An exploratory study of treatment goals as specified by patients undergoing surgery requiring critical care admission

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Thesis Declaration

I, Timothy Martin Leen, certify that:

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Abstract

Background

Healthcare costs are rising in a manner that is not sustainable (1) and despite the investment in health, over one billion people worldwide do not get the care they need.(2) Basic weaknesses in models of care and associated clinical decision-making contribute to variations in quality, access and harm to patients. Patient preferences and goals are often overlooked which could have consequences as harmful as misdiagnosing disease.(3) A system where the care and treatment was directed around the realistic goals of the patient (patient centred treatment goals (PCTG) may reduce waste and improve health.

PCTGs are goals for an episode of healthcare expressed as a direct measure of how a patient feels, functions, or survives (4). Literature related to PCTG and goal discussions is sparse and through clinical audit, it was identified that PCTG are not documented in the medical record. This study explored the concept of PCTG in a cohort of patients undergoing elective surgery that involved critical care admission.

Aims

The aims of the current study were to:

- Describe the goals of treatment specified by the patient (participant) and determine if these goals were patient-centred.
- Determine if the goals of treatment specified were not patient-centred, can, with appropriate assistance, patients specify treatment goals that are patient centred.
- Describe the concordance between goals that were specified by patients and treating clinicians goals as understood by the patient.
- Determine if the goals of treatment that were obtained can be specified in metrics and over a time-frame that can be measured practically.
Setting

The study was conducted in a 755 bed tertiary-referral teaching hospital

Patients and recruitment

Purposeful sampling was used to recruit participants. A total of fifteen participants that met the inclusion criteria were interviewed, 3 withdrew leaving a final sample of 12 (8 male, 4 female).

Research Design and Methods

One-off in-depth individual participant interviews were conducted. The duration of each interview ranged from 45 to 60 minutes. The interviews were audio recorded with consent and notes were taken during the course of the interview to highlight and remind the investigator of pertinent points.

Data Analysis

Audio recorded interviews were transcribed verbatim, minus any identifying information, by the study investigator and the transcripts were checked against the original audio recording to ensure accuracy and that pauses and emotions were captured. The transcripts and notes taken during the course of and after the interview were entered into the qualitative computer based data analysis program, NVivo10, to facilitate data management, analysis and interrogation.

Each participant was considered a single case. The initial coding phase was completed through the process of structural coding with data organised around the specific interview and research questions. The comparison across the cases constituted the next step in the analysis that followed Tesch's, (105) approach of “decontextualization and re-contextualization”. This resulted in the identification of fourteen categories. The relationships between the dimensions were analysed and abstracted into three themes
Findings

The first theme related to the participants’ desired outcomes for their episode of care and includes the dimensions of reasons that healthcare was accessed, the participants’ goals, trade-offs, the participants’ ‘timeframe for achievement of goals and the participant perception of clinician goals’. The second theme related to information and incorporates the dimensions of information given to the participant by clinicians, the manner in which the information was delivered and the information given to the participant from sources other than clinicians. The third theme related to the clinician and participant’s relationship that included participant’s confidence in clinicians, shared decision making between the participants and clinicians, participants view on clinicians’ responsibilities for the care of the patient, participant’s emotions related to upcoming procedure and congruence between clinician and participants goals as dimensions to the theme.

Significance

The significance of the study is seven-fold. First, an in-depth understanding of the patients knowledge of their goals, incorporating the risks, harms, and benefits of an upcoming health intervention were identified as well as detailing the participants’ relationship with healthcare workers. Second, the patients were be interviewed at a point when they may have been anxious and uncertain about the upcoming surgery and/or may have difficulty accepting their illness, so the findings offer a true real time reflection of personal, interpersonal and system issues that the participants faced when considering their goals when in the midst of an episode of care. Third, the findings identified whether the participants can set and articulate patient centred treatment goals and what is required to assist them do so. Fourth, the findings also provided an insight into the participants’ perception of what the clinician’s involvement in setting or facilitating the patients understanding of their goal that could be utilised to inform future clinician professional development. Fifth, the findings provided an insight on how shared decision making and collaborative goal setting occurs in clinical practice and questions the value of the consent policy to aid this process. Sixth, information being sought and received from people other than clinicians was another notable new finding and seventh, it was discovered that
some goals identified could have a timeframe of achievement allocated to them. The findings are significant in that they have direct relevance to clinical practice.

Conclusion

The study found that participants could set PCTG either independently or with assistance but it was not certain whether the goals set were consistent and reliable as the goals seemed dependant on patient’s emotions, confidence with the healthcare system or their frame of mind at that time. The conclusion from for this study is such that it is uncertain that the participants knew what they wanted or could achieve from their episode of care. The findings provide information to guide the first steps in designing and developing a healthcare system around the preferences of the patient and further research is required to drive the concept forward.
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Chapter 1

Introduction

Healthcare costs are rising in a manner that is not sustainable with the increasing financial burden attributed to the demand from the ageing population, new diagnostic and therapeutic technologies and the current models of healthcare.(1,5) Despite the investment in health, over one billion people worldwide do not get the care they need.(2) Basic weaknesses in the manner that care is delivered and associated clinical decision-making contribute to the wide variations in quality, access, harm to patients, and waste that now consumes 20-40% of health resources(6,7) and deprives others of valuable treatment and care. An additional and most important deficit is the overlooking and misunderstanding of patient preferences that could have consequences as harmful as misdiagnosing disease (3). A system where the care and treatment was directed around the realistic needs and goals of the patient (patient centred care) could reduce this waste and improve health. This study, unlike earlier work in the field, engages with patients at a challenging point in their healthcare journey and focuses on their goals, how their goals are expressed and how the goals are utilised to inform clinical decision making for their current episode of care. In this introductory chapter, firstly, the research territory is established, the relevant background to the issue is highlighted and described and items from a preliminary literature review are introduced: second, the gap in the previous research is examined and the importance of the current work in closing this gap and extend the knowledge in this area is reinforced and third, the study’s aims, structure and significance are detailed and an overview of chapters is provided.

1.1 Background

1.1.1 Cost of healthcare the Organisation for Economic Co-operation and Development (OECD)

Advanced societies devote a substantial proportion of economic resources to the delivery of healthcare. The Organisation for Economic Co-operation and Development (OECD) 2011 data highlighted that the proportion
of Gross Domestic Product (GDP) utilised in the provision of healthcare services was 8.7% in Australia and 17.4% in the United States (US). (8) The cost of healthcare is rising, and rising at a rate that is substantially higher than the rate of growth in GDP. (9,10) Based on current projections US expenditure on healthcare will equal GDP in 2082. (11) While the absolute cost of healthcare is substantial and rising, there is also evidence that much healthcare spending is wasted. The primary drivers of waste include failures of care delivery, failures of care coordination, unnecessary over treatment, administrative complexity, pricing failures, and fraud. (12) If the expectation was to get a positive return in terms of effective, efficient, safe, high quality care with a favourable patient experience, it has not occurred but it serves as a reminder that increased financial investment without adequate redesign and reform does not improve patient outcomes.

1.1.2 Decision making

Decision making is a broad term that applies to the process of making a choice between options as to a course of action. (13) Clinical decision-making is the choices that clinicians make with respect to diagnostic and treatment options. Clinical decision-making plays a central role in healthcare (7), is a major determinant of variation in practice (1) and is responsible for more than 80% of all healthcare expenditure. (14) Improving clinical decision making may have the capacity to both improve health outcomes and reduce waste. Wide, unwarranted variations in clinical practice that cannot be explained by illness severity or patient factors are frequent, and clinical practice is often idiosyncratic and unscientific leading to poor outcomes. (15) Overseas and Australian reports indicate that variation in clinical practice is common even where agreed clinical practice guidelines exist. (16,17) There are multiple, diverse reasons behind variation in clinical practice, reflecting personal, organisational and systemic levels. The reasons why gaps occur between evidence and practice are complex, and efforts to improve uptake are unlikely to be successful if they are one-dimensional or focus on individual health professionals (18,19) but it could be argued that it is reflective of poor quality decision making. Clinical decision making that leads to high quality care does occur but it is not universal which offers hope that a shift in the paradigm should be possible.
1.1.3 Current models of healthcare

The current models of healthcare are predominantly ‘treatment-oriented’, mainly due to convenience of measurement so as to evaluate and improve the system’s performance. Some of these measurements have become the subject of targets, designed to influence clinical decision making, including surrogate outcomes such as waiting times, infection rates, and compliance with guidelines.(20) The risk with the use of surrogate measures is that true (patient-centered) outcomes can be worse, even when targets have improved. (21,22) It is also acknowledged that medical interventions that consume more than 90% of healthcare spending in high income countries avert as little as 10% of the preventable mortality in these countries.(23) Personal and social factors, particularly early education and later opportunities for productive engagement in society, exert far more influence on health and longevity.(24) Numbers of doctor visits and diagnostic tests are not associated with mortality, whereas behaviour and social circumstances are. (25,26) Therefore, system reform that puts the patient at the centre of their care is necessary. That is, a system that focused on defining desired outcomes (i.e. the goals of treatment in terms of patients’ health goals), working out what treatment options to use or try in order to achieve those goals, then measuring the success in achieving those goals, would represent a focus on achievable health for a patient, rather than the means by which healthcare is delivered. (27)

1.1.4 Patient centreness

The concept of ‘patient-centred outcomes’ has long been familiar to clinical trialists as a direct measure of how a patient feels, functions, or survives. (4) In general, phase III Randomised Controlled Trials (RCT) have a patient-centred outcome as their primary end-point. Any end-point that is not a direct measure of how a patient feels, functions or survives is a surrogate. The importance, and primacy, of patient-centred outcomes as end-points for clinical trials is emphasised by the observation that there have been innumerable examples of divergence between the effect of a candidate intervention on surrogate outcomes compared to patient-centred outcomes. As such, patient-centred outcomes are always outcomes about which we can be confident that they are both important and valid.
The Institute for Patient and Family-Centered Care (28) defines patient centred care as an innovative approach to the planning, delivery, and evaluation of health care that is grounded in mutually beneficial partnerships among health care providers, patients, and families. Studies, in certain areas of healthcare, show that when healthcare administrators, providers, patients and families work in partnership, the quality and safety of health care rises, costs decrease, and provider and patient satisfaction increase.(29, 30) In addition, for optimal use of resources, patients’ preferences, what the patients want and need from an episode of care, should inform decisions about investment and disinvestment in services.(1, 31) There would be little debate that care should be delivered around the needs of the patient, but how patients would feel and respond to being asked to set patient-centered treatment goals is unknown. The purpose of this research study was to explore the concept of patient centred treatment goals from a patients perspective and determine to what extent it is or is not occurring in clinical practice.

1.2 Preliminary literature review

A preliminary review of the literature was conducted in order to ascertain whether the concept of patient centred treatment goals (PCTG) had previously been described, and if so the context and findings. The relevant literature touched on patient centred treatment goals and shared decision making in various settings with recommendations offered but follow up studies and loop closing were not evident making it difficult to see how practice has been influenced (32,33). Palliative care clinicians identify strongly with the concept and studies described how PCTG’s were set for palliative patients with advanced disease but acknowledge that clinicians deviate from these goals at times due to patient pressure (34). No study was discovered that catalogued how clinicians and patients’ collaborated to develop patient centred treatment goals. Studies that involved patients recognised patient information and communication with clinicians as major themes as decisions made and patient expectations are very much dependent information provided by surgeons early in the treatment course (35). It was also highlighted that the information given by the clinician varied but patient perception and understanding of the information given was not explored (36). The DECISIONS survey (37) highlighted that patients facing common medical decisions are not able to
accurately assess how well informed they are and that clinicians needed to be proactive in providing adequate information to patients and testing patients' understanding to ensure informed decisions are made. It did not explore what the patients goals were and whether the patients were getting what they wanted out of their episode of care. Different methodologies (a retrospective review of postoperative clinical notes (36), retrospective questionnaires (32), cross-sectional surveys (37) interviews (33) have been employed to investigate the subject matter. This research examines the patient experience after the event where the patient mindset would have differed from the point of waiting for treatment and not knowing the outcome. The finding suggest that further research is needed to identify the ‘real’ treatment goals of the patient that in turn will inform decision making and lead to improved patient outcome and experience.

1.3 Importance of Patient centred treatment goals

The concept of PCTG from the patient viewpoint has been given little attention in the literature as established in the preliminary literature review. Most of the findings pertain to treatment goals, the decision making process and broadly touched on the patient’s requirements for decision making. The question remains, however, as to whether the patient knows exactly what they want to achieve from an episode of care and can express this in a manner that is understood and acted on. The wants and needs of the person living with the disease remains should be known, as otherwise our care and treatment could potentially be at risk of misdirection.

Providing care that people need and want—no less but no more - may offer several possible advantages. First, it ensures that patient preferences and values are incorporated into clinical decision making. There is substantial evidence that clinicians make invalid assumptions about patient preferences and values.(1) To set goals, clinicians must first understand the priorities of their patients. Second, it requires clinicians to consider what is actually achievable, in terms of patient-centred outcomes, and then ensures that patients and families understand what is achievable. If a treatment option that might have been applicable in a different clinical context is not being recommended, it would be explained that it is not being recommended because it cannot achieve
patient-centred goals. Third, it allows quality and business improvement activities to be focused on achieving the patient-centred goal that the patient has specified and the clinician believes is achievable. This would facilitate the removal of a multitude of surrogate end-points, of uncertain value, to focus only on patient-centred outcomes. Fourth, it provides incentives for clinicians to coordinate their care because, for patients who have multiple coexisting illnesses, it is the combined and balanced impact of all treatments for all of these illnesses that determines patient-centred outcomes. Fifth, a treatment goals approach aligns incentives for clinicians to avoid treatments that have low value either because of low likelihood of effectiveness or because of the risk of complications that impact on patient-centered outcomes. It serves to undermine the fallacy that if some medical treatment is good, more must be better. (38)

There is no substantive existing empiric evidence to evaluate the hypothesis that goal-oriented care would result in better outcomes and reduce costs. However, it may be relevant that patients with recently diagnosed advanced non-small cell carcinoma of the lung randomised to receive early palliative care integrated with standard oncological management (maybe… with ‘goal-orientation’) compared to standard oncological management (maybe… with ‘treatment-orientation’) had not just better quality of life, less depression, and less aggressive end-of-life care but also longer median survival.(39) Our study was the first step in creating this body of evidence, albeit long overdue, by exploring the concept of patient centred treatment goals with patients undergoing a realtime journey through the healthcare system.

1.4 Study aims and structure

The study involved twelve adult patients undergoing an episode of care involving non-emergency surgery for which admission to the Intensive Care Unit or High Dependency Unit was planned. The study was conducted in a 755 bed tertiary-referral teaching hospital. The specific aims were to describe the goals of treatment specified by the patients and determine if these goals were patient-centred. If the goals of treatments specified were not patient centred, further exploration occurred to determine whether the patients with appropriate assistance, could specify treatment goals that were patient centred. The concordance between goals that were specified by patients and treating
clinicians goals as understood by the patient was described. Finally, it was determined if the goals of treatment that were obtained could be specified in metrics and over a time-frame measured practically.

The study was qualitative in design, underpinned by a post-positivist philosophical framework and utilised a multiple exploratory case study approach, as described by Stake (40), to gain in-depth insight into the setting of patient-centred treatment goals as specified by patients consented for non-emergency surgery. This area of concern was extended to several cases to explore the issue and to study the cases both for their uniqueness and commonality.

One-off in-depth interviews were conducted with patients as they provided an ideal method by which to explore the complexity, meanings and interpretations of patient centre treatment goals.

1.5 Study Significance

The significance of the study is seven-fold. First, an in-depth understanding of the patients knowledge of their goals, incorporating the risks, harms, and benefits of an upcoming health intervention were identified as well as detailing the participants’ relationship with healthcare workers. Second, the patients were be interviewed at a point when they may have been anxious and uncertain about the upcoming surgery and/or may have difficulty accepting their illness, so the findings offer a true real time reflection of personal, interpersonal and system issues that the participants faced when considering their goals when in the midst of an episode of care. Third, the findings identified whether the participants can set and articulate patient centred treatment goals and what is required to assist them do so. Fourth, the findings also provided an insight into the participants’ perception of what the clinician’s involvement in setting or facilitating the patients understanding of their goal that could be utilised to inform future clinician professional development. Fifth, the findings provided an insight on how shared decision making and collaborative goal setting occurs in clinical practice and questions the value of the consent policy to aid this process. Sixth, information being sought and received from people other than clinicians was another notable new finding and seventh, it was discovered that
some goals identified could have a timeframe of achievement allocated to them. The findings are significant in that they have direct relevance to clinical practice.

1.6 Outline of the thesis

In this chapter, the research territory has been established, the relevant background to the issue described, items from a preliminary literature introduced and reviewed. The gap in the previous research has been identified and the importance of the current work in closing this gap and extending the knowledge in this area has been declared. Finally, the aims of the study, its structure and its significance have been described.

The remaining chapters are organised as follows. Chapter 2 contextualises the study in the relevant literature. Chapter 3 is an account of the research methodology describing how the study was undertaken and the strategies, design and techniques used. Chapter 4 describes and defines the data collected from the patient interviews without assigning significance, value, or meaning. Chapter 5 discusses the findings in greater detail and assigns significance, value, and meaning to some of the pertinent issues raised and offers recommendations for clinical practice and further research. In Chapter 6, recommendations and implications for theory, research, and practice are proposed.
2.1 Introduction

This preamble to the literature review aims to identify and define certain concepts that are relevant to the context in which this work was conducted. It introduces the concept of goals of healthcare, the unit of evaluation in which goals might be aimed for, the concepts of patient-centred care and patient-centred outcomes, the role of clinical decision making in the achievement of goals, and the measures used to evaluate the performance of the healthcare system.

2.1.1 Does healthcare have goals?

The purpose of healthcare is to optimise the health of patients. This is achieved by preventing and treating illness. As such, it is clear that healthcare has goals. However, although implicit in how patients receive care that is designed to prevent and treat illness, neither individual episodes of care nor the way the healthcare system is structured and operates appear to be particularly focused on the explicit specification of goals of healthcare and whether such goals are achieved.

In considering how delivery of healthcare could, or should, be oriented around the achievement of goals it is worthwhile considering several interrelated issues. These issues are what defines patient-centred care, the measurement of outcomes from an episode of care (and the distinction between outcomes measured that are ‘patient-centred’ in comparison to those that do not meet this definition), how the healthcare system measures its performance currently, that a critical ‘unit’ in the evaluation of healthcare is the ‘episode of care’, and that a possibly under-appreciated element that influences the quality of healthcare relates to the quality of decision-making regarding the options and elements that are packaged within an episode of care. This introduction will
seek to define and describe these elements and provide a narrative as to how these elements can be integrated around the concept of patient-centred goals of care.

2.1.2 Episodes of care

An episode of care consists of all clinically related services for one patient for a discrete diagnostic condition from the onset of symptoms until treatment is complete (41). In seeking to understand whether goals of healthcare (either implicit or explicit) are achieved, an episode of care is the obvious ‘unit’ of evaluation. From the perspective of the healthcare system, its attempts to improve health arise from the aggregate impact of all episodes of care. From the perspective of a patient, his/her health state arises from the aggregate impact of all episodes of care provided. As such, it seems logical that each episode of care has a goal and that this is true, irrespective of whether the goal is stated or assumed. If this is accepted, it follows that a candidate method for evaluating the healthcare system is to determine whether or not the goal of each episode of care is achieved. Whether or not this is practical depends on whether goals can, firstly, be expressed and expressed with sufficient clarity and fidelity and, secondly, whether the achievement of goals can be measured.

2.1.3 Patient-centred care

The World Health Organisation (WHO)(42) defines patient-centred care as care that is respectful of and responsive to individual patient preferences, needs, and values, and ensuring that patient values guide all clinical decisions (43). The WHO document, ‘People-Centred Health Care policy framework’ (42), integrating patient-centred care, highlights that the aim of people-centred healthcare is to achieve better outcomes for individuals, families, communities, health practitioners, health care organisations and health systems by promoting a culture of care and communication. This ensures health care users are informed, involved in decision-making and have choices with providers showing respect for their privacy and dignity and responding to their needs in a holistic manner. The WHO emphasises the need for responsible, responsive and
accountable services and institutions that provide affordable, accessible, safe, ethical, effective, evidence-based and holistic health care. These are worthy and universal aspirations but the extent to which they are achieved by healthcare systems and within individual episodes of care is largely unknown.

2.1.4 Patient-centred Outcomes

Evidence-Based Practice (EBP) is the conscientious, explicit and judicious use of current best evidence in making decisions about the care of the individual patient.(44) The purpose of clinical trials is to generate such evidence so that, when appropriate, trials provides guidance to patients, clinicians and policymakers regarding the decisions that they make. However, for clinical trials to provide such evidence it is necessary to measure the consequences of different treatment options that are compared in a trial. Such measurements are known as outcome measures (as distinct from process measures) and their validity and relevance is central to achieving the purpose of clinical trials. Within this context, the concept of ‘patient-centred outcomes’ has long been familiar to clinical trialists as a direct measure of how a patient feels, functions, or survives (4). This has an element of universality and completeness - that is, a person’s health is defined by their experiences with respect to survival, disability, and symptoms. In general, phase III Randomised Controlled Trials (RCT) will have a patient-centred outcome as their primary end-point. Any end-point that is not a direct measure of how a patient feels, functions or survives is a surrogate. Surrogate end-points are useful, only to the extent that they capture or predict, validly, the impact of an intervention that may contribute to patient-centred end-points (surrogate end-points can and are used for phase III trials, but generally when they are validated with respect to a patient-centred end-point). The importance, and primacy, of patient-centred outcomes, as end-points for clinical trials is emphasised by there being innumerable examples of false assumptions about the validity of a surrogate end-point to predict beneficial impact on patient-centred end-points (45). What provides value and relevance for patient-centred outcomes is that their can be complete confidence that they are both important and valid.
2.1.5 Clinical decision-making: the link between healthcare goals and their achievement

Clinical decision-making plays a central role in healthcare (7), is a major determinant of variation in practice (1) and, by implication, must be a major determinant of healthcare expenditure.(14) In current healthcare, some decision-making (treatment limitation, living wills, advanced care planning) take patients’ goals into account but there are barriers to their consistent use that results in poor adoption in the clinical setting. However, much existing decision making (for example consent for surgical or interventional procedures, medication prescription and management) relates to provision of information or consent or both to specific treatments and does not explicitly take into account the individual, patient-centred goal for which the treatments are being proposed. The potential consequences of a treatment-oriented healthcare system are a risk of a misalignment between the goals of a patient and the treatment being proposed, such that treatments are withheld when achievable goals might have existed, and/or treatments are undertaken when there is little or no possibility of achieving the patient-centred goals. (43)

2.1.6 Measuring healthcare system performance

Whilst few would argue that the delivery of healthcare should be patient-centred, the extent to which this is currently achieved as part of routine care is unknown. Activity and performance of the healthcare system are measured in detail and organisations have emerged, such as the Australian Institute of Health and Welfare and Health Round table, to provide hospitals and other organisations that deliver healthcare with activity and performance data. Furthermore, many of the existing metrics, waiting times, infection rates, most of the national health and safety standards and compliance with guidelines, that are used to evaluate the healthcare system and the implementation of reform processes may have critical failings because they are not patient-centred (20) although they do have the advantage that they are easy to count. The use of easy to count, but not patient-centred, performance measures provides no information about the value of the treatment to the patient; leaving healthcare
predominantly treatment orientated and activity based. Policy, protocols and
guideline emphasise the necessity of patient-centredness in the approach to
care. Evidence to support the value and guide the clinician, however, is either
absent or vague and there is currently a lack of metrics to assess extent to
which treatment is patient-centred. (27)

2.1.7 Aim of literature review

The aim of the literature review is to systematically explore the published
literature with regard to the concept of PCTG, particularly, from the patient’s
perspective with some emphasis on clinician and system issues related to
PCTG. Key questions include: are patient-centred goals of care a recognised
concept, can clinicians and patients communicate to define PCTGs, in what
disciplines of medicine are PCTGs established, can PCTGs be measured, and
identify the gaps where new knowledge is required.

2.2 Search Strategy

Table 2.1 Literature review search strategy

<table>
<thead>
<tr>
<th>Step</th>
<th>Description</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Mesh terms &amp; Key words identified - Patient outcomes, decision making, patient centred treatment outcomes, Physician/clinician decision making, patient centred treatment goals, shared decision making, goals of care, goal-directed care, treatment goals</td>
<td>104</td>
</tr>
<tr>
<td>2</td>
<td>Electronic Search - Cochrane, Medline, Cinahl, Pubmed</td>
<td>60</td>
</tr>
<tr>
<td>3</td>
<td>Titles screened, checked keywords, duplicates removed</td>
<td>39</td>
</tr>
<tr>
<td>4</td>
<td>Abstracts collected, screened and articles collected</td>
<td>15</td>
</tr>
<tr>
<td>5</td>
<td>Secondary literature search from reference list of searched papers</td>
<td>8</td>
</tr>
<tr>
<td>6</td>
<td>Secondary literature search abstracts collected, screened and articles collected</td>
<td>47</td>
</tr>
<tr>
<td>7</td>
<td>Overall numbers of articles (39+8)= 47 Articles screened for relevance to inclusion criteria and review question.</td>
<td></td>
</tr>
<tr>
<td>8</td>
<td>Final number of articles included in the review=14 Quantitative articles=1 Qualitative articles=13</td>
<td></td>
</tr>
</tbody>
</table>
A literature search was conducted in Cochrane, Medline, Cinahl, Pubmed. Medical Subject Heading (MeSh) and keywords (Table 2.1) were used in different combinations to facilitate the search. The search was conducted for the period between 2005 and 2015. The WHO document, ‘People-Centred Health Care policy framework’ was published in 2007 so the timeframe chosen identified literature pre and post release when patient centred care should have been contemporary and topical. Seminal, landmark or key papers in this field, that were cited in the included studies, outside the timeframe were considered. Citations were screened based on title, keywords and abstract and duplicates were deleted. Secondary searches based on the reference list of articles from the primary search were conducted and appropriate papers were identified.

The retrieved articles were screened for inclusion based on the following criteria: 1. a patient-centred concept was considered, 2. the goal-setting process was explored, 3. the patient's perspective of goal setting was examined, 4. full peer-reviewed publication and 5. published in English language. Both qualitative and quantitative study designs were included in the review and worldwide studies that may add cultural nuances to PCTG were also of interest.

2.3 Results

The search results, screening results and the final numbers of studies included are presented in Table 2.1. The primary scope of the search was initially limited to patients in acute pre-interventional settings. However, as the literature available was sparse, in order to gain a thorough understanding of goal setting from the patient’s perspective a broader search was conducted inclusive of all specialties. Papers that focused on goal directed therapy, clinical pathways and surrogate goals were excluded as inclusion would reinforce some of the misconceptions around understandings of PCTG. The context of each of the fourteen included studies has been summarised in Table 2.2. Five studies used instruments or tools to assist with data generation either independently or in combination with a focus group or interview. Six of the studies used open-ended or semi-structured interview techniques that allowed for further
exploration of participants' responses. These studies focused on participants' thoughts, feelings, experiences, knowledge, skills, ideas and preferences. Three studies were undertaken through focus groups which allowed the participants to provide candid response and build on each participants' ideas to glean rich data about the subject. A randomised control trial, case studies and a systematic review were included. The participant numbers, excluding case studies, ranged from 11 to 774 and included patients, clinicians and family members/carers.

The included papers were reviewed, themed and grouped into the following categories: models of decision making, documentation of PCTG, communicating PCTG and limitations of PCTG. Gaps in the literature were identified and recommendations for further research are proposed. The data that contributed to the generation of these themes are presented narratively in the following results subsection with the appropriate source references identified.
<table>
<thead>
<tr>
<th>Title</th>
<th>Author</th>
<th>Year</th>
<th>Specialty</th>
<th>Country</th>
<th>Inclusion Criteria Used</th>
<th>Tool Used</th>
<th>Relevant: Y or N</th>
<th>Study Type &amp; Size</th>
<th>Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Primary Care Clinicians' Experience with Patient Treatment Decision-Making for Older Persons with Multifaceted Conditions</td>
<td>Fredi, Seth L.; Thrift, Mary E.; Seibert, Lynne E.</td>
<td>2011</td>
<td>Primary Care</td>
<td>USA</td>
<td>N/A</td>
<td>Y</td>
<td>N/A</td>
<td>N/A</td>
<td>Understanding view; no new clinician approaches in decision making - conflict of interest; provider vs hospital perspective</td>
</tr>
<tr>
<td>Behavior Change Action in Primary Care - A Qualitative Study of Decisions</td>
<td>Njei-MacGregor, MP, Miss; Anderson-Harvey, PME; Vhm, Shereen Wingo; MPH, Caleb Brittain; MD, Kathleen Naphols; MD, Beth Protas; MD, Thomas Underheimer; MD</td>
<td>2006</td>
<td>Primary Care</td>
<td>USA</td>
<td>Y</td>
<td>Action plan</td>
<td>Y</td>
<td>Survey, semi-structured interviews - 43 clinicians &amp; 274 pt</td>
<td>Documented action plans existed despite collaborative goal setting between PM &amp; clinicians</td>
</tr>
<tr>
<td>Goal setting as a shared decision-making strategy among clinicians and their older patients</td>
<td>Geno J, Schumier-Green, A; Kingma, D; Grace, Elizabeth H; Bradley, Ruth M; Couto, Stacie T; Borgen, T.</td>
<td>2005</td>
<td>Primary Care</td>
<td>USA</td>
<td>Y</td>
<td>N/A</td>
<td>Y</td>
<td>Focus groups n=42, clinician n=11</td>
<td>Participants recognized the benefits of goal setting, however, unclear if and how they integrate goal setting into routine practice</td>
</tr>
<tr>
<td>Enhancing awareness of treatment goals among patients and their caregivers: a longitudinal study of a dynamic process</td>
<td>Catterall M, Buma Barry, M; Bonsor Mary E; Smith Keith-Dorf; D; Slay B; Kraft</td>
<td>2007</td>
<td>Cancer</td>
<td>Australia</td>
<td>Y</td>
<td>N/A</td>
<td>Y</td>
<td>Interview question at weeks 1 and 12. N = 198</td>
<td>13 of the participants did not understand the concept as well as those who did</td>
</tr>
<tr>
<td>Why do some patients prefer to base decisions on the doctor's advice while others prefer a more involved role in their care?</td>
<td>Chowdhury, Naeem; Ahmed, Naeem</td>
<td>2013</td>
<td>Cancer</td>
<td>USA</td>
<td>Y</td>
<td>Trust in Physician Scale, Control Preferences, Social Determinants - Patient Self-Efficacy Scale</td>
<td>Y</td>
<td>Self-report survey, patient n=774</td>
<td>Physicians need clear and concise communication to encourage participation and trust in the clinician's expertise in the decision-making process</td>
</tr>
<tr>
<td>Patient perception of physician compensation after a more optimistic vs. less optimistic message</td>
<td>Kimball-Fitzgerald, MD, Wash Rhyne, MD; Patton-Pereira, NR; Story, ND; MD, Gary D, Crisp, MD, Wills-River, MD; Storer, J B, PhD; Williams, MPH, CQIP, Charles Musial, BA, MSci, Hake C, MD, Amy Swener, MS, NCL, Joseph Arkin, MD, Ecuador Scours, MD</td>
<td>2015</td>
<td>Cancer</td>
<td>USA</td>
<td>Y</td>
<td>PlayScreen: Physician Compensation Questionnaire</td>
<td>Y</td>
<td>RCT - patients completed assessments after receiving a standardized video depicting a physician discussing treatment information (more optimistic vs less optimistic) with a patient with advanced cancer &amp; a tool to help the Physician Compensation Questionnaire</td>
<td>Patients perceived a higher level of compensation and preferred a more optimistic message that could provide better outcomes and ensure the patient's satisfaction</td>
</tr>
<tr>
<td>Patient's Preferences for Participation in Treatment Decision-Making at the End of Life: A Qualitative Interview with Advanced Cancer Patients</td>
<td>Linda Chen, N; Tuckey, M; Tierney, G; Davis, J; M; Widdowson, Susan J; D; L, van der Vleuten, C; P; Walshe, M; P; R; Proctor, J; Walshe, K; Cross, C; Grossi, P; P; Grossi, P;</td>
<td>2014</td>
<td>Cancer</td>
<td>Holland</td>
<td>Y</td>
<td>Control preference scale</td>
<td>Y</td>
<td>In-depth interviews - n=19</td>
<td>Note: Pre-decision life is Y quality of life. Patient want to be involved in decision making often discussion of withdrawing treatment occurs</td>
</tr>
<tr>
<td>Nutritional intake during goal-setting at the time of admission (n=192)</td>
<td>Martin, Seth J; Roeske, John C; Saha, Nik</td>
<td>2010</td>
<td>ICU</td>
<td>USA</td>
<td>Y</td>
<td>Patientcentre questionnaire</td>
<td>Y</td>
<td>Case study, n=67</td>
<td>ICU patients are older and more fragile with increasingly more chronic illnesses, need support to communicate to the clinician about their goals of treatment and care for better outcomes.</td>
</tr>
<tr>
<td>Conflict in the ICU: a qualitative study of administration and patients' perspective</td>
<td>Nathalie Deutey Math-Fernandez; Lenore Luce; Heeney-Ray</td>
<td>2006</td>
<td>ICU</td>
<td>Canada</td>
<td>N/A</td>
<td>Qualitative case studies using semi-structured interviews</td>
<td>N/A</td>
<td>N/A</td>
<td>The most common source of conflict in the ICU is a lack of agreement about the goals of treatment cause by conflicting priorities.</td>
</tr>
<tr>
<td>Patient empowerment in intensive care - a qualitative study</td>
<td>Ingulsdottir, Arna; Oxholm, Stefan; Brinch, BR; Greenaway, DP</td>
<td>2006</td>
<td>ICU</td>
<td>Sweden</td>
<td>Y</td>
<td>Open-ended interviews, n=11</td>
<td>N/A</td>
<td>The ICU patient, when empowered, was able to experience some form of control over their own care and contributed to better outcomes.</td>
<td>The ICU patients are not real patients, instead they are real people who need to make their own decisions and feel empowered.</td>
</tr>
<tr>
<td>A systematic review and meta-analysis of the qualitative and quantitative evidence behind patient control goal setting in stroke rehabilitation</td>
<td>Rosewall, S; Rostom, CA; Farley, AO</td>
<td>2011</td>
<td>Stroke Rehab</td>
<td>UK</td>
<td>Y</td>
<td>Y</td>
<td>N/A</td>
<td>Y</td>
<td>Healthcare professionals working in rehabilitation need to have a clear understanding of patient's disease and their expectations regarding goals of setting and understanding the importance of goals setting in stroke rehabilitation.</td>
</tr>
<tr>
<td>Goal setting interventions in neurological rehabilitation: a qualitative study of patients' experience of goal setting</td>
<td>M. C; Holleman, C; Ballinger, A; C; Playford</td>
<td>2007</td>
<td>Stroke Rehab</td>
<td>UK</td>
<td>Y</td>
<td>Y</td>
<td>N/A</td>
<td>Y</td>
<td>Goal setting is beneficial in improving motivation and physical functioning for patients and their families.</td>
</tr>
<tr>
<td>Performance of goal-setting in a neurological rehabilitation ward: a qualitative study of patients' experience of goal setting</td>
<td>Young CA, Mahanty OP; Ward JOR</td>
<td>2008</td>
<td>Stroke Rehab</td>
<td>UK</td>
<td>N/A</td>
<td>Semi-structured interviews, n=40</td>
<td>Y</td>
<td>N/A</td>
<td>Goal setting is beneficial in improving motivation and physical functioning for patients and their families.</td>
</tr>
<tr>
<td>Patient-centred Shared Decision-making</td>
<td>Megan O'Sullivan, MD; MPH, A; Victor Montori, MD; MD, B; Al-Najjar, M; MD, B</td>
<td>2012</td>
<td>Cardiology</td>
<td>USA</td>
<td>Y</td>
<td>Decision Aid</td>
<td>Y</td>
<td>Clinical case follow up</td>
<td>Shared decision-making emphasizes respect, autonomy, the right to self-determination, and activation as much as patient participation as patients desire in making consequential decisions.</td>
</tr>
</tbody>
</table>
2.3.1 Models of decision-making

2.3.1.1 Shared Decision making

At the commencement of an episode of care, patients and their clinicians should come to a consensus that combines evidence-based medicine with the patient’s values and preferences to identify goals and treatment options (47) with personalised estimates of risks and benefits derived for each option.(48,49) This process, known as shared decision-making, is highlighted in the literature, promoted by medical organizations and policy makers and is included in the US Patient Protection and Affordable Care Act as a means to assist patients take an active role in their health care decisions.(14) Shared decision-making emphasises respect, autonomy, and the right to self-determination, and advocates as much patient participation as patients desire in making consequential clinical decisions. (47) Brindis (50) acknowledges the elevation of patient involvement will lead to a reduction in decisional conflict between clinician recommendations and patient preferences and improve treatment compliance as a result of the better understanding and shared expectations. (51)

Coylewright (47), recognises that it is important to acknowledge that not all clinical care decisions are appropriate for shared decision-making. Decisions can have a “right answer” in which the benefits clearly outweigh risks, such as emergency situations where patient involvement may not be feasible, or be purely technical in nature. Shared decision-making is best applied to decisions involving a trade-off of between benefit and risk (for example, risk of thromboembolism with atrial fibrillation or bleeding with warfarin) or treatment decisions that require the patient to be motivated to comply with therapy (for example, adherence to clopidogrel). (52)

While the literature promotes shared decision as the ‘right thing to do’, it does not detail where shared decision making effectively and consistently occurs and it does not offer guidance on implementation or measurable benefits. It also does not make the distinction between shared decision-making about treatment options or shared-decision making about goals. Most
importantly, it does not identify whether the patient wants to be a part of this process.

2.3.1.2 Patients preferred role in decision-making

A major theme that was evident among the included studies related to patient engagement in setting treatment goals. Patients who choose to be involved in setting treatment goals can vary in their level of participation with some opting to take complete control for the final decision, others preferring shared decision making while some default to clinicians. Chawla et al. (53), in a study of patients with a primary diagnosis of leukemia, bladder, or colorectal cancer between two and five years before the study, investigated the desired level of involvement among this patient cohort. The findings of the study demonstrated that the majority of the sample preferred shared control, followed by physician and patient control. Interestingly, patients who preferred to have control over decision-making had significantly more cancer-related worry that could potentially lead to depression, high levels of anxiety and may have an adverse affect on length of survival compared to other patient groups. Patients preferring shared control were more likely to be younger, have a higher level of education, know their physician for two or more years compared to those preferring physician control. Patients preferring physician control were as likely to engage in the decision-making process as other patients but had less confidence in taking responsibility for the final decision. Singh et al.’s (54) meta-analysis concurs with the findings of Chawla et al. (53) and adds that significantly more women prefer physician control. These findings also suggest that patients who leave decisions up to their doctor do not fare worse compared to those who prefer either shared decisions or control over their own decisions. This was supported by the work of Makoul et al. (52), O’Brien et al. (55) and Charles et al. (56) which questions the necessity and relevance of patient involvement in setting treatment goals if the outcome is no different.

All in all, the findings underscore the need for early comprehensive assessments of decision-making style that should assess not only who makes the final decision but also evaluate the extent to which patients are engaged and want to be engaged in the deliberation process. It is important to note that
that the above cited studies assess patients’ desired level of involvement in the
decision making process related to treatment goals, which is an intervention,
rather than a patient centred treatment goal, what the patient wanted to
achieved as a result of the intervention. While understanding how patients want
to be engaged allows us to tailor our approach to ensure maximum
participation, more emphasis should be placed on involving patients in
identifying the goals that are valuable and meaningful for them and their family.

2.3.1.3 Barriers to patient involvement

Through the literature the reasons why patients choose their desired
level of engagement in the decision making process can be recognised,
identifying that patient engagement can be very dependent on patients
confidence, self esteem and their ability to contribute. Holliday et al.(57) and
Young et al.(58) in their exploratory study of patients’ perceptions of goal setting
with Stroke Rehabilitation(SR) patients claim that patients may hesitate to
participate in the decision-making process and instead hand over responsibility
to experts due to their lack of confidence in their ability to participate. Patients
had attributed this passivity to their current medical condition, lack of
information about their condition, minimal encouragement from clinicians to be
involved, and their inability to accept their condition especially in the early
stages of the stroke. In this cohort of patients, standardised goals are to help
patients relearn skills lost post stroke, regain independence and improve quality
of life (59), however, patients’ individualised goals are unknown, and if known,
could contribute to a more effective and timely recovery. There is strong
evidence in the SR literature that patients want and are capable of being
involved in, and can contribute positively to goal setting (60,61) but what is
absent and not offered in the literature is the process for patient engagement.
There may be an argument to suggest that if the patient was prepared
appropriately (at the right stage of the illness, had the right mindset and the right
information given and the right motivation/encouragement provided) a greater
level and quality of engagement would occur.
2.3.1.4 Alterations to level of involvement when the direction of care alters

Even though the previous paragraphs identify patients’ desired level of involvement, it is uncertain whether or not this changes over time or changes when faced with a different decision type. Brom et al. (62) investigated this question with 28 advanced cancer patients, facing palliative treatment decisions, at the start of their first line treatment. The study consisted of patients diagnosed with glioblastoma (GBM), and patients diagnosed with metastatic colorectal cancer (stage IV) who were not eligible for surgery. In both patient groups, when progression of the disease occurs, a decision is often required on whether or not to start a second line treatment aimed at prolonging life, but with the disadvantage of burdensome side effects. The study reported similar findings with regard to desired level of involvement as the study undertaken by Chawla et al. (53) of six hundred twenty-three bladder, leukemia, and colorectal cancer survivors, adding that patients who highly valued keeping control over their own life felt it was their responsibility, with the adequate information, to make appropriate decisions and not to burden the clinician. However, in Brom’s study, the patients reported that their role was not static and would probably change along with the illness trajectory when the direction changes from active treatment to a quality of life focus. The findings indicate that this “active to non active” decision point came as a shock to the participants who were unable to face or accept a transition in aims from life prolongation to the quality of life. As a result, they assumed a more active role in their care and felt as if they had no choice other than go on with new treatments because the alternative, no treatment, would lead to death and this was not acceptable.

Brom et al. (62) and Chawla et al. (53) catalogue previous studies to support how patients change their approach when faced with a different decision type at a crucial point in their illness. It is known that patients change their goals and are willing to go on with treatment with little chance of benefit (63, 64) because they do not want to ‘give up’ and face death (65). Donovan’s (66) study among recurrent ovarian cancer patients found that the patients considered quality of life of secondary importance and were willing to tolerate the toxicity of chemotherapy in the expectation of some life prolongation,
regardless of the fact that the cancer was not curable. However, it is not clear in the cited studies, what goal agreement has been made at the commencement of the episode of care. Nevertheless, it is evident that when a critical decision point arose, the patient altered his/her approach to suit their circumstances and those of their families at that particular time without regard for what they have may or may not have previously been agreed.

2.3.1.5 Clinician’s role in the decision making model

Clinicians who are committed to the concept of shared decision making and the involvement of patient in developing goals for their care are required to drive this process. The clinician will need to allocate the time, present the options to the patient and his/her family, listen and comprehend their personal goals and together decide the best approach. This discussion is essential to occur at the beginning of an episode of care and it should involve a senior decision maker (67). Brom et al. (62), however, found that this did not frequently occur and when it did, it lacked detail and depth in relation to surgical and non-surgical treatment options, life prolongation versus quality of life and emphasis placed on the fact that the disease was non-curative. The authors recommended that more attention is paid at initial treatment goal discussions to prepare patients for the transition from active to non-active treatment and therefore avoid situations in which opting to withhold life-prolonging treatment is perceived as doing nothing but, rather, part of the plan.

Chawla et al.(53), however, discovered that even if clinicians had some discussion initially with the patient about the plan of care, there are challenges to enforcing the plan along the illness trajectory. Chawla et al.(53) also highlight that when clinicians are confronted with treatment dilemmas, despite the futility of the treatment or the potential toxicity to the patient and the damage to the patient's remaining quality of life, compromises are made. Clinicians often agree to ‘trying out one more dose’ rather than remaining with the original plan. On personal communication with Dr Doug Bridge, a retired Consultant Oncologist, on the 23rd May 2014 at a Perth Tertiary hospital, he recognised this as a problem. The way he addressed it was by directing his intern each day to document the goals of care (peaceful dignified death in x days/month time) in
the medical record to maintain consistency and reinforce the plan to the patient/
family and his/her medical team. In addition to role modelling by experienced
clinicians, medical education must be engaged to ensure medical students as
well as junior medical staff acquire the knowledge and learn skills to set patient
centred treatment goals as part of core curriculum and orientation into clinical
areas. (68) However, the challenge is to change the mindset of current senior
clinicians to embrace this concept and role model it to junior staff. As in Dr
Bridge’s case, some senior clinicians already perform well.

2.3.1.6 Factors affecting decision making

The challenge to the successful implementation of effective decision
making is acknowledged throughout the literature. Clinician time and busy
workload are identified as major factors inhibiting the process of goal setting
(69) and may result in poor decision making. Additionally, Hagerty et al. (70)
acknowledge that doctors have difficulties in discussing prognosis with patients,
particularly in the transition from curative to non-curative treatment, with cultural
differences, geographic differences, literacy, numeracy, learning and
communication styles also posing challenges to assist patients and clinicians
reach the correct decision. Hagerty et al. (70) go on to highlight that properly
designed decision aids integrated within the clinical workflow and point-of-care
risk prediction tools would be invaluable to guide the patient and clinician
through the goal setting encounter. These, nonetheless, are not available.

Coylewright (47) points to systematic rather than personal and
professional issues that impact on setting effective PCTG. Traditional fee-for-
service models that offer incentives to recommend diagnostic and therapeutic
treatments, regardless of patient benefit, may contribute adversely to decision
making. Schulman Green’s (71) study highlighted that the brevity of a visit
affected what could be discussed. This is particularly important because before
meaningful and open goals are discussed with a GP, a trusting relationship
between the GP and patient needs to be established. While the factors
identified are useful to inform the clinician, little is offered in terms of
recommendations for future practice to enhance the goal setting process and
ultimately decision process for the patient and clinician.
2.3.1.7 Next of Kin (NOK) involvement in decision making

Ideally, patient-centred treatment goals are set by the patient and clinician but in certain situations such as in the ICU environment, time critical setting of PCTG are frequently required. Often patients are severely ill and incapable of involvement in informed discussions. In these circumstances medical teams are mandated to turn to substitute decision-makers, namely the NOK. Martin et al. (72) highlighted in their study that the NOK may be aware of the patient’s wishes but may not have the confidence or sufficient information to set PCTG accordingly. It is also claimed that is it more common that the patient’s wishes are unknown, especially in relation to life sustaining treatments when the family are given the role and responsibility to make this life or death decision (74).

Heyland et al (74) claim that among patients, families and the public, there is a general lack of understanding of what life-sustaining treatments entail, what is achievable, and the risks and discomforts involved. Meth et al. (73) state that as a result of this, conflicts with patients and families are common in ICU and the most common types of conflicts reportedly occur in the decisions to withdraw or withhold treatment (75). There is significant pressure on the NOK to make a decision on behalf of their loved one. This can result in increased anxiety levels adding to their inability to comprehend the information provided to them and adequately participate in the goal setting. The challenges, complexity, and confusion related to NOK setting PCTG during emotional and stressful times in ICU was acknowledged by Martin et al (72). No recommendations, nevertheless, were put forward on what help and support can be provided for them during this time.
2.3.2 Documentation of PCTG

2.3.2.1 Approaches for documenting PCTG

It is accepted that some clinicians discuss treatment goals with their patients. However, there is a lack of a systematic and widely validated approach to documenting PCGT and so it is uncertain what proportion of the absence of documentation relates to the absence of discussion or the absence of a method for documenting discussions that have occurred. To address this issue, and improve the quality and consistency of setting PCTG, Macgregor et al.'s (76) study explored whether it is feasible for clinicians to engage patients in collaborative goal-setting and concrete action planning during a primary care visit. This setting, it was argued, provides the ideal opportunity to set meaningful patient-centred goals as part of a shared decision making process at the point where the patient first accesses healthcare. For the study the action plan was a simple pro forma that consisted of patient-centred goals and behaviour change goals. The patient and clinician completed the action plan together with both signing their agreement of the chosen goals. The primary care clinicians were trained for sixty minutes in goal-setting and action planning techniques and asked to conduct action plan discussions with study patients during medical visits. Two hundred and seventy-four patients with Coronary Heart Disease (CHD) risk factors participated in the study and 83% of the patient encounters resulted in a documented action plan. The main findings indicated that clinicians reported that the action plan training made it easier to discuss goals with their patients and to measure the achievement of these goals. The majority of clinicians stated that they would continue to use the action plan with some of their patients after the study.

Clinicians, in Macgregor et al.’s (76) study, felt that all primary care clinicians should be trained in goal-setting and the use of action plans and reported they had recommended the action plan idea to other clinicians. Lack of time and training in the complexity of the primary care visit was a significant barrier to holding these discussions and sustaining this paradigm in practice. Huby et al. (77) concurred with this finding in their study of SR patients. Formal
documentation of the patient’s views and the use of grading systems to measure their goal achievement were ways identified as essential to consistency in goal setting and to facilitate the patients understanding the goals that had been set. It was argued that the goals set and documented should be sufficient to encourage and motivate the patients to engage in the goals and not to overwhelm them, as well as to guide and direct the multidisciplinary team to goals’ achievement.

A key conclusion of the review of literature related to approaches to documenting PCTG is that while there is interest in setting goals and that methods have been developed for facilitating the setting of goals, these are difficult to implement in a sustainable way and there is no evidence that their use is widespread in routine healthcare delivery.

2.3.2.2 Transfer of goals between primary to secondary/tertiary care

Clinicians and patients also face challenges with documentation when information is transferred from primary care to secondary/tertiary care. The current documentation process involves a referral from a GP with sometimes limited clinical information and almost no information about PCTG. On discharge from hospital, a discharge letter is sent to the GP that mostly deals with that episode of care and not a holistic view of the patient. Fried et al. (78) examined hospital discharge processes and found that patients often presented to GPs with a complex documented medical regime from a previous hospital admission that was almost impossible to adhere to and required tailoring to ensure it was appropriate for the patient’s lifestyle and patient-centred goals. Conflict arose among patients and clinicians as the patient felt that the GP was taking away a treatment that a more experienced clinician, ‘the specialist,’ had prescribed. This demonstrated the major detrimental effect poor documentation and handover can have on the development or maintenance of a trusting relationship between clinician and patient.

Concerns about patients and families having an inaccurate understanding of their plan of care in relation to overall health goals, as well as the time required to convince patients what is important and relevant for their
situation and lifestyle, were also highlighted by Fried et al. (78) in the same study. Even though organ-specific problems are important components of a discharge letter to the GP, ongoing treatment should be considered holistically, discussed with the patient and an appropriate patient-centred treatment plan should be documented in the discharge letter. (78) However, the idea of encouraging the specialty clinicians to consider the patient as a person, with 'home' needs as well as 'hospital' needs, was not explored. Nevertheless, the tools and processes for documenting PCTG exist, the challenge is how to utilise these tools. Macgregor et al. (77), Huby et al. (77) and Fried et al. (78) identified that clinicians require training and development to support them to consider the patient holistically and to agree and document plans that seamlessly transfer PCTG goals from one healthcare setting another.

2.3.3 Communicating PCTG

2.3.3.1 Providing misleading information to patients

The patient's ability to fully understand and engage in the setting of PCTG can very much depend on the manner in which the clinician delivers the message, the information given and methods used to evaluate the comprehension of the message. (79) Giving patients potentially misleading information violates cultural norms and ethical standards and results in a complete misunderstanding of the purpose of the treatment plan. (69) Past research suggests that 90% of physicians are reluctant to provide specific prognostic information, 75% shade their prognostic estimates to be more optimistic than they believe are true, and 44% wait to be asked before discussing prognosis. (80,81) This is important because goals cannot be set without there also being discussion about prognosis, as this is necessary to provide context about goals that are actually achievable.

Apatira et al. (82) identified that even when clinicians do give patients specific information about their prognoses, it may be conveyed in a manner that may confuse the patient. In situations where poor prognosis should be discussed with the patient, clinicians often shy away from engaging in these conversations. Tanco et al. (69) consider a clinician's desire to be perceived as
compassionate, the time pressures, fear of being blamed, fear of destroying hope or provoking emotional distress, and being in pursuit of higher patient satisfaction scores, as rationales for the clinician’s method of communication. Regardless of how clinicians wish to be perceived by patients, a patient must receive the correct and honest information about their condition in a manner that is understandable and that allows for them to plan for the future and to actively participate in PCTG. Some clinicians are naturally skilled at communicating with patients but communication training and scripts can be provided to assist the clinicians who find it challenging. The extent to which poor skills or reluctance to discuss prognosis, particularly poor prognosis, is a barrier to discussion of goals has not been explored but may be relevant to the relative absence of discussion about achievable goals of care.

2.3.3.2 Patient perception of clinician delivery of PCTG

A commonly accepted component of high-quality communication in the process of discussing treatment goals is patients’ perceptions of physician compassion. Tanco et al. (69) undertook a study with one hundred patients with advanced cancer, randomized to four study groups. Each group viewed two videos of a patient-physician interaction: one with a ‘less optimistic’ message from one physician and one with a ‘more optimistic’ message from another physician. Study participants then rated each physician's compassion. Study participants reported significantly greater physician compassion in the more optimistic video compared with the less optimistic video.

The majority of study participants also preferred the physician that delivered the more optimistic message, describing them as compassionate and caring, over the physician who delivered the less optimistic message. Further chemotherapy and not ceasing treatment are examples of optimistic messages, however most patients, in similar situations, would concur with this and will prefer the clinicians that will ‘try out one more dose’. (53). What is important in the setting of PCTG is not what the clinician is labelled but the emphasis placed on ensuring the patient receives honest information, given time to comprehend the information and then goals for their care set. (69) Initially the patient may be confronted by this approach and it may involve substantial clinician time to aid
understanding. Such investment of time, however, may lead to treatments that may adversely affect the quality of life of the patient and have little hope of extending life being avoided and allow resources to be distributed to patients who will benefit. While the patient’s perception of clinician compassion is important in healthcare delivery, it should not be replace or interfere with the delivery of honest information, if culturally accepted, to the patient.

2.3.3 Patients’ perceptions of the goal setting process

There is consensus within the literature under review that patients, if provided with the correct support and information, should participate in deciding their PCTG to the degree of their desire and capability. There are few studies available that review and reflect on this progress. One such study undertaken by Schulman-Green et al. (71), however, examined this issue with an elderly cohort in the primary care setting as they sought to understand how older adults considered and discussed their life and health goals during the clinical encounter. Many patient participants in this study did not believe their clinicians were interested in goal setting. The participants did not view their interaction with clinicians in a positive light and perceived that clinicians preferred to prescribe medications instead of utilising the time to have a goal discussion. By contrast, some patient participants were taken aback at the idea of talking about goals with their clinicians. For these participants, goal discussion was not seen as part of the medical encounter as symptom deliberation seemed to dominate. Some of the participants felt that discussion of goals was personal or even embarrassing, and that taking the time to develop trust with their clinician was important to facilitate meaningful conversations about goals. The findings highlight the educational, cultural, and emotional requirements of the patient, as well as clinicians, in the goals setting process and the requirement of an instruction sheet that guides patient and clinician on what needs to occur before, during and after a goal setting encounter.

Other studies have provided feedback on the patient perceptive of the goal setting process that can be used to design a more effective goal setting encounter. Holliday et al’s (85) study of goal setting in stroke rehabilitation patients identified that most patients were neither given verbal nor written
information about the goal-setting process to facilitate their involvement. Martin et al. (72) reported that patients and patients’ families did not think that clinicians provided honest, realistic information about prognosis and end-of-life issues with them. Findings from studies undertaken by Gross (85) and Auerbach et al. (86) supported this communication deficiency, especially in the ICU with critically ill patients of uncertain prognosis. Information on the likely or potential outcomes of treatment is essential before goals setting can commence. The value of this finding is of limited use as it is necessary to undercover what honest, realistic information looks like to each individual patient so it can be compared against the information provided by the clinician. Clinicians may in fact have perceived that they did provide effective information. One strategy to alleviate this is for the patient to be given an outline of the goal setting discussion and what is expected of them pre goal setting meeting and for the clinicians use this to inform the discussion and allow opportunities post meeting for shared evaluation and review.

2.4 Limitations of PCTG

2.4.1 Patient understanding

One of the most concerning themes evident in this review is the patient’s low level of understanding of the treatment plan or goals despite been told by their clinician. One would argue that if comprehension is not there, then their contribution to the setting of PCTG is not valuable and could lead to the patient opting for ineffective, futile and expensive treatments. An example of this is an Australian observational study conducted by Burns et al (87), who measured the understanding of 163 patients, with incurable cancer, and their nominated principal family caregivers of their treatment goals at weeks one and 12. One-third of both patients and caregivers understood that the treatment goal was not curative. In 13.6% of pairs, however, both patient and caregiver did not know whether the treatment was curative or not and 6.8% believed that the goal of treatment was curative. At week 12, one-third were fully aware, 9.5% did not know and 4.8% still believed it the goal of treatment was curative. Despite the goal of treatment being a peaceful dignified death, patients were not cognizant of this and from the findings the reasons why are not clear. Burns et al (87) do
acknowledge that time-to-death, gender, and place of residence were important predictors of patient knowledge and understanding, but the patient’s unwillingness to accept the condition, the clinician’s communication skills or the patient’s intellectual ability as contributing factors were not explored or discussed. The patients’ understanding of their goals is significant as other research has found that patients who are aware they are dying are able to stay at home, obtain better hospice and palliative care, and have their families with them. In contrast, those who are not aware of the seriousness of their condition are more likely to have a rushed emergency admission and face unnecessary undignified death in an acute hospital. (88,89)

2.4.2 Developments in literature during the course of the study

It is important to acknowledge that the literature search was limited to studies up to 2015. Since 2015, developments have occurred to address some aspects of patient centred care. Health literacy and the Australian Commission on Safety and Quality in Healthcare Care: partnering with consumers are examples of such initiatives. Health literacy explores how people understand information about health and health care, and how they apply that information to their lives, use it to make decisions and act on it (116). Partnering with consumers aims to ensure that health care is based on partnerships can benefit patients, consumers, clinicians, health service organisations and the health system that create a positive experience for patients, as well as high-quality health care and improved safety(117). The Initiatives were development and implemented following a recognition that the complexity of the health system is challenging for everyone who uses it and works in it, and this complexity contributes to poor quality and unsafe care(116). Auditing and research is required to measure the effectiveness, however, this candidate literature review is significant as it serves to provide a baseline for other future review to be measure against and evaluate future performance.
2.5 Recommendations to assist patients setting patient-centred treatment goals

Even though recommendations for future practice are limited in the literature under review, some are proposed that can assist the patient emotionally and psychologically to facilitate a more meaningful contribution to the goal setting process. Chawla et al. (53) in their study of cancer patients’ desired level of involvement in goal setting, recommended that patients required increased self-efficacy to have confidence to carry out a behaviour, that is assuming responsibility for their goals, necessary to reach a desired and realistic goal. Wåhlin et al’s (90) study explored the concept of patient empowerment in a cohort of ICU patients with the aim of enhancing goal comprehension and advocated for this as a means of improving ownership and involvement of goals and goal setting. The importance of self-efficacy and empowerment have been acknowledged elsewhere in the literature. For example, Rodwell’s (91) study found that empowerment resulted in positive self-esteem, ability to set and reach goals, a sense of control over life and change processes, and a sense of hope for the future. Brom et al. (62) recognised that patients’ involvement in decision making and goal setting can have a negative impact on their mental health and anxiety, so developing their self-efficacy and facilitating empowerment may support them through this process. However, further exploration is necessary to identify how we can develop these concepts with patients and the feasibility of their implementation into clinical practice.

2.6 Chapter Conclusion

The literature review set out to systemically explore the published literature with regard to the concept of PCTG, particularly, from the patient’s perspective. The available literature, within the defined scope, was limited, talked around the subject of PCTG but did offer valuable insight and direction to guide clinical practice. The review commenced by looking at the PCTG across specialties to display the depth of the issue as well as similarities and difference between specialties across health. The decision-making model theme identified key aspects of the goal setting process including shared decision making, patients’ preferred role in decision-making, barriers to decision making, clinician
and NOK role and how the level of desired patient involvement changes over time and illness trajectory. The documentation theme focused on the current available approaches to documenting goals and the challenges of transferring goals from secondary/tertiary to primary care. In the communication theme the provision of misleading information to patients, the patient perception of the clinician’s communication method, conflict and patients’ perception of the goal setting process were discussed. The limitations of PCTG such as patient understanding were discussed as well as strategies to assist patients setting PCTG.

Little consideration has been given in the literature into the actual goals that patients have set, whether or not these goals are patient-centred and how their achievement is measured. No evidence is apparent on how and when they are set, who agrees that they are realistic and achievable and whether or not the goals are appropriate upon which to base a schedule of care. The patient’s capability and skill set required to effectively contribute to goal setting has been highlighted in the literature but has not been detailed. Setting comprehensive goals is a standard management procedure and a common start to any project, yet while this is common practice in other fields, medicine seems to be an exception.

There is a major gap in understanding, therefore, that contributes and will continue to contribute to the lack of engagement and conflict. It needs to be determined what happens at the time the patient and clinician unite to discuss a future plan of care as this is the point that it is necessary to ensure patient preferences and values are incorporated into clinical decision making. There is evidence that clinicians make invalid assumptions about patient preferences and values but to set goals, clinicians must first understand the priorities of their patients. The Clinician-Patient bond ensures that patients and families understand what is achievable, the reason that a treatment is being proposed and, that if a treatment option is not being recommended, it is because it cannot achieve patient-centred goals. It will take time to develop the patient/clinician relationship to facilitate effective goals setting and the current demands and approaches to healthcare delivery do not support this model.
The roles and responsibilities of players are clearly defined, goals are rightly the province of patients, but decision making around how the goals should be achieved and what is achievable lies with clinicians. Each component of the patient-clinician relationship plays to its strength with clinicians the experts on the medical options and implications and patients and families are experts on the patient’s values and preferences. This approach to goals setting is not particularly novel and many clinicians intuitively practice and think using a ‘goal-oriented’ approach. Little documented evidence exists to validate that goal setting has occurred. As the consequences of applying these patient-centred principles in goal setting have not been evaluated rigorously, its adoption to practice warrants further research and a candidate intervention is required to describe how this concept is currently executed in the clinical setting.
Chapter 3

Methodology

The literature review identified that PCTG is an under-researched area and the available literature, within the defined scope, was limited. Little consideration has been given in the literature into the actual goals that are set, the extent to which they are set by patients or clinicians or both in combination, whether or not these goals are patient centred, and how and whether their achievement is measured. The literature, mostly, retrospectively reviewed the patient’s episode of care and did offer valuable insight and direction. Data on the quality of communication and decision making between clinician and patient is sparse and an audit conducted by Dr Webb, Dr Litton and Mr Leen, in 2012 on 51 ICU patients to assess whether PCTG were documented in the patient’s medical record, found that they were not.(Appendix 3.1)

It is likely to be incorrect to assume that clinicians do not discuss PCTG with their patients as some clinicians engage effectively with their patients, but this does not occur universally and consistently. The standard must be reached where the patient feels fully informed and involved and healthcare has systems in place to facilitate this.

3.1 Defining the Research Aims

The broad purpose of this study was to determine whether patients had goals and if so, whether these goals had been determined in discussion with their treating clinician and whether the participant could express these goals. The study also aimed to explore the concept of the setting and measuring of PCTG from the perspective of patients being treated within the tertiary hospital sector so as to determine if there were gaps in routine processes that might promote better and more collaborative decision making and to ensure the patient understands what might be achieved from a proposed episode of care.
The research plan for the study was to involve adult patients undergoing an episode of care involving non-emergency surgery for which admission to a Perth tertiary hospital Intensive Care Unit or High Dependency Area was planned (such as post-operative cardiothoracic surgery and vascular surgery). The specific aims were to:

- Describe the goals of treatment as specified by the patient and determine if these goals were patient-centred.
- If the goals of treatment that were obtained in aim 1 were not patient-centred, determine if the patients, with appropriate assistance, can specify treatment goals that are patient-centred.
- Describe the concordance between goals that were specified by patients and treating clinicians goals as understood by the patient.
- Determine if the goals of treatment that were obtained can be specified in metrics and over a time-frame that can be measured practically.

A fifth research aim, to establish the opinions of treating Intensivist about whether specified goals were achievable, was not pursued due to lack of clinician involvement.

It was hoped that the findings from the study would demonstrate that PCTG can be set by clinicians and their patients.

### 3.2 Research Design

The study utilised a multiple exploratory case study approach, as described by Yin (92), to gain in-depth insight into the setting of patient-centred treatment goals as specified by patients consented for non-emergency surgery. This area of concern was extended to several cases to explore the issue and to study the cases both for their uniqueness and commonality. Each participant constituted a case.

A multiple exploratory case study approach is used to explore situations in which the concept being discussed and evaluated has no clear, single set of
outcomes (92) using a variety of data sources - in this case we used patient interviews and patients’ medical records. The data sources ensured that the issues were not explored through one lens, but rather a variety of lenses which allows for multiple facets of the phenomenon to be revealed and understood. A multiple case study approach allowed the study investigator to analyse each case, within the current setting (inpatient, outpatient, operation type, specialty) and across settings. Overall, the evidence created from this type of study is considered robust and reliable, but it can also be time consuming to conduct. To prevent the study becoming too broad and unmanageable, each case was bound by patients waiting for elective surgery in a public teaching hospital, either as an inpatient or outpatient with an admission to ICU/HDA as part of the pathway. Guidance on case binding was taken from Creswell (93) (by time and place) and by Stake (94)(time and activity).

3.3 Philosophical Framework

The study was underpinned by a post-positivist philosophical framework. The post-positivist framework allows for emphasis to be placed on meaning and the creation of new knowledge with the construction of truths through dialogue. (95) The framework, as well as investigating the problems that are under investigation, allows for problem setting and proposing additional questions for further research. Discovering the most appropriate way to formulate a problem is often as important in the advance of knowledge as hypothesis-testing.(96) Post-positivism claims that post-positivistic knowledge is more certain and objective than knowledge which originated from other paradigms. (97)

The post-positivist framework lends itself well to the concept of understanding PCTG from the patient perspective. Truth is multiple and sought from each patient about his or her unique feelings and expectations from an episode of care. A post-positivist framework allowed the study investigator to explore what was important to the participants, the challenges faced and the potential solutions to the identified problems. The attractiveness of the post-positivist approach is that it requires a degree of passion, drive and motivation(95) — especially for justice and the ability to subject one’s own
assumptions to scrutiny and reflexivity. This is essential when considering the relatively unexplored concept of the application of PCTG in the clinical setting.

### 3.4 The Study Investigator

The study investigator is undertaking a qualitative study to explore the PCTG as qualitative inquiry is still the most humanistic and person-centered way of discovering and uncovering thoughts and action of human beings. (98) Reflexivity is an integral component of qualitative research-the assumption being that the researcher and the research are inextricably linked. (99) As such, qualitative researchers must position themselves in their studies so that they reflect on self-understanding and also, in the understanding of others. Positioning themselves within and outside the research enables the researcher to note differences and similarities between researcher and participants(100) which, in turn, enhances the validity of the research.

The study investigator has substantial experience as a clinical nurse and senior nurse in Intensive Care and ward environments both nationally and internationally but no longer has any direct clinical responsibilities and did not provide direct care for any study participant or influenced their care and treatment in any way. He is skilled in interviewing staff, patient and family members as part of routine working practice and therefore chose to conduct the interviews independently. However, the study investigator acknowledged that conducting interviews as part of a research project is different and some self development and reflection was required. The study investigator acknowledged that he was part of the setting, context and social phenomena that he sought to understand and was aware of the importance to maintain the researcher/participant delineation throughout the research process to avoid role conflict.
3.5 Research Methodology

3.5.1 The Setting

The study was conducted in a 783 bed tertiary/Quaternary referral teaching hospital that provides a full range of emergency services for adults and paediatrics and serves as the state referral centre for many specialities including interventional neuroradiology, cardiac and lung transplant, burns management, bone marrow transplantation, rehabilitation medicine and trauma. Annually, the hospital treats approximately 90,000 in-patients, receives about 300,000 outpatient attendances, and its Emergency Department has more than 100,000 presentations. The hospital has a 30-bed ICU and High Dependency Area (HDA). The ICU and HDA operate as a closed unit in which consultant ICU Intensivists have primary responsibility for clinical decision making in conjunction with the referring team.

The patient interviews were conducted and recorded in the ward environment or in the outpatient setting at the Pre Admission Assessment Service (PAAS). In both locations, the interviews were conducted in a quiet, neutral room where the participants felt safe and as free as possible from feelings of intimidation or coercion.

3.5.2 Description of Population and Sample.

Purposeful sampling was used to recruit patients. Adult English speaking patients who were booked and consented for an elective non-emergency surgical procedure and for whom post-operative care was planned to occur in the ICU or the HDA were potentially able to be included in the study. Patients with known cognitive impairment sufficient that they were not considered competent to consent for elective surgery were excluded. A total of fifteen interviews were conducted of which twelve were eligible to be included in the study. Of the three not included, two were due to patient withdrawal from the study and one was as a result of the recording device failure. Table 3.1 provides description of the study participants.
Table 3.1 Description of the participants

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<td>Acute pulmonary embolism</td>
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<td>Acute renal failure, ischaemic heart disease</td>
<td>Atrial fibrillation, COPD, lung disease</td>
<td>Epilepsy, T2 diabetes</td>
<td>Pancreatic carcinoma</td>
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3.5.3 Recruitment Process

The recruitment process for patients comprised of the outpatient referral pathway and the inpatient referral pathway

The outpatient referral pathway

Patients who had been referred from his/her GP and had been seen in the Outpatient department by a surgeon and decision for operation made, were of interest. At this point a request for an ICU/HDA bed and a Pre Admission Assessment Service (PAAS) clinic appointment was generated on the Electronic Booking System (EBS). The study investigator monitored EBS daily to identify suitable patients. At least one week prior to the PAAS appointment, the study investigator sent, by mail and email, study details and a consent form to the patients who had been booked for ICU or HDA admission, requesting their consideration to participate in the study. At the PAAS appointment, after consent for operation process had occurred, the study investigator met the patient, reiterated details of the study and offered the patient the opportunity to participate. If the patient agreed to be part of the study, the patient was then enrolled in the study and the patient interview was conducted on the same visit that they attend the PAAS. Five patients were identified through this process.
The inpatient referral pathway

The study investigator identified inpatients who had a planned operation on the EBS system, met with them in the ward environment and provided them with details of the study. The study investigator returned the following day, further discussion took place about the study and the patient was given the opportunity to ask any question they may have. The patient was then offered the opportunity to participate in the study. If agreeable, the patient was enrolled and consented in the study and a mutually convenient time to undertake the interview was arranged. Appendix 3.2 details the Recruitment materials.

3.5.4 Recruitment Issues

The main barrier to recruitment was related to the outpatient referral pathway. The challenge with this approach was the accuracy and consistency of the PAAS clinic schedule as it changed without notice and three patients who were scheduled for recruitment discussions, were cancelled. The study investigator worked with the outpatient manager to lock the PAAS schedule a week in advance to prevent late adjustment occurring. However, this did not consistently prevent alteration to the scheduling.

The practice of conducting PAAS clinic appointments for patients, who were planned for ICU admission post-surgery, on the day of surgery was discovered. This caused unnecessary stress to the patient and family and, on occasions, resulted in the patient being cancelled for theatre at the last minute, further increasing the patient’s anxiety. For the patients whose surgery was allowed to proceed, it was at this point that the patient first learnt about their planned admission into ICU and despite fitting the study recruitment criteria, given the potential of causing further stress to the patient and their family, it was decided not to pursue this cohort.
3.5.5 Data Collection and Management

Data collection was guided by Stake (94) for evidence in case studies, and included interviews and medical records. This was used to provide an insight into the setting of PCTG.

Other data collected for each patient comprised the following:

- Age and date of birth
- Gender
- Past medical history
- Planned procedure/ type of surgery as described on hospital booking
- Treating Clinician

All hard copy data were stored and secured in a locked cupboard in a locked office and electronic data are stored on a password protected folder only accessible to the study investigator and his supervisors.

3.5.6 Participant interviews

One-off in-depth interviews were conducted with participants as they are an ideal method by which to explore the complexity of PCTG. Each participant interview lasted 45 to 60 minutes. The participant was offered the opportunity to have a family member or significant other present at the interview to provide support and advice to them. Five participants' partners participated in the interview process, three of whom assumed a supportive role and became involved in the discussion when invited by the participant to reiterate a participant’s point. The other two partners were keen to take a more active role. One such partner attempted to answer on behalf of the participant and despite the participant appearing comfortable taking this passive role, the study investigator reinforced the interview aims and redirected the questions back to the participant. The second partner who also attempted to contribute to the interview did so against the participant’s wishes. This participant quickly reminded her that it was not her ‘life’ each time she endeavoured to interject. This created an uncomfortable atmosphere at times during the interview but it is not considered that data quality was impacted. The interviews were audio
recorded with consent and in addition, some notes were taken during the course of the interview to highlight and remind the study investigator of pertinent points.

The participants were asked a series of open questions in relation to the setting of PCTG. A recursive method of interviewing (101) was used which helped the participant feel at ease as data are generated through conservational interaction. The questions addressed issues or areas of interest including the development of their current treatment goals, their perception of the clinician's opinion of the set treatment goals and their involvement in treatment goal setting. Treatment goals were explored in relation to survival, function and symptom control and the patient's perception of these concepts sought. At the conclusion of each interview, the study investigator summarise the information received and then question the participant to determine accuracy. Appendix 3. details the Interview materials.

The subject matter did appear to confuse the participants at the beginning of each interview and at times the answers seemed to be what the participants thought that the study investigator wanted to hear and not what they truly felt. In fact, some participants treated it as a test of their knowledge of their condition. The interviews, however, returned to the participants’ thoughts and feelings naturally as the interview progressed but on occasions when it did not occur, the study investigator acknowledged with the participants that the information that was being provided was extremely useful and now it was time to hear about them as a person.

Probing was essential and as the study investigator was a novice interviewer, probing skills improved and became more natural as more interviews were conducted. This was evident when comparing the richness of data in the early interviews to the later interviews. On reflection, the silent probe was the most effective and only interjecting when the conversation deviated from the subject matter.
3.5.7 Interview Location

The outpatient setting is a busy environment not conducive to interviewing a participant. Prior to the interviews, the study investigator met with the outpatients manager and identified a quiet comfortable room, free of distractions that would assist the patient feel at ease. For the inpatient setting, the study investigator gave the patient the choice of being interviewed in their room or in a designated interview room on the ward. Most patients chose to conduct the interview in their room. Prior to each interview, the coordinator of the area was informed of the interview process and permission sought to put a “do not disturb’ sign on the door.

3.5.8 Patient Medical notes

Collection of data about the occurrence, manner and content of discussions related to PCTG has the potential to be fraught with problems in reliability. To enhance reliability the medical notes were assessed post interview using a similar process that was utilised in the pre study clinical audit that reviewed each participants case notes to identify if PCTG had been documented and if so, how the PCTG were described.

3.5.9 Data Analysis

Information for the twelve eligible participants for whom valid consent existed were included in the analysis. Audio recorded interviews were transcribed verbatim, minus any identifying information, by the study investigator and the transcripts checked against the original audio recording to ensure accuracy and that pauses and emotions were captured. The first four interviews were transcribed by the study investigator as this was an opportunity to re-listen to the interviews in great detail and rethink the conversation. Even though this was extremely beneficial to gain familiarity with the data, it was time consuming and a transcription company was procured to transcribe the remaining eight interviews. Participants were given pseudonyms at transcription
to ensure confidentiality. The transcripts, from audio recorded interviews and
notes taken during the course of and after the interview were entered into the
qualitative computer based data analysis program, NVivo10, to facilitate data
management, analysis and interrogation.

The initial coding phase was completed through the process of Structural
coding with data organised around the specific interview and research
questions(102). The patient was considered a single case and through
immersion in the transcripts of individual interviews, the study investigator
attempted to make sense of individual cases (103) and unique statements,
words and concepts were identified. This was an important step as it allowed
the study investigator to become more familiar with each case as an individual
entity. According to Eisenhardt (104), this is a process that allows the unique
patterns of each case to emerge before the investigators push to generalise
patterns across cases. In addition it gives investigators a rich knowledge of
each case which, in turn, accelerates cross-case comparison.

The comparison across the cases constituted the next step in the
analysis following Tesch's,(105) approach of “decontextualization and re-
contextualization”. Data are decontextualized when they are separated into
units of meaning through coding and sorting. These data are decontextualized
because they are separated from the individual cases in which they originated.
Data are recontextualized as they are reintegrated into themes that combine
units of like meaning taken from the accounts of multiple research respondents.
These recontextualized data create a reduced data set drawn from across all
cases. The study investigator used the reduced data set to explore theoretical
or process relationships among these clusters of meaning.

Through the initial coding process, the following dimensions were
identified: ‘reasons for access to healthcare’, ‘desired involvement in goal
of goals’, ‘information from clinician’, ‘non-clinician information’ ‘information
delivery’, ‘confidence in clinician’, ‘shared decision making’, ‘clinician
responsibility for patient care’, ‘emotional response to upcoming procedure’ and
‘congruence of goals’
The next step in the coding phase was to analyse the relationships between the categories and abstract them into themes. Three multidimensional themes were identified. The first theme related to the participants’ ‘desired outcomes’ and includes the dimensions of ‘reasons for access to healthcare’, ‘patient goals’, ‘trade-offs’, the participants’ ‘timeframe for achievement of goals’ and the ‘participant perception of clinician Goals’. The second theme relates to information and incorporates the dimensions of information given to the participant by clinicians, the manner in which the information was delivered and the information given to the participant from sources other than clinicians. The third theme related to the clinician and participant’s relationship that included participant’s confidence in clinicians, shared decision making between the participants and clinicians, participants view on clinicians’ responsibilities for the care of the patient, participant’s emotions related to upcoming procedure and congruence between clinician and participants goals as dimensions to the theme.

3.5.10 Rigour

Lincoln and Guba’s (106) criteria for trustworthiness was used to ensure a rigorous and valid study was undertaken. Credibility was facilitated through member checking at the end of each interview, audio recording of interviews and conducting numerous reviews of the transcriptions against the audio recording. Credibility was also ensured through the maintenance of field notes and prolonged engagement in the field to enable rapport with participants to be established. This allowed for the participant to feel at ease and for multiple perspectives to be collected and understood by Krefting (107). Methodological triangulation as described by Denzin (108) and Patton (109), in the form of checking the patient’s medical notes and planned procedure on the consent documentation against the interview transcriptions was undertaken. During analysis regular discussions were held between the study investigator and supervisor Fisher regarding the coding, the developing analysis and discussions, as deemed necessary, were undertaken with supervisors Webb and Litton to ensure interpretations made reflected appropriate clinical
understandings. This process ensured robust, comprehensive and well-developed findings.

An audit trail of decisions made during data collection and data analysis was maintained to enhance the dependability of the study. Confirmability was ensured through objective discussions with, and presentations of the evidence to, experienced researchers and supervisors during field work sampling and data analysis stages. Discussions around the transferability of the study findings to different settings and contexts were debated at this point.

3.6 Ethical Considerations

It was recognised that patients, particularly those who were eligible for this study, are highly vulnerable, in a dependent relationship, and may be anxious. It was highlighted at the time of recruitment that participation was voluntary and that the participants could withdraw from the study at any point and/or not answer any question that they felt uncomfortable answering. All prospective participants were informed that the decision to participate would not have any influence on their medical treatment and prior to excluding clinicians from the study, were informed that the study investigator may discuss the goals of treatment with their surgeon and intensivist.

The study investigator ceased an interview on one occasion as it was obvious that the patient was becoming very anxious and distressed. This was displayed through her body language and tone of voice. She had been electively admitted to hospital pre-operative for a work up for a vascular procedure where a HDA admission was planned post operatively. The main issue for her was she had not been spoken to about her surgery which was planned for two days after the interview. Because of the emotional state of the participant the study investigator decided to cease the interview and omit the interview from the study. The study investigator subsequently discussed the situation with the nursing shift coordinator and surgical registrar who counselled
the patient and informed her of the plan of care. The Senior doctor was unable to be contacted. To ensure that the issues had been effectively dealt with and to confirm that she did not require formal counselling and support, the study investigator returned to the ward the next day.

As part of the interview process, the study investigator routinely visited inpatients and telephoned the outpatients the day after interview to ensure that no concerns had arisen post-interview. On one occasion, on returning to a lady who had been waiting as an inpatient for cardiac surgery, a significant issue was discovered. Her surgeons had not been very positive about her chances of a successful outcome post-operatively but had still decided to continue with the surgery as she was insistent that it was in her best interest. She had confided in the study investigator the previous day that she wanted to have her operation as it was what her family would have wanted. However, the next day she disclosed that she had not seen her family in two weeks and felt they were avoiding her as they did not want to be involved in the decision making process about the upcoming operation. The study investigator spent substantial time with the patient discussing the situation and then referred her to the ward Clinical Nurse Specialist who arranged for the consultant to discuss this with the patient. It was reported back that the consultant contacted the family, arranged a family meeting with the patient and a decision was made not to proceed with the operation.

Prior to commencement of the study the study investigator met with the Hospital’s Aboriginal Health Worker (AHW) to identify special considerations that need to be taken into account when interviewing indigenous patients should they be included in the study. One Aboriginal lady was interviewed as part of the sample and in the study investigator’s assessment, the interview progressed in a similar manner to other interviews. However, a referral was sent to AHW to ensure that this assessment was correct.

Approvals from South Metropolitan Human Research Ethics Committee and Recognition of Existing Ethics Approval, UWA Research Ethic committee were obtained prior to the commencement of the relevant field work (Appendix 3.4).
3.7 Chapter Conclusion

A multiple exploratory case study approach, underpinned philosophically by post-postivism was utilized. It extended to several cases to explore the issues and to study the cases both for their uniqueness and commonality. Data were collected through interviews and information extracted from medical notes. Data were analysed in case initially by structural coding and across case using Tesch's,(105) approach of “decontextualization and re-contextualization” to produce three multidimensional themes and a rigorous study ensured through the utilization of processes described by Lincoln and Guba. (106)

At the initial stage of data collection, it became apparent that the clinician participation was going to be challenging and after various attempts and persistence to actively engage clinicians, a decision was made to ensure the project could progress, and through respect for the interviews already conducted, to revise the research aims to focus on the patient’s perspective. The study was undertaken in an ethically responsible manner ensuring that wellbeing, privacy, dignity and rights of the participants were respected at all times.

In Chapter 4 the findings of the study are presented.
Chapter 4

Findings

4.1 Introduction

The exploration of PCTG from a patient perspective is under researched as highlighted in the literature review. Little consideration has been given to what the patient expects or desires from their episode of care, whether these goals are patient centred with domains of feels/functions/survives and how the achievement of these goals is measured. No evidence is apparent on how and when the goals are set and who agrees that the goals are realistic and achievable upon which to base a schedule of care. This study set out to investigate these issues and in-depth interviews were conducted and audio recorded to consider what happens at the time the patient and clinician unite to discuss a future plan of care. As noted in Chapter 3, the interviews were transcribed verbatim and analysed. In this chapter, the findings of the research are presented.

4.2 Participants

Purposeful sampling was used to recruit patients (Table 3.1, Chapter 3). Twelve patient interviews were included in the study of which eight participants were male and four participants were female. The age of the participants ranged from 19 to 83 years old with a mean age of 62 years. Eleven participants were caucasian and one participant was Aboriginal. Three participants were under the care of consultant 04, two participants were under the care of consultant 01 and the remaining participants were under the care of different consultants. Twenty-five percent of the participants (AB, LM, GS) died within one month after their planned procedure. DL died 4 months and LW died 5 months after their planned procedure.
4.3 Findings

The Medical notes of each participant were reviewed post interview. The findings of this review demonstrated that no participant had a PCTG or PCTG type statement documented in their medical record despite having a signed consent form present.

Table 4.1 highlights the themes identified through the data analysis. The first theme related to the participants’ ‘Desired Outcomes’ and includes the dimensions of ‘Reasons for Access to Healthcare’, ‘Patient Goals’, ‘Trade-Offs’, the participants’ ‘Timeframe for Achievement of Goals’ and the ‘Participant Perception of Clinician Goals’. The second theme relates to ‘Information’ and incorporates the dimensions of ‘Information Given to the Participant by Clinicians’, The Manner in which the Information was Delivered’ and, the ‘Information Given to the Participant from Sources Other Than Clinicians’. The third theme related to the ‘Clinician and Participant’s Relationship’ that included ‘Participant’s Confidence in Clinicians’, ‘Shared Decision Making Between the Participants and Clinicians’, ‘Participants View on Clinicians’ Responsibilities for the Care of the Patient, ‘Participant’s Emotions Related to Upcoming Procedure’ and, Congruence Between Clinician and Participants’ Goals’ as dimensions to the theme.

Table 4.1 Theme and dimensions

<table>
<thead>
<tr>
<th>THEMES</th>
<th>Desired outcomes</th>
<th>Information</th>
<th>Clinician and participant’s relationship</th>
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<tbody>
<tr>
<td>Dimensions</td>
<td>Participant’s understanding of why they accessed healthcare</td>
<td>Information given to the participant by clinicians</td>
<td>Participant’s confidence in clinicians</td>
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<td></td>
<td>Participant’s desire to be involved in the goal setting process</td>
<td>The manner in which the information was delivered</td>
<td>Shared decision making between the participants and clinicians</td>
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<td></td>
<td>The participant’s goals</td>
<td>Information given to the participant from sources other than clinicians</td>
<td>Participants view on clinicians’ responsibilities for the care of the patient</td>
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<td></td>
<td>Trade-offs</td>
<td></td>
<td>Participant’s emotions related to the upcoming procedure</td>
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<td></td>
<td>The timeframe the patient considers the goals will be achieved</td>
<td></td>
<td>Congruence between clinician and participants goals</td>
</tr>
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<td></td>
<td>Clinician’s patient centred treatment goals</td>
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4.4 Desired outcomes

The ‘Desired Outcomes’ theme concentrated on the participants understanding of the purpose and desired outcomes of their current episode of care. The participants role and their views on the clinician’s role in the process is highlighted as well as the participants’ consideration of adverse health events as a consequence of their goal achievement.

4.4.1 Reasons for Access to Healthcare

The initial phase of enquiry explored what the patient expected or desired from their episode of care, whether these goals are patient centred with domains of feels/functions/survives. It was important to capture what had happened to the participants’ health that resulted in a requirement for accessing healthcare in the first instance. It was anticipated that this patient centred event would provide an understanding of the participants' thought processes related to goal setting pre-hospital. Participants engaged in an extended narrative about what had led up to this point in their life and what they hoped would be achieved from the episode of care.

Some participants focused on pathological reasons for being in hospital and having the operation, cited the mechanical reason of what was wrong with them and what can be done to treat and manage the underlying issues. Some patients had an in-depth knowledge of their condition and described what the surgeon had planned to do in great detail. For example, DL, diagnosed with a pancreatic tumour, discussed,

It is the combination of a series of events where I have a partial whipples and while that is going on they will be able to put, as there was an obstruction in the duct, stents in and all sorts of things, which leads up to the partial
whipples and they will be able to do tests while I am under the anaesthetics for something that they couldn’t do successfully.

Other participants relayed it in more simple lay terms. GS, diagnosed with acute coronary syndrome, stated, “Two of my tubes are blocked so they’re gonna do bypass on me”.

Other participants focused on how their current condition made them feel that forced them to seek help to relieve the symptoms. MC, diagnosed with coronary stenosis, explained,

Severe pain that I did not realise was cardiac in nature even though it was a classic presentation, tried numerous ways of relieving it with normal pain killers.

Many participants cited symptom reasons such as shortness of breath, pain and fevers and vomiting as the rationale for their reason for accessing healthcare.

Functional reasons were highlighted for being in hospital waiting for their operation. LW, an inpatient who presented to hospital with shortness of breath, did not discuss her condition per se but, rather, how it affected her everyday life and travel,

Apart from travelling, which we’ve given up the idea of going overseas again until this is fixed, because we were two weeks off of going back to America to family, when the leads snapped, that had to be cancelled. And America is not the place to be - I mean, our insurance, we lost three and a half thousand dollars on the insurance. It’s not a big issue for us to alter our lifestyle a little bit.
NC, who had been diagnosed with ischaemic heart disease, described how he loved playing golf and his health affected this and this forced him to seek help,

I play a lot of golf and so on the golf course, I would probably do 18 holes and five years ago, I started to get the emphysema, I thought, (this is) slowing me down, so I got a buggy with battery to pull my clubs, right? And eventually that was pulling me instead of me walking beside of it. You know what I mean? But I couldn’t hit as far. Well, you don’t as you get older. Anyway, again about a year and a half ago, I realised I couldn’t play much more with the buggy, so I got myself a ride on buggy. That got me around the golf course but even now when I go in a bunker, I find it hard climbing out of the bunker and I thought it was time to do something about it.

Survival was highlighted by one participant as a reason why he had accessed healthcare in the manner that he had. BW, who was an outpatient and was waiting for a date for his aneurysm repair, stated,

See, I have had to give up everything at home, put it that way, cause, if I put stress on myself, sideways, front ways, back ways, lifting, whatever and burst that aorta, the aneurysm, then that is the end of me. I will not bleed out, I will bleed in and that is the end of me. It seems that nobody cares about what happens to me. By the time that they find me I will be full of blood from my toes up to here [points to his neck] and my wife will have to deal with this and our life is buggered.
4.4.2 Desired involvement in Healthcare

A range of levels of involvement in setting treatment goals were apparent among participants. The interview process facilitated an in-depth understanding of the participants' views on their goals. It also uncovered the unique attitude of many participants toward their health in terms of taking responsibility for their current condition and engaging the clinician to identify suitable treatment options. A mismatch in level of desired involvement of their health problems existed between some of the participants. Some participants appeared to take responsibility for their goals and became actively involved in their care. DL, an outpatient, waiting for a major operation, felt out of control and his way of resuming some control was by learning about his treatment and actively managing his preparation for his operation and his life afterwards. However, this was visibly stressful for him and when his wife tried to add comment or clarity in the interview, he snapped at her as if to emphasise that it was “his life” and he was in charge!

DP, an inpatient waiting for a cardiac bypass operation, demonstrated a desire to be involved in goal setting, by engaging the clinicians and seeking honest information about her prospects. The clinicians told her openly that she would not survive the operation and she acknowledged that she “likes honesty and bluntness”. However, she ignored the expert opinion and aligned her goals “to prove them wrong”. The clinicians did not attempt to dissuade her and she remained on the theatre list.
The way GS, diagnosed with acute coronary syndrome, got involved in her care and goals setting, was to know the physiological issues of her condition and she developed an in-depth understanding from talking to people,

I asked a lot of questions and (about) exactly what's gonna happen (to the doctors) And you have to break it down and tell me. And I had my husband with me. I had our pastor and I had a sister-in-law. And there's three that's telling me – One of the doctors is just telling me all that. Then the next day one of the cleaner men came and he told me [about what was going to happen].

This helped her cope with the anxiety, feel in control and empowered.

Some participants appeared completely disinterested in the process of goal setting and assumed no responsibility for their condition and treatment. This view appeared more predominant in some of the male participants. For example, NC appeared to lack interest in the upcoming operation, the criticality of it, the potential complications and highlighted that he does not really care what they are going to do “as long as I survive”. He compared accessing healthcare for the treatment of a condition to getting on a bus to reach a destination, “you don't worry about whether the bus driver will crash or they are skilled enough, it's expected. Same here”.

AB, in hospital waiting for a complex vascular procedure, let his wife do most of the talking in the interview and this did not seem to concern him as the experience was difficult for him to comprehend. His wife highlighted that they could not get involved (in goal setting) as “the choice was made for us but we are informed about it”. Yeah, it's out of our hands but in a good way”.

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LM, who was diagnosed with aortic stenosis, did not appear to take any interest in his situation,

The good thing is my wife, being a nursing sister in orthopaedics, there’s not much she doesn’t know about this thing and she has a good relationship with the nurses and she relays it back to me in really simple ways.

4.4.3 Patient goals

The participants’ goals were further explored to bring the focus back to what they anticipated may improve for them after their current episode of care. Their medical history and the circumstances leading to their current condition and what their expectations of surgery were discussed in terms of survival, function and symptom control.

Survival, as a possible expectation would be considered a priority for most and some emphasised this immediately when asked what their goals were. DL, who was extremely knowledgeable of his condition and of his plan of care simply answered this with a one word answer, “Survival” and did not speak for almost two minutes after this answer. DP stated that survival was the only thing on her mind and she “cannot think beyond this at the moment”. MM, diagnosed with carotid artery stenosis, on answering how life will be different for her stated “I do not know and I am unable to focus. I feel like a walking time bomb and just want to get through this”. Similarly, ‘survival’ was the most important thing that MC, wanted to achieve but was not confident that this would happen suggesting that “one operation will lead to another”.

Most participants highlighted their expectations of an improved functional performance leading to a better quality of life. In some cases, the participants cited improved function rather than survival as their primary goal despite survival being a pre-requisite for better function and quality. Others required further discussion and exploration to move their thought process away from the survival goal to other relevant goals. BW stated,

I want to do my house work and my lawns. My wife and son do the lawns now and that is a kick in the arse to me. They [lawns] are still good but I was known as ‘king of the lawns’ in Killarney. I used to do my own handy work but now I just can’t do it. I have no strength in my fingers or hands and I can’t lift the top off a jar. If it doesn’t allow me to get back to what I was doing, then I will just live this life out.

AB’s goals were to:

Be able to function as normal — without having any sort of hiccups or taking medication or that sort of thing, probably, just being able to have a decent life for the rest of it. To me (with) less complications.

The most important aspect for LW to achieve following the operation was to travel like she used to, but was not confident, “if this [travel] may not be possible, I am happy to take what I get.” PJ, diagnosed with ischaemic heart disease, had a personal goal of “being able to help his wife in the garden more as well as being able to work another 15 years and not to rely on other people.”
GS, who had a stroke in the past and is unable to walk far distances would like to feel better, to:

Be able to breathe easier to allow me to talk, sing and play with my grandkids and I can be able to go and sit down with people. And go walking out to the bush and do the things that I used to do.

And she was confident that her cardiac operation would enable this to occur despite the fact that her stroke has permanently restricted her mobility.

4.4.4 Trade-Offs

A trade-off is an aspect of their health that the participants would accept a deterioration in to achieve their most significant goal. Most participants (described below) either had not considered, or did not want to consider that there may be trade-offs that they would have to adapt to. DL, however, knew that this was a strong possibility following his surgery:

I know life will be different, how much, I am unsure but I know if I do not have this operation, I may not survive. So I have to take this punt and put up with whatever consequences. Our focus is to make sure that there is no cancer and to get rid of the cells that may cause cancer. I cannot think beyond that.
He went on to say how he had planned to deal with the expected trade off,

A member of surgical team made an appointment with Dr 10 in West Perth. He is a diabetes specialist so we spent an informative ¾ of an hour and he talked me through the whole deal. Showed me how to give an injection and I gave myself an injection. No problem with that. The hardest thing is trying to learn how much insulin that you are going to use and when. That is just something that you learn. I will probably be carting a little book around myself for a while and then you just know (what the correct dose is).

Discussions about trade offs, side effects and complications, is a standard component of the consent process and should have occurred for each participant (prior to this interview being conducted). Most participants, however, believed that their operation would cure everything and had not considered that they may have to make some ‘trade-offs’. For example, GS was “not interested in thinking about what could go wrong I don't want to talk about it”. JC, an outpatient waiting for spinal surgery, stated

Everything is good at the minute but I now need to get it fixed. So to fix one thing that results in another problem developing would be pretty bad. I would have to think about it. Is that what is going to happen?

BW was singly focused on actually having his surgery because “the operation has been cancelled so many times, I am just focused on getting it done”. PJ did not want to consider the potential that there may be adverse outcomes and had not discussed the possibility with his surgeon,

It (the thought of something going wrong) wouldn’t stop me from having the bypass because I wouldn’t know until the bypass had been done whether I had to go on to medication that'd make me woozy.
Some participants adopted a ‘wait and see’ attitude. For example LW noted,

I am happy to wait and see what happens and then deal with the consequences. This happened before when I first got heart problems, I used to exercise but then could not do it, gave it up and did something else.

NC, however, would have preferred not to have the surgery if it affected his lifestyle:

If having the op affected any of my lifestyle afterwards I would not have it, I would just carry on as is and wait until death happens.

4.4.5 Timeframe for achievement of goals

The participants’ expectation as to when they should achieve their goals was a point of discussion during the interview. It was not clear how some participant came up with the timeframe but there was a variation in responses.

Some participants discussed the potential time that they should expect to achieve their goals with their clinician. DL’s wife recalls,

It’s a little bit hard to say. I have heard anything from 9 days to 2 weeks (from the clinician). When we saw him [surgeon] last week, he threatened a week and I was quite uncooperative about that. They [the hospital] threw him [DL] out after a week last time and I had to get him back again. It was too soon. I had to get him back again and it was awful.
DP received different guidance from two senior clinicians with regard to her stay in ICU that will have an impact on the time her goals will be achieved, “the cardiothoracic surgeon says 8 weeks in ICU, ICU Doctor says 2 weeks,” this is when I hope to start achieving my goals”.

The other participants were unsure when their goals would be achieved. GS stated, “I do not know when I will achieve my goals but, this is not important to me”.

4.4.6 Participant Perception of Clinician Goals

This dimension centred around participant’s views on what their clinician would like for them to achieve as a result of the surgery. The participants offered some insight into how goals setting occurred or did not occur between the participant and their treating clinician.

DL reported that the goal setting discussion he had with his surgeon was effective,

I asked him [clinician] to be blunt and open and not to mince his words. Just say what the story is and he has, which is all that I expect. I don’t want anything wrapped up in pink tissue paper and presented to me in a ribbon. I just want to know what is going on (and that is what I got). He told me the operation will prolong my life but to what degree I don’t know. There is the outside chance that pancreatic cancer would develop, however, given the scope of experience of the surgeon and his team, his advice is to do it or I will definitely die. You don’t ask for advice if you don’t want to take it.
MM recalled the goal setting conversation with her doctor,

He did a lot of talking, told me he was going to unblock my carotid. He didn't really ask me what I wanted, he told me what he was going to do. I did not know there is a high risk of stroke.

DP stated that her surgeon was extremely blunt with her,

He told me I would not die on the table but would die in ICU. He said I was old, fat, and had lung problems. He didn't want to do the operation, but I insisted and in the end, (he) gave me a date.

AB’s operation was complex and required coordination among four specialties. He did not have a discussion with the lead surgeon about what he wanted and when it was discussed with him, there was so many people in the room that he considered it intimidating and confusing,

I think the choice was made for us [his wife and him] but we are informed about it but don't really understand it. I think it’s out of our hands at the moment because we’re not capable of saying anything else.

LM stated that “my doctor wants to give me a longer life”. However, he had not seen or had a discussion with a senior doctor at the time the interview was undertaken but made the judgement around what he thought the surgeon wanted for him.

NC reported that the surgeons were unsure what they were going to do and this did not fill him with confidence. They have, however, told him that he will be able to play golf again in three or four months’ time, “I believe in these chaps when they say, “We’ll get you right, but it may take three or four months”.
Other participants reported that they were unsure of what their surgeon would want for them as they have not seen them. For example, PJ had been in hospital for seven days prior to the interview and had not seen anybody involved in his operation. Similarly, LW reported, “In the seven weeks that I have been in hospital, I have not seen the consultant that will be doing my operation”.

BW felt as if his surgical team did not care as he had not spoken to a senior doctor,

It’s like talking to this (hits the table) I have only seen a surgeon once and I do not know who this second one is going to be. It is always not the same one twice, It seems that nobody cares about what happens to me.

MC who also had not seen the doctors was quite disparaging of the intent of surgeons,

Doctors don’t give a rat’s arse: you may be just a slab of pork on the table. It’s (the operation) not that important to them, it’s not just a big issue, you know, why are they complaining. If (it) affected them like it affects the patients then all decisions would be mulled over for sure.

4.5 Information

One of the most significant themes that emerged from the data was information. As noted previously, this theme consisted of a number of dimensions that included information given to the participants by clinicians, the manner in which the information was delivered and information given to the participants from sources other than clinicians.

4.5.1 information given to the participants by clinicians

The patients, when recalling the conversation about their plan of care with their clinicians, identified that much of the dialogue was around the process of resolving the presenting problem with a focus on the technical aspects of
what the surgeon was planning to do. The patients’ narratives suggested that
the medical staff had explained the medical issues sufficiently enough that they
had a good appreciation of the upcoming procedure and what was likely to
occur.

LW explained,

They told me it’s a matter of having to take the valves out. They're not working, they won’t work. And the pacemaker
has to come out. They want to replace the valves with tissue and the pacemaker, they’re not sure yet whether to
do the external thing. But it's still gonna be metal going in some places.

GS required a different approach to help her understand her condition,

Well, I was so confused when they told me about my heart
operation. I said “if only you bring me (a) resource like – a
heart thing over there” (points to a drawing of a heart on
the whiteboard). So, that demonstrates what they're
talking about so I can know about it.

BW highlighted his interaction with his surgeon where the surgeon told
him what he was going to do but this made no sense to him,

Well, this is all that he [the surgeon] has told me. I have
only seen the surgeon once and I do not know who this
second one [surgeon] is going to be. It is always not the
same one twice. He has tried (accessing the) right and left
(artery) in me legs and now he says he is going to try it
[accessing the artery] through the left arm. Now that
sounds bloody ridiculous in my way.
NC, even though he was given similar information to LW and GS, found the information he was given was not consistent with the plan,

I only met the surgeon once and he focused on what he was going to do in the operation but nothing about how it would affect me. He said he was going to do two bypasses but then he sent me a letter saying it was going to be four.

Some clinicians, as well as discussing the medical issue with the patient, went on to provide the patient with information on how this was going to affect their life and lifestyle. For example, JC reflected on the impact of his surgery on his mobility,

He [clinician] has gone through what he is going to be doing and I am seeing him again tomorrow actually. He told me exactly what he is going to be doing. I am not going to be able to ride my bike or drive for two months and that sort of thing, no heavy lifting - not that I do much of that anyway. He has gone through a few of the risks and I have talked to the anaesthetist today about this.

Some patients, however, had minimal discussions with the clinicians and the information that they received was limited. MC was not aware of his clinician’s plan,

I have been in hospital for 11 days and no one is able to tell me when I will have this operation or the likelihood that I will be discharged. You have told me that my operation is scheduled tomorrow and that is the first I have heard of this.
PJ recalled a similar experience,

He [surgeon] hadn’t said anything about that at all. He said, “You need a bypass”. That’s it. End of story. As long as they can find enough veins and the lungs are sufficiently mobile.

And went on to describe the occasion when he was misinformed by the junior medical staff.

Well, so I haven’t met the one that’s gonna do the bypass, so that doesn’t matter. I mean, so far, I’ve been seeing registrars and residents, ………… and I’m confused. I mean, well, to give you an example, this afternoon, one of the, I don’t know whether it was a resident or a registrar, ………..one of the team came to me and said, “Oh. Look, it’s interesting about your operation tomorrow, which was what I was told a couple of days ago”. And I said, “No. I don’t think that’s right.” One of the nurses just said to me it’s gonna be postponed, not on the list. And so, she went back and checked. And then another doctor come in, “Oh, no. You are not on the list, you are back on Monday’s list.”

On one occasion, a participant had a conversation with two senior clinicians, involved in her care, that resulted in the participant receiving information from different view points., DP recalls this experience,

Well, 02 [a surgeon] said, “You’ll be eight weeks in intensive care” and doctor from intensive care called and he said a week in intensive care, we’ll take care of you, we’ll get you out. We’ve got worse than you. I will, we’ll be right”. And I said, “Wow! Just a week. RL said eight” and he said, [the intensivist] “Well maybe two.
4.5.2 The manner in which the information was delivered

While the content of the information given is extremely important, the method by which it is delivered is also important and facilitates patient understanding and a functional patient and clinician relationship.

JC felt totally at ease with his clinician and the information that was being provided,

He is such a nice guy, (pause), he has obviously got a job to do and I do not want to sound so cynical but he gets paid to fix people. He does do everything for the benefit of the patient and I think that he genuinely cares.

AB, however, had a different view of the information exchange. He felt that it was conducted through his wife as she was a nurse,

I don’t know really [about the procedure the doctors are planning to do]. They [surgeons] haven’t sort of said a great deal or what it entails or to sort of do afterwards, (but) obviously to stay fit and all the rest of it. They usually discuss things with my wife.

The participants reported that they felt uninvolved, disempowered and disrespected that other people were making decisions about their care and their opinions seemed immaterial.
PJ and MC identified some areas that the communication process is not as effective as it could be. PJ recalled,

I mean, well, to give you a good example, the operation was gonna be tomorrow, originally. Doctor came in and then said, Oh. Look, we’ve got to change it. Now, immediately I think, “well, what do I – what’s wrong with it that you can’t do it just now?” And he said, “No. It’s ‘cause you got bumped. Basically there are some people in here that are more urgent”. This is understandable if someone told me, as to, when I have to explain it to my friends and wife, that’s where the problem starts. Because I’m not informed, I can’t tell them and that makes them…[gets upset].

MC identified an occasion in his experience where he observed an interaction between a patient and a senior clinician,

I have seen others [doctors] with the blokes opposite. He walked in and must have spent one-second and shouted “no drip” and walked out. He didn’t talk to the patient or he didn’t talk to the woman in charge. That was the worse example. Mine is pretty good but all he does is look at the chart and modify medicines and that’s about it. To be honest he is the best that I have see, ‘cause he spends most amount of time chatting to you, he does chat to you, but nothing about surgery? I suppose if you ask questions, but he does not spend that much time.
4.5.3 Information given to the participants from sources other than clinicians.

This dimension highlighted the alternative avenues where participants received information about their upcoming procedure. This was identified as important to participants with some being very effective in utilising the resources around them.

AB and NC received health information from friends who have had similar conditions. As the information had come from a patient perspective, it was trusted and was given using language that was understandable and meaningful to the participants. For example, AB stated,

Friends at work have told us about something similar that they have been through and basically just, I've sort of taken in what they had to say, and sort of made for ourselves which are more important ones (goals) to sort of do, rather than leave out. It worked for me, this sort of thing.

NC explained,

Well, I got a friend of mine who has had a double bypass himself, who I called when I was getting unwell and he told me go to hospital straight away 'cause if I don't I will be in an ambulance'. He tells now what is going to happen to me over the next few weeks and after that.
GS had an unexpected discussion with a hospital cleaner who had previously had the same operation and found that quite useful. While he was cleaning her room, he noticed the drawing of the heart on the whiteboard. GS recalls,

That's my picture, picture of my heart. And he tell me, “I'll show you something.” He lifted up his shirt and then he showed me. Well, he had this bypass too. And then he showed me where they took it out from there and from the leg. And he said, "You go, not with your mind, you go with your heart. And you'll come back with that heart." And that little picture made me stronger.

PJ and LM considered that nurses were the best for giving information about their condition. However, this is not universal as not all nurses are able to do this effectively and, according to PJ, you have to carefully choose your nurse,

And some of the doctors don’t have the bedside manner that the nursing staff do. When I got to know some of the nursing staff, they were forthcoming because they knew that — they instinctively knew that it was useful (information) for me, whereas some of the doctors tend to talk down to me. The nursing staff that I’d been able to get that information (from), by asking questions, have been brilliant, (but) it took me a while to find the right ones.
4.6 Clinician Patient Relationship

4.6.1 Confidence in clinician

In the interview I enquired whether or not the participants had confidence in their clinician which created much discussion. Participant views were widely divided depending on how much contact they had with their clinician.

A number of participants had a high level of confidence in their clinician. DL, for example, who was scheduled to have a major operation with a high complication rate reflected on his belief in all members of his surgical team,

This [the operation] is not something that we would have chosen but we have enormous confidence in the team and should things not work out the way we want them to it won’t be because of mistakes. Last time there was no way that we could have predicted that the cells would be found in the tail and all the time before we’re looking at the cyst in the head. Things happen, shit happens and you can’t prevent it.

Whilst DP held differing views about her operation to her clinician, she had great faith in him, “he is arrogant, I know, but he is still the best.” This confidence remained even for many of those participants who had limited contact with their clinician. For example GS stated, “I know they are good at what they do and I got faith in the lord”. NC was also very confident in his clinician even though he had not seen him, “Very confident; very, very confident. Well, you just believe and that’s what I think.”
LW, however, was unsure whether she had confidence in her clinician as the discussion around her care left her with some doubt,

Well I was not sure whether I am or not (confident in her clinician) because they were more or less saying, “No. Well, it’s gonna to be a long procedure and it’s a tricky one”. So it’s things like that that stuck in my mind, were they confident? But there’s this one particular doctor who comes and he seems to be pretty confident so far. God! But whether they are head ones (surgeons) or whatever, until it happens, it happens.

Not only did BW not have confidence in his clinician, he also lacked confidence in the healthcare system as his operation had been cancelled on a few occasions. BW perceived that the stress was making his condition worse but he felt the surgeons did not care about this,

I went in to see them twice and they said they were going to cut here and here on this day and that and 2 or 3 days before I was supposed to go in they sent me a letter or a phone call saying the operation was cancelled again. They have put a cancellation on it again. That why I have been waiting until this time. I tell you what, mate, if they cancel it again they can shove their operation up their arse, pardon my French. I will forget about all of this and I will persevere with what I have got. If it bursts, then its burst.
4.6.2 Shared decision making

The participants varied in their approach to decision making with their clinician. DP’s clinician did not want to proceed with the operations due to his view on the futility of the treatment,

“You’re not fit enough, and you’ll die. You don’t die on my table, Nobody dies on my table. Five in ten years have I lost on the table. You’re not dying on my table,” he said, “but you’ll die in intensive care”.

However, DP was very insistent and clinician ended up agreeing to operate,

He said I’ll die.” I said, “I’ll show him,” …….. But it’s more than that. ………, “I'll get better and say thank you.” …….., “I’m really grateful.

LW, took a very passive role as she felt that clinicians are powerful and she felt that she was unable to challenge them as she does not have the medical knowledge (to challenge). AB’s approach was also passive and was not part of the decision making and “does not want to be part of it and is happy for the clinicians to take control of it”. He has not been given an option and happy with this.

MC was angry about not being involved and felt that he was not part of the “pow wow” that make decisions on the plan of care for the patient so they never know what the patient actually wants, they tell him what he gets. Lack of information while he was in hospital causes him to be extremely frustrated about the place. He was transferred from cardiology to a cardiothoracic ward six days prior to the interview and no one has told him why. It feels like prison to him and he lacked direction about what to do and not to do,
The main problem here is that the patient is not part of the pow wow that happens at the nurses’ station with the doctors and the nurses sometimes. So there is secret information that is squirrelled away that the patient isn’t important enough to know. That bloody information might be crucial to the patients success and they might say “let’s do a CABG” and the patient might say “I don’t want a CABG”, who knows cause the patient has not been asked or whatever. That happens every single time.

4.6.3 Clinician responsibility for patient care

It was clear from the interviews that participants had a range of perspectives on the responsibility of clinicians in setting patient centred treatment goals or for their treatment in general, evident through their narrative and the language they used. LW did not consider the clinician as part of the goal setting process or responsible for preparing her for any complications as a result of the surgery. GS felt the clinician has no responsibility for her care and treatment, “It’s down to me for getting in the condition that I am in”. NC concurred “if it gets done, fine, if it doesn’t, I will have to live with it”.

However, unlike other participants, MC felt the clinicians have a major responsibility for the healthcare delivered to their patients,

They treat it [cardiac surgery] like a conveyor belt because they conduct so much of the same surgery, they minimised the importance of it for the patient and underestimate how the patients feels about this. Clinicians need to realise that each patient is having this for the first time and their anxiety is high.
4.6.4 Congruence of goals

As highlighted in some of the findings above, when the participant and clinician have come together, to discuss the patient centred treatment goals, it is important to understand whether or not there is congruence between them. Some of the participants discussed their goals with their clinician, however most didn’t and others were informed of the plan without discussion. DL and DP had contrasting views on this particular aspect of their care. DL acknowledged that he has,

This [the operation] is not something that we would have chosen but we have enormous confidence in the team and should things not work out the way we want them to it won’t be because of mistakes. Last time there was no way that we could have predicted that the cells would be found in the tail and all the time before we were looking at the cyst in the head. Things happen, shit happens and you can’t prevent it.

DP, however, was not congruent with the clinician with what each party wanted to achieve. DP recalled the conversation with the clinician,

“You’re too old, you’re too fat, you got lung problems” This, that and the other. “You’ll die”………..Then he said “it’s too dangerous, I’m not doing it [surgery]”, But I was determined and he eventually agreed. He’s arrogant and he’s horrible but he is the best (surgeon).

4.6.5 Emotional response to upcoming procedure

It was evident in the interview process that the participants were experiencing various emotions related to their wait for surgery, the potential outcome of their procedure and communication issues. DL was very much in denial about his condition and coped with this by focusing on the process and how he will have to adjust his life afterward. When the study investigator
mentioned “cancer”, it caused him to go from calm to rage instantly. In the end, he acknowledged “Basically you are taking a punt, it may not develop but the chances are that it will, so out it comes. There is no safe option.”

GS journeyed through a range of emotions during the course of the interview. She was unhappy and sad because of the effect her condition has had on her as she is unable to sing at church, go out bush, hunt, fish, cook and play with her grandchildren. She now regrets that she did not spend more time with her grandchildren when she was well. When asked how she was at this particular time, after much thought, she admitted that she was scared as “I don't really know what is going to happen.”

MC learned that he was going to have his operation the next day from the study investigator so he initially had an overwhelming feeling of anxiety. He had been in hospital for 11 days and had witnessed deaths and discharges and he was feeling low as he was unsure of the plan of care. The information that he received from the internet and other patients caused extreme distress as he imagined all sorts of eventualities. PJ expressed frustration and lack of confidence in what was going to happen to him. He stated that this feeling had got better over the last week as the nursing staff had provided him with some reassurance. He again expressed regret on how he was unable to help his wife more and stating that he hoped to work for another fifteen years after his operation.

BW emphasised that he had lack of control in his life. The waiting was causing him to become very stressed and angry and he felt to powerless because of it. He had always been independent and this condition had forced him to become dependant. His condition had stopped him walking, and doing his garden. He feels useless because his wife and son had to do it. LW felt completely disempowered and insignificant. His wife is a nurse and everyone talked directly to her, ignoring his feelings and needs.
4.7 Chapter Conclusion

The purpose of this chapter was to present the findings from the patient interviews that aimed to explore the concept of patient centred treatment goal from the patient’s perspective. Three themes were identified from the data analysis and, although the themes were interrelated in complex ways, they were presented discretely here for clarity purposes.

The first theme was participant’s ‘Desired Outcomes’. This theme was multidimensional describing the participant’s journey through healthcare, the participants own particular goals and the goals of their clinician’s for them. The participant’s desire to be involved in the goals setting process and the participants views on trade offs was reported. The second theme was ‘Information’ and included dimensions of ‘Information Given to the Participant by Clinicians’, The Manner in which the Information was Delivered’ and the ‘Information Given to the Participant from Sources Other Than Clinicians’. The final theme incapsulate the ‘Clinician and Participant’s Relationship’ and included ‘Participant’s Confidence in Clinicians’, ‘Shared Decision Making Between the Participants and Clinicians’, ‘Participants View on Clinicians’ Responsibilities for the Care of the Patient, ‘Participant’s Emotions Related to Upcoming Procedure’ and Congruence Between Clinician and Participants’ Goals’ as dimensions to the theme.

In Chapter 5 the findings will be discussed in detail and placed in the context of the research aims and the current body of knowledge in the area. Their significance, value, or meaning will be highlighted and recommendations for clinical practice and further research will be described.
Chapter 5

Discussion

5.1 Introduction

In chapter 4, the data collected from the patient interviews, that aimed to explore the concept of PCTG from the patients’ perspective, were defined, described and categorised into three themes. The first theme related to the participants’ ‘Desired Outcomes’ and includes the dimensions of ‘Reasons for Access to Healthcare’, ‘Desired involvement in Healthcare’, ‘Patient Goals’, ‘Trade-Offs’, ‘Timeframe for Achievement of Goals’ and the ‘Participant Perception of Clinician Goals’. The second theme related to ‘Information’ and incorporates the dimensions of ‘Information Given to the Participant by Clinicians’, ‘Information Delivery’ and ‘Non Clinician Information’. The third theme related to the ‘Clinician and Participant’s Relationship’ that included ‘Confidence in Clinicians’, ‘Shared Decision Making’, ‘Clinician Responsibility for Patient Care’, ‘Congruence of Goals’, ‘Emotional Response to Upcoming Procedure’ as dimensions to the theme.

In chapter 5, the intent is to assign significance, value and meaning to the findings in relation to the research aims and the existing literature in the area. The discussion is presented by addressing each research aim and summarizing the findings in relation to each. Interspersed with this, the findings will be positioned and discussed in terms of the available literature including how the findings confirm or, alternatively contribute to the literature. This original contribution made by the findings will be highlighted through emphasising where the work is different and how new knowledge generated from the research study has filled a gap in the current literature.
5.2 Research aims

The study aimed to explore the concept of the setting and measuring of PCTG and to highlight gaps in routine processes to promote better and more collaborative decision making to ensure the patient is receiving the right care, at the right time and in the right way. Participants in the study were adult patients undergoing an episode of care involving non-emergency surgery for which admission to the ICU or HDU was planned.

Study aim 1 was to describe the goals of treatment specified by the patient and determine if these goals were patient-centred. Participants cited a variety of goals that included mainly non-PCTG and some PCTG. The non-PCTG specified mainly their physiological or technical issues for having the procedure, such as aneurysm and blocked coronary artery, and how the planned surgical operation will alleviate the issue. The participants that expressed PCTG did not display any patterns to the way they initially cited and prioritised their goals. The goals were expressed in lay person terms that were categorised to the domains of patient’s centredness. One participant, who had high level of anxiety, did express survival, a patient centreness domain, immediately as his main goal as he felt that this was all he could focus on at this time. Aspects of symptom control were the most common PCTG identified by the participants with specific desires to alleviate pain, breathlessness, fevers and vomiting. These participant were inpatients and were admitted to hospital for investigation of their symptoms and as a result of the investigations, an operation was scheduled and as their condition was not stable sufficient to be discharged home, they were required to wait in hospital for their operation. Functional reasons proposed were to travel and to play golf by two participants who were clear what their priorities in life were and saw this episode of care as a means to facilitate this with little desire to know the details and specifics involved to achieved their goal.

The participants’ ability to specify PCTG appeared to be dependent on their condition and emotional well-being. The participants whose condition was stable at the time of interview and had been in hospital waiting for their procedure appeared to be less anxious and more confident. This could be
attributed to the fact that should, their condition deteriorate, immediate help was on hand. These inpatients had time to think about their procedure, listen to other patients’ experiences and the opportunity to discuss their condition with a healthcare professional that facilitated their ability to focus about what they wanted to achieve from the procedure and hospitalisation. Alternatively, those participants recruited as out-patients appeared to have a higher level of anxiety and did not elicit the same sense of feeling safe and in control, making it difficult for them to identify goals. This could be related to the uncertainty whether the procedure will occur or be cancelled and their focus was more survival-related.

Even though the participants were able to identify their goals, either PCTGs or non PCTGs, for their episode of care, the majority appeared to be hesitant to answer this question. It was anticipated that the participants would, at this stage in their surgical plan, have had the opportunity to consider what their goals were, have had a discussion with their clinician and could confidently and reliably state them. In addition, their clinician would have informed them through discussion and the consent process, what the potential achievable goals for them were and in turn, the participants would be aware of their goals. This, however, was not the case, as some of the participants approached the question as if it was the first time that they were asked about, and had considered, their goals. This brought into the question the reliability of their answers as it was uncertain that similar responses would be received if the interview was repeated at a later date and time.

Study Aim 2 reviewed the non PCTG obtained in aim 1 and determined whether the participants, with appropriate assistance, could specify treatment goals that are patient centred. Most participants were able to identify and expand on their PCTG but this did not come naturally to them. Additionally, the concept of asking what they wanted as a result of their surgery was alien to some. In order to explore participants’ ability to identify PCTG, if they were not stated initially, participants were prompted through focusing on how they wanted their life to be different rather than use of the patient-centredness approach. Having an understanding of, and coaching about, what PCTG means in lay terms, as well as being able to accept their illness, appear to be critical factors in successfully identifying and setting PCTG. Most participants were able to
elaborate on their goals further and some participants who, at first, could not identify PCTG were able to acknowledge what they wanted to achieve out of their episode of care. This remained the case even for participants whose goal was survival. For participants who were able initially to identify PCTGs without prompting, it became apparent that their level of understanding of the goals was limited and greater exploration was needed to extract what goals were valuable and meaningful for them.

The literature under review concurs with the finding that patients can if provided with the correct support and information, identify and participate in deciding their patient centred treatment goals (71) but this depends on the methods used to document the discussion and goals, the manner in which the clinician delivers the message and the evaluation of the patients understanding. (69). It was identified through audit in the pre-intervention phase and the literature that there is a lack of a systematic and widely validated approach to documenting PCTG. Studies reported that action plans and goal setting tools designed to document and measure PCTG were evaluated positively by clinicians who planned to continue with their use post trial. Nevertheless, in this study, when the patient’s medical notes were searched to look for evidence of goal setting or goal discussions, no use of action plans or goal setting tools or other manner of goals setting documentation was found.

The study findings highlighted the manner in which information was delivered by clinicians, with some participants being extremely content with the clinician’s style and approach with one clinician spending time with the participant, arranging second opinions to validate the plan and organising early post-operative diabetes education. Others stated that the process was not as effective as it could be with some participants dissatisfied on the way this occurred, emphasised in one situation when a participant’s contact with his clinician was limited to such a degree that he was unaware when his operation was scheduled. Again, how the participants reacted to this varied with some appreciating the bluntness and arrogance and some disgruntled by the clinician’s bedside manner. Information about the clinician’s style and approach to goal setting was not discovered in the literature under review but in one study the participants commented that they would find goal discussions embarrassing
with a clinician that they have not developed a trusting relationship with (71). The literature seems to be at the stage of considering how goals discussion might occur, whereas the current study has reflected on what and how discussion has happened in clinical practice.

Participants’ understanding of their goals was not explored in depth and would have benefited by further investigation. On further exploration of the PCTG that were identified initially, it was apparent that the participants did not fully comprehend the goals and when provided with more clarity, one participant changed his goals. A prime example of a disconnect in understanding of what goals would realistically achieve was demonstrated when one participant was convinced that her limitation in walking due to a past stroke would be resolved with the upcoming cardiac surgery. Similar cases were reported in the literature as 13.8% of patients with incurable cancer, in a study undertaken by Burns et al (87) did not know their condition was not curable and 6.8% considered that it was curable. To fully understand goals it is important to accurately appreciate the risks as this will inform decision making and future plans. MM was convinced that she had a high risk of stroke following her carotid endarterectomy, when in reality the risk of stroke is probably around one or two percent. Whether this risk is high or low is for an individual patient to decide, but views could be attributed to lack of understanding that could easily be resolved by further discussion.

Patients should participate in deciding their PCTG to the degree of their desire and capability (71) but require the correct support and information to do so. Could add in a section about patient wanting to set goals. Some of the participants were not content with the information that they had received from their clinician, due to its quality or that it did not come from a senior decision maker so information was sought from other sources such as family, friends and other patients. One participant received what was perceived to be extremely beneficial information from the ward cleaner, who had previously had cardiac surgery and the participant found that listening to his story and advice was more beneficial than the majority of the information that she received from the clinician. Participants spoke with confidence about this information acquisition method that was pitched at the right level for them and felt comfortable in
seeking further clarification. This is different to their recollection of clinician encounters as some felt that they (the clinicians) were too “powerful” to be challenged. The practice of patients seeking information from non-clinicians is a practice that constantly occurs and this is extremely useful in providing clarity to the information that the clinician provides that in turn will increase the patient’s confidence and encourage their involvement in shared decision making and goal setting. However, some patients are better at this than others and the quieter patients miss out on this opportunity. The challenge for healthcare workers, therefore, is to somehow harness this information source, develop a process to ensure the information is accurate and contemporary and make it available for all.

The current study focused on the real time goal setting encounters and experiences of participants at the start of their episode of care, at a time where the participants were at their most vulnerable, their future unknown and coming to terms with their illness or system challenges. This created a heightened sense of anxiety and stress for the participants. The focus of the study was on their highlighted goals that are valuable to them and their relationships with clinicians to develop and agree the goals. The resulting rich data gave a contemporary, detailed insight into the personal, interpersonal and systemic issues that the participants faced when accessing the public system for an elective procedure. The reviewed literature differs to the manner the current study was undertaken as little consideration has been given to the actual goals that patients have set, how the patients have expressed their goals, whether or not these goals are patient centred and how their achievement is measured. The reviewed literature offers no evidence on the goal setting process to develop goals upon which to base a schedule of care. The majority of the literature (78, 71, 53, 69,60,57) looked retrospectively at the process and included participants who were at the end or completed their episode of care which could bias the value of the findings. This study is original in its approach and differs significantly to past approaches and assists, to some extent, alleviating the identified gap in the reviewed literature by providing new knowledge to assist patients at a crucial time on their healthcare journey that could have a significant impact on their outcome.
Study aim 3 described the concordance between goals that were specified by participants and treating clinicians as understood by the participants. At the start of the episode of care, it is essential that all people involved agree on the way forward to achieve the most appropriate outcomes. In the case of healthcare, agreement should be between the patients (expert about themselves) who are aware of their goals and the clinicians, (experts on what can be achieved by healthcare) who have the responsibility for offering to explain to the patients what they (the clinician) would regard as the potentially achievable goals and the risks associated with the achievement of these goals. The literature promotes this shared decision-making approach as a means to assist patients take an active role in their healthcare decisions (47) and acknowledges that the elevation of patient involvement will lead to a reduction in decisional conflict between clinician recommendations and patient preferences and improve treatment compliance as a result of the better understanding and agreed expectations (51,50). Involving patients in decision making was not a routine finding in the study with some participants feeling extremely frustrated as a result of this while other participants were accepting of this as they felt they did not have the ability to challenge the clinicians. For some participants the process of goal setting with their clinician was very much being told what was going to happen and were not given an option, their goals not considered, or informed of what the clinician felt the goals were, or whether the participant concurred with the goals. This approach occurred in situations where the upcoming operation was complex, unique and required multiple surgical and medical involvement. Despite the lead clinician, in these particular cases, devoting time to the participants, they were told what was going to happen. Situations will arise when clinicians must take the lead on clinical decision making but the patient should be taken on the journey with them so that they know what the purpose is and understand what is hoped to be achieved. Consideration, nevertheless, should be given to each individual’s involvement desires as one participant did not want to be part of the goal setting process and favoured the clinician taking control.

Two participants in the study reported that clinicians had involved them and considered their views in setting goals. For one participant, both he and his clinician were unified on their goals of survival despite the goal setting process
interpreted as coming across in a manner that gave the participant no other choice: it was either operate or die. The alternative option of not operating may have been discussed with the participant but this was not apparent in the interview nor was clarity around whether or not all options and consequences fully explained to the participant and the most achievable and realistic goal advocated for. For the other participant, the clinician, despite initial reluctance because of the lack of medical benefit of doing so, finally agreed to operate as a result of much persuasion on behalf of the participant. This reinforces Chawla et al’s (53) findings that when clinicians are confronted with treatment dilemmas, despite the futility of the treatment, the potential toxicity to the patient and the damage to the patient’s remaining quality of life, compromises are made and clinicians agreeing to “try out one more dose” frequently occurs. Whilst the goal of clinician was evidence based, how his goal was conveyed to the participant was not conducive to collaborative goal setting as the participant had not received the clinical input regarding the extent that her goals were realistic and achievable. This situation exemplifies those where both parties may benefit from coaching on how to set goals and how to negotiate to ensure they are agreement with the future plan. Such coaching could potentially avoid situations where care, that clinicians do not agree with, is delivered at the insistence of patients and thus redirecting scarce resources away from patients where the evidence for improved outcomes is greater.

Other participants found that the discussions related to their care and treatment was made through their partner and not with them. Two of the participants in the study, had wives who were senior nurses and much of the conversation that the medical staff had with the participants was directed through the participant's wives. While one of the participants was content with this approach, the other appeared uninvolved, disempowered and did not seem to care that other people were making decisions about their treatment. Clinicians often use family members or friends with health background to translate the medical jargon into information that is easily understood by the patient. The intent is benevolent with the hope that the patient receives a better understanding of what has happened or what is going to happen to them with little consideration given to the negative impact of this approach. While it is necessary to utilise all available resource to assist the patient understanding
and developing their goals, the focus and all discussion needs to remain with the patient, otherwise there is a risk that what is important to the patient will be missed.

The literature advocates that the important components of the goal setting process are senior clinician’s time to present the options to the patient and their family, listen and comprehend their personal goals and together decide on the best approach. Ideally this occurs at the commencement of an episode of care. Brom et al. (62) recognised that this did not frequently occur and when it did, it lacked detail and depth in relation to treatment options. The study findings concur with the literature as the participants, when recalling the conversation about their plan of care with their clinicians, identified that much of the dialogue was explaining the technical nature of the proposed procedure only, with a focus on the treatment that was planned to occur. The medical staff appeared to have explained the medical issues sufficiently enough that some patients had a good appreciation of the upcoming procedure but the goals that might be achieved with the procedure that the patient wanted for their future, were not generally discussed or considered. It was recognised in the study that in most situations, it was junior medical staff (JMO) that spent substantial time with the participants and they may have lacked the experience and skill required to establish a goal setting rapport and focused on the aspect of care with which that they were most comfortable.

A couple of clinicians communicated effectively with the participants and inspired confidence and some communicated less effectively leaving the participants angry after the encounter while others did not have any interaction with the participants. The consultants in question were from surgical disciplines, have many competing demands and their job plan allocates time for theatre and clinic sessions with ward rounds conducted at the beginning of the day prior to the commencement of theatre. While best practice highlights the importance of daily senior clinician review and senior clinician involvement in patient centred treatment goal discussions, the current WA healthcare system does not facilitate this. It would not be achievable for a surgical consultant to conduct a meaningful goal setting discussion with a patient one day, then return the next day to answer questions related to the discussion, as this would have an adverse
effect on theatre time and may lead to cancellation of surgery and increase length of stay for other patients. Some surgeons are better skilled than other at communicating with patients, highlighted by the example in the study when of the participant insisted on going ahead with a futile operation and the surgeon, instead of spending time to help the patient understand why this was not the best decision, agreed to perform the surgery. So in terms of the surgical consultant, the reality is that the interaction with patients that has been observed will continue to be varied with some clinicians naturally performing this role more effectively than others.

WONCA (110) describes quality in healthcare as the best possible health outcomes given the available circumstances and resources, consistent with patient centred care. In relation to the surgical specialty and considering the variation in availability and interaction of the surgical consultants with patients, it is necessary to consider other resources available to develop patient centred goals. In the study, the JMO’s had the most interaction with the participants but are not suitably skilled to undertake a goal setting discussion. An example of this is when TJ was told the incorrect date of his operation by a JMO. However, if setting patient centred treatment goals was considered a process, with clearly defined steps and escalation pathways, could JMOs be trained on how to effectively set patient centred treatment goals? Currently, JMOs are responsible for documenting admission and discharge information so a rapport has already been established between clinician and patient. They are, therefore, in the ideal situation to begin the discussion about what is most important for the patient. This would take a shift in medical culture and training, but would indoctrinate future senior decision makers with the patient centredness ideals from beginning of their clinical exposure. Effective use of the JMO resource, in surgical specialties, could have the potential to improve patient and clinician decision making, patient outcomes and quality of care.

An effective clinician–patient relationship is fundamental to good care and outcomes with clear roles and responsibilities defined for each party.(111) ‘Clinician responsibilities’ was identified as a theme in the study and conflicting opinions arose from the participants. Some participants felt that the clinician had a major responsibility for patient care and patient outcomes and accused the
clinician of ‘conveyor belt care’ rather than treating their upcoming surgery as a unique event for each individual patient. Others, however, believed their condition was down to them and they should be grateful that the clinician was able to offer assistance. They also felt the clinician was in no way responsible for the outcome.

Most participants were unaware whether their clinician had similar goals to them as some had not spoken to their senior clinician. Despite one participant not seeing this as an issue as he was confident that he and the clinician had the same goals, most perceived this as the clinician not caring and not treating them as a whole person. Schulman-Green et al’s (71) study concurred with this finding as many patient participants in their study did not believe their clinicians were interested in goal setting. It is undetermined, both in this study and the literature, as to how clinicians view the goal setting process and the patient’s knowledge and understanding of their goals. There is, thus, insufficient evidence exist to support that the belief that the clinicians do not care. Although, it is not commonly known and understood, patients are discussed routinely in various platforms by senior decision makers and clinical experts in some specialties - for example, in elective surgery meetings, multidisciplinary meetings and journey board meetings. (112) If this were known to patients, it would potentially work to dispel the concern that clinicians do not care and help them to realise that much effort is put into deciding the best approach to treat their condition.

Some participants displayed a high level of anxiety, frustration and stress that could be attributed to their uncertainty about their upcoming procedure. It took time to refocus their attention on their goals as the time to have meaningful goal setting discussion had lapsed and the participants desired to vent their disappointment in the first instance. Even if all the recommended elements for effective goal setting aligned at this point, the participants were now not in the frame of mind to have a productive conversation about what their goals were and goals produced from the discussion, therefore, may not be valid for the patient. Alaszewski (113) supported this observation stating that impracticable goals can be attributed to poor timing of goal setting and decision making. Appropriate timing is essential component of a goal setting discussion and the
literature and study findings agree that this practice varies or may not be considered in the clinical setting.

According to the WA Consent to Treatment policy (114), the approved policy at the time of the study, seeking informed consent involves an interactive process that commences with the health professional who discusses treatment options with the patient. The most senior health professional responsible for providing the treatment must be satisfied that valid consent has been obtained prior to conducting the treatment. Another clinical member of the treating team who has sufficient clinical knowledge of the proposed treatment and understands and can communicate the risks and benefits involved, can obtain the consent on behalf of the senior clinician. The junior clinician should refuse to undertake the consent process if the necessary skills and experience are not present. The patient is then assessed as having the capacity to consent. The patient must be provided with, and be able to, understand information relevant to their circumstances and a discussion or offer to discuss the goals occurs so that s/he can reach an informed decision to consent or not to the proposed treatment. This is the minimum mandatory requirements for health professionals in obtaining a patient’s consent to treatment and any deviation to these prerequisites would put the validity of the consent into question.

The participants in the study were undergoing an episode of care involving non-emergency surgery and were required to have undergone a consent process as stipulated by WA Consent to Treatment policy (114). Each participant in the study had a signed a consent form for the relevant planned procedure, however, the participants’ recollection of the consent and information sharing process varied significantly from the requirements of the policy. Clinicians, according to the majority of the participants, discussed the procedure only and omitted patient centred information unless directly asked. Some participants had not spoken to a senior clinician and in one situation, the participant found out that he was having his operation the next day from the study investigator. JMO’s were the medical workforce that had most contact with the participants and may not have been adequately experienced to obtain informed consent. The participants were asked about trade offs as in what aspect of their health would they accept an alteration to in order to achieve their
goals. This should be a routine discussion during the consent process but this question evoked a variety of concerning responses. Some of the procedures that were planned for participants had high peri-operative mortality and had important trade-offs for individuals such as shorter life due to complications of procedure versus longer life if they survive the procedure. In the majority of cases the participants became anxious at this question and said they were prepared to deal with consequences if they did happen. One participant knew exactly what was going to deteriorate and was prepared while another said he would not correct one problem if it caused another. This leaves doubt as to whether the consequences of not having the operation were truly explained to him. It is recognised that the sample for the current study is small, but if this is a reflection of how consent is obtained currently, then a review needs to occur within the health system to implement informed consent as per policy to adequately protect patients.

Identifying PCTG was an important step for participants as they sought to understand what they wanted to achieve out of their episode of care. The next logical step was to pinpoint when the goals will be likely to be achieved. Study aim 4 sought to determine if the goals of treatment that were obtained can be specified in metrics and over a time-frame that can be measured practically. The participants gave a wide variety of answers as to when it was expected that their goals would be achieved. Only three out of the 12 participants had had a discussion with their clinician about when their goals are expected to be achieved. Others did not know or only had their own views. In situations where multiple clinicians were involved, the clinicians’ inconsistency and incongruence with the timeframe led to confusion and increased participant anxiety as was the case for DP in this study where there was variation between eight and two weeks between her cardiothoracic surgeon and the ICU clinician. Even though this is what DP understood from discussions with both clinicians, in reality predictions within a likely range may be possible and that the precision of that estimate might vary between patients, procedures and goals. The timeframe for when their goals would be achieved for participants in this study, derived from their desires rather than knowledge, and varied from immediately to a few months. The participants who could not specify a timeframe were too anxious about the upcoming operation to focus on anything else or had goals that were
unrealistic or unrelated to their operation. Each identified goal could be allocated an expected time of achievement but the important component is the validation of the timeframe by the clinician so that a realistic and achievable target is set. Exploring the participant views on the timeframe that they or their clinician expect goals to be achieved was innovative in its approach as it was not discussed in the literature under review and highlights a major gap that requires future investigation.

5.3 Limitations of the study

When considering the findings of this study and their potential implications for practice, it is necessary to highlight the limitations. Twelve participants, who were waiting for an elective surgical procedure that included an admission to ICU/HDU in a metropolitan tertiary hospital as part of their episode of care, were included in the study. Therefore, the findings are only relevant to this small sample of patients even if potentially transferrable to other patients and sites. Additionally, the data came from patients only, even-though the original aim included clinician interviews on patient centred treatment goals, logistical difficulties in coordinating clinician interviews to coincide with patients forced a change in the study aims. Clinician involvement would have validated or disputed the views of the participants and potentially reveal the some of the root causes of the challenges of setting PCTG in the clinical environment; patient perception and understanding, clinician role and responsibility or a mixture of both. It was acknowledged that some of the participants were not satisfied with the care that they were receiving that may have prevented them from having an objective approach to the questions and the answers that they gave. The study investigator’s interviewing skills developed over time and experience that may have influenced the data generation and data richness that arose from the earlier interviews in comparison to the later interviews. It is unknown whether PCTG can be consistently set and not changed over time as the responses from some participants could be related to the interviewer, their anxiety, their dissatisfaction with their experience of the healthcare system or their frame of mind on that particular day. The ability to utilise the broader literature to support the findings was impeded which reinforces the fact that PCTG is an under research area.
5.4 Chapter conclusion

In chapter 5, significance, value and meaning was assigned to the findings and new knowledge was generated on the concept of setting and measuring of PCTG. The study aims were addressed to a limited degree and proposed that participants, with low anxiety levels and in the correct stage of acceptance of their illness are able to express goals, some of which are patient centred, however require coaching to understand and develop goals that truly are. The extent to which clinicians are involved in and the methods used to set goals was inconsistent and the manner in which goals were agreed either varies or was non-existent for this cohort of patients. The findings give us an insight on how shared decision making and collaborative goal setting occurs in clinical practice and questions the value of the consent policy to aid this process. It was discovered that some goals identified could have a timeframe of achievement allocated to it, however, this was participant dependent and the goal timeframes required validation through a clinician-patient discussion.

As well as answering the research questions, the findings were compared with the findings of the literature review that highlighted similarities in terms of clinicians’ responsibilities, lack of documentation of goals, the goal setting process and information provision. The study identified valuable information on the participants’ views on the clinician’s style and approach to goal setting discussions which was not evident in the literature under review. Information being sought and received from people other than clinicians was another notable finding that was not discussed in the literature and could have beneficial effects on clinical practice. The concept of assessing whether a timeframe could be allocated for the achievement goals was another novel component that had not been previously explored in the literature. The originality of the study, with a focus on participant’s PCTG at the beginning of their episode of care, alleviated some of the identified gaps in the reviewed literature. The resulting rich data gave a real time, detailed insight into the personal, interpersonal and system issues that the participants faced.

In Chapter 6, recommendations and implications for theory, research, and practice are proposed.
Chapter 6

Conclusion

6.1 Purpose

The purpose of this study was to explore how participants, who were undergoing an episode of care, involving non-emergency surgery for which admission to the ICU or HDA was planned, determined and expressed their goals of care. The expressed goals were arranged into PCTG and non PCTG and the participants were subjected to further enquiry to identify whether they could, with assistance, express PCTG. The identified goals were compared with the participant’s understanding of their clinician’s goals for them and ways of measuring and adding a timeframe for the achievement of the goals was investigated. The focus was on the actual goals that participants set and whether the goals that were set were meaningful and valuable, not just for their hospital stay but for the participant as a person and as a member of the community. The process of goal setting, goal validating and goal evaluation was also of interest in terms of how the current goal setting process occurred, how the goals are communicated and how goal achievement was measured. The study is unique in its approach as no other studies in the reviewed literature has approached PCTG in this manner.

6.2 Method

The study had four research aims that reflected the impetus of the study. Twelve adult patients who met the inclusion criteria were recruited for the study. The participants, who were waiting for surgery, either as an inpatient or an outpatient were interviewed by the study investigator and the interviews transcribed verbatim. The data were analysed and resulted in the identification of three themes. The first theme related to the participants’ ‘Desired Outcomes’, the second theme related to ‘Information’ and the third theme related to the
‘Clinician and Participant’s Relationship’ with each theme consisting of a number of dimensions.

6.3 Results

The results demonstrated that some participants were able to identify PCTG. The participants who were apprehensive about the procedure or potential surgery cancellation, found it difficult to engage in goal setting. The participants recruited from the outpatient setting were more anxious that the patients waiting in hospital for a procedure. When coached, most participants were able to identify goals that were patient centred, however it became apparent that the participants did not fully understand their goals. Most participants had not discussed their goals with their clinician so it was difficult to confirm if both parties’ goals aligned. Most participants were able to identify a timeframe in which their goals should be achieved but this timeframe had not been validated by a senior clinicians. It is not certain that PCTG can be consistently set as many factors existed that could altered or influenced the goals set by the participants.

6.4 Critical Evaluation of the Study

There is a fundamental gap in the literature as little consideration has been given to the actual goals that patients have set, whether or not these goals are patient centred, who validates the goals and how their achievement is measured. The majority of the literature looked retrospectively at the process and included participants who were at the end of or completed their episode of care which could bias the value of the findings. The current study filled this void with its novel approach as it focused on the patient’s goals at the start of their episode of care at a time when the participants were at their most vulnerable, their future unknown and they were coming to terms with their illness or with health system challenges. This study is the first step in building a stronger evidence base on setting and measuring PCTG and the limitations of this study, will, hopefully, be a future researcher’s inspiration.

The findings revealed that, although participants in this study could set goals, some required assistance to do so. Symptom related goals were the
most commonly expressed goals however many participants initially focused on what was going to happen in the procedure rather than how the procedure will benefit them and their activities of daily living post discharge from hospital. The participants seemed to be surprised that they were asked what they wanted to achieve for themselves out of their current episode of care. This may have influenced their initial responses and had they been allocated time to consider what their desires were, participants may have answered differently. Normalising goal discussions with patients can be easily addressed by ensuring that the patient is aware, pre-healthcare encounter, what their goals are and during each healthcare touchpoint, (GP, outpatients, pre assessment clinic, inpatient and on discharge planning) the goals are discussed and validated. A patient centred goal setting process or pathway is required to ensure this agreed level of performance between clinician and patient consistently occurs.

The participant’s degree of understanding of their goals was unclear, with some participants having a good comprehension whereas the comprehension of others was limited. Likewise, some were able to effectively express their goals and others were not able to do so. Therefore, their ability to have positively contributed in a goal setting discussion with a clinician is questionable. It was also highlighted in the findings that the participant’s ability to engage in goal setting discussions can be dependent on their emotional and psychological wellbeing. A formalised process of the patient documenting their goals prior to a consultation, similar to the maternal log book, would give the clinician an understanding about the patient’s thought processes about their goals and allow for targeted support and assistance. In addition to this, coaching is required, either by allied health clinicians, doctors or nursing staff, to assist patients comprehend and review their goals as well as caring for the patient’s and their family’s psychological and emotional well-being. This multidisciplinary approach at the beginning of care and/or treatment would allow a focus on each patient’s unique and individual needs with targeted input delivered to the PCTG that are truly important to that patient.

The findings indicated that some of the participants were not given the information that they needed to assist with the setting of PCTG. While it is acknowledged that the clinicians viewpoint is not included in this study, the
provision of information that could assist with goal setting is a deficit that could be easily addressed. All healthcare providers have information about their facilities and their facilities’ services. In the first instance this information requires auditing to assess its effectiveness and it could be adjusted to highlight the patients responsibilities to set goals and who to contact if help is required with this. It is also necessary to investigate contemporary based methods of delivering the pertinent information to patients. The use of podcasts and blogs, although not traditionally used, may improve the way the information is not only transmitted but also received. (113)

6.5 Implications for future research

Despite sufficient information and context being provided for the reader to assess transferrability of the study findings to other locations, further research is required to investigate the patient goals’ and the goals setting process for patients from other specialties and backgrounds to either support the current findings and/or identify variance in practice. Evidence from this study suggests that goal discussions with a senior decision maker did not frequently occur. The immediate effect on the patient and impact on the patient’s recovery and long term goals is unknown, but not having a senior clinicians involved would certainly not add value to the patient’s experience, the patient’s care and the patient’s outcomes for what could be considered a routine admission. A patient follow-up component at a certain time period post hospital discharge would be beneficial to measure goals or progression to goal achievement and the influence of senior clinician involvement or lack of involvement on each. Unsuccessful attempts were made to include the clinicians in the study so it is essential to undertake further research that includes the clinician’s views on the goal setting process to enable a thorough understanding of what occurs in clinical practice.

It was reported by the participants that the JMO played a significant role in goals setting as the senior clinician’s time is utilised for theatre and clinic sessions. This is the current reality of healthcare in the Australian public system and it is unlikely to change in the near future. Therefore, it would be useful to develop and implement an intervention-based research study, in
which all levels of clinicians are provided with professional development around setting patient centred treatment goals, their achievement of setting patient centred treatments evaluated and feedback about their achievement provided. This would provide guidance on the development of a goals setting education framework for clinicians to be developed as a core part of medical training and on orientation to the hospital setting.

From the findings of this research, patients seeking information from non clinicians is a practice that frequently takes place and it is extremely useful in providing clarity to the information that the clinician provides. This in turn may increase the patient’s confidence and encourage their involvement in shared decision making and goal setting. However, some patients are better at asking for information than others and the quieter patients often miss out on this opportunity. The challenge for healthcare workers, therefore, is to somehow harness this information, validate its accuracy and make it available for all. It would be important to explore, on a wider scale, how patients receive information about their health and how we could develop a technology platform to share this information with the wider community.

The goals that the patients set can be measured using traditional formats including paper and online forms as well as employing focus groups and follow up interviews. However, this approach is often a component of a research project or a quarterly patient experience survey that may have limited long term value to the patient and usually the results are outdated by the time they are published. It is also expensive, time consuming, dependent on patient engagement and not practical. Mobile health may offer alternative opportunities and despite having experienced tremendous growth over the past few years, the use of health ‘apps’ has been limited. Social networks and social platforms could be utilised as a means to measure goals in real time, but this will require healthcare providers becoming more comfortable sharing information and engaging patients in this manner. It is important to measure patient centred treatment goals but methods used must be simple and contemporary as well as offering direction and advice to the patients.
The literature and the study findings highlight the issues in respect to the timing of goal setting discussions (113), documentation of the goals and consistency in how the goal setting discussion occurs (76). There is sufficient evidence to implement a process to address these challenges and take the initial step in developing a goal setting pathway for patients and their clinicians that may improve the quality of goals setting discussion and allow for measurement of the process. Once a patient decides to access healthcare and contacts either the GP surgery or health centre for an appointment, the clerk, booking the appointment, directs the patient to the online resource/questionnaire that generates the thought process of the patient to start considering what they want from their initial contact with healthcare. The visit occurs and some time is spent at the start of the visit to go through the goals with the patient. The goals are agreed and documented in a log book, similar to the maternal log book, for the patients to keep and bring to their next appointment. The patient could be then managed by the GP or referred to secondary/tertiary care. A similar process could occur at the outpatient appointment, where the clinician reviews the goals and confirms whether the goals remain the same or altered and considers how they (the clinician) can contribute to their achievement. Again the log book is updated and the goals realigned, if necessary, to reflect the specialist discussion. Similar steps would follow if an inpatient episode was required with a review of the goals on admission and on discharge to the care of their GP. The patient at all times would have control over their goals that have been developed and refined over time and the clinician, if a patient log book review occurs at the start of all patient consults, would have access to the patient desires and direct care, if realistic, towards achieving them. Figure 6.1 outlines a draft ‘GOAL book” process of how this pathway could work. This may in some ways addresses patient’s concerns with communicating with clinicians and also focuses the clinician to think more about the patient rather than the procedure. The first step would be to pilot a RCT of this proposed pathway compared with standard care. Once the pilot RCT findings were reviewed and process adjusted, the possibility of developing an emergency goals setting pathway could be investigated. The goals discussion pathway may not effectively address all the issues and may initially be viewed by clinicians as impeding
clinician practice and not an effective use of their time, but it allows action to occur from the available evidence to drive the concept and importance of patient centred treatment goals forward. It is acknowledged that further research may be needed prior to the implementation of this intervention.

Figure 6.1 Proposed ‘GOAL book’ process.
6.6 Implications for Practice and Policy

It is recognised that the sample for this study was small but if it is a reflection of how consent is obtained currently, then major redesign needs to occur within the health system to implement informed consent as per policy. All participants had a valid consent form which requires the clinicians to go through the procedure, potential complications and the outcome. This knowledge was not apparent in the interviews with the participants. Therefore, the risk exists that the surgery may not achieve the patient-centered goals that they expect. The current method for auditing the consent process is quantitative (consent - Yes/No). This requires amendment to ensure additional rich qualitative data of the patient’s understanding the plan of care, the procedure and the associated risks is captured.

While most clinicians would advocate for a patient centred approach to care, the extent to which this occurs in practice varies. The study findings highlight the perception of twelve participants waiting for surgery and their patient centred experience was mostly substandard. As an advocate for patient centred care, it is important to share the findings with colleagues, either through local forums or national conferences and discuss opportunities for practice improvement and learn from people with similar interests.

6.7 Key Message

As no previous work had examined the real time goal setting process, the current findings reveal how it occurred in the public healthcare system for this cohort of patients from their perspective. The participants could set patient centred treatment goals either independently or with assistance but it is not certain whether the goals are consistent and reliable, as the goals may potentially change according the patient’s emotions, the skill of the interviewer, confidence with the healthcare system or their frame of mind on the particular day that they were interviewed. The outcome for this study is such that we are unsure if the participants know what they want and can truly achieve from their episode of care. The findings are the first steps in designing and developing a healthcare system around the desires and preferences of the patient and further research is required to drive the concept forward.
References


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114. WA Consent to Treatment policy. 2009 p 3, 11-17.


Appendix 3.1

Treatment Goals Audit of 50 Consecutive Admissions

Results

Between 14/03/2011 and 25/03/2011 the notes of 51 consecutive admissions to the RPH ICU were examined for documentation of treatment goals by the hospital admitting and ICU teams prior to or during the ICU stay of the patient.

Table 1. describes the characteristics of the included patients. Table 2 describes the documentation of treatment goals.

Treatment goals were documented by the admitting team in 2 cases and the ICU team in 7 cases. Goals were documented in a total of 8 patients. No elective surgical patients had documentation of treatment goals. In 25% of emergency surgical and 20% of medical admissions a goal related to how the patient felt, functioned or survived was documented.

The documentation of goals was one of two types. Firstly, documentation by the ICU team when the patient was deemed to have a non-survivable injury and the treatment was being shifted to palliation. Secondly, documentation of pain management by either the admitting or ICU team.

In none of the patients in whom a goal of treatment was documented was a time frame and a scale provided to allow quantification of success in achieving the goals.

Table 1. Admission Characteristics

<table>
<thead>
<tr>
<th></th>
<th>Consecutive ICU Admissions n=51</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age Median (IQR)</td>
<td>62 (40-76)</td>
</tr>
<tr>
<td>% Male (95%CI)</td>
<td>78 (67-90)</td>
</tr>
<tr>
<td>Admission Type n (%)</td>
<td></td>
</tr>
<tr>
<td>Elective Surgical</td>
<td>15 (30)</td>
</tr>
<tr>
<td>Emergency surgical</td>
<td>16 (31)</td>
</tr>
<tr>
<td>Medical</td>
<td>20 (39)</td>
</tr>
<tr>
<td>ICU length of stay Days Median (IQR)</td>
<td>2 (1-5)</td>
</tr>
<tr>
<td>APACHE</td>
<td></td>
</tr>
</tbody>
</table>
Table 2. Results

<table>
<thead>
<tr>
<th>Description of Treatment Goals Documented</th>
<th>Patients with Treatment Goals Documented by Admitting Team or/and ICU Team n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>active treatment withdrawn</td>
<td>8 (16%)</td>
</tr>
<tr>
<td>admitted for organ donation</td>
<td></td>
</tr>
<tr>
<td>not for resuscitation due to neurologic condition</td>
<td>2 (4%)</td>
</tr>
<tr>
<td>pain control</td>
<td></td>
</tr>
<tr>
<td>pain management by pain team</td>
<td></td>
</tr>
<tr>
<td>palliation</td>
<td></td>
</tr>
<tr>
<td>unsurvivable intracranial bleed, palliation</td>
<td>7 (14%)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Documentation of Treatment Goals by Admission type number with goals/total number (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>0/15 (0) Elective Surgical</td>
</tr>
<tr>
<td>4/16(25) Emergency Surgical</td>
</tr>
<tr>
<td>4/20(20) Medical</td>
</tr>
</tbody>
</table>
Discussion

We found that on review of 51 consecutive ICU admissions that treatment goals are rarely documented in the patient notes. Explicit treatment goals were not documented in any elective surgical admissions despite signed consent forms in all. Where treatment goals were documented this was not done in such a way as to allow an assessment of their success and in ICU were almost exclusively confined to the documentation of palliation for a non-survivable condition.

In order to be effective in informing the true risks and benefits associated with an episode of care as well as benchmarking treatment success, a treatment goal must not only be a documentation of a patient centered outcome (feels, function, survives) but must also have:

1. patient centered unit of measurement. e.g. for pain not simply 'improvement in pain' but improvement pain so that able to walk to shops, dress self…
2. A timeframe over which this will be achieved.
Documentation of treatment goal must occur at the start of episode of care so that the eventual outcome is a reflection of the initial intent. Uncertainty in outcome for emergency admissions is due in part to lack of prognostically important information. A goal of reducing this uncertainty and a timeframe over which it could be achieved may also be incorporated into a treatment goal model of care.

Elective surgery does not have the same time pressure as an emergency admission and so all possible prognostically important information should be available prior to setting treatment goals. Currently, cardiac surgery due to its standardization of procedures and large databases is closest to being able to incorporate treatment goals into the consent process. This process requires not only large databases with long-term outcome information available, but also an individual clinician feedback to allow re-calibration of prognosis on the basis of current performance and results. Whilst it is cardiac surgery that is currently closest to achieving this, it is notable that morbidity and mortality is significantly higher in many categories of other non-cardiac elective major surgery.

Similarly in the ICU, illness severity scores such as APACHE have high calibration but sub-optimal discrimination limiting the individualization of their use in setting treatment goals. A model of care based on treatment goals has the potential of bypassing some of the deficiencies of other performance based models. For example, rather than concentrating purely on low risk surgery to avoid costly complications, the surgeon and high risk patient who understand these risk may both be prepared to accept them knowing that the individual results of the surgeon place the likelihood of success and reward above others. It has also been documented that the admitting team specialist over-estimates the likelihood of a positive outcome in patients admitted to the ICU. Treatment goals may best be set with an independent clinician as an arbiter of feasibility.

Further prospective study is required to ascertain whether treatment goals are considered by the clinician, the factors associated with lack of documentation and potential outcomes to measure compliance and achievement of goals.
Appendix 3.2

Recruitment materials

Participant CONSENT FORM

Title of Project: An exploratory study of treatment goals as specified by both patients undergoing surgery requiring critical care admission and their treating clinicians.

Name of investigators: Mr Tim Leen, Dr Steve Webb, Dr Edward Litton, Prof Colleen Fisher

Please tick to confirm

I confirm that I have read or have had read to me in a language that I understand the information sheet dated ...............for the above study.

I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.

I understand that the investigators will adhere to the usual standards of confidentiality in the collection and handling of personal information and the standards of the Privacy Act 1988, will apply to how the information is handled.

I agree to take part in the above research study.

I agree to be contacted in the future, should a follow up study occur.

Name of Patient ____________________________ Date __________ Signature ____________________________

Name of Person taking consent (if different from researcher) ____________________________ Date __________ Signature ____________________________

Investigator ____________________________ Date __________ Signature ____________________________
What this study will involve?

If you agree to participate, the lead researcher, Mr Tim Leen, will interview you. He will ask you questions about your beliefs and understanding about what the surgical procedure may be able to achieve for your health.

The study will involve you participating in an interview after your Pre Admission Assessment Service (PAAS) clinic appointment or mutually convenient time. The interview will take about 45-60 minutes to complete and will be recorded on a digital audio-recorder. The questions that you will be asked relate to you and what you are hoping to achieve for your health from your planned admission to hospital for surgery.

Risks

Some people can get anxious or worried about their health and sometimes talking about their health can cause distress. You are allowed to have a friend or family member with you during the interview for support. If you become upset you can ask to take a break or completely stop having anything to do with the study. If you decide not to take part in the study this will have no impact on the care you receive, the doctors and nurses looking after you will not know that you decided not to be in the study. If you feel that participating will distress you, then we suggest not taking part or that you discuss it further with the study investigator prior to enrolment.

Benefits

You will not benefit directly from this research. The study will take up your time (45-60 minutes). You will not receive payment, or any other compensation, for participation in this study. The knowledge gained from this study, however, may benefit others in the future with the aim being improved communication and understanding between staff and patients.

Participation

You do not have to take part in the study. Participation is entirely voluntary. Declining to be involved will not prejudice your subsequent treatment in any way. You are entitled to withdraw at any time during the interview or later.

Investigator Payment Sponsorship

The study has been initiated and is being undertaken by staff members of Royal Perth Intensive Care Unit and High Dependency who work on daily basis with patients and their families in ICU and HDA. The investigators receive no payment or financial incentive for participating in this study.
Questions

When you have read this information, the investigator, Tim Leen, will discuss it with you and any queries you may have. If you would like to know more at any stage, please do not hesitate to contact him on 08 9224 2423. This study has been approved by the Royal Perth Hospital Ethics Committee.

If you have concerns or complaints about the conduct of this study, you should contact the Ethic Coordinator, Mr Mark Woodman, on telephone number 0418195399

Confidentiality and Privacy

The study will protect your confidentiality and privacy. Only the Study Investigators, your surgeon, and doctors who treat you in the Intensive Care Unit or High Dependency Unit will know if you are participating in this study. The results of the research will be published in medical journals or presented at meetings, but your identity will not be released. A pretend name, a pseudonym, will be given to all participants to ensure confidentiality. Any identifiable information that is collected about you in connection with this study will remain confidential and will be disclosed only with your permission, or except as required by law. The information gathered for this study will be stored securely on site at Royal Perth Hospital in a locked filing cabinet inside a locked office or on a password protected computer in a locked office. Only research personnel associated with this project or members of the ethic committee will have access to this information.

The research project and findings will be submitted for the Masters of Medical Science, UWA.

Thank you for taking the time to consider this study.
If you wish to take part in it, please sign the attached consent form.
Appendix 3.3

Interview material

Royal Perth Hospital

Interview Questions for patients

1. You are having ________ operation on the ________
   Tell me what has led up to this operation being scheduled?
   • Prompts: survival, function and symptom control
   • Probe for detail and specific examples

2. What do you hope to achieve by having this operation?
   Prompts: survival, function and symptom control
   Probe for detail and specific examples
   • How soon do you want to achieve it?

3. How do you think your life be different for you following this period of hospitalisation?
   • Prompts: survival, function and symptom control
   • Probe for detail and specific examples.

4. If you had to pick the most important thing that you want to achieve following this period of hospitalisation, what would it be? Why?

5. What other aspects of your health would accept deterioration in order for you to achieve your goal, would you alter your goals? (give example related to their current condition, explore trade offs)

6. What has your Surgeon told you about what results you can expect?

Patient information/cancer/interview question 131112 TL, SW, EZ, CF
7. What does your [patient] want to achieve for you as a result of having [condition] and how did he/she come up with this plan?

- Prompts: survival, function and symptom control
- Probe for details and specific examples

8. How is what your [patient] wants to achieve similar to what you want to achieve?

- Prompts: survival, function and symptom control
- Probe for details and specific examples

9. Is he/she confident that the goals will be achieved and in what timeframe are they expected to be achieved?

<table>
<thead>
<tr>
<th>Patient demographics</th>
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<tbody>
<tr>
<td>Age</td>
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<tr>
<td>Gender</td>
</tr>
<tr>
<td>Education</td>
</tr>
<tr>
<td>Past medical History</td>
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<tr>
<td>Planned procedure</td>
</tr>
<tr>
<td>Rationale for ICU/HDA admission</td>
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</table>

| Patient Probes |

**Survival probes** - What period of survival are you aiming for? What is the minimum increase in survival that would be worthwhile?
Function probes - What is your current level of function? Is your goal to improve or maintain this level of function? Is there a risk that your function will decrease following this episode of care and if so, what level would you accept?

Symptom control probes - What are your current symptoms? In relation to these symptoms, what is the minimum benefit that you are hoping to achieve? How long do you think it will take for this benefit to occur and how long do you expect it to last for?
Appendix 3.4

South Metropolitan Human Research Ethics Committee REF/EC2012/183

HUMAN RESEARCH ETHICS COMMITTEE

Ref: EC 2012/183
14 March 2013
(This number must be quoted on all correspondence)

Tim Leen
Intensive Care Unit
Royal Perth Hospital

dear Tim,

EC 2012/183 An exploratory study of treatment goals, as specified by both patients undergoing surgery requiring critical care admission and their treating clinicians

I am pleased to advise that the above study is APPROVED.

The following general conditions apply to all approvals by this Committee, and starting a trial or research project following the issue of ethics approval will be deemed to be an acceptance of them by all investigators:

1. The submission of an application for Ethics Committee approval will be deemed to indicate that the investigator and any sponsor recognises the Committee as a registered (with AHEC) Health Research Ethics Committee and that it complies in all respects with the National Statement on Ethical Conduct Research Involving Humans and all other national and international ethical requirements. The Committee will not enter into further correspondence on this point.

2. All income arising from the study must be lodged in a hospital special purposes account. Performance of a clinical trial for a sponsor is a service for tax purposes and all GST obligations must be met.

3. The investigator will report adverse events accompanied by a statement as to whether or not the trial should continue. The Committee reserves the right to not receive reports whose complexity or level of detail requires the expenditure of unreasonable time and effort. The Committee receives voluminous paperwork relating to adverse event reporting. From time to time the Committee chairman may require these reports to be summarised and approval is granted subject to the agreement of the investigator that he or she will prepare such a summary on request.

4. The Committee has decided that, as the responsibility for the conduct of trials lies with the investigator, all correspondence should be signed by the investigator.

5. All trial drugs must be dispensed by the Pharmacy Department. A fee is levied for this service and investigators must regard this fee as an item requiring a budget allocation. Alternately, if a sponsor agrees, separate direct funding of pharmacy services may be undertaken. There are provisions for this fee to be waived for locally inspired unfunded studies not having an external sponsor.

6. Though state institutions are outside the jurisdiction of the Privacy Act and related legislation, the Committee will assume that the privacy provisions of that Act will be the minimum standards applying during the conduct of a trial at Royal Perth Hospital. Traditional standards of patient confidentiality will apply.

7. The Committee will not acknowledge trial communications as a matter of course, unless they relate to a matter requiring Committee approval. Evidence of dispatch of a letter will be deemed to be evidence of receipt. This rule may be waived at the Committee's discretion on provision of a pro forma receipt by the investigator for the Chairman's signature and return. However, trivial correspondence (as judged by the Committee) will not be acknowledged even if a pro forma receipt is provided. Where an investigator requests written approval or written record of a matter for special purposes (say at the request of a sponsor), the investigator should prepare the required letter for the chairman's signature rather than expect the Committee secretary to prepare it. This mechanism increases the probability that the trial details in the letter are correct.

8. The Committee will provide the names and representative affiliation of members on request, but will not provide personal details or voting records.

9. A brief annual report on each project approved will be required at the end of each fiscal year, in default of which approval for the study may be suspended. Ethics approvals at RPH do not carry an expiry date so the annual report is an important part of Ethics Committee procedure.

The RPH Human Research Ethics Committee (HREC) is constituted and operates in accordance with NHMRC Guidelines.
10. The Committee has the authority to audit the conduct of any trial without notice. Exercise of this authority will only be considered if there are grounds to believe that some irregularity has occurred or if a complaint is received from a third party, or the Committee wishes to undertake an audit for QA purposes.

11. Complaints relating to the conduct of a clinical trial should be directed to the Chairman and will be promptly investigated. Complaints about the Ethics Committee decisions or policies that cannot be resolved by discussion with the Chairman or about any actions of a particular member including the Chairman, should be directed to the Director of Clinical Services. Only written complaints (not e-mail) will be accepted for investigation.

Investigators of sponsored studies are advised to draw the above conditions to the attention of the sponsor. Investigators are reminded that records of consent or authorisation for participation in special studies (including clinical trials) form part of the Acute Hospital Patient Record and should be stored with that record in accordance with the WA Health Patient Information Retention and Disposal Schedule (Version 2) 2000. A copy of the 'Patient Information Sheet' should also be included in the medical records as part of informed consent documentation.

Yours sincerely

PROF FRANK M VAN BOCKXMEER
Chairman, Royal Perth Hospital Ethics Committee