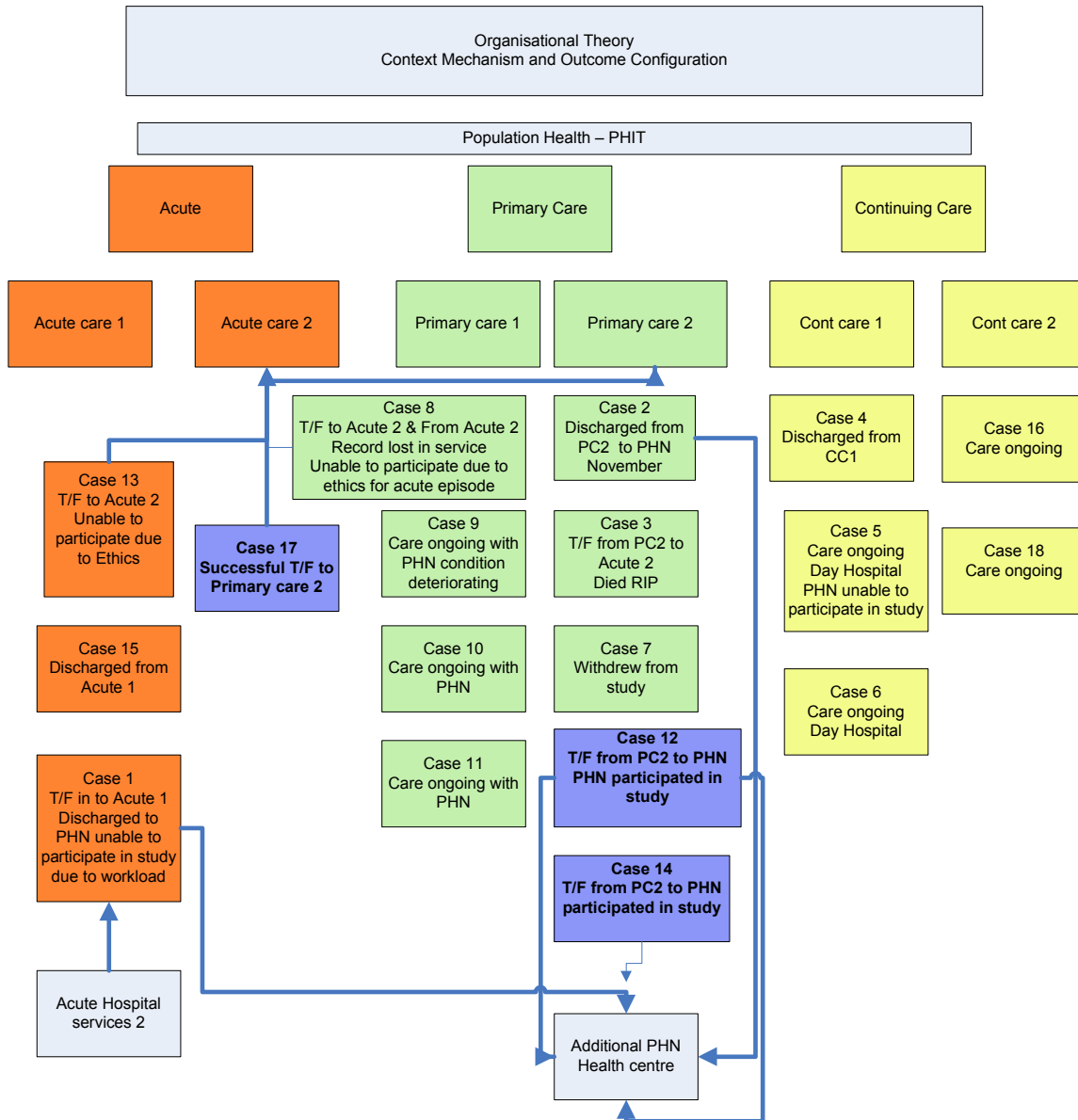


Figure 32 : Interagency communication overview

Note case 17, 12 and 14 achieved successful inter agency communication with the PARTNERS tool.

4.1 Additional supporting information

Patient held packs

For those patients who are elderly and have mobility issues, the idea of a patient held pack proved to be problematic. In one case the pack was misplaced when the patient attended an acute service. For those patients who attended the day hospital and day care services they were keen to leave the packs with their respective health care providers. Those patients who completed the evaluation of the PARTNERS programme indicated that they liked having access to their own health record.

Trust and fear

The pack contained two additional key data tools for use with older persons - the mini mental score tool and the geriatric depression scale. One client who was keen to be in the study on the first week we met him on review of these two data tools became concerned as to what this information would be used for. In the second week he opted to withdraw from the study.

Roles and responsibilities

Leadership roles and access were themes that became quite prevalent in many of the sites. Roles in the various organisations were coming under pressure to change to adapt and to adopt new initiatives. This in turn manifested into an emotionally charged environment as individual practitioners did not know what the implications of this change would have on their practice domain. Strong leadership qualities were evident in a number of services which demonstrated advocacy for patients and the development of new care programmes. The evaluation of the practitioners indicated that programmes such as the PARTNERS initiative assist in offering a bottom up approach to change management and the transformational programme in general.

Networking in communities

Networking capacity between the home help and the public health nurses was excellent and this was most evident in case 10 and 11. As a consequence the author opted to visit the home help co-ordinator and asked her what she believed was best practice for collaboration between the home help services and the public health nurses. She listed a number of factors including strong communication, active project management on resource allocation and careful selection of home help personnel. She noted in the discussion that patients and their families did not always agree with the decisions she would make in regard to tailoring of services as the patient became more independent. Also issues relating to cleaning of individual homes where more than one person was living on the premises was prevalent. The home help is a service for the patient therefore home helps do not attend to cleaning of bedrooms that independent family members live in.

5 Conclusion

EHR and their variants are necessary tools to support the often complex and dynamic nature of interagency communication within the sphere of health care. Future HSE initiatives seeking to support integrated care processes for health service providers will require clinically appropriate designed forms fit for local purpose. Adopting a bottom up approach to define user requirements using conceptual maps in the form of concept mechanism and outcome configurations is one method to achieve consensus across service providers. Translating local nursing language using formalised terminology such as ICNP and C.HOBIC outcomes is a helpful technique to achieve consensus on language that is fit for purpose and supports semantic interoperability. This report describes the core process of an evaluation completed on a prototype patient assessment form designed by clinicians and health informatics researchers in line with best available evidence. The intention of completing this evaluation is to identify what processes work for which service providers, what components within the form are relevant and what insights can be gleaned to inform the next phase of archetype development in the EHRLand project. The notion of not treating research as a black box but rather attempting to discern at least some quite distinct shades of grey is argued as significant by some researchers and is one

that the PARTNERS group ascribe to (Pawson and Tilley, p.114). Nursing as one of the largest professional stakeholder groups within health care in Ireland cannot be inactive recipients, but rather must articulate their experiential knowledge on clinical core processes within healthcare in order to inform future service delivery programmes. This tenet is documented well by O’Shea, when she describes nursing and midwifery as the lynchpins for the success of the clinical directorate model because of their role, scale of presence, and their close position to the patient or client (O’Shea, 2009, p. 127). Despite the educational and training initiatives introduced over the course of the past two years the complex outcome pattern made evident in this evaluation cannot be entirely explained by the PARTNERS project alone. In order to understand the often complex outcome patterns additional non PARTNERS interventions triggered a series of mechanisms which could have affected the outcomes identified in the study. The agenda of the PARTNERS group on reflection and given the existing resources available to them could be described as ambitious. However the blending of local practitioner wisdom and formal academic knowledge has led to the development of new social networks and offers a more informed choice and set of preferences for nurses engaged in the process of developing documentation of archetypes in the future. In summary this evaluation concludes with a lengthy but appropriate quote from Weiss who states that

Evaluation will never provide all the answers. What it can do – and this is no minor contribution – is help to rally support for effective programs, identify innovative programs that are making advances over current service, and expose the failings of existing programs, along with indications of the kind of change that would make them work. At one point I bemoaned this slow and indirect approach to social change and yearned for bolder contributions. In recent years, however, I have come to appreciate how difficult social change is and how resistant social problems are to intervention. I am more impressed with the utility of evaluation findings in stimulating incremental increases in knowledge and in program effectiveness. Over time cumulative increments are not such small potatoes after all.

Weiss, C.H. 1998: 319

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