Healthcare Chaplaincy: the Lothian Chaplaincy Patient Reported Outcome Measure (PROM)

The construction of a measure of the impact of specialist spiritual care
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EXECUTIVE SUMMARY

Background

All NHS employees are required to provide economically sound, evidence-based care. In Scotland this is articulated in The Healthcare Quality Strategy for Scotland (The Scottish Government, 2010). In line with this agenda this report describes a project designed to generate evidence for the efficacy of specialist spiritual care in NHS Lothian.

A patient reported outcome measure (PROM) is a self reported questionnaire that assesses quality of life or perceived health status. The aim of this project was to develop a valid patient reported outcome measure following specialist spiritual care (chaplaincy) intervention.

The conceptual model underpinning the construction of the Lothian PROM was developed from the literature, and refined over a series of workshops and expert panels including local chaplains and world leaders in chaplaincy research. The Lothian PROM entailed five short sections:

1. Demographic details
2. Patient reported experience of the spiritual care support offered (5 Likert1 questions)
3. Patient reported outcome of that encounter (5 Likert questions)
4. Statements pertaining to spirituality (8 Likert questions)
5. Free text section for additional comments

Data

The Lothian PROM was completed by 39 of 70 people invited to participate. Chaplains recorded their impressions of these encounters independently. Telephone feedback on the experience of completing the PROM was obtained from 13 patients. Data from the first four sections was converted into summary descriptive and inferential statistics. Free text data was thematically analysed, and comparisons were generated between chaplain interpretations of encounters and patient accounts. This analysis was then synthesised into findings from ongoing national2 and local projects, and the wider literature.

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1 A Likert-type scale assumes that the strength or intensity of an experience can be measured, usually on a five point range, allowing the individual to express how much they agree or disagree with a particular statement.

2 Community Chaplaincy Listening 2 report by Mowat and Bunniss is due later 2012. It is strongly recommended these reports be read together as they entail strikingly similar conclusions by independent means. This increases the likelihood that the findings of both projects are generalisable and consistent across the Scottish population.
Results

Most participants (32/39) came from the acute services. More women than men responded, although the 3:1 ratio found here was virtually identical to current national work undertaken in community chaplaincy listening, suggesting transferability of the findings on this basis.

The responses pertaining to patient experience of the spiritual care intervention (section 2) were overwhelmingly positive. If listening, enabling people to speak what is on their mind, being understood and having faith and beliefs valued are important, then chaplains may be the best people to facilitate such outcomes. From a psychometric perspective these questions would benefit from piloting in different staff groups in order to provide comparative data and hence empirical evidence of the chaplain as specialist in spiritual care. The responses pertaining to spiritual care outcomes (section 3) were also unanimously positive.

The responses relating to spirituality trait descriptions in section 4 were heterogeneous, suggesting the sample was diverse, and that spirituality was not necessarily an important factor to the recipients of chaplaincy interventions. For example some people described themselves as spiritual but not religious. Many believed in God but not all the time. Others indicated they were not spiritual at all. Because the scores in sections 2 & 3 were so high this infers that a spiritual care encounter was useful for everyone with a need for hope and control, regardless of their beliefs. The more existential traits (spirituality, meaning) were not correlated with any outcomes. This can be explained by the secular nature of this population. A major finding from this study was that spiritual care was important to all the participants wherever they sat on the spirituality spectrum.

Positive outcomes of spiritual care intervention were strongly associated with the chaplain enabling people to talk about what was on their mind. A sense of peace was the clearest correlation between chaplaincy involvement and patient outcome. This strongly suggests that being enabled to speak about whatever was on their minds led people to achieve a sense of peace. This was highly valued by people, as corroborated in the free text data.

Analysis of the free text comments did not suggest that any aspects of spiritual care involvement or outcome had been missed within the body of the PROM (the Likert questions). Rather, the free text added explanatory depth to the responses already captured within the quantitative elements. We therefore concluded that free text data had an importance and function in allowing for expansion of quantitative responses, and should be retained for future iterations of the PROM. The telephone feedback on the wording of the questions strongly supported this conclusion by clarifying that participants understood the items within the Lothian PROM. Participants considered them personally relevant. In psychometric terms, the Lothian PROM has face and content validity.

Free text data was interpreted by the following four interrelated themes, explained in detail with exemplars in the body of the report:

- The significance of religion,
- Unmet needs in routine hospital care,
- Grateful recognition of the unique skills of chaplains (the ‘guide through the gruesome’),
The need for a sense of peace in the midst of a stressful time

The quote overleaf illustrates aspects of all these themes and is repeated in full with permission of the author:

The final days of my partner’s life were the most distressing situation of my life. I had no idea how to deal with it or my feelings. The counseling that I received during those final days and in the months thereafter has been immensely helpful. I had also built up a lot of anxiety in anticipation of how her life might end. [Chaplain] was incredibly helpful in ensuring that I was able to have those final moments with her and that I could say all the things that I needed to say, without later regret of missing the moment. It was also vital that I was given the reassurance from a non clinical body about how the end would be for [her] and that she would not suffer, which was so important. I have also seen [chaplain] several times in the months since [my partner] has died, with him even visiting me at the Sick Kids hospital where my daughter was staying at the time. I have been through a roller coaster journey of emotions and I am incredibly grateful for his continued support. I have received counseling before under much lesser situations and felt that on reflection this was by far the most effective I have received. I do not follow any faith and although at first I thought the help from a chaplain might be inappropriate for me, it immediately transpired to be irrelevant and [chaplain] seemed to tailor his counseling to suit my life. I am indebted to his help in those final days for [my partner] and wonder how I might ever have survived myself without it. It’s a vital service which is a must in that most gruesome environment of the intensive care ward 118.

One of the most significant findings was that these free text responses demonstrated a strong coherence with chaplain interpretation of interventions as evidenced by their independent descriptions. There was no case where the chaplain’s view of the encounter was different from the patient’s. This finding closely mirrors Mowat and Bunniss’ finding in a parallel NES Scotland research project, Community Chaplaincy Listening (CCL2). They cite this phenomenon as Pastoral Integrity3. Pastoral Integrity is person centred care. Evidence such as this therefore goes some way towards articulating not only the existence but the measurement of person centred care. The difficulty of articulating and measuring person centred care is discussed in the body of the report4. This finding in particular puts NHS Lothian chaplains not only at the forefront of research in their field, but of health service research and practice more generally.

Recommendations

We recommend that the overall structure of the Lothian PROM be amended to mitigate the psychometric issues discussed in detail within this report. In brief, these issues entail clarifying demographics in section 1, reversing some of the questions in sections 2 & 3, adding a specific timeframe to the outcome questions, and omitting section 4. The revised version incorporating these proposed changes is in appendix 5.

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4 Much of this discussion is grounded in Cribb’s (2011) deconstruction of shared decision making in NHS. This is recommended reading.
In order to make best use of the outcomes of this project the validation process should continue. To this end the following projects should be considered:

**Would the findings from the Lothian PROM hold in a larger sample?**

We strongly recommend that the new version should be tested in a national population. This larger study should also include cross referencing the PROM with an agreed measure of quality of life so as to assess its construct and criterion validity. Although the Lothian PROM showed great promise, and is already clinically useful as it is, its utility will be much stronger if it proved demonstrably valid and reliable in a national sample.

**Could 3 questions discriminate referral?**

A short form of referral could be developed and tested based on the principal component analysis of Galek’s trait factors, discussed in the body of this report. That is, a positive answer to any of the three questions would warrant referral. The New Lothian PROM could then be used to measure whether these interventions were effective. This could be used alongside a treatment as usual group to ascertain the utility of the referral method.

**Would chaplains score higher than other disciplines in interventions as measured by this scale?**

We don’t know if the overwhelmingly positive responses of the people in this study were a function of poor psychometrics of the measure (ceiling effect) or a true reflection on the skills of the chaplains. In order to test this, the Lothian PROM could be adapted to also assess interventions from different disciplines. This would probably work best in comparable ‘talking’ roles such as psychology, psychiatry or mental health nursing, although given the claims made for palliative care nurses it may be interesting to include them. If it emerged that chaplains consistently scored higher than their counterparts then this would be a useful finding in relation to a discussion on chaplaincy, complexity and speciality.

**Does chaplains’ understanding of patients improve over time as measured by language convergence?**

This interesting linguistic hypothesis was raised in the chaplain feedback session discussed at the end of chapter 4. In order to test it we could use specialist techniques (Richard & Lussier, 2006) to analyse language and conversation during interventions, or use concurrent analysis (Snowden & Atkinson, 2012) to identify analogy and symmetry in encounter descriptions. This would provide deep evidence of person centred care and add to the theoretical understanding of this important aspect of communication.

**Does using Lothian PROM feedback in clinical supervision improve confidence, competence, and the value of the supervision?**

Again, in the chaplaincy feedback focus group in chapter 4, there was a deep sense of personal and professional pride in the finding that chaplain and patient descriptions of interventions were congruent. This was both very welcome and previously unknown. The most obvious issue was how to translate this information into service improvement. The general consensus was that this data would be useful in supervision sessions. There would be a number of ways to test this. For example in order to ascertain measurable improvement in relation to usual practice we would need some objective measures and a comparator group. Valid measures of self reported competence and confidence could follow supervision in groups that used this data, and be
statistically compared with those that did not. Interviews on the impact of supervision could add depth to these quantitative measures. There would be many ways of constructing such a study.

**Should chaplains continue engaging with research?**

One of the strongest elements of this project has been the involvement of chaplains throughout. They were involved in the construction, development and ongoing critical appraisal of the Lothian PROM. They provided and gathered data, and in Iain’s case managed this process. They provided feedback on the results and this feedback went much of the way to suggest that these chaplains in particular saw the personal and professional value of this research. Hopefully this will translate into further consistent engagement. One of the main benefits of this process has been the growing feeling that research is not something done by other people but something done by us. We cannot recommend strongly enough that chaplains continue to engage with research as practice.

To cite this report:

This report is a powerful testament to the value of healthcare chaplaincy as it provides spiritual care for patients in the Scottish NHS. The work described in this report is corroborated and supported by the companion report Community Chaplaincy Listening : Phase 2. Together these two pieces of research have set chaplains hefty challenges but also provided them with the basic practical and evidential kit to meet those challenges.

Challenge one is to recognise the value of their work and to broadcast this value as part of their professional development. Other healthcare professionals and healthcare managers do not know what chaplains do. The world in which chaplains work values highly well conducted research which demonstrates positive patient outcomes. In CCL and PROM we have overwhelming evidence from both qualitative and quantitative research traditions that chaplains impressions of their interventions closely correlate with the patient impressions. This is person centred care. Not every healthcare profession can boast this degree of coherence. We have powerful conclusive evidence that patients value the chaplains’ work. We can now show that facilitating the conditions by which people can just talk, is an end in itself and provides the patient with the opportunity to regain peace and control even in unchangeably difficult situations.

The second challenge is to become research active in addition to research aware. This has implications for professional development and training. Chaplains must evaluate their work on a regular basis in terms of patient outcomes and experience. They must adopt a measure that can be used across all sectors of healthcare chaplaincy which will evaluate their performance as a group as well as individually. This report shows that the building blocks for a chaplaincy patient reported outcome measure are in place and that there is now no reason why this cannot be used by chaplains. This means chaplaincy teams in each of the Health Boards will need to collect audit data and learn to analyse the PROM, feedback the results to colleagues both within Chaplaincy and other healthcare professionals and act upon the findings of these analyses. Thus the research goes into practice. This is a challenge for every healthcare profession.

The third challenge is to own the uniqueness of the chaplaincy role as potentially spiritual and religious but always patient led. The data we have gathered from the two projects shows quite clearly that people of all faiths and none, people of confirmed atheistic backgrounds and people of strong religious traditions all value and trust the chaplaincy service. The reason that the service is trusted and valued so highly is because of the theological training and behaviour demonstrated by the chaplains. The chaplains hold a place in healthcare delivery which is uniquely non clinical, non medical and specifically dealing with the individual search to manage the complexities of life events.

With the emphasis on patient centred care dominating the strategic thinking at Government level the chaplains have a chance to lead the way in showing how complex interventions can be patient centred. I hope they will take it.
I am delighted that this piece of significant research in the field of specialist spiritual care provision has been carried out in NHSScotland. It marks an important milestone within the development of research into the effectiveness and impact of healthcare chaplaincy on patient care. The findings reveal not only what the patients involved felt was the outcome for them as individual persons of chaplaincy intervention but also their lived experience of such encounters. In addition, and of real significance, this was found to be entirely congruent with chaplains’ intention of care. In a political context where person-centred care is currently a key policy driver such evidence is gold dust indeed! Until now chaplains in NHSScotland have had a paucity of culturally appropriate evidence not only to help them reflect on their practice but to utilise strategically to prove their worth and value for money in healthcare.

We are indebted to the generosity of the Scottish Government for their funding of the Specialist Spiritual Care Lothian PROM Project and the vision and openness of Pat Dawson (Associate Nurse Director), Sandy Young (Service Lead) and the Spiritual Care Team in NHS Lothian to enable this hugely valuable piece of work to be carried out. The relational and influencing skills of Iain Telfer and the research expertise and doggedness of Austyn Snowden have enabled not only the PROM to be developed but much learning and collaboration to have occurred. The process through which this project evolved as well as its outcome has made a lasting impact. Researchers and academics, Harriet Mowat and Suzanne Bunniss have been great friends of Scottish healthcare chaplains over several years and their willingness to share of themselves and their insights has also enriched this project. Thanks also must go to medical student Naomi Howard for her contribution to the overall analysis, and to Margaret Snowden for editing and formatting the report. Finally, it is important to mention that this research project has come to fruition as a result of much networking, collaboration and sharing by leaders in the field of healthcare chaplaincy research from across the world. I am not only grateful to them but to the Scottish Government and NES for their support of knowledge transfer opportunities in conference settings where the latest spiritual care research from across the world has been presented, relationships formed and practice influenced.

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1. **INTRODUCTION**

A patient reported outcome measure (PROM) is a self reported questionnaire that assesses quality of life or perceived health status (McClimans & Browne, 2011). PROMs are regularly and increasingly used as the main measure of clinical effectiveness following a diverse range of interventions (Palfreyman, 2011).

This report describes:

1. The construction of the Lothian PROM; a questionnaire designed to measure outcomes of specialist spiritual care intervention in NHS Lothian, Scotland.
2. The results of a pilot designed to test this measure in a patient population.

The construction of the questionnaire is detailed in the first part of the report. The context and background are first described in order to situate the aims and objectives of the project. The method of questionnaire development is then detailed in order to show how and why the individual questionnaire items were generated. A standardised method of outcome measure development underpins this section, providing a theoretical framework to optimise validation. In brief, the purpose of a questionnaire should always be kept in mind throughout its development (Pilkonis et al, 2011; Streiner & Norman, 2008). A critical perspective of this position is maintained throughout the report.

The second part of this report describes the results of a pilot study designed to begin the validation process of this measure. In total 70 questionnaires were sent out, 39 returned. Thirteen people were telephoned to ascertain their opinion on the PROM. From this it was found that respondents were overwhelmingly positive about their experiences with chaplains, and that chaplains’ skills facilitated positive health outcomes. Free text analysis showed consistent themes in support of these findings. Strengths and limitations of these findings are discussed in relation to methodological, practical and philosophical issues.

It is concluded that these findings are consistent with companion research projects currently being undertaken in Scotland. Recommendations are made for further development of chaplaincy PROM.

1.1. **Context**

All NHS employees are required to provide economically sound, evidence-based care. In Scotland this is articulated in *The Healthcare Quality Strategy for Scotland* (The Scottish Government, 2010). The stated aims of this strategy are:

*Putting people at the heart of NHSScotland. Those working in the health service will listen to peoples’ views, gather information about their perceptions and personal experience of care and use that information to further improve care.*

*It is about building on the values of the people working in and with NHSScotland and their commitment to providing the best possible care and advice compassionately and reliably by making the right thing easier to do for every person, every time.*
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It is about making measurable improvement in the aspects of quality of care that patients, their families and carers and those providing healthcare services see as really important.

(The Scottish Government, 2010, p5)

The final conclusion of this report considers the findings in relation to this strategy. For chaplains in Scotland the Quality Strategy translated into the following strategic priorities, agreed by all lead chaplains in 2010:

1. Service Development
2. Developing an Evidence Base
3. Engagement in shaping healthcare policy at local and national levels
4. Professional Development for lead chaplains
5. Developing reflective practice as normative
6. Developing a Communications Strategy

These priorities are consistent with current legislation on patient rights in Scotland (The Scottish Government, 2011a). The Lothian PROM development can therefore be seen to be coherent with this context in general, whereby measurement of intervention feeds back into service development in a structured manner. In this we follow Cornwell (2012) from the King’s Fund in remaining focused on the practical utility of this project. In discussing how projects such as this one contribute to health improvement she summarises the relevant questions as:

1. What problem are we trying to solve?
2. When we have the data, what will we do with it?

Cornwell found very few NHS organizations had considered both questions:

We found very few NHS organisations with an overall strategy for improving patient experience, a defined budget, personnel with relevant expertise to collect data, analyse and present it, and an education and training plan with a budget for improving patient experience

These questions remain uppermost in the development, articulation and dissemination of this project. The report shows the Lothian PROM development has the potential to add to the developing evidence base for specialist spiritual care as a unique, important and measurable contribution to care.

1.2. Background

1.2.1. Methodological issues

Identifying outcomes of spiritual care interventions is not straightforward. There is no existing spiritual care PROM. There is continuing discussion over whether the project is possible at all. Some of this is grounded in the enduring debate of whether it is possible to define an outcome of spiritual care consistent with the wider PROM projects, given that PROMs originated in clearly

http://www.kingsfund.org.uk/blog/patient_exp.html
defined interventions. By contrast clear definitions of spiritual care remain elusive (Kalish, 2012), and so Fitchett’s (2011) position is reasonable when he suggests that more case studies are needed to define the impact of chaplaincy before we can proceed to more quantitative methods of evidence gathering such as PROMs.

Efforts to define specialist spiritual care have been made though, and seminal work *What Do Chaplains Do?* deconstructed the activities of chaplains in order to clarify what could be interpreted as spiritual care (chaplaincy) intervention. Both Fitchett and Mowat & Swinton conclude that further qualitative analysis should be a prerequisite for any alternative method of enquiry. However, despite their caution there are clearly commonalities regarding what chaplains do. This leaves room for authors such as Galek et al (2011) to argue the case for the generation of more robust quantitative evidence *now*, and to support this position they note a slow improvement in the quality of quantitative studies attempting to define chaplaincy impact over the last 10 years.

Both perspectives are valuable. Quantitative evidence is traditionally seen as more robust, and certainly easier to understand from a planning perspective (Palfreyman, 2011), and so Galek et al’s view is strategically popular with workforce planners. Fitchett and Mowat & Swinton’s perspective is that such evidence will not be valid without extensive testing of its practical application. One of the purposes of this project is therefore to take a first step to bridging this gap by addressing these practical concerns.

### 1.2.2. Political and professional issues

As described at the beginning of this section the drivers to develop robust evidence of clinical interventions are both political and professional. From a political perspective it makes sense to develop and utilise efficacy measures that are comparable and brief in order to develop the best care for the most people from limited resources. From a professional perspective, chaplains need to be able to define what is unique about their input in order to contextualize any claim to patient benefit.

There is also a more important driver however; the patient perspective. The move to facilitate and act upon patient feedback in genuine ways continues to grow⁶, and this project offers a significant opportunity to translate this rhetoric into action within the field of specialist spiritual care. There is no doubting the will to involve people better in their care (The Health Foundation, 2008). For example Scotland’s Quality Strategy is mirrored by England’s NHS Constitution (Department Of Health, 2010a) in this regard, and operationalised in explicit quality standards (National Institute for Health and Clinical Excellence, 2011). People should be listened to and involved.

However, there is an increasingly eloquent literature illuminating the practical complexities of such agendas (Cribb, 2011; Cribb & Entwistle, 2011; Frosch et al, 2012). Without recognition of this complexity sound bites such as ‘no decision about me without me’ (Department Of Health, 2010a) are likely to remain just that. The evidence for the enactment of these quality standards is therefore best gathered through analysis of structured patient feedback. A chaplaincy PROM could provide this evidence.

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⁶ See [https://www.patientopinion.org.uk/](https://www.patientopinion.org.uk/)
1.2.3. Design issues

This report describes the first phase of a project designed to develop such a measure in NHSScotland. It shows the construction and development of the first iteration of this tool. It shows how it was developed from the literature in the first instance, and then amended over a series of workshops and conferences. It describes a field evaluation over a three month period in 2012 in NHS Lothian, and results and patient feedback are presented. The analysis shows the strengths and limitations of the study, and recommendations are made for follow up.

In brief, the credibility of inferences that can be drawn from PROMs is a function not only of the technique of validation but the robustness of the initial conceptual model (Pilkonis et al., 2011). As such, although this report stops short of traditional validity work, we need briefly to discuss the issue of validation in order to understand its role in the development of health measurement scales.

The detail of this process was informed by Health Measurement Scales: a practical guide to their development and use (Streiner & Norman, 2008). Currently in its 4th edition this text articulates in detail the relevant psychometric issues pertaining to health measurement scale development. Historically, the validation process has been broken down into various stages of validity testing, such as the three C’s or the ‘trinitarian’ view of validity (Landy, 1986):

1. **Content validity** refers to the extent that a measure captures all elements of a social construct. The higher the content validity the broader the inferences that can be drawn about a respondent under various conditions and situations.

2. **Construct validity** refers to the degree to which a scale matches a particular theoretical construct (eg, the impact of chaplaincy). It is the extent to which what is measured relates to what should have been measured. It is intricately linked to our theory and there is no single study that can prove a construct.

3. **Criterion validity** refers to the correlation of a scale with some comparable measure of the trait under study. It can be predictive, for example where a score on a test (blood pressure) predicts future outcomes (cardiac problems), or it can be concurrent, whereby a score on the test correlates with a score on a similar test given at the same time.

However, whilst these three aspects of scale development may appear distinct Streiner & Norman (2008) point out that all validity testing is in fact hypothesis testing, and the process of validation is a unitary construct. A valid scale is one that allows us to make accurate inferences about someone. What this means in relation to scale development is that rather than arguing which ‘type’ of validity a study supports, the central questions are rather:

> ‘Does the hypothesis of this validation study make sense in light of what the scale is designed to measure’, and ‘Do the results of this study allow us to draw the inferences about the people that we wish to make’ (Streiner & Norman 2008, p252)

These issues are not just semantic as they impact upon scale development by focusing attention on the **purpose** of the scale, as discussed in the introduction (Cornwell, 2012). It makes no sense to talk about the validity of a scale. Validation is an ongoing process, linking predictions to the developing construct. So, although we discuss face and content validity within this report, these
discussions are always grounded in the recognition that validation is a unitary construct that
tests the theory and the measure at the same time (Streiner & Norman 2008, p259). This in turn
highlights the importance of grounding the PROM development in a sophisticated and testable
conceptual model of what it is that chaplains do. The aims and objectives of this study are
therefore as follows:

1.3. Aims and objectives

1.3.1. Aim

To develop a valid measure of patient outcome following specialist spiritual care intervention

1.3.2. Objectives

1. To develop a conceptual model of chaplaincy
2. To translate this model into items: the Lothian PROM
3. To test the Lothian PROM in a clinical population.
4. To analyse the results of the test.
5. To contextualise this analysis: discussion.
6. To make recommendations for further development

This report takes a linear approach to these objectives. The development and construction of
the Lothian PROM is detailed in the next chapter. The method and study design is discussed in
the following chapter. Results of the study are presented, and then detailed analysis of the
results follow. The discussion integrates these findings within comparable work, and
recommendations for further study complete the project.
2. THE DEVELOPMENT OF THE LOTHIAN PROM

2.1. Generation of the conceptual model: literature search

An initial search of the literature for an existing PROM for chaplaincy intervention revealed no such measure. It became clear very early that we would need to develop a new tool from scratch.

As a starting point, some common themes have been articulated as discussed above. For example the concept of comfort was a particularly common theme within the spiritual care literature as was discussion on hope, and coping. Being listened to and being valued featured widely. Being involved, understood and in control featured as common themes. These commonalities were all therefore very useful search terms pertaining to patient reports of the impact of chaplaincy.

![Figure 2.1. Themes associated with chaplaincy (Mowat & Swinton, 2007)](image)

At this conceptual stage we also explored the literature to consider how PROMS had been developed in similar contexts. For example, do other non medical groups such as psychologists, gather patient reported outcomes of their interventions, and if so, how? The purpose of the literature search to support the conceptual clarification was therefore twofold:

1. To analyse questionnaires pertaining to known spiritual care themes, in order to generate putative questionnaire items for the Lothian PROM
2. To evaluate the PROM development literature in comparable professions, in order to be mindful of any salient conceptual issues
We adapted the literature search string used by Mowat & Swinton (2008) in *What Chaplains Do*. The following terms were combined in multiple searches in Medline, Cinahl, Psychinfo, Mendeley, Google Scholar, Cochrane library:


Strict inclusion/exclusion criteria were not applied at this iterative stage. Literature was considered to be pertinent if it fell within the scope of the 2 identified issues above. Interesting references and leads were followed as a result of this reading. For clarity the results are presented in relation to the 2 issues separately, but this section finishes by integrating the salient points from both aspects of the search to show how they both drove the development of the Lothian PROM.

### 2.1.1. The literature

#### Measurement issues in chaplaincy themes

In summary, there is considerable literature pertaining to the measurement of spiritual care themes such as hope, comfort and listening (figure 1). The benefit of facilitating peace and relief from distress in a spiritual sense was widely claimed. Many authors attempted to systematically measure these themes. Table 1 shows the source, summary and salience of the illustrated papers, and where relevant shows the measure used.

<table>
<thead>
<tr>
<th>Authors</th>
<th>Summary</th>
<th>Measures</th>
<th>Salience to PROM development</th>
</tr>
</thead>
<tbody>
<tr>
<td>(Ai &amp; McCormick, 2009)</td>
<td>Case studies are used to illustrate the actions of the chaplain at the bedside in end of life care. A new scale is presented for chaplains to assess diverse afterlife beliefs.</td>
<td>Connection of the soul (COS)</td>
<td>Recognition of importance of ‘being with’, caring and compassion as unique contribution of chaplain. Within the health care team the chaplain is often uniquely situated as one who is designated to take time to “be with” the patient and who by both personal virtue and professional training can embody a caring and compassionate presence to the vulnerable patient.</td>
</tr>
<tr>
<td>(Pargament, Feuille, &amp; Burdzy, 2011)</td>
<td>Pargament was the original developer of the 14 item brief RCOPE, a measure of religious coping with life stressors. The items within the scale were developed from interviews with people suffering life stressors. Important distinction emerged between negative and positive religious coping. The negative religious coping subscale has been particularly useful as a predictor of health outcome.</td>
<td>Brief RCOPE</td>
<td>This paper integrates discussion of psychometric quality with religious coping, a factor specifically associated with spiritual care. This may be particularly pertinent in light of discussions that suggest there is little unique to the chaplaincy role, given that other professions can claim to meet certain spiritual needs.</td>
</tr>
<tr>
<td>(Farber et al., 2010)</td>
<td>This study sought to quantify the degree to which personal meaning accounted for various</td>
<td>LRI-R, GWB, MOS, Social Support Survey.</td>
<td>Personal meaning is a pertinent construct to the work of chaplaincy, so this study illuminated some of the</td>
</tr>
<tr>
<td>Authors</td>
<td>Summary</td>
<td>Measures</td>
<td>Salience to PROM development</td>
</tr>
<tr>
<td>---------</td>
<td>---------</td>
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<td>-----------------------------</td>
</tr>
<tr>
<td>Health care Chaplaincy: the Lothian Chaplaincy PROM</td>
<td>differences amongst a cohort of 132 people with HIV. They found that personal meaning was associated with psychological well-being.</td>
<td>LOT-R, CHIP</td>
<td>issues in trying to account for such a variable. The Life Regard Index seems promising in this regard, although this particular study could not identify any causality because of its design.</td>
</tr>
<tr>
<td>(Gonzalez, Hartig, Patil, Martinsen, &amp; Kirkevold, 2011)</td>
<td>This small (n=46) study measured the efficacy of therapeutic horticulture on depression and in particular existential issues. The intervention significantly correlated with a consistent improvement in depression but not existential issues. Existential issues were measured with the LRI-R.</td>
<td>LRI-R, BDI</td>
<td>This paper is relevant because existential issues were postulated to be relevant to chaplaincy interventions. The findings suggested that depression in this case may not be directly correlated with existential issues as measured in this way. This could be a function of the measure, the sample size or genuine discord, although the authors imply the former because the ..participants claimed the intervention was meaningful and influential on their view of life. These all need to be considered in PROM development</td>
</tr>
<tr>
<td>(Hebert, Jenckes, Ford, O’Connor, &amp; Cooper, 2001)</td>
<td>Study designed to ascertain the preferences and concerns of seriously ill people when discussing religious and spiritual beliefs with clinicians. God, prayer, spiritual beliefs were all mentioned as sources of support and healing. Willingness to discuss these issues was closely related to the therapeutic relationship.</td>
<td>Thematic</td>
<td>Relevant in ascertaining the pertinent categories of discussion and also relevant that clinicians didn’t always meet these needs. In general people didn’t expect clinicians to fulfill these needs but if they disclosed them then they hoped the beliefs would be valued.</td>
</tr>
<tr>
<td>(Kannan, 2008)</td>
<td>The purpose of this study was to describe the relationships among symptom experience, symptom management, and symptom outcome based on spiritual well-being. Kannan found that greater spiritual existential well-being was significantly associated with improved physical function.</td>
<td>Revised Symptom Management Conceptual Model</td>
<td>Important because they found a relationship between self reported spiritual well-being and physical function. This type of result supports chaplaincy from a clinical perspective. The self report methodology makes it relevant to a potential spiritual PROM</td>
</tr>
<tr>
<td>(Van Gestel-Timmermans, Van Den Bogaard, Brouwers, Herth, &amp; Van Nieuwenhuizen, 2010)</td>
<td>Discusses the function of hope in recovery from mental ill-health. The study develops and validates a Dutch version of the Herth Hope Index to assess the degree to which hope may be construed and measured.</td>
<td>HHI, MANSA, RAND-36, CISS, MHCS</td>
<td>Although the authors conclude the tool is a valid measure of hope they warn against using subscales within it in isolation. This may be due to ’interconnectedness’ as being an historical factor of this index. Useful for showing how scales can and should be compared with each other in order to develop and clarify constructs like hope, loneliness and coping.</td>
</tr>
</tbody>
</table>
Table 2.1. Source, summary, measure and salience to chaplaincy PROM

<table>
<thead>
<tr>
<th>Authors</th>
<th>Summary</th>
<th>Measures</th>
<th>Salience to PROM development</th>
</tr>
</thead>
<tbody>
<tr>
<td>(Bay, Beckman, Trippi, Gunderman, &amp; Terry, 2008)</td>
<td>RCT studied the efficacy of chaplaincy against patient outcomes of anxiety, depression, hope, positive and negative religious coping, and religious coping styles. They found chaplain visits increased positive religious coping and decreased negative religious coping</td>
<td>Hamilton Anxiety and Depression Scale (HADS); Herth Hope Index; 14 item brief RCOPE; Religious Problem Solving Scale</td>
<td>No significant differences were found between any of the major scales, suggesting it may be difficult to detect efficacy using this type of methodology. Nevertheless, some non significant trends towards positive religious coping were encouraging. The measures used in this study were highly pertinent to our project.</td>
</tr>
</tbody>
</table>

The next phase of the initial PROM development was to consider the methodological issues highlighted in the second part of the literature search.

**PROM development literature in comparable professions**

The methodological issues are tied to the practical issues raised in the introduction (Dawson et al, 2010). The purpose of the Lothian PROM is to generate systematic evidence of the impact of specialist spiritual care encounters. This section therefore considers comparable literature on PROM development in relation to the measurement of complex interventions.

Health is complex (Downe, 2010) to the extent that health improvement is subjective. Chaplaincy interventions are also complex and so the purpose of the Lothian PROM is likely to differ according to stakeholder (chaplain, patient, manager). There is no externally valid endpoint to which a spiritual care intervention can be deemed a success, unlike in surgery for example, where PROMs originated. PROMs are consistent with a disease centred view of health (Gershon et al, 2010). Success of hip surgery can be measured by a PROM focused on mobility for example. Success in chaplaincy is not so clear. The ‘gold standard’ for PROM development is the PROMIS databank. This is a multimillion dollar project culminating in PROM questions validated in various disease models (Pilkonis et al., 2011). It is a very useful measurement resource for articulating change in various disease states. Although this process of PROM development is extremely useful in relation to identifying key psychometric considerations in self reported questionnaire development the process is not transferable to spiritual care because the question remains as to what would constitute a positive outcome to that intervention.

So, without agreement on a desirable external endpoint, it is impossible to develop an outcome measure in a rational manner. Nevertheless, there are scales that attempt to quantify complex concepts, such as the meaning of life measure (Morgan & Farsides, 2009). Morgan & Farsides’ project is probably pertinent to the outcomes a chaplain would hope to achieve, in that it could be hypothesised that chaplaincy would impact on such a measure. Their article is therefore of great technical use in that it describes the construction of this scale in clear detail. The problem with such scales is that they arguably measure experience as opposed to outcome. It is important to understand that such debates are extremely important for empirical claims, as outcome and experience are considered to be very different constructs. In medical literature experience is considered to be a ‘soft’ outcome (Looi, 2008), although the philosophical literature is less clear.
(Risjord, 2010), and the political literature is overtly moving towards valuing experience as outcome (Department Of Health, 2010a; National Institute for Health and Clinical Excellence, 2011).

Therefore, in targeting the development of the Lothian PROM to its purpose in this particular study, this is a debate that needs to be acknowledged. It may be more coherent to focus on constructing a measure of experience rather than outcome in this instance. For example Palmer & Miedany (2009) point out the irrelevance of clinician constructed outcome measures to some patients. Their study suggested that physicians taking care of patients with rheumatism focused on hand deformity, counting nodules and affected joints; whereas patients were more concerned with issues such as pain and fatigue. They investigated this further in their next study (Palmer & Miedany, 2010) by showing there was a correlation between ‘self helplessness' and other psychological problems. This suggests that if people had improved ‘self efficacy' (experience) then they may manage other problems (outcomes) better. If this is generalisable, and there is evidence within the cancer literature (Snowden et al, 2012) and the medicine management literature (Jones et al, 2010) that it may be, then there is evidence that patient reported experience is more important than externally constructed outcomes to patients in these cases.

At the extreme of the health measurement debate McClimans (2010) rejects the idea of PROMs altogether. She suggests that the only way genuinely to enquire as to someone’s health is to ask questions we don’t already know the answer to. In this sense she is arguing against standardisation of questionnaires, given that they only provide presupposed information. However, whilst this is a philosophically robust argument, essentially pointing to the limitations of internal validity, it is difficult to maintain an argument against all standardization per se. In a clinical sense it would be hoped that questionnaires and standard tests would only provide part of the clinicians skill set (Benner, 1984). However, they have their place, and despite the shift in government rhetoric from valuing outcomes to recognizing the value of experience, the political desire is still for ‘hard' data (Guyatt et al., 2011). Movement away from this is difficult because of the simplicity and apparent objectivity of quantitative data (Greenhalgh, 2010), and the political pressure to provide evidence of impact across all the health professions remains very strong (The Scottish Government, 2010).

There is therefore a strong pragmatic argument for delivering an outcome measure. We had been tasked with constructing a PROM for spiritual care and therefore that is what we aimed to deliver. The purpose of the PROM was to provide systematic evidence of the activity of chaplains and the consequences of this activity on the patients they saw. The purpose of this project was to provide data that would further support service improvement. Having analysed the existing methodological data it appeared that such a venture may be unattainable from a rational perspective (Gershon et al, 2010), undesirable from a moral perspective (McClimans, 2010), and possibly suboptimal from a clinical perspective (Palmer & Miedany, 2009, 2010). Nevertheless, these claims have to be situated against the real world position that complex organizational development is better supported when grounded in acknowledgement of that complexity (Cribb, 2011).

In summary, the process of attempting to construct a spiritual care PROM was likely to be useful in itself, as many of these issues could be better articulated along the way. This did not require a judgement on the outcome or experience distinction outside the recognition that the distinction
was not clear cut. One person’s experience is another’s outcome. Whilst the clear distinction originating in hip surgery may appear to be a desirable benchmark, in practical terms such clarity is rarely transferable outside equivalently simplistic interventions. In the world of complex interventions the benchmarks are more blurred. Perhaps the most useful indicator came from PROMIS, who consider a range of experiences such as ‘I felt grouchy’ as suitable outcome indicators. In the light of this lead we chose to maintain focus on developing an outcome measure at the offset, whilst maintaining an open mind on the practical aspects of this choice.

These issues will be reconsidered in more detail by considering the evidence generated here in relation to their impact in clinical practice. In other words, the purpose of the Lothian PROM evolved with its development. In terms of process, the literature studied in this section supported the structured approach mirrored in this study. For example Morgan & Farsides (2009) showed that a psychometrically adequate questionnaire needs to be constructed from pertinent themes. Mercer et al’s (2004) Care and Relational Empathy Measure (CARE) was constructed in a similar manner. The next section describes this process in the Lothian PROM.

### 2.2. Construction of the Lothian PROM

#### 2.2.1. Generation of item pool

In order to develop a pilot PROM from the literature review above, we developed statements pertinent to each theme. For example for the theme of control; we translated this into the statement ‘I am in control of my situation’. Statements pertaining to each theme are highlighted in table 2. The assumption underpinning this process was that the statements chosen would have face validity (Sartori, 2009). The last column in table 2 illustrates an example of a comparative statement from an existing validated scale. The purpose of this is to show that the statements are different enough to avoid copyright issues whilst measuring something of the same concept (McDonald et al., 2010; Van Gestel-Timmermans et al., 2010).

<table>
<thead>
<tr>
<th>Theme</th>
<th>Example of citation</th>
<th>Item in pilot PROM</th>
<th>Example validated scale and question</th>
</tr>
</thead>
<tbody>
<tr>
<td>Control</td>
<td>(Farber et al., 2010)</td>
<td>I am in control of my situation</td>
<td>Herth Hope Index (I have a sense of direction)</td>
</tr>
<tr>
<td>Hope</td>
<td>(Van Gestel-Timmermans et al., 2010)</td>
<td>Everything is going to be ok</td>
<td>Herth Hope Index (I have a positive outlook towards life) BDI (opposite: pessimism scale)</td>
</tr>
<tr>
<td>Being listened to</td>
<td>(Ai &amp; McCormick, 2009)</td>
<td>I was listened to</td>
<td>GESS-R (In future I expect that I will be listened to when I speak) Duke-UNC (I get chances to talk to someone about problems…)</td>
</tr>
<tr>
<td>Being understood</td>
<td>(Gonzalez et al., 2011)</td>
<td>My situation was acknowledged and understood</td>
<td>Sources of meaning profile (being acknowledged for personal achievements) Ways of Coping (WAYS) (I accepted sympathy and understanding from someone)</td>
</tr>
<tr>
<td>Being valued</td>
<td>(Hebert et al., 2001)</td>
<td>My faith and/or beliefs were valued</td>
<td>Spiritual Well Being Scale (I believe that God is concerned about my problems)</td>
</tr>
<tr>
<td>Comfort</td>
<td>(Pargament et al., 2011)</td>
<td>I was able to talk about what was on</td>
<td>Social Support Questionnaire (Whom can you count on to console you when you were upset?) Brief COPE (I’ve been trying to find comfort in my</td>
</tr>
<tr>
<td>Theme</td>
<td>Example of citation</td>
<td>Item in pilot PROM</td>
<td>Example validated scale and question</td>
</tr>
<tr>
<td>------------------------------</td>
<td>--------------------------------</td>
<td>------------------------------------------------</td>
<td>-----------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Involved in decisions</td>
<td>(Palmer &amp; Miedany, 2009)</td>
<td>I was involved in decisions about my care</td>
<td>GHQ (I felt capable of making decisions about things) Warwick-Edinburgh Mental Well-being Scale (I've been able to make up my own mind about things)</td>
</tr>
<tr>
<td>Honesty</td>
<td>(Ai &amp; McCormick, 2009)</td>
<td>I could be honest with myself about how I was feeling</td>
<td>CARE (How was the [chaplain] at being honest but not negative about your problems)</td>
</tr>
<tr>
<td>Relief From Distress</td>
<td>(Bay et al., 2008)</td>
<td>My levels of anxiety had lessened</td>
<td>HADS (I can sit at ease and feel relaxed)</td>
</tr>
<tr>
<td>Relevant information</td>
<td>On faith: (Ai &amp; McCormick, 2009) On illness: (Mercer &amp; Murphy, 2008b)</td>
<td>I found I was able to gain a better perspective on my illness</td>
<td>CARE (How was the [chaplain] at: fully answering your questions, explaining clearly, giving you adequate information; not being vague)</td>
</tr>
<tr>
<td>Cope</td>
<td>(Bay et al., 2008)</td>
<td>Things seemed manageable again</td>
<td>[Opposite construct]: BDI screening question (Have you often felt helpless about the future?)</td>
</tr>
<tr>
<td>Peace</td>
<td>(Kannan, 2008)</td>
<td>A sense of peace that had previously not been there</td>
<td>RCOPE (Sought help from God in letting go of my anger [anger is described in this section as ‘an offense to peace’])</td>
</tr>
</tbody>
</table>

Table 2.2 Origins of themes from literature with questionnaire item and comparable item from existing tools

2.2.2. Focus groups and qualitative item review

This first draft was piloted at a national chaplaincy conference in June 2011 and tested for face validity (Nicklin et al, 2010). See appendices for all presentations conducted during this study. In brief, the PROM was reviewed by 40 attendees, mainly chaplains who offered valuable insight into their first impressions of it. The most significant criticisms related to:

1. Whether the questionnaire items represented outcomes or experiences;
2. Whether the items were chaplain specific enough. Ie, comfort, hope and peace could and perhaps should also be provided by other health professionals

The first point relates to the discussion above, and will be reviewed in detail in chapter 4. In regard to the second point, it was widely agreed that we needed to increase the focus on spirituality within the measure.

2.2.3. Galek’s trait measure of spirituality

The choice of spirituality indicators for inclusion in the Lothian PROM was pragmatic. Running alongside our study was a qualitative analysis of the impact of chaplaincy in NHS Lothian, undertaken by 4th year medical student Naomi Howard. Her project involved analysing chaplain referral notes and interviewing patients with a specific focus on these interventions. To this end she had organized her semi structured interviews around Galek et al’s (2005) model of spirituality. Her interview therefore included discussing:
A need to experience love and belonging
A need to live an ethical and moral life
A need to experience beauty, music or nature
A need to feel hopeful
A need for peace and contentment
A need to feel thankful or grateful
A need to find meaning and purpose in life

In order to be able to triangulate Naomi’s data in a coherent manner (Risjord et al, 2002), and indeed for her to use ours, it made sense to adopt equivalent statements into our questionnaire. The trade off for this was that the statements are trait descriptions and not state descriptions and thus not outcomes or experiences. Nevertheless it was felt that the addition of these items meant that a perspective on people’s usual state of spirituality could be correlated with other aspects of the Lothian PROM to see if any of these factors related to their experience of a chaplaincy encounter. This allowed us to gather data to compare people’s spirituality traits with their self reported impact of such an intervention. This would go some way to test whether more or less spiritual people got more or less out of their spiritual care encounter. If any associations were found then these trait descriptions may be useful for chaplaincy referral screening. They could also potentially provide hypotheses for longer term outcomes of spiritual care intervention. The revised version was agreed by the local chaplains following joint discussion 28th September, 2011.

2.2.4. Face and content validity: phase 2

This version was then presented and further reviewed at an international conference on spiritual care in Glasgow, March 2012. As a consequence of feedback from a workshop attended by world leaders in the field of chaplaincy research it was decided also to add a qualitative element to the questionnaire to capture any pertinent data the recipient wanted to add that was not covered elsewhere. The issue regarding whether the questionnaire was a genuine measure of outcome persisted, and the majority felt it may more accurately reflect experience. However, no alternative outcomes were suggested during this discussion, and therefore the initial process of face and content validity culminated with the PROM in figure 2.1.

Three versions of the final draft were created; one for acute care patients, one for mental health patients and one for paediatrics. They are essentially the same in terms of item content, but worded differently according to target group, with some minor variations to demographics. Mental health and paediatric PROM are in appendix 1. Figure 2.1 illustrates the acute care PROM.
Spiritual Care PROM (Acute Care)

Project Identification Number (LP)  

This survey is designed to gain a broader understanding of the impact of Spiritual Care support (Chaplaincy services) in NHS Lothian. Recently you received the support of a chaplain or member of the Spiritual Care Team. We would very much appreciate you answering the following questions about that support.

### Section One

<table>
<thead>
<tr>
<th>Gender</th>
<th>Male</th>
<th>Female</th>
<th>Other</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Age</th>
<th>16-25</th>
<th>26-40</th>
<th>41-55</th>
<th>55-70</th>
<th>71-85</th>
<th>85+</th>
</tr>
</thead>
<tbody>
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</tr>
</tbody>
</table>

**How long were you/was your relative/friend in hospital?**

- Less than one week [ ]
- Between one week and one month [ ]
- Between one month and three months [ ]
- Between three months and six months [ ]
- Six months to one year [ ]
- More than one year [ ]

### Section Two

During my meeting with the chaplain I felt ...  

<table>
<thead>
<tr>
<th>Experience</th>
<th>Not at all</th>
<th>Rarely</th>
<th>Some of the time</th>
<th>Most of the time</th>
<th>All of the time</th>
</tr>
</thead>
</table>

- I was listened to. [ ]
- We focused on decisions about my/my relative’s/friend’s health care. [ ]
- I was able to talk about what was on my mind. [ ]
- My situation was understood and acknowledged. [ ]
- My faith and/or beliefs were valued. [ ]
Section Three

After meeting with the chaplain I felt ...

<table>
<thead>
<tr>
<th></th>
<th>Nor at all</th>
<th>A little</th>
<th>Some of the time</th>
<th>Most of the time</th>
<th>All of the time</th>
</tr>
</thead>
<tbody>
<tr>
<td>I could be honest with myself about how I was really feeling.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>My level of anxiety had lessened.</td>
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<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I had gained a better perspective on my illness/ the illness of my relative/friend.</td>
<td></td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Things seemed under control again.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>A sense of peace I had not felt before.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Section Four

Statements that describe me now

<table>
<thead>
<tr>
<th></th>
<th>Not at all</th>
<th>Seldom</th>
<th>Some of the time</th>
<th>Most of the time</th>
<th>All of the time</th>
</tr>
</thead>
<tbody>
<tr>
<td>I see myself as a spiritual person.</td>
<td></td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>I believe in God or in some Higher Being.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I am a religious person.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I feel a need to experience love and belonging.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I feel a need to find meaning and purpose in life.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I feel a need to be hopeful.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I feel I have something to be hopeful about.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I feel I am in control of my situation.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Section Five

Please add any further comments you wish to make about how the chaplain’s input affected you.

Finally, we are in the early stages of this study and would be interested in hearing how relevant this questionnaire is to you. If you are happy for Iain Telfer to give you a short telephone call to discuss this, please tick this box:

☐ Yes I am happy for Iain to ring me about this questionnaire

My telephone number is:

Thank you very much for completing this questionnaire. Please return it in the stamped addressed envelope.
3. Testing of the Lothian PROM

3.1. Study Design

3.1.1. Method

Ethics

Permission to undertake the study was granted by NHS Lothian Research and Development department and North East Scotland Research Ethics Committee (11/NS/0056).

Participants and process

Data collection ran from May 1st to August 31st 2012. People were eligible for inclusion in the study if they were patients and carers using the spiritual care services in NHS Lothian. People under 16 or with capacity issues were included in this study with the consent of their carers. There were 11 chaplains in all, working in acute care, paediatrics and mental health (both inpatient and community). The chaplains are all members of NHS Lothian Spiritual Care Team and on average discharge 2 people per week, giving a maximum possible participation number of 264.

Protocol stipulated a Lothian PROM questionnaire should be posted to every significant encounter on chaplaincy caseload following discharge from the service. Each PROM was sent out with a participation information sheet, consent form and a stamped addressed envelope. Consenting patients returned the anonymous questionnaire and consent form to Iain Telfer (IT) at The Royal Infirmary of Edinburgh. Chaplains recorded their impression of the encounter on the referral record (appendix 3). The purpose of this was to take the opportunity to compare chaplains’ assessment of outcome with that of the patient/carer.

In order to establish how people interpreted the questionnaire we adapted the PROMIS interview schedule (Pilkonis et al, 2011) to ascertain structured feedback on participants’ understanding of the content and structure of the PROM. IT telephoned consenting participants and asked them about their general views of the PROM and its function.

The final aspect of data collection was with the participating chaplains. A preliminary summary of the results was presented to them in August 2012 and feedback on the process and the results were facilitated, audiorecorded and transcribed for analysis by Austyn Snowden (AS).

Data management

All PROM data was transcribed into a Microsoft excel database by IT and anonymised version exported into SPSS for generation of descriptive and inferential statistics by AS. Qualitative data from the PROM responses was thematically analysed using a framework method (Smith & Firth, 2011). The framework was provided by the items in the PROM. The purpose of this was to identify PROM content associated with particular free text themes, and therefore easily highlight where free text data fell outside this framework. This process was supported by NVivo 9 software.

The feedback from the cognitive testing process was transcribed into word documents. Responses to the questions were saved alongside their respective questions/statements so they could all be analysed thematically in relation to their purpose. The purpose of the thematic
analysis was to ascertain the clarity and range of understanding evident in the responses in order to amend questions in future where necessary.

The chaplain feedback session was transcribed by AS and summarized for themes supported by NVivo 9.

### 3.2. Results

#### 3.2.1. Demographics

Seventy patients and carers were sent the PROM and thirty nine returned the questionnaire, a return rate of 56%, favourably comparable with most postal questionnaire returns (Connon, 2008). Summary demographics show that respondents were mainly women who had been in hospital less than three months (figure 3.1). Thirty responses were from adult, four responses came from paediatric services and one from mental health (figure 3.2).

![Figure 3.1. Count of number of respondents grouped by length of time in hospital bars stacked by gender.](image-url)
3.2.2. Quantitative data

All Likert responses were transcribed into ranked data for statistical manipulation, with 1 the lowest score, equivalent to ‘not at all’ and 5 referring to ‘all the time’. Overall responses to the questions in Section Two were high (figure 3.3). Although none of the items was endorsed at maximum by everybody, some of the items came very close to this, suggesting low discriminant validity of these particular items. Eleven people endorsed every question in this section at the maximum possible score, further suggesting a potential ceiling effect of the questions.

Only 2 people endorsed all the questions in section 3 at the maximum, and the mean response was just under 4 (figure 3.4), suggesting better discriminant validity with these questions. In section 4, the trait questions, only one person endorsed all the questions at maximum. This person had endorsed all the questions at maximum but had not added any additional comments to the free text section, making further analysis difficult in this case. The mean for section 4 was 3.9 with a wider range of response than the other sections (figure 3.5). The items with the lowest mean were ‘I am religious’ (3.49) followed by ‘I am a spiritual person’ (3.78).
During my meeting with the chaplain I felt...

**Statistics**

<table>
<thead>
<tr>
<th></th>
<th>I was listened to</th>
<th>We focused on decisions</th>
<th>I was able to talk about what was on my mind</th>
<th>My situation was understood</th>
<th>My faith/beliefs valued</th>
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<tr>
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*Figure 3.3 Responses to: During my meeting with the chaplain I felt...*
After the meeting with the chaplain I felt...

![Graph showing responses](image)

### Statistics

<table>
<thead>
<tr>
<th></th>
<th>I could be honest</th>
<th>My anxiety lessened</th>
<th>Better perspective</th>
<th>Things under control</th>
<th>Sense of peace</th>
</tr>
</thead>
<tbody>
<tr>
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<td>37</td>
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<td><strong>Mean</strong></td>
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</table>

*Figure 3.4 Responses to: After the meeting with the chaplain I felt ...*
Statements that describe me now.

Statistics

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<th></th>
<th>Spiritual person</th>
<th>I believe in God</th>
<th>I am religious</th>
<th>Need to experience love and belonging</th>
<th>Feel a need to find meaning and purpose</th>
<th>feel a need to be hopeful</th>
<th>feel I have something to be hopeful about</th>
<th>I feel in control</th>
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</thead>
<tbody>
<tr>
<td>N</td>
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<tr>
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<td>1</td>
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<td>5</td>
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</tr>
</tbody>
</table>

Figure 3.5. Statements that describe me now
3.2.3. Qualitative data

Twenty nine of thirty nine people provided free text comments in section 5, and this provided data for thematic and concurrent analysis which will be detailed in the next sections. In brief people largely took the opportunity to thank the chaplains for their input and support. The specificity of this support entailed the ability to distinguish chaplain skills from other NHS staff and the importance of this.

Thirteen people responded to the request for telephone feedback on the structure and function of the questions. In order to ascertain the patient perspective of the PROM questionnaire we adapted an interview schedule kindly emailed to us by Pilkonis et al (2011) for the purpose of gaining systematic feedback on face validity at this stage of PROM development. What follows is a summary of responses given to IT in July and August 2012.

Q. Can you tell me what your overall impressions of the questionnaire were?

Most responses were straightforwardly positive:

- Pretty clear …easy to understand
- Seemed positive / good quality / a spiritual person so good to have that affirmed in a non-religious way
- Perfectly reasonable / logical thing to do / can understand interest in knowing whether this kind of support is working
- Quite reflective, with regard to things looking for from chaplain because clear what I needed from a chaplain

The addition of section 5 was mentioned specifically by two respondents:

- Pleased to have additional comments space – didn’t take too long to complete – not off-putting – very good balance in questions
- Appreciated a place for additional comments

The more critical responses pertained to the personal relevance of particular outcomes and circumstances:

- Some of options not best for describing benefit of service, e.g. not necessarily ‘more at peace’ but still very helpful to have seen chaplain – but doesn’t necessarily help in the sense of changing things

However, having spoken to the person IT’s understanding of what she was saying was that she had appreciated contact with the spiritual care service and the chaplain whom she had seen. Answering a questionnaire did not, however, fully encapsulate the benefit experienced. For example, feeling ‘more at peace’ was not always an obvious outcome. Yet, that did not detract from the value of spending time with the chaplain.

Also, when she said that seeing the chaplain didn’t necessarily result in a dramatic change in her circumstances, nonetheless, she did feel strengthened in her resolve to live within the limitations her experience places upon her. She went on to say, in fact, that “for me, the support of the chaplain is one of the essential elements in my…care.”
The two other critical comments entailed a query related to its complexity (although this didn’t personally apply) and an important point about the need to clarify the target group in the questionnaire:

Maybe a bit complicated (not for me) but for others (if I was just an ordinary person) – a wee bit long (if I had been a wee woman sitting in her house on her own)

Not entirely relevant because did not consider myself as ‘ill’ but made me realise the service is and should be available to all – a wonderful service

On the whole it was clear that the questionnaire appeared understandable and broadly pertinent, further clarified by general positive response to the follow up question:

Q. In your own words, can you tell me what you understood it to be about?

Six people simply affirmed that the purpose was clear, with statements such as ‘to get feedback on the spiritual care service’. A couple of respondents went further, clearly situating the need for such a venture in wider organizational context, and in one case spelling out the potential importance of it in raising the profile of specialist spiritual care in NHS:

Value of chaplaincy service to patients – hope for it to lead to increased awareness / presence in wards because patients not always aware of how to approach and get support (treading a careful (precarious?) path in NHS) – feel service needs more publicity

Looking for affirmation of worthwhile nature / value of service – wanted to say how worthwhile it was for us; as well as recognising that organisations like NHS place great emphasis on being able to improve the service they offer.

The next question focused in on personal relevance of the PROM

Q. Did you find the questions personally relevant?

The responses to this were almost unanimously positive, with two people in particular going into more detail on why they were relevant:

Section Two very good because really important and because [chaplain] completely listened to us – found it emotional to think back but nice to do that – easy reading

Especially questions about ‘control’ and ‘meaning and purpose’ because I struggle with these things and only speak about these with a chaplain

The only critical comment was difficult to interpret because the follow up questions did not offer clarification:

There is a discrepancy between the comments asked for and answers that are not always positive

Q. Can you give me an example?

More succinct questions about the service – what particular aspects of the service are worthwhile – e.g. a must in ICU

The next questions focused on the general relevance of the PROM and the ease of completion. These questions were all answered positively with the following exceptions:

Q. Did you feel any part of the questionnaire was not relevant?

Some of the questions seemed to be addressed to someone with faith
Because I did not regard myself as ill or terminal, not all the questions seemed relevant

Q. Can you give me an example?

Recognise that some sections will be more relevant to certain people depending on circumstances and, that there is a need to be all-encompassing / adaptable – I think you achieved that

Q. Was it easy to complete?

This question was uniformly positive, with one person suggesting more questions would have been appropriate:

Language appropriate and accessible
Worded well – not overpowering
Maybe, why not more questions, because such help from [chaplain] – really grateful for
Terribly well put together

The final question asked if the questionnaire made sense, and again this was answered in a uniformly positive manner. As with the free text comments in the PROM itself the bulk of the feedback came from giving people free reign to comment:

Q. Is there anything else you would like to say before we end the interview?

The vast majority of these responses entailed further expressions of gratitude, reinforcing the important and valued work of the chaplain pertaining to the facilitation of peace as a function of a non medical perspective, but not further informing the question of PROM validity:

Hope people appreciate what you (chaplains) do - meant a lot to us from first time we met (in a state of shock) – brought a sense of peace

Your role is greatly valued – people may not come forward but if it is suggested it is very helpful – appreciated the support of a non-medical person and the chance to address the bigger questions of life

However, some comments did hint at further improvement that could be made. For example in line with the earlier comment on target group one person talked about the need to specify the demographics better:

Maybe ask more specific questions to clarify whether illness or accident ...a box for particular circumstances? Had no concept of range of service chaplains could be drawn into – very specific – ? mostly during negative experiences of life – support for friends and family – for us, a very positive experience

Four respondents recognized the difficulty in targeting chaplaincy care, and talked about the difficulty in identifying and delivering spiritual care in general. They articulated the specialist skills of the chaplains, the personal necessity of them, and the complexity of marketing a service such as this to the non religious. These themes will all be returned to:

Nurses are good at talking in ICU but, the distinction between clinical and spiritual is important, i.e. the value of the non-clinical person on the unit – someone who is able to pull you aside in a room and offer the kind of comfort in the idea that the spirit of the person lives on (things not so bleak) – would be astonished if threat to service –
perhaps use of word ‘chaplain’ not always easy for non-religious person to identify with – issue of how a unit like ICU offers this service to the non-religious – ? some kind of counsellor / hybrid

Question regarding how staff identify the spiritual needs of patients – occasions when not done very well – ‘as if it doesn’t really matter’ – offering spiritual care is an opportunity when people are up against it – cannot speak highly enough of [chaplain] – lifted me up again when I felt God had deserted me – chaplain very important when people are sick – I am extremely grateful because I thought I was dying

Tried to explain that for me, spiritual care support is one of the essential elements in psychiatric care – for a long time I was ignorant of the existence of the service – my CPN is not Christian and had assumed I was receiving that kind of support from church but because of ignorance about mental illness, I wasn’t, at least not all of the time. So there was a void in my life. It was my psychiatrist who suggested chaplaincy two years ago – I have since found the support really helpful. Box on admission remained blank because don’t like the term ‘religious’ – raises questions about staff perceptions of patients’ needs and the spiritual care service

Service and its availability need to be publicised and awareness raised (clerking in process could be improved in this regard) because sometimes patients not been in hospital before; so do not realise support provided by spiritual care and, that chaplains can be a source of immense help. Also need to publicise Sanctuary space more – about raising profile

The final practical comment reinforced the importance of having free text comments in the PROM:

Free text space very important to enable responses not covered by questions or, to elaborate on answers already given

Finally, 8 participating chaplains attended a focus group to discuss the findings of the study in August 2012. These findings will be discussed at the end of the analysis chapter because the focus group followed a presentation of the findings discussed in this next chapter.
4. **ANALYSIS**

This section analyses all pertinent data gathered in this project. It first analyses the numerical data in order to ascertain patterns and future potential hypotheses. It then thematically analyses the free text data in order to offer a deeper explanation for the patterns found in the quantitative data, and to generate further hypotheses. In particular it seeks to identify areas of importance in specialist spiritual care intervention that were *not* covered in the existing PROM items. It briefly analyses the feedback provided by people who completed the questionnaire in order to discuss the face validity of the PROM. There is then a more detailed reflection on the coherence between chaplains’ records of their interventions as reported on their referral records, and their patients’ reports of the intervention(s), as reported in the free text comments on the PROM. The almost universal agreement between these accounts is important and unusual evidence, and raises important questions for future study. The final section analyses the outcome of a focus group designed to ascertain chaplains’ reflection on the feedback of these results. The chapter concludes by synthesizing the main findings for contextual discussion.

4.1. **Quantitative data**

The small number of returns raises the real probability that the sample was unrepresentative of the larger population of patients seen by chaplains (Streiner & Norman, 2008). The following analysis is therefore predicated with the warning that any claim needs to be substantiated in future studies. This section will first analyse the responses to section 2 of the Lothian PROM (figure 2.1), the description of the spiritual care intervention, in order to reveal the salient aspects of these responses. Trends will be discussed and individual questions and responses highlighted where appropriate. It will then do the same with the section 3, the outcome responses. Section 4 will be analysed in a similar manner. The findings will be contrasted with the free text comments in the subsequent section in order to offer further explanation for the developing analysis.

The most striking initial impression was the overwhelming positive response to the patient descriptions of chaplaincy intervention in section 2. This is problematic psychometrically because it means these questions fail to distinguish differences in the quality of the experience between people (Streiner & Norman, 2008). This could be a function of ‘yeah saying’ because none of the items was reversed (Knapp et al, 2009). Nevertheless on face value the results showed that people felt listened to, able to speak about what was on their mind, had their situation understood and their faith valued. The maximum possible score for each item was five, and minimum was one. All of these 5 items scored above 4.74 on average with 3 items scoring above 4.9, suggesting almost universal endorsement of these questions.

The only exception to this in this section was ‘we focused on decisions’, which still scored very highly at an average 4.15. Four people omitted this question, the most omissions in this section, suggesting it may have been the least relevant (Streiner & Norman, 2008). However, even with this proviso the results are an impressive testament to the skills of the chaplains as perceived by their patients. Patients reported that the chaplains listened, put the person at ease so they could both agree on what was important, and valued everyone’s faith, regardless of what it was. Whilst they focused on decisions as well, this was clearly not the most pertinent aspect of the chaplain...
visit. This supports analysis that the chaplains entered the individual discussions with no preconceptions and that this was highly valued by people. The free text comments further support this conclusion and will be discussed shortly.

Section 3 explored the impact of the chaplain’s visit on various mental states. The results showed a high level of satisfaction with all these outcomes following chaplaincy intervention. Moreover, the results are not so high as to create the ceiling effect notable in section 2 (Streiner & Norman, 2008). To this extent they are more psychometrically useful, whilst still indicating considerable success. ‘I could be honest’ averaged 4.44, with a minimum individual score of 3. This was also the question in this section that was answered by most people, with only 2 missing it. This suggests that honesty was the most consistently valued outcome of spiritual care intervention. This makes sense given the findings of section 2. To the extent that the chaplain can be seen as fulfilling the need for people to be listened to and valued regardless of faith, then being honest with oneself could be predicted as an outcome of facilitating this environment.

To examine this issue statistically Spearman’s rho was calculated for correlations between the items in sections 2 & 3. On the left of table 4.1 are the items from section 2. Across the top are items from section 3. The intersections identify the value of Spearman’s rho, a correlation coefficient utilized to ascertain significant connections between variables. The cells that contain stars indicate significant correlations. This means that there is a likely connection between for example being listened to and having reduced anxiety.

<table>
<thead>
<tr>
<th>Spearman’s rho</th>
<th>I could be honest</th>
<th>My anxiety lessened</th>
<th>Better perspective</th>
<th>Things under control</th>
<th>Sense of peace</th>
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<td>I was listened to</td>
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* Correlation is significant at the 0.05 level (2-tailed). **. Correlation is significant at the 0.01 level (2-tailed).

Table 4.1 Item correlations: sections 2 & 3

As mentioned table 4.1 shows that ‘I was listened to’ was correlated with a ‘my anxiety lessened’ in this sample. ‘We focused on decisions’ was also associated with a lessening of anxiety, as well
as gaining a ‘better perspective’ and a ‘sense of peace’. ‘I was able to talk about what was on my mind’ was strongly associated with all the outcomes, whereas the opposite was true of ‘my situation was understood’. Having ‘my faith/beliefs valued’ was associated with a ‘sense of peace’.

These findings can all generate causal hypotheses for further study. For example the clearest association was between being ‘able to talk about what was on my mind’ and all of section 3. This strongly suggests that being able to talk about what is on my mind is of prime importance. Future studies could be designed to test the prediction that being able to talk about what is currently important would lessen anxiety and give a sense of control and peace. The value of testing this as a causal hypothesis is that if corroborated would then empirically demonstrate the value of creating the conditions to facilitate this process. This would value the skills of chaplains (and others) in facilitating the conditions for allowing people to talk as an end in itself. This will be discussed further in the next chapter in relation to the ongoing debate about whether outcomes can and should be differentiated from experiences for the purpose of health improvement measure.

The trait descriptions in section 4 nicely illustrated the diversity of the sample in relation to their beliefs. All of the items generated a large range of responses with five of them entailing at least one response at each extreme. As far as patterns within responses were concerned some people were spiritual but not religious. Many believed in God but not all the time. Others felt no need to experience love and belonging or any need to feel hopeful, despite feeling they had something to be hopeful about. The main summary of this section is therefore that people interpreted these questions in a unique manner in that no two set of responses were the same.

However, it was noted that there were patterns within the trait question responses. Factor analysis seeks to expose underlying factors in order to explain linkages between patterns of responses. In other words although there were 8 questions in this section, it may be that a smaller number of factors were actually being measured. Principal component analysis (Streiner & Norman, 2008) of the 8 trait questions in section 4 revealed three distinct factors. This suggests that one question may suffice to capture the factor underpinning being religious, spiritual and/or believing in God. One question may capture the need to find meaning and purpose, and a final question may be all that is needed to describe locus of control. The benefit of such reduction could be a further shortening of this section of the tool, thus making it quicker and less onerous without losing validity. This is how PROMIS operate. As with the analysis above, the next phase of validation would require confirmatory factor analysis in a wider population.

In order to examine whether any of the traits in section 4 were associated with any outcomes in section 3 Spearman’s rho was calculated as above. Only 6 significant correlations were obtained out of possible 40, which is not much higher than would be expected by chance (Cabin & Mitchell, 2000), so further speculation needs to be treated with caution. The three strongest correlations (P<0.01, and therefore less likely to be obtained by chance) associated:

1. ‘I feel in control’ with ‘things are under control’ and,
2. ‘I feel I have something to be hopeful about’ with ‘things are under control’.
3. ‘able to talk about what was on my mind’ and ‘I feel in control’.
These associations would suggest that it may be important for chaplains to assess the necessity for people to feel in control within their interventions. Psychological theories of internal and external locus of control could be useful here to further develop this particular hypothesis (Snowden et al, 2011), given the relationship between spirituality and control is complex (Ai et al, 2005; Holt et al, 2003). It would suggest that chaplains may benefit from establishing the individual need for control at any particular time.

However, perhaps the most important point is that this sample is so diverse. It was hoped that this trait description section could be considered as a potential pilot screening tool for identifying prospective clients of chaplains, or possibly an identifier of putative long term spiritual care outcomes. To this end it could be hypothesized that the need for control, or deviation from normal state of control could identify those in need of referral to the spiritual care service. Likewise, the resolution of control issues may be seen as a desirable long term outcome. However, little can be generalised from these correlations in relation to who benefited most from a specialist spiritual care intervention. They all did. To this extent the results would suggest that benefits of specialist spiritual care should be available to all.

<table>
<thead>
<tr>
<th>Correlations</th>
<th>Spiritual person</th>
<th>I believe in God</th>
<th>I am religious</th>
<th>Need to experience love and belonging</th>
<th>Feel a need to find meaning &amp; purpose</th>
<th>feel a need to be hopeful</th>
<th>feel I have something to be hopeful about</th>
<th>I feel in control</th>
</tr>
</thead>
<tbody>
<tr>
<td>I could be honest</td>
<td>Correlation</td>
<td>-.045</td>
<td>-.186</td>
<td>-.143</td>
<td>.162</td>
<td>.039</td>
<td>.129</td>
<td>.338</td>
</tr>
<tr>
<td></td>
<td>Sig. (2-tailed)</td>
<td>.799</td>
<td>.277</td>
<td>.413</td>
<td>.345</td>
<td>.820</td>
<td>.452</td>
<td>.044</td>
</tr>
<tr>
<td></td>
<td>N</td>
<td>34</td>
<td>36</td>
<td>35</td>
<td>36</td>
<td>36</td>
<td>36</td>
<td>36</td>
</tr>
<tr>
<td>My anxiety lessened</td>
<td>Correlation</td>
<td>-.122</td>
<td>-.020</td>
<td>-.002</td>
<td>.118</td>
<td>.256</td>
<td>.156</td>
<td>.372</td>
</tr>
<tr>
<td></td>
<td>Sig. (2-tailed)</td>
<td>.484</td>
<td>.908</td>
<td>.991</td>
<td>.491</td>
<td>.132</td>
<td>.365</td>
<td>.023</td>
</tr>
<tr>
<td></td>
<td>N</td>
<td>35</td>
<td>37</td>
<td>36</td>
<td>36</td>
<td>36</td>
<td>36</td>
<td>36</td>
</tr>
<tr>
<td>Better perspective</td>
<td>Correlation</td>
<td>-.145</td>
<td>-.011</td>
<td>.072</td>
<td>.045</td>
<td>.139</td>
<td>.121</td>
<td>.368</td>
</tr>
<tr>
<td></td>
<td>Sig. (2-tailed)</td>
<td>.415</td>
<td>.948</td>
<td>.681</td>
<td>.798</td>
<td>.427</td>
<td>.488</td>
<td>.027</td>
</tr>
<tr>
<td></td>
<td>N</td>
<td>34</td>
<td>36</td>
<td>35</td>
<td>35</td>
<td>35</td>
<td>35</td>
<td>35</td>
</tr>
<tr>
<td>Things under control</td>
<td>Correlation</td>
<td>-.195</td>
<td>.053</td>
<td>-.034</td>
<td>.113</td>
<td>.265</td>
<td>.170</td>
<td>.451</td>
</tr>
<tr>
<td></td>
<td>Sig. (2-tailed)</td>
<td>.269</td>
<td>.758</td>
<td>.844</td>
<td>.518</td>
<td>.124</td>
<td>.328</td>
<td>.006</td>
</tr>
<tr>
<td></td>
<td>N</td>
<td>34</td>
<td>36</td>
<td>35</td>
<td>35</td>
<td>35</td>
<td>35</td>
<td>35</td>
</tr>
<tr>
<td>Sense of peace</td>
<td>Correlation</td>
<td>.155</td>
<td>.321</td>
<td>.308</td>
<td>.053</td>
<td>.147</td>
<td>-.010</td>
<td>.081</td>
</tr>
<tr>
<td></td>
<td>Sig. (2-tailed)</td>
<td>.373</td>
<td>.053</td>
<td>.068</td>
<td>.760</td>
<td>.391</td>
<td>.956</td>
<td>.634</td>
</tr>
<tr>
<td></td>
<td>N</td>
<td>35</td>
<td>37</td>
<td>36</td>
<td>36</td>
<td>36</td>
<td>36</td>
<td>36</td>
</tr>
</tbody>
</table>

**. Correlation is significant at the 0.01 level (2-tailed).
*. Correlation is significant at the 0.05 level (2-tailed).

Table 4.2 Item correlations: sections 3 & 4

4.1.1. Free text data

The free text data was particularly useful in contextualizing the quantitative findings and identifying potential issues with its validity. One of our main aims had been to balance brevity of
the questionnaire with broad utility of the responses (Knapp et al., 2009). In order to ascertain our success in this venture we thematically analysed the free text, and then contrasted this analysis with the theoretical framework of the questionnaire. The purpose of this was to identify coherence and incoherence, in particular identifying issues that had been missed entirely from the questionnaire so we could amend the next iteration of the PROM accordingly. The main themes identified in the free text data were:

1. The significance of religion,
2. Unmet needs in routine hospital care,
3. Grateful recognition of the unique skills of the chaplains (the ‘guide through the gruesome’),
4. The need for a sense of peace in the midst of a stressful time

As ever, comments underpinning these themes are interrelated. Some were contextual, others about skills and a few pertained to outcomes. However for ease of discussion the themes will be discussed in turn.

The significance of religion

Three respondents felt the need to describe the importance of their religious needs in this section, referring to the chaplain as a source of meeting these needs. Examples are given below.

*As a Christian my need was totally met by the chaplaincy person who read from my Bible for me as I was not well enough to do this for myself. This was the greatest service that they could do for me.* (A5)

*I have been a Christian since I was youngster and old enough to understand. We talked about family; she asked how my son was coping with situation. She was very kind and I valued her visits immensely. I think it is a wonderful service.* (A6)

*I have an excellent CPN, but she is not familiar with Christian beliefs and experiences even though she sees the value of them in my life. [Chaplain] has an understanding of both.* (MH2)

Conversely religion was not significant in many encounters. For example one participant spoke of the functional benefits of the chaplains regardless of their faith:

*[Chaplain] was very patient with us and took time to explain and offer suggestions as to how we could respectfully mark the birth of our baby boy and the loss of his twin. [Chaplain] was very respectful of our beliefs and wishes.* (A32)

This snapshot of the obvious importance of the service to people of different faiths would suggest that screening referral to the spiritual care service using faith alone would be appropriate for those of religious nature, but would exclude people for whom the service is clearly very valuable. That is, chaplaincy is an essential service for religious people, but just as important for the non-religious. This is consistent with the wider literature and also the conclusion of the analysis of responses to section 4. Chaplains are clearly equivalently valued in all these examples. This could further explain why religious or spiritual conviction failed to strongly correlate with any of the responses in sections 2 and 3 of the PROM. In psychometric terms, religion is sensitive but not specific to the need for specialist spiritual care.
The unmet needs of routine hospital care

Participants referred specifically to unmet needs in hospital, and the personal importance of these, by delineating these needs from medical/clinical care:

*I most enjoyed having someone non-medical to talk to and the support of her prayers.* (P5)

*[Chaplain] has an understanding of both [illness and spirituality], but she makes it clear that she is not there to address my illness, more to give me a listening ear and she does make helpful suggestions, which I can use. She was especially helpful during an extended period of absence from church.* (MH2)

These comments point to a distinct and necessary service uniquely delivered by chaplains in these cases. Perhaps a question probing the extent to which people believe medical staff are able to meet all their needs may be useful to identify those people in greater need of spiritual care intervention and hence referral. The fact that these free text comments were made could suggest that the questionnaire had not captured this adequately. This will be discussed further in the next chapter.

Grateful recognition of the unique skills of the chaplains (the ‘guide through the gruesome’)

Many people who added free text were grateful for their treatment and so took this opportunity to express that gratitude:

*I always felt that while my mother had [chaplain] looking after her spiritual needs, she had a good friend and, if I was perfectly honest, an angel on earth to look after her. I can’t really give anyone higher praise than that!* (A2)

*[We] decided to get our son ...christened when he became very ill, the nurses organised for the chaplain to come and it was all done with such ease and grace at a time of utter despair for us. So I can’t thank him enough for the peace of mind he has given us now knowing [our son] was christened before he passed away.* (P6)

The gratitude expressed often entailed describing the skilled presence of the chaplain (‘ease and grace’) in guiding them through unknown and unwanted times (despair), summarized eloquently by A10:

*[Chaplaincy is] a vital service which is a must in that most gruesome environment of the intensive care ward* (A10)

This recognizes that a guide is essential to navigate people through the harsh environment of serious illness (Kelly, 2011), and in the case of P6 the nurses recognized this and organized a chaplain visit. In this case the act of christening was something only chaplains could do, so referral in this case was quite straightforward for the nurses to recognize. Other cases are not so clear cut. Intensive care nurses are known to become less sensitive over time to the emotional nature of the environment (Bakker et al, 2005), thus raising the possibility that they may be less able to recognize when onward specialist referral may be appropriate. The description of intensive care as ‘gruesome’ by A10 conjures unpleasant images of alien surroundings and thereby contextualizes the requisite specialist skills of chaplains working there. For example one
respondent referred to the chaplain’s timing as ‘just the right call’, suggesting important sensitivity to that person’s individual needs. The capacity to intervene without intruding, visit but not overstay was gratefully portrayed by P5:

[Chaplain] was very supportive, friendly a great listener and encourager. She was never intrusive - only helpful. She visited regularly and I always felt she made just the right call with how often to call by and for how long. (P5)

This discussion of time and the importance of sharing it with someone knowledgeable and interested in them was also mentioned:

My time with the chaplain was generally the only time I got to think about myself. (P3)

The chaplain has always listened to me with full attention and seemingly complete recall of our previous conversations... Now I am home I continue to meet occasionally with the chaplain and she always puts my mind at ease. (A14)

This ‘gratitude’ category therefore had many respondents pointing to the unique skills of the chaplains in providing personally relevant, continuous, compassionate and difficult care. The volume of comments suggests that whilst people were overwhelmingly grateful and wanted to articulate this gratitude, perhaps the specialist skills of the chaplains were not adequately articulated in the outcome descriptors within the main body of the PROM. This will be returned to.

**Need for a sense of peace in the midst of a stressful time**

The capacity of the chaplain to facilitate peace was a major theme. Peace of mind and comfort were significant outcomes of a successful spiritual care intervention:

My conversation with the chaplain helped me find a sense of peace and the naming ceremony for my daughter and her funeral were of great benefit to me, my partner, our son and my best friend. It helped us all grieve for [her] and even though the pain is still very raw I know she is at peace. (A13)

I can’t thank him enough for the peace of mind he has given us now knowing [our son] was christened before he passed away. (P6)

We met with [chaplain] a few times during our stay at the Infirmary...He composed a beautiful reading and performed a sincere and poignant blessing for our babies and this really helped my husband and I to get through a very difficult time. We really appreciated [his] support during our stay and were very grateful to him for making time for us - it was a huge comfort. (A32)

Whilst these comments also articulate the skills discussed in the section above they are illustrated here to show the endpoint of these interventions. In these cases the outcome of the specialist spiritual care interventions was peace and comfort from potentially unbearable times. In one case the outcome was transformational:

My treatment has helped me find who I truly am. Without this treatment, I would never have found the true me. [Chaplain] is a fantastic, special person, who I will always think of. (A11)
From the Lothian PROM perspective, it would appear this last theme is adequately covered in the existing item 'sense of peace'. For example the participants discussed above all scored maximum on the peace question in the PROM. Whilst statistically irrelevant (this would need to be hypothesized and corroborated in a larger sample) it points to consistency between free text and the questionnaire item in these cases. Finding peace is an important outcome of spiritual care.

Case example of all four themes

We would like to finish this section by including the full transcript of one of the responses. We have obtained permission from the writer for this. The reasons are twofold. First, it shows examples of all the thematic categories discussed in this section and is therefore a good illustration of the whole (Toftagen & Fagerstrøm, 2010). Second, it speaks louder than any secondary analysis to the impact of specialist spiritual care:

_The final days of my partner’s life was the most distressing situation of my life. I had no idea how to deal with it or my feelings. The counseling that I received during those final days and in the months thereafter has been immensely helpful. I had also built up a lot of anxiety in anticipation of how her life might end. [Chaplain] was incredibly helpful in ensuring that was able to have those final moments with her and that I could say all the things that I needed to say, without later regret of missing the moment. It was also vital that I was given the reassurance from a non clinical body about how the end would be for [her] and that she would not suffer, which was so important. I have also seen [chaplain] several times in the months since [my partner] has died, with him even visiting me at the Sick Kids hospital where my daughter was staying at the time. I have been through a roller coaster journey of emotions and I am incredibly grateful for his continued support. I have received counseling before under much lesser situations and felt that on reflection this was by far the most effective I have received. I do not follow any faith and although at first I thought the help from a chaplain might be inappropriate for me, it immediately transpired to be irrelevant and [chaplain] seemed to tailor his counseling to suit my life. I am indebted to his help in those final days for [my partner] and wonder how I might ever have survived myself without it. It’s a vital service which is a must in that most gruesome environment of the intensive care ward._

4.1.2. Face validity of the PROM

The feedback in this section was almost uniformly positive suggesting people understood the PROM and found it personally relevant. No specific changes were suggested except to the demographic data, which should further delineate the role of the person filling in the PROM. For example one person said that they were not ill, and could not see where to record this. This does not mean spiritual care is not relevant to them and so this needs to be clarified in any future iteration of the PROM. The main criticisms voiced by respondents related to the wider service as opposed to the PROM, in its failure to systematically identify people suitable for spiritual care. Whilst only 13 people responded to this follow up, it is fair to conclude that they were all positive. Nobody complained the PROM was too long, a common issue with pilot questionnaires (Knapp et al., 2009) and nobody misinterpreted the meaning or purpose of any
of the items within it. The PROM therefore has good face and content validity (Streiner & Norman, 2008)

4.1.3. Coherence between chaplains and patients

For this analysis we included only those comments for comparison where both the chaplain and the participant had independently entered free text comments on the nature of the encounter. The reason for this was that it would be more difficult to infer detail of an intervention from the quantitative responses. Because not all interventions were commented on by chaplains, or free text comments offered by everybody, this left 22 dyads for this analysis, 56% total possible sample.

In order to interpret the text in a consistent manner concurrent analysis was used (Snowden & Atkinson, 2012; Snowden & Martin, 2010). In brief, this method seeks to ascertain analogous links between narrative data for the purpose of identifying meaningful connections across different texts. The data was imported into NVivo qualitative software and each dyad was analysed for analogy, explanation, and strength of connection (Hollins-Martin et al, 2012).

The most striking aspect of this analysis was that the majority of the pairs were clearly in agreement as to the purpose and outcome of the encounter, suggesting considerable coherence between chaplain and patient in these cases. For example 14 of the 22 pairs used identical or closely analogous language to describe the nature of the encounter(s). Below are some examples, first of identical language, then close analogy:

<table>
<thead>
<tr>
<th>Patient free text</th>
<th>Chaplain summary of encounter</th>
</tr>
</thead>
<tbody>
<tr>
<td>I found my meetings with the chaplain greatly beneficial. I always felt at peace and reassured, and these meetings went a long way to help in my recovery.</td>
<td>Journeying with this patient has been a very humbling experience. I believe spiritual care input has been a significant factor in the patient’s continued recovery.</td>
</tr>
<tr>
<td>always feel very supported after meeting with the chaplains</td>
<td>Hopefully the patient felt affirmed and supported and comforted by prayers.</td>
</tr>
</tbody>
</table>

*Box 4.1. Identical language used to describe the outcome*

<table>
<thead>
<tr>
<th>Patient free text</th>
<th>Chaplain summary of encounter</th>
</tr>
</thead>
<tbody>
<tr>
<td>[Chaplain] has an understanding of both [mental illness and spirituality], but she makes it clear that she is not there to address my illness, more to give me a listening ear and she does make helpful suggestions, which I can use.</td>
<td>Being able to talk to me in confidence allows her to analyse and reflect on her situation and come to her own conclusions. My understanding is that the relationship between her mental illness and her spirituality is not something she discusses in depth with anyone else.</td>
</tr>
<tr>
<td>[Chaplain] took time to explain and offer suggestions as to how we could respectfully mark the birth of our baby boy and the loss of his twin.</td>
<td>They were both very focussed on [baby son] without ignoring in any way the loss they were feeling. I think the blessing which included both twins was a healthy thing to do for [the parents], articulating both their hopes and sadness.</td>
</tr>
</tbody>
</table>

*Box 4.2 Closely analogous language evidencing similar description of relationship and outcome*
Sometimes the analogies were more nuanced, with connections evident nonetheless. For example whilst the patient in box 4.3 describes raw pain combined with peace, and the chaplain records this as ‘amelioration of anger’, the pair are clearly both referring to analogous outcomes from the same event.

<table>
<thead>
<tr>
<th>Patient free text</th>
<th>Chaplain summary of encounter</th>
</tr>
</thead>
<tbody>
<tr>
<td>Following my mother’s death he came to her bedside and gave us all words of comfort, which will remain with all the family forever. We used the scripture that he read out at her bedside at her funeral. My mother entered the next stage of her new life with the blessing of the chaplain and for that I am personally thankful. E</td>
<td>I am sure E, her mother and other members of the family appreciated the support [other chaplain] and I gave, particularly the prayers offered. Church and faith meant a great deal to [them]. Along with input from their parish minister who also visited, I think they felt the right things were happening at the end of [mother’s] life.</td>
</tr>
</tbody>
</table>

| My conversation with the chaplain helped me find a sense of peace and the naming ceremony for my daughter and her funeral were of great benefit to myself, my partner, our son and my best friend. It helped us all grieve for [son] and even though the pain is still very raw I know she is at peace. | I would hope that the outcome of this part of my involvement was clarification and reassurance about final act of care processes and possibly the amelioration of some anger. |

**Box 4.3. Analogous descriptions of events and outcomes using different language.**

Sometimes the two parts of the dyad fitted together nicely by the chaplain demonstrating appropriate skills to the situation, thereby implicitly recognizing and meeting the needs of the person. For example in order to benefit from talking, arguably you need a listener. The use of silence is congruous with expressed recognition of a traumatic situation in box 4.4.

<table>
<thead>
<tr>
<th>Patient free text</th>
<th>Chaplain summary of encounter</th>
</tr>
</thead>
<tbody>
<tr>
<td>We talked about my ailments; she was very sympathetic and encouraging. We talked about faith. I have been a Christian since I was youngster and old enough to understand. We talked about family; she asked how my son was coping with situation.</td>
<td>... I feel she benefits from someone taking time to listen to her concerns and offering some support, encouraging her to keep her spirits up.</td>
</tr>
</tbody>
</table>

| [Chaplain] was very sensitive and understanding when dealing with us following the stillbirth of our baby son. I found dealing with (chaplain) very comforting during a very difficult and traumatic situation | I did leave gaps of silence to give the impression that should they wish to take things a little deeper that would be appropriate. I also wanted them to realise that in this contact there was acknowledgement of a devastating loss. |

**Box 4.4 Demonstration of fit between expressed and delivered needs.**

This data showed that chaplains clearly understood their role and function and expressed this in a range of different ways, all of them coherent with the expressed needs of the individual patients they were seeing. In order to investigate any case where this wasn’t evident the data was closely examined for instances where the assessments of patients and chaplains differed. There were certainly two dyads where connections were not obviously as strong. For example it
is not entirely obvious that ‘coping’ and ‘keeping going’ are the same, or that being supportive lessens worry (box 4.5):

<table>
<thead>
<tr>
<th>Patient free text</th>
<th>Chaplain summary of encounter</th>
</tr>
</thead>
<tbody>
<tr>
<td>[focus of intervention] was very much on me and how I was coping, rather than my son</td>
<td>my work [has] enabled her to ‘keep going’ in a tremendously difficult situation</td>
</tr>
<tr>
<td>...he has been so supportive and helpful to both my brother and myself which makes things a lot easier. [He] continues to be a good friend and a very spiritual leader and carer.</td>
<td>[Patient] left with a sense of having unburdened her concerns. In my opinion she left looking less worried.</td>
</tr>
</tbody>
</table>

**Box 4.5 Less clear examples of analogous dyads**

In one case there was clearly no connection at all, because the chaplain had written ‘difficult to assess’. However, on reading the patient transcript it could be argued that this was a coherent claim. In all, the connections between the dyads appeared deeply congruent, and this is potentially of great significance. However, the strength of this claim needs to be contextualized.

It is difficult to conclude too much from these findings for two main reasons. The first is that the sample is small and uniformly positive about the service. We would need a wider diversity of responses to make any general assumptions. The second is that any profession would routinely expect to align their actions with the needs of the service user, and that therefore these results would be expected in any professions.

However, it is widely recognized that in practice this is not the case (Cribb & Entwistle, 2011). For example there is high quality evidence that nurses believe they are practising the principles of person centred care when in fact they are not (Latter et al, 2007). Doctors have different views from their patients on the importance of various factors in relation to medicine taking (Gray et al, 2010), suggesting in these cases their perceptions are at odds with those of their patients. People with cancer often feel misunderstood by their clinicians (Dabrowski et al., 2007), a finding often repeated in other disease focused disciplines. For example clinicians in rheumatology have a tendency to define important outcomes of consultations in relation to counting symptoms in order to ascertain the severity or change in the disease (Treharne et al, 2006). These measures have been shown to be irrelevant to patients who were more interested in other aspects of their health(Kwoh & Ibrahim, 2001). This not only calls into question the clinician defined outcome agenda as a method of ascertaining important health measures, but suggests that if the findings from this section are replicable in a wider sample then chaplains are actually far superior to other professions in actually meeting the needs that are important to patients.

These results may therefore be indicative of an important finding that chaplains meet the needs of their patients in a manner that is unusually coherent and personally relevant. Again, this would need to be tested in a much wider sample, and it could be argued that the significance of this finding, even if corroborated would still beg the question of whether any outcomes had been identified. This argument will be rebutted in the next chapter.
4.1.4. Focus group on feedback to chaplains

The ongoing analysis was presented to 8 participating chaplains in NHS Lothian on 15th August 2012. The presentation is in appendix 4. The subsequent focus group was audiorecorded, transcribed and imported into NVivo for thematic analysis. It lasted two hours and is summarized here in relation to a discussion on the responses to the questions posed at the end of the presentation:

- how the process has been for everyone?
- what criteria did the chaplains use to guide referrals?
- how have chaplains interpreted ‘significant encounter’?
- did chaplains find it difficult to make that judgment?
- might we need to offer more specific guidelines for the future?
- who is the PROM useful for?

Following the presentation there was a sense that the venture had been worthwhile and that it had generated some useful and interesting data. There was a sense in which chaplains regretted not having obtained more data because larger numbers would have been better, and having seen the trends, chaplains recognized there were perhaps instances when they could have sent out more PROMs and added to this evidence base. However, this led on to a wide ranging discussion throughout the focus group about some of the barriers to ascertaining feedback from patients in this way. For example, tension remained for some in sending out forms following on from what were construed as very sensitive encounters. Whilst the chaplains could see the value of such feedback it seemed to challenge somehow the authenticity of the encounter. This was discussed in depth, and a significant finding was that no chaplains ever thought about the PROM during their encounters. This appeared to protect the authenticity and ended as a point to ponder on for future. That is, all the chaplains saw the value of the PROM but remained unclear about the potentially intrusive and counterproductive nature of it. In the words of one of the participants ‘perhaps it may drop through the door of a dead person’. The inappropriateness of this was recognized by all.

A related process based issue focused on the criteria for sending out a PROM as defined in the study protocol. Some chaplains felt the discharge criterion was inappropriate as they may not discharge people for a long time. There was therefore scope for looking at different criteria here. Others were uncomfortable about sending a PROM to someone who was discharged and then may be readmitted, with the associate anxiety that the PROM may in some way change the nature of future interactions. This led to a discussion on the idea of being comfortable with continuous feedback becoming part of everyday practice. Each extreme of this idea was illustrated. Feedback from the patients had clearly shown that patients are aware that all professions, including chaplains, are under increasing obligation to demonstrate efficacy of their interventions. This position was contrasted with an anecdote about a lady who upon discharge confided in the chaplain that she never wanted to see another tickbox paper again. In this case the chaplain rightly refrained from sending out a PROM. Views in between these positions are not so easily understood however, and so a discussion was had on the nature of assumptions, resolved by recognition of the freedom of people to ignore the PROM if they so wish. This does not make assumptions other than that the recipient is free to choose. The consensus of the group therefore appeared to shift towards recognizing the value of giving
patients opportunity to feedback. The timing of giving out the PROM was also discussed, particularly in relation to giving it as soon as possible after the encounter so as to minimize recall bias (Kahneman, 2011).

Discussion about the nature of the data we have collected culminated in a discussion about what sort of data would be needed to demonstrate outcomes. This brief philosophical foray into the PROM/PREM debate finished with a useful discussion on the distinction between specialist and generic practice. It was grounded in a discussion of the increasing skills of palliative care nurses, and the anecdotal observation that they were becoming more competent to deliver spiritual care. This of course needs to be contrasted with the empirical observation of the reasons underpinning burnout in stressful environments such as palliative care. A systematic review found no statistically significant increase in burnout in palliative care compared to other health environments, but Pereira et al (2011) did find that risk factors underpinning burnout in these (and other) environments included communicating bad news, dealing with death and dying, and being uncomfortable in general about communicating in relation to these issues.

In practice local palliative care nurses refer on to chaplains when the patients’ needs are so complex that they can no longer meet them. This would appear appropriate, given the nurses understood when this point was reached, and in light of Pereira et al’s findings this would suggest a burnout protection mechanism for the nurses concerned. In some cases referral is a matter of religion based activity that may appropriately be delivered by the chaplain. However, in other cases the distinction is not so clear cut, and chaplains end up managing complex needs of patients that cannot be met by nurses but are not necessarily religious. The discussion therefore moved to a future iteration of a PROM that could perhaps distinguish and identify these cases.

This ties in to the wider debate on referral processes that broadly conclude this process is not as effective as it should be (Galek et al, 2007). A discussion was therefore held on what criteria would identify such people and in line with other evidence gathered the suggestion was to facilitate that response from people who have had direct experience of specialist spiritual care. Perhaps in the first instance this could be achieved by asking patients on the PROM whether the care delivered by their chaplain could be delivered by anyone else, and if not, why not. This would provide further user based data in order to define the distinction. One of the chaplains pointed out in line with (Jankowski et al, 2011) that she gets much more appropriate referrals from teams of professionals she knows well. There is therefore an educational element to this project, in that the findings need to be widely disseminated in order to clarify better that spiritual care is for all, and that engaging with a spiritual care service is the best way to delineate those for whom it is most appropriate.

This led to an interesting discussion on the skills of chaplains as identified in the PROM. That is, section 2 could be viewed as a grading of chaplaincy competence by others. A specialist graded according to these criteria would listen to people all the time, value their beliefs and facilitate the conditions to encourage them to speak what’s on their mind. The fact that these skills were rated so highly in this population of chaplains suggests specialist level skill. Of course this could only be established by testing other professionals’ levels of these skills and comparing the chaplains to them. Nevertheless this is a testable hypothesis. Given that these are essential skills for a chaplain to possess and specialist status would require a demonstration
that chaplains possessed more of these skills than other professionals, then if corroborated this PROM demonstrates that chaplains are specialists.

Perhaps the most enthusiasm was reserved for the finding that the chaplains and their patients had similar views about their encounters. This information was considered highly valuable from both a personal and professional perspective. On trying to explore the factors underpinning this apparently unusual finding one chaplain suggested that this could be a function of time spent with each person, leading to the testable hypothesis that more time spent would lead to more of a shared language. One of the most striking aspects of the data was that often as discussed above, the chaplain and the patient used the same language. Other explanations were offered for this such as the current trend in mental health to describe all progress as ‘recovery’ (Scottish Government, 2010)(box 4.1). Nevertheless it raised an interesting hypothesis and also pointed to a design flaw. Whilst the data is very encouraging, the demographic data collection could have been clearer. It would have been useful to ascertain the length of the encounter, the number of previous encounters, and the type of relationship in terms of ‘patient’, whether service user, bereaved relative, other relative and so on; only some of which information could be gleaned from the Chaplain Referral Record. It was not always clear how to categorise someone on the current form and therefore some important details and potential variables may have been missed.

4.2. Conclusion

In summary, the focus group was characterised by deep engagement with the findings and a general sense that the findings could go some way to providing systematic data that was highly relevant to them. This participants’ eye view of the project was a particularly useful method of design review and the suggestions made at this stage can be integrated into the next iteration of the PROM.

The quantitative data illustrated correlations between the skills of chaplains and the outcomes of chaplain intervention. In particular there was a strong correlation between the chaplain facilitating the person to be able to speak their mind and the person feeling a sense of peace, control, honesty, perspective and calm. This strong statistical association allows for solid theoretical grounding of any future causal hypotheses.

Perhaps just as significantly, there was an almost total absence of association between any of the ‘statements that describe me now’ and immediate outcome measures following spiritual care intervention. The only exceptions related to feeling in control and ‘I feel I have something to be hopeful about’. The ‘statements that describe me now’ were added to the PROM to make more explicit the spiritual component of the questionnaire. As it turned out these measures were not strongly associated with the majority of outcomes as measured in the Lothian PROM. The interpretation made here is that spirituality as a trait is not a significant factor in gaining benefit from chaplaincy intervention. The qualitative data supports this view in that everyone reported positive outcomes of specialist spiritual care intervention but not everyone reported being either spiritual or religious. In fact these categories (I am religious, I am spiritual) recorded the lowest averages of any question on the PROM. Spirituality was not correlated with positive outcomes to such interventions. Everybody can benefit from spiritual care and
therefore referral criteria that fail to take this into account will fail to deliver a worthwhile service to a significant section of the Scottish population.

The free text data primarily illustrated the value of gathering such data. It contextualized the findings above and provided deep insight into the patient view of the purpose, experience and outcomes of chaplain interventions. It showed that spiritual care was highly valued by these respondents, and that the PROM questions were understandable and appropriate. Any future PROM should retain a free text section and a framework for analysis and feedback. The four main themes articulated the diversity of spiritual needs as discussed above, as well as the skills of the chaplains, the need for peaceful resolution to turbulent times and the need for an expert guide in this. These themes tie in closely with the existing literature on the nature and purpose of chaplaincy, and for that reason are already embedded in the PROM questions. Perhaps the only missing question in relation to outcome pertained to whether anyone else could deliver this service. That is, many free text respondents differentiated what chaplains did by commenting on the need for an opinion or discussion with someone non-clinical or non-medical. However, there was less evidence of exactly what the benefit of this was. The correlations suggest benefit in relation to control, which ties in with all the current policy drives supporting self-management, and the literature suggests a potential benefit to offset burnout in other staff. It would be interesting to add a question probing this in order to differentiate further what is unique about chaplaincy.

The next chapter considers the strengths and limitations of these conclusions and advances hypotheses, contextualising them within relevant national and international work.
5. **DISCUSSION**

This chapter contextualizes the previous analysis by situating it within wider issues related to PROM development in spiritual care. This discussion has three distinct sections.

It starts by situating our findings within comparable relevant research, particularly closely related work such as the community chaplaincy listening project and local qualitative research undertaken by medical student Naomi Howard. This discussion is then broadened further to include international findings related to spiritual care in order to highlight relevant gaps for further research, and best understand the potential practical and professional implications of this work.

The second section discusses the methodological issues that have been associated with this project. It includes a discussion by IT on his experience of functioning in the dual role of researcher and practising chaplain. In light of some of the issues raised by the chaplains in the focus group in the previous section this analysis is particularly timely and adds to the practical and professional implications discussed in the first section. Limitations of the study are detailed here, and as part of this discussion it revisits the issue of whether the Lothian PROM was actually a measure of outcome or experience. To this end it discusses the ‘gold standard’ of PROM development to delineate the Lothian PROM’s methodological assumptions from a widely understood benchmark. We conclude that the distinction between outcome and experience is irrelevant for clinical purposes in this case because the justification for either position entails irreconcilable presuppositions grounded in differing perspectives of what is important to measure. We cite examples from existing clinically useful and valid outcome measures that appear to be measuring experience to support the position that utility should take priority over dogma. The Lothian PROM is useful, which was a primary aim in its development.

The final section discusses the broader political and strategic implications of this position by revisiting the stated aims of the *The Healthcare Quality Strategy for Scotland* (The Scottish Government, 2010). The chapter finishes by suggesting that the data gathered here provides empirical evidence to elucidate person centred care. This is significant beyond the interests of a spiritual care service, as evidence for person centred care is particularly elusive.

### 5.1. Situating the study findings in the local context

Community Chaplaincy Listening (CCL) is a ground-breaking initiative entailing an action research methodology situating chaplaincy within primary care in Scotland. It is a ‘sister’ initiative to the Lothian PROM in that both will dovetail into the next phase of funded research by the Scottish Government.

In 2010 the first community chaplaincy listening project (CCL1) began. This national action research project was piloted in 4 Health Boards with the help of NES and SG funding. It built

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7 See also the principles in *Spiritual Care and Chaplaincy*
on innovative work in NHS Highland, Tayside and Western Isles. Funding enabled some chaplaincy back-fill to be secured and Dr. Harriet Mowat and Dr. Suzanne Bunniss were employed to educate chaplains in action research and help co-ordinate the research itself. Provisional findings from activity in Phase 1 included evidence of:

- Increased self-management, self-worth and confidence in decision-making
- Reduced GP time with patients exhibiting existential issues
- Normalisation of sadness, anxiety and loss of meaning during times of transition and loss
- Potential reduction in prescription costs

CCL2 rolled out the initial project nationally. Eight health boards delivered community chaplaincy listening across Scotland with 15 chaplains and 18 GP practices. In the eleven months between September 2011 and July 2012 250 patients were seen on average for 3 sessions of 1 hour duration. Although CCL took place in community as opposed to hospital patient gender and age mirrored the sample studied in the Lothian PROM almost exactly, allowing for generalization based around these factors. Their description of what happens within the encounters was particularly striking for the comparison with the findings in this study. In brief, chaplain reports on encounters closely mirrored patient reports, suggesting, in line with the findings here, that chaplains deliver person centred care. It is strongly recommended that the full CCL2 report is read in conjunction with this report.

At the same time as the Lothian PROM 4th year medical student Naomi Howard conducted a research project as part of her medical studies. She studied spirituality and chaplains in order to gain a greater understanding of the spiritual needs of inpatients and how well these are recognised and met. She conducted semi-structured interviews with 13 patients who had seen a chaplain. Nursing staff were asked about their perception of patients’ spiritual needs and as in our study the referring chaplain recorded their perceived outcome of the intervention. The main reason for integrating this small study in particular was that it took place in NHS Lothian around the same time as the Lothian PROM. There was crossover between the studies both methodologically, with both studies utilizing Galek’s model of spiritual care, and also with some of the participants.

Data from these projects was integrated into this chapter where salient. That is, the Lothian PROM revealed interesting findings in relation to peoples’ experience of specialist spiritual care intervention. Many of these mirrored existing findings. An important aspect of interpreting the Lothian PROM findings was to situate them within a wider context. This section therefore integrates primary CCL data and data from Naomi’s study in order to illustrate commonalities and differences within the findings. The section then goes on to integrate this discussion into the contemporary international evidence base for spiritual care, although much of the discussion remains focused on UK data, Scottish in particular.

One of the main reasons for remaining focused on Scottish research rather than the wider literature is that much of the wider evidence base remains focused on case studies. These studies offer rich data, but much of this evidence is arguably incompatible with UK culture. For example a national survey of American adults found that 58% pray at least once a day or more

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8 The CCL2 report by Mowat & Bunniss will be available late 2012
often (Pew, 2008) whereas this figure has been estimated at 18% in UK according to White & Ashworth (2007). Just as this means more nurses are likely to welcome the integration of spiritual care into their roles in US, they are much less likely to engage or understand this role in UK (Paley, 2008). Any generalisations therefore have to be made with extreme caution, and to this extent CCL and Naomi’s data are more relevant to day to day practice in Scotland than case study research from US. For example in US the majority wanted to see a chaplain “to be reminded of God’s care and presence” (Piderman et al., 2008). This makes direct synthesis of the international literature difficult because this claim is not transferable to the sample studied in the Lothian PROM.

In order to structure this section in a logical manner the thematic analysis developed from the analysis of the free text in the previous chapter was used to frame the discussion (fig 5.1). The reason for using this method was to integrate and discuss data consistent with this analysis, and most importantly spot where evidence sat outside this framework. This could identify and generate missing PROM items. This method also gave opportunity to develop the analysis started in the previous chapter and consider its meaning in relation to wider evidence. The purpose of this discussion was to consider where different theories, data and methods of evidence gathering may fit in future, and thus identify where the Lothian PROM may be improved in future iterations as a function of this analysis.

![Figure 5.1. Thematic analysis of free text responses/framework for wider discussion](image)

Figure 5.1 shows the themes discussed in detail in chapter 4. Here they are discussed in turn to consider what the wider evidence brings to the future development of the Lothian PROM.
5.1.1. On religion and spirituality

Consistent with the free text discussed earlier there was evidence from Naomi’s interviews and CCL2 that the issue of religion remains a barrier for some on contemplating whether or not to see a chaplain. The quotes are anonymised.

“when [the chaplain] first introduced herself I thought, ‘oh no, here we go’, but she’s never forced religion down my throat...I really appreciate that.”

I’m a completely non-religious person. I would consider myself an atheist. I was at first a wee bit anxious when Dr suggested him, I wasn’t sure I wanted to see somebody like that, for me there had been issues about that...actually being able to speak to that particular person who was a chaplain actually clarified it for me that I had done the right thing...it helped with all that really. (CCL patient)

Religion is discussed extensively in the spiritual care literature, and as discussed is contextualised differently around the world in relation to the local culture. It is the biggest predictor of self referral to chaplains in US (Piderman et al., 2010). It predicts how chaplains act, to the extent that Galek et al (2009) found chaplains exhibited a statistically significant higher rate of prayer with patients from their own religion than they did with patients of different religion. The main finding from the PROM statistics is that religion and spirituality were not associated with outcomes of specialist spiritual care interventions in Lothian. So, whilst all people of faith benefit from religion concordant interventions (Galek et al, 2009), all people in NHS Lothian who saw a chaplain appeared to benefit from it, whether they were religious or not. This brings us to the issue of referral, because referral should be consistent with need, and unlike US where religion plays a larger part in culture, we need to consider what the absence of correlation between spirituality, religion and outcomes means closer to home.

Winter-Pfändler et al (2011) found that in Switzerland head nurses didn’t refer to chaplains in a systematic way and in many cases were biased by their own religiosity. If this is a transferable finding to NHS Lothian, and there is anecdotal evidence from the chaplains that it is, then this would suggest that some clinical staff have an inadequate understanding of the current role, function and hence value of specialist spiritual care. If a nurse does not value religion or spirituality then it may be difficult to understand its value to others. This appears to be the case found in Naomi’s study when she described one patient’s difficulty in getting a referral to a chaplain even when asking directly:

“I don’t think [referral] ever happened successfully, and that’s really hard to deal with. This is such a busy unit...I did ask, but it obviously went in and straight out again”.

It is difficult to infer anything about the motivations, biases or otherwise of the failed referee, but the outcome was that for this person spiritual needs became unmet needs. In order to investigate the issue of referral Naomi gathered baseline referral data in relation to the people she interviewed. She found that most patients had played a significant part in their own referral to the spiritual care service. Four people were referred as a result of ‘chance encounter’ with chaplain on the ward. Of the 6 people referred to chaplains by staff, 3 had been requested by the patients. It is difficult to generalise from this small convenience sample, but the impact of referrer assumptions has been tested more systematically in a larger study. In order to investigate thinking underpinning chaplaincy referral Galek et al (2007) undertook a cross
disciplinary survey. They asked hospital directors from medicine, nursing, social work and pastoral care when they would consider referral. This hypothetical study found that all surveyed discipline directors would refer to chaplains for issues relating to loss, meaning and death. The pastoral care directors also felt referrals for anger, treatment issues and pain issues were relevant, but the others did not. Despite the study being US based the findings are transferable in this case because arguably they relate to common issues: the assumptions of the referrer on the need for referral and a judgement on the capacity of the referred service to meet this need. Galek et al’s findings therefore imply a relationship between presuppositions of relevance (whether or not this includes religion), grounded in the knowledge and culture of the referrer, and consideration of chaplaincy referral.

Referral to specialist spiritual care is therefore generalisably unsystematic. So could the Lothian PROM help? Some method of screening is required. For example it would be inappropriate and unmanageable to invite everyone to see a chaplain when they are admitted to hospital. There are 10.85 WTE chaplains in NHS Lothian and in 2010/11 there were a total of 210,315 people discharged. However it is reasonable to deduce that the people who would benefit from this service (everybody in distress) could be identified better than they currently are. The CCL2 project details reason for referral in its findings and although predictable issues such as bereavement and loss are at the top of this list the issue of identifying people in need of referral remains difficult from a systematic perspective because it entails assumptions on behalf of the referrer. In order to frame the main issue it may be useful to compare the discussion on referral for spiritual care with the discussion on referral for distress management in cancer care.

In the case of distress management clinicians refer people to specialist services (eg psychology, Macmillan Cancer Support) when they recognise distress. However, studies show that clinicians are poor at recognising distress (Campbell et al., 2009). To this end the distress thermometer has been validated as a screening tool for recognising clinically meaningful levels of distress (Mitchell, 2010). The problem is that clinicians do not routinely use the distress thermometer but rather only use it when they suspect someone of being distressed (Snowden et al., 2012). In other words the development of the distress thermometer has done little to change the behaviour of the clinician. This means that there are still likely to be people who are distressed who are not being appropriately referred because the people who need to refer them do not know that they do not know how to recognise distress (Ehrlinger et al., 2008).

In other words screening tools are only useful if they are used systematically within a clear model of how and when to use them. They are a significant step towards systematic service improvement however. It was therefore disappointing that the Lothian PROM did not appear to offer a clear solution for identifying potential referrals. One of the potential problems is related to the assumptions we had to make in our model of spirituality. For example we had grounded the PROM items in Galek et al’s (2005) model of spirituality that may not in retrospect have been measuring aspects of spiritual care interventions important to a UK population. Having said that Galek’s model is an evolution of Narayanasamy’s (1991) deconstruction of spirituality so it is a well established and widely utilised model in healthcare (The Scottish Government, 2009). This may need to be revisited if the results from this study were found to be generalisable. That is, religion, belief in God and even spirituality were the lowest scoring items on the Lothian PROM. In order to develop a better screening tool a future iteration would need to be grounded in a UK model of specialist spiritual care. The Lothian
PROM data can contribute empirical evidence to this process. A UK model of specialist spiritual care requires a UK model of positive outcomes in order to target interventions. Given that peace and control were the most significant aspects underpinning positive experience of chaplaincy, this model may need to consider inclusion of these important outcomes.

5.1.2. Chaplain skills

The skills chaplains demonstrate are also the subject of considerable literature. The benefit of these skills to the recipients is clear:

"It’s not always easy to express yourself; to say what is going on inside. He [the chaplain] helped me do that”.

 Mostly they would just say ‘how are you today?’ They just seemed to find the right questions to get me to open up, talk about things that were worrying me, how I was feeling and giving me strength to carry on. (CCL patient)

 “There’s something about his manner… I always feel quite relaxed after I’ve seen him, it’s like a little quiet time.”

 I just went in... [chaplains] do very little talking, they’ve got this ability to say a bare few words and you are off at a tangent, start to talk. It was her voice too, a very consoling voice, she just was a very nice person.. Yes that ability to get you talking...

(CCL patient)

These quotes from CCL2 and Naomi’s study all point to the positive function of facilitating ‘little quiet time’. This is closely analogous with the free text data and the skills identified in section 2 of the PROM. Participants described chaplains who listened and helped people speak about what was on their mind, just as illustrated here. Section 2 therefore entails strong and useful questions to identify high quality skills in specialist spiritual care.

The literature articulates these skills, often embedded in the narrative style of case studies. These often use metaphor to articulate the togetherness and partnership involved in essentially person centred interactions. For example King (2012) used the metaphor of ‘faithful companioning’ to encompass the essence of the care as he saw it. By contrast 20 years ago Dykstra (1990) used the metaphor of the biblical ‘Stranger’ to describe the chaplain’s role in entering someone’s life at a time of great distress. Edmeads (2007) integrates both when talking about being ‘present to, and with...patients’ (p549), articulating something of the dual roles of witness and companion. He goes on to use poetry to express what he calls ‘hospice language’ (box 5.1). This use of language is interesting when compared with the competence based descriptions of other professions allied to medicine for example(Nursing and Midwifery Council, 2008). To some extent it can be explained with the fact that the chaplain is faced with an increasingly secular society (Paley, 2008), and therefore the need to articulate skills and their relevance has become a matter of more urgency given that the religious aspect of their legitimacy is not necessarily valued by all.
**Box 5.1. Hospice language. A poem by chaplain Andrew Edmeads (Edmeads, 2007) p549**

Twenty-six letters in the alphabet  
Mixed together to make up words  
That explain everything  
So why is it so hard to find the right words?  
This poem is a contradiction  
Words trying to express the inexpressible  
Words count for so little  
In the face of this enormity  
This full stop marking the end of a sentence  
Which is life  
Words dry up and leaving them behind  
Another language is rediscovered  
The forgotten language of tears, a smile,  
Touch - a hand  
On the shoulder, a hug, perhaps even  
silence  
If I dare  
No more words.  
What is needed now is that  
The Words become flesh  
(Andrew Edmeads)

This urgency has been accompanied by a proliferation of case studies, the purpose of which is to

‘advance our individual and collective abilities, learn to better articulate to other disciplines what we do and why/how it is important (i.e., evidence-based care), and build a foundation of multiple case studies for further analysis, theory building, and research.'(King 2011, p45)

This suggests two relevant points to a discussion on the Lothian PROM and its capacity to identify and delineate chaplaincy skills:

1. King doesn’t believe other professionals understand the skills of chaplains
2. After Fitchett (2011), he believes that more case studies are needed to build theory and research

The first point is supported in this study, compounded by the fact that there is limited literature on the efficacy of specialist spiritual care interventions (Jankowski et al., 2011). It is not necessarily true that more case studies are needed to establish this efficacy. This Lothian PROM has been built from a theoretical model and produced very useful data, much of it articulating the skills of chaplains that other people think are valuable. We would argue that there is already enough theoretical data to work with in a practical sense, as evidenced by the absence of any data pointing to skills of the chaplains not already captured in the Lothian
PROM. We would also argue that more Lothian PROM type data is needed to test theoretical models appropriately in practice. This is not to argue against case studies. They stimulate reflection, engender personal engagement and a recognition of the complexity of living with many different points of view (Schlauch, 2012). These are all valuable functions, but case studies are not the best test of the efficacy of specialist spiritual care as King (2011) argues. This requires more systematic evidence of efficacy. The Lothian PROM has articulated the skills of chaplains. They are in section 2:

### Section Two

**During my meeting with the chaplain I felt ...**

<table>
<thead>
<tr>
<th></th>
<th>Not at all</th>
<th>Seldom</th>
<th>Some of the time</th>
<th>Most of the time</th>
<th>All of the time</th>
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<tbody>
<tr>
<td>I was listened to.</td>
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<tr>
<td>We focused on decisions about my/my</td>
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<td>relative’s/friend’s health care.</td>
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<td>I was able to talk about what was on</td>
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<tr>
<td>my mind.</td>
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<td></td>
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<tr>
<td>My situation was understood and</td>
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<tr>
<td>acknowledged.</td>
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</tr>
<tr>
<td>My faith and/or beliefs were valued.</td>
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</table>

5.1.3. **Unmet needs**

"It's nice to have someone else to talk to, other than the nurses who are there to do a job. Someone who sees me as a person, not a patient."

I introduce myself as the hospital chaplain, saying I spend most of my week listening to people. (Chaplain, CCL2)

I’ve not seen one patient at all since she has been at the listening service! (GP, CCL2)

The quote from Howard’s study (top) fits with a general pattern of response that highlighted the value of non clinical interventions when in a clinical environment. This quote is interesting because it implies that person centred care is otherwise not being delivered to this patient. As with the involvement agenda in general there is mounting acknowledgement that person centred care is easier said than done (Cribb, 2011)*. This will be discussed in more detail in the next section in terms of operationalisation of policy and strategy, but for here it is safe to say

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* Cribb is a pharmacist and philosopher. His deconstruction of shared decision making in this citation is an excellent practical deconstruction of the person centred care agenda.
that the Lothian PROM provided evidence that chaplains can mitigate the iatrogenic spiritual harm caused by the hospital environment. For example recall in chapter 3 Lothian PROM respondents spoke about their need to talk to a non medical/clinical person for reassurance, checking information, and most importantly discuss a view of themselves unrelated to their illness. These comments pointed to a distinct and necessary service uniquely delivered by chaplains in these cases.

In order to systematically understand this distinction further we suggest that future PROM iterations might entail a probe question asking the respondent to articulate whether they believe clinical/medical staff could and should be meeting their spiritual needs. The advantages of such information would be twofold. First it would provide evidence to add to the debate on who should be providing this care (Wright & Neuberger, 2012), and how this is articulated in practice. Secondly it would operationalise the current maxim that spiritual care is everyone’s business by finding out what this actually means to people in need of it. Everyone has spiritual needs (Walter, 1997), and it is clear from the free text responses here and CCL2 that clinical staff cannot (and should not) meet some of these needs. This fits with a systematic review that found generic (non chaplain) spiritual interventions failed to demonstrate any improvement in quality of life (Candy et al, 2012).

The data gathered in this study, Naomi’s and CCL2 show it is clear that chaplains successfully meet peoples’ needs, particularly in relation to regaining peace and control,

*I think it’s absolutely a great idea to get somebody in the surgery like that. You know yourself the time you wait for an appointment is too late for some people. He put me at ease made me feel... I couldn’t thank him enough, for what I went in and what I came out.* (CCL patient)

Lothian PROM section 3 recorded positive outcomes in relation to anxiety, honesty, perspective, control and peace. There was no example within the free text data of other specific outcomes that would be worthwhile measuring, suggesting these five outcomes were a meaningful outcome measure of specialist spiritual care intervention. They can also be framed as ‘unmet needs’ if reversed. For example it could be inferred from these questions that before people saw the chaplain they could not come to terms with how they were feeling, they were anxious, did not have an optimal perspective on their illness, felt out of control and in despair. The same items could therefore facilitate referral criteria. For example anxiety, despair, denial, loss of control are relatively easy external signs to spot. If the clinician recognized that the chaplain could impact upon these issues then referrals may become more appropriate. To some extent this links to the screening tool discussion earlier. Because this is cyclic (people will only screen people they think they should screen, and if they don’t understand the criteria then screening doesn’t work), identifying these unmet needs as something chaplains can impact upon will be a significant step.

To some extent these outcomes appear simple, perhaps too straightforward, particularly when contrasted with other attempts to define the outcomes of specialist spiritual care. For example King described outcomes of chaplaincy intervention as pertaining to the themes of ‘Sustaining and Nurturing Relationships’, ‘Religious/Spiritual Struggle’, ‘Valuing of One’s Life and Being Attentive to One’s Core’, ‘Values & Transformation’ (King, 2011). This is entirely consistent with his interpretation of the case study. By contrast Maddox’ (2012) comments in response to King’s
case study are organized about the chaplain’s characterization of the ‘seven parts of the patient’s spiritual profile’ (p33): courage, meaning, psychological issues, courage and growth in facing spiritual/religious struggle, rituals, community, and authority. In other words King’s themes and Maddox’ comments on them do not translate for the purpose of generalizing unmet needs. For this to take place a simpler more generic language is required, fit for purpose. So, whilst some people filling in the Lothian PROM may have been ‘attentive to their core’ others may not have recognized this description at all, yet all could have felt a sense of peace they had not felt before. Feeling a sense of peace is therefore a generalisable expression of outcome wholly consistent with the purpose of a PROM. Section three is an articulation of the meeting of unmet needs by chaplains. The theory underpinning it is strong and nuanced, but not visible in the language. This is as it should be. Case studies and the PROM have different purposes. Both may articulate unmet needs and both are useful. Each may inform the other, but for the purpose of generating generalisable data to inform systematically unmet needs, generalisable language is required.

5.1.4. On peace

"Going in [to the sanctuary] and not seeing anything remotely clinical... for the first time since [my leg] has been treated, I felt completely calm."

This sense of peace was associated with the ease of the chaplain encounter:

"She [the chaplain] was very soothing and calming, easy to talk to... she just listened."

The question in section 3: After meeting with the chaplain I had a sense of peace I had not felt before was arguably the most salient outcome measured in the Lothian PROM. It correlated strongly with three of the skills of the chaplain in section 2: ‘focusing on decisions’, ‘having faith/beliefs valued’ and ‘being able to talk about what was on my mind’. Only one other outcome (‘my anxiety lessened’) also correlated with as many skills as this, although those correlations were not as strong as the associations related to a ‘I had a sense of peace’. This infers that peace (perhaps as a function of lowering anxiety) is a primary outcome of spiritual care, and that chaplains facilitate this by allowing people to talk about what is on their mind. Peace is what people hope to gain as a consequence of seeing a chaplain. Interestingly this was also the only correlation associated with ‘having faith/beliefs valued’. As we saw in the analysis chapter, having faith and beliefs valued was not associated with any of the religious or spiritual trait questions. Therefore it appears that the chaplains facilitated peace in our sample by valuing their beliefs regardless of what they were. This is person centred care.

One person said to me “I thought I had to carry this guilt for the rest of my life, and now I see I don’t”. That happened in one session. (CCL2, chaplain)

The claim for peace being a primary outcome of specialist spiritual care intervention is uncontroversial. It is a significant endpoint in numerous case studies (Cooper, 2011; King, 2011; Maddox, 2012) and appears in most definitions of spirituality (King & Koenig, 2009), often as an outcome of spiritual reflection (O’Connor et al., 2012). In line with the findings in our study Whitford & Olver (2012) found peace to be the most significant factor of a multidimensional model of spirituality in 1000 cancer patients. This is a particularly relevant study as they further found a strong association with quality of life in this sample. The inference is therefore that we are measuring the correct outcome and that this outcome is extremely important to people.
could test this putative causal link between the facilitation of peace and improved quality of life by repeating the study in a larger population and adding a valid measure of quality of life (Lorig et al, 2001; The Health Foundation, 2008). This would also function as a validation study for the Lothian PROM, essentially testing two hypotheses at the same time.

5.2. **Situating the study findings in the wider research context**

This section reviews methodological issues in depth. The idea of active chaplain researchers is part of long term Scottish Government strategy (The Scottish Government, 2009). The section therefore begins by describing the journey of IT through this project. This is particularly relevant for any chaplain wanting to engage further in research as many of the issues raised will be salient. It shows the bumpy road of research from the view of an insider. Whilst the outcomes and reports generated from such projects do their best to appear logical, linear and planned, serendipity and pragmatics have their place, and this section articulates this clearly.

The second part of the section revisits the ongoing issue of whether we have measured outcomes or experience in the Lothian PROM. It does this by contrasting our project with the gold standard PROM development organization PROMIS, and concludes that we have measured outcomes. The final part of this section discusses related limitations of the study but concludes on a positive note, showing how the Lothian PROM can be further developed to obtain the best data to support the changing face of specialist spiritual care in NHS Scotland.

5.2.1. **The chaplain as active researcher: Iain Telfer**

Research continues to be vigorously promoted within the healthcare chaplaincy community in Scotland through the Programme Director for Healthcare Chaplaincy and Spiritual Care within NHS Education for Scotland (NES) and, appointed Research Champions in each Health Board; as well as through the profession's Scottish Journal for Healthcare Chaplaincy.

In December 2010, a new project was initiated by NES to develop a Patient Reported Outcome Measure (PROM) for Spiritual Care to be used within NHS Scotland. It was considered important to include someone actively engaged in the provision of spiritual care as part of the research team. Iain Telfer, a member of the Spiritual Care Team based at the Royal Infirmary of Edinburgh agreed to participate.

Initial conversations took place with healthcare professionals engaged in similar and related projects, in order to gain from other’s experience in the research process. This activity was complemented and guided by a parallel systematic literature review, which amongst other useful articles, identified one which suggested a tested direction of travel for the Scottish project. Clark et al (Addressing Patients’ Emotional and Spiritual Needs: Paul Clark, Maxwell Drain, Mary P Malone, Joint Commission Journal on Quality and Safety, December 2003, Volume 29 Number 12) raise three important questions in relation to patients’ emotional and spiritual needs, viz.

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10 [http://www.nihpromis.org/about/overview](http://www.nihpromis.org/about/overview)
1. Are patients’ emotional and spiritual needs important?
2. Are hospitals effective in addressing these needs?
3. What strategies should guide improvement?

In brief, data analysis had revealed

a) a strong relationship between the degree to which staff addressed emotional/spiritual needs and overall patient satisfaction; and
b) the emotional and spiritual experience of hospitalization remains a prime opportunity for Quality Improvement.

A visit to the United States in March 2011 enabled contact to be established with colleagues engaged in similar PROMs research in Chicago; as well as attendance at the Annual Conference of the Association of Professional Chaplains in Dallas. There, workshop sessions focussed on development of spiritual care provision, in the light of patient-satisfaction survey results (Clark et al being one such), which clearly evidence the benefit to patients whose emotional and spiritual needs are addressed.

Following this exploratory visit, NHS Lothian Associate Nurse Director, Strategic Development commissioned a Lothian specific questionnaire that would provide hard data, describing significant spiritual care encounters with patient assessment of these interventions. The Scottish Government awarded a Grant of £12,500 (negotiated through NES) to enable this development of a PROM to continue, in critical partnership with a parallel project (referred to in this Report), the Chaplaincy Community Listening 2 Project (CCL2). Coincidentally, the Department of Spiritual Care in the Royal Infirmary of Edinburgh had been approached by a fourth year medical student wishing to pursue a limited research project (Student Select Component (SSC4)), on the impact of spiritual care interventions upon patient wellbeing. It was decided the PROMs and SSC4 projects should stand alone but that data from the SSC4, based on qualitative interviews, could be incorporated in this Report.

All members of the NHS Lothian Spiritual Care Team were enlisted to pilot a PROM amongst patients and relatives with whom there had been ‘significant encounters’, in acute, paediatric and mental health settings, over a three month period (February to April 2012). However, in the light of feedback gained at an international conference in March, a substantial amendment to the study protocol was approved, to include a free text section for respondents to add any additional comments; along with a request that participants be telephoned for their reaction to the style and content of the questionnaire. This delayed the start of the project, which subsequently ran from 1st May to 31st July 2012.

The task of the Principal Investigator (IT) was to encourage colleagues to submit referrals of patients or relatives to whom questionnaires were subsequently posted. Participation in the project was entirely voluntary and was indicated by return of a completed questionnaire. Anonymous data was entered into a password protected database before being forwarded to the Chief Investigator (AS) for systematic analysis.

Throughout the entire process the raison d’être and benefit of engaging in such an innovative project were seen as opportunities (1) to gather hard evidence of the impact of spiritual care interventions during the healthcare journey and, (2) for practitioners (chaplains) to enhance
their skills through reflecting upon the feedback gained from people with whom they had been closely involved. Both these aims have been realised.

Some observations on both the process and the results achieved deserve further consideration. Originally, the number of anticipated referrals from colleagues had been estimated at approximately three per chaplain per week; giving a possible total of somewhere in the region of three hundred and sixty (360) over the three month period. This proved to be extremely optimistic, with the actual number recorded being seventy (70). The numbers of referrals by chaplains ranged widely from zero to thirty-one.

Taking these figures at face value raises some interesting questions. Firstly, how helpful the criteria set to guide referrals proved to be in practice. Chaplains had been asked to refer from what they considered to be significant encounters. They were encouraged to use their own judgement regarding the vulnerability of those they might refer. Questionnaires would be sent only upon discharge from hospital; and, no-one with incapacity was to be included in the project.

It is entirely likely other influences were also at work. For example, it was fully expected that chaplains would feel some reticence regarding the project, as none had previously been engaged in this kind of research. Colleagues later reported on having been aware of a bias to protect people’s perceived vulnerability and disordered lives. They were guarded about the possibility of contaminating existing pastoral relationships. This latter concern appeared to be more of a consideration for colleagues in Mental Health, whose responsibilities regularly take them into the community to work with people on a long-term basis.

It may be legitimate to ask whether the extent to which a low number of referrals could be a reflection of fewer ward staff recognising a need to make referrals to the spiritual care service. It may also be worth considering whether chaplains tend to be involved with less people, but with those whose needs are complex and, over a longer time-scale, than anecdotal evidence suggests they were in the past. Were this to be a significant factor, it would throw into question the value of a three-month project of this kind, when some patients’ recovery will take considerably longer.

At least one member of the team was honest enough to say that a reluctance to use the Lothian PROM arose from feeling that some questions seemed irrelevant. Interestingly, one chaplain's reticence to refer a case (that had resulted in considerable involvement and support being given), for fear that being asked to complete a questionnaire would exacerbate a sense of grievance, might well have provided the kind of evidence cited by Clark et al. Namely, that complaints being acknowledged can result in a more satisfactory outcome, often as a direct result of good spiritual and pastoral care.

Proportionately, the number of returns was remarkably high (39) considering the limited size of the project – over 50% (when normal expectation would be 25 – 33 per cent). The positive nature of the returns could be interpreted in a variety of ways, viz. that most encounters chaplains have with patients and relatives are worthwhile; that respondents feel reticent about being critical of the spiritual care service; that the quality of returns was contaminated by the Principal Investigator being allowed to submit referrals to the project (again, respondents might have felt constrained to give positive feedback); that the Likert scale categories did not
facilitate a more varied or honest response; that the free text option afforded the opportunity to describe in detail the benefit of the spiritual care support received.

Although it is readily recognised that such a small sample does not permit unequivocal conclusions to be drawn, the findings do seem to confirm an already widely surmised opinion; that most chaplains appear to provide a quality of spiritual and pastoral care that contributes positively to outcome on the patient journey and, that what chaplains say they do may be evidenced by feedback from those with whom they have meaningful encounters.

The fundamental question whether or not the NHS derives value for money from a specialist spiritual care service is not so easy to answer in the light of findings from this limited study. From the responses to the questionnaire, it is clear that patients and relatives benefit directly from engaging with chaplains and, from their various needs being acknowledged. A refined questionnaire, inviting participants to reflect on specific outcomes related to their conversations with chaplains might identify a likely fiscal benefit more satisfactorily. Also, commitment on the part of chaplains to engage fully with the process, it is anticipated, would generate more referrals and potentially a greater variety of response, leading to a more robust evidence base.

It would have to be said, however, that the most useful element of the feedback received in this project was to be found in the free text where participants took the opportunity to articulate in detail the benefit to them of spiritual care support. This finding adds weight to the argument that it is reliable qualitative research that will best describe the worth of specialist spiritual care.

5.2.2. The gold standard process of PROM development

The Patient Reported Outcome Measure Information System (PROMIS) is a US network of 12 research centres and a statistical coordinating centre. It has been developing item banks and measures for disease specific patient reported outcome measures since 2004, and has received considerable funding from National Institutes of Health (NIH) over this period. In short it has access to considerable resources. For example we mentioned earlier that Pilkonis et al (2011) tested their item bank in 20000 people. The issue for our study was therefore to emulate the PROMIS process of PROM development as far as possible whilst working within our means. What we attempted to do therefore was develop and test a theoretically robust item pool whilst recognizing the methodological implications of the necessary shortcuts taken. The alternative would have been to focus attention entirely on a small aspect of the process. However, this would have assumed ongoing funding for future studies, and we did not want to make this assumption. That is, we wanted to gather the best data possible for this as a potential standalone project. Recall from our introduction:

The credibility of inferences that can be drawn from PROMs is a function not only of the technique of validation but the robustness of the initial conceptual model.

A valid scale is one that allows us to make accurate inferences about someone. What this means in relation to scale development is that rather than arguing which ‘type’ of validity a study supports, the central questions are rather:
‘Does the hypothesis of this validation study make sense in light of what the scale is designed to measure’, and ‘Do the results of this study allow us to draw the inferences about the people that we wish to make’ (Streiner & Norman 2008, p252)

The robustness of the initial conceptual model was demonstrated in chapter 2. The face validity responses from the study participants in the analysis section and the broad agreement on the relevance of the questions to people support the credibility of the model. In short, the conceptual model underpinning the Lothian PROM appeared sound, which supported credible inferences. The model should evolve as a function of the data gathered here, but it was nonetheless robust enough to explain all findings.

However, credible inferences also depend upon clarity about what we intend to measure. This requires a final visit to the outcome/experience debate. We claimed in chapter 3 to be measuring outcomes. This claim was grounded in a philosophically pragmatic argument. It showed that the distinction between outcomes and experience was irrelevant when judged against the quality beacon of utility. This discussion revisits this in the light of our findings to see how it measures up in practice.

5.2.3. PROM or PREM: philosophy

The degree to which something is considered an outcome is a function of ideology. The more fundamentalist view is that outcomes are essentially behaviourist. In Pavlov’s classic experiment the dog heard the bell and salivated. Salivation was therefore the outcome; a behavioural response to the bell. The experience the dog had (becoming aware of the sound of the bell) was irrelevant to the behaviourist. Experience under this view is a cognitive function, operationally unknowable and of limited interest. Even if the dog could self report that it had heard a bell this would be only of intermediate interest to the behaviourist.11

This is a difficult position to sustain because it presupposes that cognitive function is unimportant. This is not how people feel, even if it were true (Gerstenmaier, 2001). Therefore any complex intervention is likely to be mediated by the way a person feels. This is the grounding for cognitive behavioural therapy for example, which bridges the gap between the more mechanistic view of the behaviourist and the theoretical view of the psychoanalyst (Bevan, 2010). In this view experience has a significant role, in that feeling a certain way may be a desirable outcome in itself. So, the difference between experience and outcome depends on ideology. Both behavioural (positivist) and cognitive (constructivist) perspectives entail presuppositions on the nature of outcomes and both are valid within their own logical frameworks. The philosophical language used to analyse these metatheoretical issues entails the interrelated concepts of ontology, epistemology, and methodology (Paley, 2011). These need to be coherent with each other in order to claim internal validity. Box 5.1 uses the contrasting perspectives of positivist and constructivist theorists to illustrate the internal validity of these different paradigms. In brief, if you believe the world is co created by people through the expression and interpretation of language, music and art then you will consider beautiful poetry as meaningful evidence to support this view.

11 It should be noted that Pavlov did not consider himself a behaviourist.
Box 5.1 Presuppositions of paradigms. From Snowden & Atkinson (2012)

It is recognised this summary is a gross oversimplification. However the purpose is to illuminate the philosophical structure of the outcome/experience debate in relation to specialist spiritual care, and this framework is useful to highlight why such arguments cannot be resolved by appealing to the way the world is, because these arguments cannot be externally verified without recourse to a mutually agreeable quality beacon.

An example within the spiritual care literature shows how presuppositions entail the conclusion. Schlauch reviews a case study through the lens of ‘pastoral theology’. This culminates with the claim that internalization of an attitude is the outcome, and that external indicators of this internalisation are less relevant to the pastoral theologian. In his review Schlauch (2012) succinctly describes the process of reducing spiritual care case study data to thematic categories and then identifying these themes in practice so as to create a language for their articulation in a more general sense. The purpose of this language is to recognise where the practice takes place so as to identify its impact. What is particularly relevant to our study is that this description broadly mirrors our approach to data synthesis and function, and so his reflection on what would constitute evidence of the efficacy of such identifiable interventions is worth considering. The important point from a philosophical perspective is that Schlauch concludes that despite noting the presence of observable measures of impact the ultimate outcome is ‘the internalization of an attitude’ (p29). This is the endpoint. Although ‘chief complaints may diminish’, or ‘persistence of painful affect may abate’, Schlauch considers these to be ‘aspects of expressions of internalization’. This is entirely consistent with Schlauch’s representation of a pastoral theological ontology. Because this perspective (ontology) values stories of changes in inner life in what it means to be human (epistemology), agreeing on reported changes in internalization are considered evidence (outcome). Our fictitious behaviourist on the other hand would be entirely disinterested in attitudes whilst claiming reduction of complaints as a measurable outcome.

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The reason this is relevant to this discussion on outcomes and experiences is that we suggest it is unnecessary (and impossible) to reconcile different ontological claims in order to make practical use of empirical data. Whilst we agree it is not necessary to acknowledge the existence of an inner life to recognize that chief complaints diminish, we also recognize the value of the utility of this model in diminishing distress for the person discussed in the case study. We therefore propose that the quality beacon to which we are drawn is entirely pragmatic and a function of ethics (Rorty, 1999). Because the purpose of the Lothian PROM was to improve the service and function of specialist spiritual care this was built into our understanding of what outcomes we should be measuring. Our understanding of outcome therefore needed to evolve with our understanding of what it was that was important to people who saw chaplains. As part of this process we recognized that focusing on outcomes as defined by clinicians is not necessarily the best way to articulate what is important to people (Gray et al., 2010). Utility in the current climate is probably best expressed in relation to articulation of person centred care (Bodenheimer et al, 2005). The Lothian PROM is therefore useful as a service improvement tool, and the outcomes we chose to measure provide data to support this. Reconsider the original question in this light:

*Do the results of this study allow us to draw the inferences about the people that we wish to make? (Streiner & Norman 2008, p252).*

Yes they do, because the results inform us what is important to the people who have been seen by chaplains. These are the inferences that we want to make. These are the outcomes that are important.

### 5.2.4. PROM or PREM: practicality

Possibly of most significance is the fact that the discussion of whether we are measuring outcome or experience is not discussed at all by Pilkonis et al., (2011). This is important here because they are part of the largest development of patient reported outcome measures in the world and considered the following to be ‘outcome’ measures:

*I was grouchy, I stayed angry for hours, I found it hard to focus on anything other than my anxiety, I felt hopeless, I felt like a failure.*

It is probably fair to say that these statements would not be considered outcomes by many.

Figure 5.1 illustrates the range of patient reported outcome measures developed by PROMIS. For example the physical health domain entails PROMs for fatigue, sleep disturbance, physical function. The pain behavior scale records observable displays such as crying or guarding, facial expressions and asking for help. These are probably less contentious outcome measures than those described by Pilkonis as part of the same project. However, whilst physical health is arguably easier to compartmentalize into this view of outcomes note how mental health domain is compartmentalized into affect, behaviour and cognition as described in the philosophical section above. Spirituality has been linked with mental health outcomes but not physical in older adults (Meisenhelder & Chandler, 2002), therefore this distinction may be important.

What is pertinent to this section is that the outcomes validated by PROMIS in the mental health section reflect all of these domains (figure 5.2). For example the anxiety scale asks questions about self reported levels of fear and worry as well as behavioural aspects such as restlessness.
and hyperarousal. The outcome measure for depression actually excludes objective measures of mood such as appetite loss and insomnia in favour of self reported measures of sadness and self-criticism because of the potentially confounding nature of the behavioural symptoms. That is, appetite and sleep problems may not be specific to depression and were therefore not considered by PROMIS as useful for this particular PROM.

This supports the argument in the first part of this section for differentiating item choice in PROMs by their utility. For PROMIS, the largest resource in the world, this does not extend to conflating the function of outcome with experience, as they are only valid in relation to how useful they are.

5.2.5. Limitations of our study

The ‘gold standard’ method of developing PROMs is the PROMIS project. Please see Pilkonis et al., (2011) for a more detailed account. Simply from a resource perspective it can be seen that we had some choices to make in where to follow this ‘gold standard’ model. As discussed previously the intention was to consider the Lothian PROM a standalone project. A different view could have entailed detailed consideration of every step in the PROMIS model. Instead we wanted to
finish the project with preliminary validity evidence and so we made certain assumptions at the beginning of the study based on how best to reach this endpoint.

Perhaps the most significant assumption was the reduction of the outcome items to five at the beginning. That is, instead of generating as many items as possible from our conceptual model of chaplaincy outcomes we instead tried to word questions to measure the factors we had discovered. The justification for this was pragmatic. We wanted to finish with a tool that could be used in practice, rather than concluding with a psychometric analysis of items that should in fact demonstrate the factors that we had intended to measure in the first place. This of course assumes that a) we selected the appropriate factors in the first place and b) the responses are related to those factors and not something else. We cannot guarantee these assumptions are correct.

Another limitation was the time frame associated with both the wording of the questions and the filling in of the questionnaire. PROMIS are specific with their questions in relation to the timeframe the questions relate to. So for example ‘in the last seven days I have felt/been’ precedes the vast majority of their questions, thus aligning the response with a useful description of course and hence outcome. This idea goes back to the Feigner criteria in mental health diagnostics and is an essential component of current conceptions of disorder (Kendler et al, 2010). Any extension of this study should therefore review this and consider adding a timeframe to the questions for comparability between responses and other studies. The second time related issue is when people fill out the PROM. Ideally this would again be equivalent, but was not necessarily so. This relates to the reticence of some of the chaplains to send out the PROM so soon after discharge, as discussed above. From a psychometric point of view this raises problems. The longer people go between event and report the more likely their accounts are to be biased by recent events (Kahneman, 2011). Recall bias can at least be accounted for if people fill in the questionnaire at the same point after discharge/intervention. So we recommend that further studies specify when the PROM should be filled in, and that this should be as soon after the intervention as feasible.

A flaw in the item design was the lack of reversed questions (Lietz, 2010). All the questions were positive, and this is known to engender ‘yeah saying’, whereby the respondent generalizes between questions and may not be concentrating as hard as they would had some of the questions been reversed (Knapp et al., 2009). Reversing questions within a scale has been shown to improve its reliability (Streiner & Norman, 2008). Aside from this however, the response categories were consistent with the gold standard method in that they all employed five response options with very common sets of responses. In fact the only difference in wording for the responses within the Lothian PROM was that ‘seldom’ was used to define the second least category in sections 2 & 4, whereas this had been mistakenly replaced with ‘a little’ in section 3.

The major limitation with the study was the small sample. Although many exciting associations have been found, and consistent patterns have emerged, all that can be concluded from this is that the findings raise interesting hypotheses (Kahneman, 2011). Having said this, the hypotheses are now solidly grounded and extremely pertinent. The findings suggest that chaplains are exceeding the requirements of the Quality Strategy by addressing issues pertinent to person centred care more generally. Person centred care can only ever be articulated in a local context and that is what this project has achieved. Also, developing a systematic method of researching
this topic has created a transferable method not only for chaplaincy research in other NHS regions, but for other disciplines as well. By engaging in the project of generating systematic evidence for complex interventions, specialist spiritual care has entered a sparsely populated landscape, and as such can take the opportunity to define its own research agenda in a manner coherent with its context and purpose. Work such as this puts chaplaincy at the forefront of empirical research in complex interventions, a significant step in the present challenging environment of NHS Scotland. Being proactive was essential here, because the alternative was to wait for someone else to do the work and thus end up with inappropriate measuring tools which would be irrelevant at best and alienating at worst (Cribb, 2011). The significance of this political element will now be discussed in more detail.

5.3. Situating the study findings in the political landscape

It is interesting that many of the outcomes and interventions attributed to chaplains are ‘person centred’, to the extent that they express some of the qualities of this characteristic as discussed in the wider literature (McCormack et al., 2010). This is important because whilst person centred care is highly valued in current health policy it is extremely hard to articulate and support in practice (Cribb, 2011). For example various strategic documents specifically value person centred care (Department Of Health, 2010b, 2010c; Department of Health, 2010; Scottish Government, 2010; The Scottish Government, 2010, 2011b) and then discuss this in high level terms, embedding it in concepts such as ‘shared decision making’, ‘self directed support’, ‘concordance’ and the choice agenda more generally. These values and aspirations offer a useful overview of general policy direction but are less helpful in terms of operationalisation. This is important because failure to operationalise them can lead to what Cribb (2011) has called a ‘deficit reading’ of professionals (p11). In other words a lack of skilled person centred care is much easier to identify than the skills required to deliver it. Staff are castigated for not being person centred and subsequently turn against the policy because it fails to acknowledge that person centred care is difficult.

Person centred care is difficult to articulate in general terms because it is a process, not an outcome (Cribb & Entwistle, 2011), or in the pragmatic language above, the process is the outcome. This doesn’t easily fit with classic measurement theory, and is one reason why the Department of Health is moving toward developing experience measures as well as outcome measures (Coulter, 2009; Elwyn et al., 2010). The utility of this distinction remains to be evaluated, but it appears to be a significant step. However, in line with our conclusions above we consider that the most important aspect of measurement relates to the extent to which service can be improved in a meaningful manner. This ties in to the discussion on person centred care because the Lothian PROM delivered data consistent with articulating this agenda. Recall the Quality Strategy requires NHSScotland to:

1. ...listen to peoples’ views, gather information about their perceptions and personal experience of care and use that information to further improve care...
2. [to make] the right thing easier to do for every person, every time...
3. by making measurable improvement in the aspects of quality of care that patients, their families and carers and those providing healthcare services see as really important.

(The Scottish Government, 2010, p5)

It is useful to take these points one at a time.

...listen to peoples’ views, gather information about their perceptions and personal experience of care and use that information to further improve care...

The Lothian PROM has gathered systematic evidence on personal experience of care. The patient responses were uniformly and overwhelmingly positive in relation to their experience of the chaplain’s involvement with them. Of particular significance was the overwhelming finding that chaplains’ impressions of their interventions closely correlated with patient impressions, suggesting coherence and hence responsiveness to individual need. This is person centred care. This method of feedback would be interesting to repeat in other professions to ascertain just how significant this finding is. Even without this comparison though, this is practical and empirical evidence that chaplains practised person centred care in this sample.

For strategists and fellow health researchers there is a lot of mileage in this finding because it starts to unpick both the expression of person centred care as a process and the measurement of it. Measurement of person centred care requires three components: the perspective of the patient, the perspective of the staff member, and a judgement on their coherence. There are existing tools and methods that analyse conversation (Roter & Larson, 2002), some with a specific focus on quantifying participation within consultations in order to calculate involvement objectively (Richard & Lussier, 2007). These methods are entirely consistent with providing evidence that people are listened to in order to improve care, but they are quite resource intensive. Alternatively the method devised here is much less resource heavy yet still provides comparably clinically meaningful data. It is easy to collect and interpret, and lends itself to individual and system review. The Lothian PROM therefore meets The Scottish Government’s first strategic requirement within the specialist spiritual care arena, and may have utility outside this field.

[to make] the right thing easier to do for every person, every time...

This strategic requirement is a function of competence and values. The full statement is:

It is about building on the values of the people working in and with NHSScotland and their commitment to providing the best possible care and advice compassionately and reliably by making the right thing easier to do for every person, every time.

In other words, doing the right thing every time entails aligning values with action in a systematic manner. This entails cross disciplinary understanding of values and skills in order to know when personal and professional values and skills are fit for purpose and when they are not. Recall in the focus group in chapter 4 that there was a discussion about whether palliative care nurses could deliver spiritual care. This follows political recognition that spiritual care is in practice given by many people; staff, carers, patients (The Scottish Government, 2009, p2). The conclusion of that focus group discussion was that palliative care nurses could deliver spiritual care, up to a point, beyond which there was a need for onward referral to specialist service, the
chaplains. Ideally then, the Lothian PROM would function as a screening tool to identify the point at which the generic spiritual care givers’ competence threshold was breached. The difficulties inherent in this project were discussed previously, but certainly part of the solution is in understanding the role and function of cross disciplinary colleagues.

Part of this discussion relates to the wider articulation of the competencies the chaplains showed in relation to meeting the spiritual needs of people. How do chaplains differ from others in this regard? According to the associations between section 2 & 3 of the PROM a specialist (chaplain) listens to people all the time, values their beliefs and facilitates the conditions to encourage people to speak what’s on their mind. This is useful from a policy/practice perspective because it shows that chaplains successfully translate their values into practice. The Lothian PROM therefore translates an aspiration (making the right thing easier to do) into empirical evidence of measurable activity (delivery of the right thing).

A related point involves research as communication activity. For example it is interesting to see that an expert consensus panel agreed that the utility of PROMs is mainly as a communication tool and aid to further structured individualised intervention (Hughes et al, 2012). This closely aligns with the distress management literature in cancer (Lynch et al, 2010; Snowden et al., 2012) and is essentially an argument for ongoing empiricism as an end in itself. This is also a political move for chaplains in that MacRitchie (2012) notes the absence of spiritual care from national health policy and argues for better integration grounded in closer involvement. That is exactly what the Lothian PROM promises. In better understanding and articulating spiritual care values (clearly aimed at providing the best possible care compassionately), this will make the right thing to do easier for every person every time.

by making measurable improvement in the aspects of quality of care that patients, their families and carers and those providing healthcare services see as really important.

This requirement needs a valid measure of the patient (family/carer) perspective of person centred intervention cross referenced with a valid measure of the healthcare service’s (chaplain) perspective of that intervention. The Lothian PROM offers a number of different measures, for example the associations mentioned above. Of potentially more practical significance was the finding that in this sample patient perspective of interventions aligned with chaplains’ perspectives. This offered the opportunity for individual reflection for the individual chaplains, and in the focus group the sense of satisfaction in seeing evidence of their impressions reinforced by their patients was palpable. It also offers evidence (consistent with CCL2) that chaplains’ ideas of important aspects of care are the same as patients/families/carers. The importance of this cannot be overstressed.

For example in 2010-2011 there were over 7000 complaints made to NHS boards and their divisions (Information Services Division, 2011) and 3200 to family health services. Most of these pertained to issues with ‘staff’ and ‘treatment’, which mainly relate to issues of communication. It is interesting to note that a specific element of communication singled out for mitigation of complaints was honesty (Tingle, 2010, p985), and openness (Giles, 2009). The Lothian PROM shows that chaplains facilitate honesty and openness. It is therefore not too much of a leap to hypothesise that where chaplains are involved in peoples’ care these people may be less likely to
complain about their treatment than those who have not seen a chaplain. Health boards would likely be very interested in empirical evidence to test this hypothesis.

5.4. Chapter Summary

This chapter has considered some of the contextual issues raised by the assumptions underpinning the design of the Lothian PROM, and the findings generated by its testing in a clinical population. It has situated our findings within comparable relevant research and found significant overlap. These overlaps pertaining to the role and function of the chaplain often extended to the international literature. Where gaps have appeared they have been explained as a function of different cultural views of the role of the chaplain. Perhaps the most significant aspect of this analysis was the finding that the Lothian PROM has the potential to generate generalisable findings. This should prove particularly relevant to both individual chaplains for the purpose of case review, and for service developers more generally, now that chaplaincy has articulated its own quality benchmarks for service delivery.

The chapter then introduced Iain Telfer’s account of undertaking this research project. Perhaps the most significant aspect of this account was the benefit attributed to the venture. If chaplains are to maintain control over their own destiny in the current turbulent territory of NHSScotland they will need to provide evidence of their impact. To do this with any credibility they will need to be able to discuss their value in language strategists and planners understand. This does not require any change in role other than in engagement with research. Iain showed the personal and professional value of this engagement, and his detailed account should provide a road map for those chaplains interested in pursuing this avenue. This section of the chapter also revisited the methodological assumptions underpinning our decision to classify the Lothian PROM as an outcome measure. In summary, the decision is practical, pragmatic, and grounded in the ethics of the purpose of its development. As discussed at the beginning, the Lothian PROM is useful, which was a primary aim in its development.

The final section discussed the broader political and strategic implications of our findings by revisiting the stated aims of the *The Healthcare Quality Strategy for Scotland* (The Scottish Government, 2010). The chapter finished by showing that the data gathered here provided empirical evidence to elucidate person centred care. The importance of this will not be lost on managers and health researchers. The success of the Lothian PROM in producing evidence for person centred care is more remarkable when related to the relative lack of success that other disciplines have had in this regard. To this end specialist spiritual care is currently at the forefront of generating systematic evidence for person centred care.
6. **Conclusion**

In this final chapter we review the King’s Fund’s questions asked at the beginning of this report (Cornwell, 2012): ‘What problem are we trying to solve?’, and ‘When we have the data, what will we do with it?’ It answers these questions by summarizing the study findings, reviewing these in relation to the aim and objectives, and then making recommendations for further study.

This project has developed and tested the Lothian PROM in a sample of 39 patients/carers. The questionnaire has demonstrated face and content validity in this sample. The responses from the participants generated some useful associations and raised some interesting issues. In brief:

The vast majority of participants understood the items within the questionnaire. They also considered them personally relevant; suggesting our underpinning theory of specialist spiritual care was robust. Most participants came from the acute services (33/39), so generalisations to other services must be treated with caution. More women than men responded. The 3:1 ratio corresponds to a 4:1 ratio in the referrals generated, viz. eleven (11) male, forty-three (43) female and eighteen (18) couple referrals in total.

The responses in section 2 pertaining to chaplaincy skills were overwhelmingly positive. From a professional perspective this may be a useful delineation of specialism. From a psychometric perspective these questions would benefit from piloting in different staff groups in order to check the extent to which this may express a ceiling effect. The responses in section 3 pertaining to spiritual care outcomes were also very positive, but not as psychometrically problematic as section 2. Again they would benefit from wider testing to establish their discriminant validity.

The responses in section 4 pertaining to spirituality trait descriptions were heterogeneous, suggesting the sample was diverse, and that spirituality was not necessarily important to this sample. Principal component analysis of section 4 suggested that these 8 items could be reduced to 3: one to cover spirituality/religion/believing in God, one for meaning and purpose, and one for hope and control, and still capture similar factors. The factor pertaining to hope and control was the only correlation with the outcomes in section 3. Again this suggests that specialist spiritual care is useful for everyone with these needs. The more existential needs (spirituality, meaning) were not correlated with any outcomes in this population. We explained this by considering the secular nature of the Scottish population in comparison to US, from where a great deal of chaplaincy literature emanates. The US population is not spiritually equivalent to this Scottish population, hence their model of spirituality, upon which these trait descriptions were based, may not be transferable.

Positive outcomes of specialist spiritual care intervention were strongly associated with the chaplain enabling people to talk about what was on their mind. A sense of peace was the strongest correlation between chaplains’ skills and patient outcome.

Free text data was interpreted as expressing the following four interrelated themes:

- The significance of religion,
- Unmet needs in routine hospital care,
- Grateful recognition of the unique skills of the chaplains (the ‘guide through the gruesome’),
- Need for a sense of peace in the midst of a stressful time

These themes reinforced and explained the items in the Lothian PROM and the correlations found between the items, but did not suggest new items. Free text therefore validated the existing items and offered deeper explanation of the results. Most participants (29/39) took the opportunity to add free text comments. We therefore concluded that free text data had an importance and function in allowing for expansion of quantitative responses, and should be retained for future iterations of the PROM. There was strong coherence between chaplain and patient interpretation of interventions as evidenced by their independent descriptions. Text analysis of these findings allowed for identification of a mutual language in some cases, suggestive of very close relationship and understanding. The overall findings related to peace and control as significant outcomes were consistent with local research into specialist spiritual care. The findings were less well explained by the international literature, probably indicative of the significant differences in cultural expression of religiosity and spirituality.

The Lothian PROM provided clinically useful data consistent with the stated aims of the Quality Strategy and the Scottish Government’s priorities as expressed in Spiritual Care in Chaplaincy. It articulated evidence of impact in a systematic manner and in particular discovered an innovative method of identifying the needs that were important to people. Evidence such as this goes some way to articulating the measurement of person centred care. This puts chaplains not only at the forefront of research in their field, but of the health research more generally.

This brings us to a final review of Cornwell’s (2012) questions in order to ensure these conclusions are practically fit for purpose.

What problem are we trying to solve?

Recall the aim and objectives:

Aim: To develop a valid measure of patient outcome following specialist spiritual care intervention

Objectives:

1. To develop a conceptual model of specialist spiritual care
2. To translate this model into items: the Lothian PROM
3. To test the Lothian PROM in a clinical population.
4. To analyse the results of the test.
5. To contextualise this analysis: discussion.
6. To make recommendations for further development

So, the problem we were trying to solve was to develop a valid measure of patient outcome following specialist spiritual care intervention. With all the caveats discussed here, we have achieved this aim. A solid theoretical model of chaplaincy, developed from systematic literature review and further developed over a series of workshops with world leaders in chaplaincy
underpinned the Lothian PROM. The Lothian PROM was then tested in a clinical population and the results analysed and contextualized within the practical, philosophical and political context. The PROM was understood by all patients who completed it. They considered all questions relevant. The free text data added depth but suggested no new items.

*When we have the data, what will we do with it?*

The answer to this question depends on who is asking the question. For example there are implications for chaplains and their managers, patients, carers, politicians and educationalists. However, we have focused on constructing recommendations based on research implications. The recommendations therefore entail answers to the questions:

*How could we make the Lothian PROM better?*

*When we’ve made it better what shall we do with it?*

### 6.1. Recommendations

We recommend that the overall structure of the Lothian PROM be amended to incorporate all the psychometric issues raised in this study. In brief, these entail clarifying demographics in section 1, reversing some of the questions in sections 2 & 3, adding an item regarding the specialist skills of chaplains, adding a specific timeframe to these questions, and removing section 4. These will be taken in turn.

Demographic data collection in section 1 needs to be revisited in order to capture all the nuances discussed in this report. In particular, if the study is repeated in a larger sample then much finer level of detail would be required for meaningful subsample analysis. For example number of visits and time spent in visits is important to know in order to estimate depth of relationship, as that has been mooted as a factor of success and it would be important to test this assumption. Type of relationship could also be clearer in order to separate patient, carer, close family member, staff member, again to make analysis clearer.

The main psychometric issue pertaining to section 2 entails the noted ceiling effect. This may be entirely a function of satisfaction with chaplain skills. In order to mitigate the possibility of this being a function of the wording of the questions two of the questions will be reversed in the next iteration. It is also recommended that an additional question will ask whether any other profession could provide the functions and skills they have just described in their chaplain. For example asking whether people could have spoken to anyone else about their issues would further delineate chaplains’ function, and supply evidence from patients as to who should be meeting these needs. This is more difficult than it seems because of the finding that spiritual needs in UK may not be well articulated in current models of spiritual care. However, this needs to be considered alongside the findings from here and CCL2 that this issue seems much more important to spiritual care providers than receivers of it. We should therefore ask the latter.

The ceiling effect was not problematic in section 3. The main issues relate to clarifying the timeframe. That is, if respondents are all referring to the same point in their journey the aggregation of these responses will be more meaningful. There is therefore opportunity here to add a set of questions to establish the immediate and longer term impact of specialist spiritual care. Asking people to score how they felt on these outcome measures immediately after...
intervention would provide data on immediate impact. Adding a further set of virtually identical questions pertaining to the last seven days would align with PROMIS method of outcome measure and gather evidence for long term impact.

The main issue with section 4 was that few correlations were obtained. In light of adding further sets of outcome questions in section 3 we recommend this section be dropped so as to keep the PROM as compact as possible. The principal component analysis in chapter 4 suggested these 8 items could be reduced to 3. These three factors may have a future as screening questions for specialist spiritual care intervention, but this is a separate project. They did not discriminate who benefited from the spiritual care service in this study. Everyone can benefit from appropriate spiritual care. Section 5, the free text question will remain unchanged as it generated extremely useful clinical data.

The revised version incorporating these changes is in appendix 5.

In order to make best use of the outcomes of this project the validation process should continue. To this end the following projects should be considered:

**Would the findings from the Lothian PROM hold in a larger sample?**
We strongly recommend that the new version should be tested in a wider sample. This larger study should also include cross referencing the PROM with an agreed measure of quality of life so as to assess its construct validity. Although the Lothian PROM showed great promise, and is already clinically useful as it is, its utility will be much higher if it proved demonstrably valid and reliable in a national sample.

**Could 3 questions discriminate referral?**
A short form of referral could be developed and tested based on the principal component analysis of Galek’s trait factors (p56). That is, a positive answer to any of the three questions would warrant referral. The New Lothian PROM could then be used to measure before and after chaplain intervention to establish whether these interventions were effective. This could be used alongside a treatment as usual group to ascertain the utility of the referral method.

**Would chaplains score higher than other disciplines in interventions as measured by this scale?**
We don’t know if the overwhelmingly positive responses of the people in this study were a function of poor psychometrics of the measure (ceiling effect) or a true reflection on the skills and outcomes of the chaplains. In order to test this, the Lothian PROM could be adapted to review interventions from different disciplines. This would probably work best in comparable ‘talking’ roles such as psychology, psychiatry or mental health nursing, although given the claims made for palliative care nurses it may be interesting to include them. If it emerged that chaplains consistently scored higher than their counterparts then this would be a useful finding in relation to a discussion on chaplaincy, complexity and speciality.

**Does chaplains’ understanding of patients improve over time as measured by language convergence?**
This interesting linguistic hypothesis was raised in the chaplain feedback session discussed at the end of chapter 4. In order to test it we could use medicode or RIAS to analyse language and conversation during interventions, or enhance concurrent analysis to identify analogy and
symmetry in encounter descriptions. In order to test it we could use medicode or RIAS (Richard & Lussier, 2006) to analyse language and conversation during interventions, or use concurrent analysis (Snowden & Atkinson, 2012) to identify analogy and symmetry in encounter descriptions. This would provide deep evidence of person centred care and add to the theoretical understanding of important aspects of communication.

**Does using Lothian PROM feedback in clinical supervision improve confidence, competence, and the value of the supervision?**

Again, in the chaplaincy feedback focus group in chapter 4, there was a deep sense of personal and professional pride in the finding that chaplain and patient descriptions of interventions were congruent. This was both very welcome and previously unknown. The most obvious issue was how to translate this information into service improvement. The general consensus was that this data would be useful in supervision sessions. There would be a number of ways to test this. For example in order to ascertain measurable improvement in relation to usual practice we would need some objective measures and a comparator group. For example valid measures of self-reported competence and confidence could follow supervision in groups that used this data, and be statistically compared with those that did not. Interviews on the impact of supervision could add depth to these quantitative measures. There would be many ways of constructing such a study.

**Do chaplains reduce complaints?**

Whilst the most contentious and the biggest leap from the data this is also one of the most potentially important for managers. Last year (2010/11) NHS Lothian received 845 complaints. It is not unlikely some of these could have been prevented with a better initial response, given that there is a correlation between staff morale and complaint levels (Hurst, 2011). To establish the potential impact of specialist spiritual care in this regard would require a model detailing:

- the average cost of complaints,
- the category of the complaint
- the staff (category) involved
- whether or not a chaplain was involved in the complainant's care at any time
- the total number of patients chaplains saw in the same timeframe

If a lower than expected ratio of [complaints including chaplaincy care: expected complaints if chaplaincy was a random factor] emerged then closer scrutiny could be paid to the details and subsamples underpinning these findings.

**Is burnout less in units with regular chaplain visits?**

A related issue pertains to the impact chaplains have on staff. This could be measured with Maslach Burnout Inventory in comparable units. Again, if unusual patterns emerge then this would further articulate chaplains’ restorative and person centred function. This would require local R&D approval but not necessarily ethical approval, thus making the project less complex than comparable patient focused research.

**Does the Lothian PROM dovetail with CCL3?**

It is strongly recommended that the components of spiritual care and chaplaincy research continue to inform each other. The diversity of approaches and personnel generate innovative
and functionally important research. All partners and stakeholders should get together and discuss the impact of their current findings in order to make recommendations on continuing research, based on national need.

**Should chaplains continue engaging with research?**
One of the strongest elements of this project has been the involvement of chaplains throughout. They were involved in the construction, development and ongoing critical appraisal of the Lothian PROM. They provided and gathered data, and in Iain’s case managed this process. They provided feedback on the results and this feedback went much of the way to suggest that these chaplains in particular saw the personal and professional value of this research. Hopefully this will translate into further consistent engagement. One of the main benefits of this process has been the growing feeling that research is not something done by other people but something done by us. We cannot recommend strongly enough that chaplains continue to engage with research as practice.
7.  References


reported outcome measures. *The breast journal*, 16(6), 587–97. doi:10.1111/j.1524-4741.2010.00983.x


8. **APPENDICES**

<table>
<thead>
<tr>
<th>Appendix 1a:</th>
<th>Spiritual Care PROM (Paediatrics)</th>
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<td>Appendix 1b:</td>
<td>Spiritual Care PROM (Mental Health)</td>
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<tr>
<td>Appendix 2:</td>
<td>Bibliography of methodological issues pertaining to PROM development in complex care</td>
</tr>
<tr>
<td>Appendix 3:</td>
<td>Chaplain referral record</td>
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<td>Appendix 4:</td>
<td>PROM Presentations</td>
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<td>Appendix 5:</td>
<td>Spiritual Care Patient Reported Outcome Measure (PROM)</td>
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Appendix 1a: Spiritual Care PROM (Paediatrics)

Version 5. 20.03.12

**Spiritual Care PROM (Paediatrics)**

**Project Identification Number (LP)  
NHS Lothian**

This survey is designed to gain a broader understanding of the impact of Spiritual Care support (Chaplaincy services) in NHS Lothian.

Recently either you or your parent/guardian/carer received the support of a chaplain or a member of the Spiritual Care Team.

We would very much appreciate you answering the following questions about that support.

Please complete this questionnaire **EITHER** as the patient **OR** as the parent/guardian/carer **OR WITH** your parent/guardian/carer.

Please indicate which here:

- I am the patient
- I am the parent/guardian/carer

We completed the questionnaire together (**in this case please complete section 1 and section 4 with patient details only**)

### Section One

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<tr>
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<th>Other</th>
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<td>□</td>
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<tr>
<td>Please state your age</td>
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<td>How long were you in hospital?</td>
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<td>Less than one week</td>
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<td>Between one week and one month</td>
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<td>Between one month and three months</td>
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<td>Between three months and six months</td>
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<td>Six months to one year</td>
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<td>More than one year</td>
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Section Two

During my/our meeting with the chaplain I/we felt …

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<tr>
<th>Statement</th>
<th>Not at all</th>
<th>Seldom</th>
<th>Some of the time</th>
<th>Most of the time</th>
<th>All of the time</th>
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<tr>
<td>I was/ we were listened to</td>
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<tr>
<td>We focused on decisions about my child/young person’s health care</td>
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<td>I was/ we were able to talk about what was on my/ our mind/s</td>
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<tr>
<td>My/ our situation was understood and acknowledged</td>
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<td>My/ our faith and/ or beliefs were valued</td>
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Section Three

After meeting with the chaplain I / we felt …

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<th>Seldom</th>
<th>Some of the time</th>
<th>Most of the time</th>
<th>All of the time</th>
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<tr>
<td>I/ we could be honest with myself/ ourselves about how I was/ we were feeling</td>
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<tr>
<td>My/ our level of anxiety had decreased</td>
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<td>I/ we found I/ we had gained a better perspective on my/ our child/ young person’s illness</td>
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<td>Things seemed under control again.</td>
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<tr>
<td>A sense of peace I/ we had not felt before</td>
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Section Four

Statements that describe me

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<th>Statement</th>
<th>Not at all</th>
<th>Seldom</th>
<th>Some of the time</th>
<th>Most of the time</th>
<th>All of the time</th>
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<tr>
<td>I see myself as a spiritual person.</td>
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<td>I believe in God or in some Higher Being</td>
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<td>I am a religious person.</td>
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<td>I feel a need to experience love and belonging</td>
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<td>I feel a need to find meaning and purpose in life</td>
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<td>I feel a need to be hopeful</td>
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Section Four

Statements that describe me

I feel I have something to be hopeful about.

I feel I am/we are in control of my/our situation.

Section Five

Please add any further comments you wish to make about how the conversation with the chaplain affected you

Finally, we are in the early stages of this study and would be interested in hearing how relevant this questionnaire is to you. If you are happy for Iain Telfer to give you a short telephone call to discuss this, please tick this box:

☐ Yes I am happy for Iain to ring me about this questionnaire

My telephone number is:

Thank you very much for completing this questionnaire. Please return it in the stamped addressed envelope
Appendix 1b: Spiritual Care PROM (Mental Health)

Version 5, 20.03.12

Spiritual Care PROM (Mental Health)

This survey is designed to gain a broader understanding of the impact of Spiritual Care support (Chaplaincy services) in NHS Lothian.

You recently received the support of a chaplain or member of the Spiritual Care Team.

We would very much appreciate you answering the following questions about that support.

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Please indicate your gender

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Please state your age

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How long were you/was your relative/friend in hospital?

- Between one week and one month
- Between one month and three months
- Between three months and six months
- Six months to one year
- More than one year

If not in the hospital, please say where you saw the chaplain

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During my meeting with the chaplain I felt ...

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<th>I was listened to.</th>
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<th>Seldom</th>
<th>Some of the time</th>
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<th>Seldom</th>
<th>Some of the time</th>
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<th>I was able to talk about what was on my mind.</th>
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<th>Most of the time</th>
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<th>My situation was understood and acknowledged.</th>
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<th>Seldom</th>
<th>Some of the time</th>
<th>Most of the time</th>
<th>All of the time</th>
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<th>My faith and/ or beliefs were valued.</th>
<th>Not at all</th>
<th>Seldom</th>
<th>Some of the time</th>
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</table>
### Section Three

**After meeting with the chaplain I felt …**

<table>
<thead>
<tr>
<th></th>
<th>Not at all</th>
<th>Seldom</th>
<th>Some of the time</th>
<th>Most of the time</th>
<th>All of the time</th>
</tr>
</thead>
<tbody>
<tr>
<td>I could be honest with myself about how I was really feeling.</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>My levels of anxiety had decreased.</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>I had gained a better perspective on my mental health/the health of my relative/friend.</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>Things seemed under control again.</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>A sense of peace I had not felt before.</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
</tbody>
</table>

### Section Four

**Statements that describe me**

<table>
<thead>
<tr>
<th></th>
<th>Not at all</th>
<th>Seldom</th>
<th>Some of the time</th>
<th>Most of the time</th>
<th>All of the time</th>
</tr>
</thead>
<tbody>
<tr>
<td>I see myself as a spiritual person.</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>I believe in God or in some Higher Being.</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>I am a religious person.</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>I feel a need to experience love and belonging.</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>I feel a need to find meaning and purpose in life.</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>I feel a need to be hopeful.</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>I feel I have something to be hopeful about.</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>I feel I am in control of my situation.</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
</tbody>
</table>
Section Five

Please add any further comments you wish to make about how the conversation with the chaplain affected you.

Finally, we are in the early stages of this study and would be interested in hearing how relevant this questionnaire is to you. If you are happy for Iain Telfer to give you a short telephone call to discuss this, please tick this box:

☐ Yes I am happy for Iain to ring me about this questionnaire

My telephone number is:

Thank you very much for completing this questionnaire. Please return it in the stamped addressed envelope.
# Appendix 2: Bibliography of methodological issues pertaining to PROM development in complex care

<table>
<thead>
<tr>
<th>Bibliography of methodological issues: how have other comparable or relevant PROMs been developed?</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>(Dawson, Doll, Fitzpatrick, Jenkinson, &amp; Carr, 2010)</strong></td>
<td>Largely methodological paper considering the difficulties of using PROMS in studies of health outcomes. In order for the study to be meaningful data from each participant must be obtained at the same time on their ‘journey’ and missing data cannot be estimated, so intense follow up is required to ensure valid results. The paper is arguing for congruity between choice and application of PROM and study purpose. In other words, poor data cannot be ‘fixed’ later and so the PROM and its purpose need to be considered together throughout. It takes a mathematical lens to the end of minimising confounders and points out the limitation of such an approach. Namely, PROMs may reveal differences between groups but would not reveal why these differences occur.</td>
</tr>
<tr>
<td><strong>(Houweling, 2010)</strong></td>
<td>This paper reviews clinical improvements that have occurred as a result of work using PROMs. It debates methods of ascertaining how to identify clinically meaningful improvements from PROM data. The authors conclude that this is complex and requires taking different measures into account to identify those who have improved and those that have not. They recommend that studies that collect data in the clinical setting need to include a calculation of the amount of people claimed to be improved. The results from change in outcome (PROM) scores appear to be comparable to more direct measures (GPE), suggesting PROMs may be useful indicators of actual clinical improvement. More work is needed.</td>
</tr>
<tr>
<td><strong>(Mercer &amp; Murphy, 2008a)</strong></td>
<td>The Consultation and Relational Empathy (CARE) Measure is a validated tool for assessing the patients’ perception of the doctors’ communication in primary care. The CARE measures some of the qualities chaplains may consider important. It is a widely used tool that has successfully made a quantitative link between empathy within a consultation and patient satisfaction. Although satisfaction may not be considered an outcome per se, evidence suggests it is a component of a positive outcome.</td>
</tr>
<tr>
<td><strong>(Gershon RC, Rothrock N, Hanrahan R, Bass M, 2010)</strong></td>
<td>The Patient-Reported Outcomes Measurement Information System (PROMIS) is a US based national project designed to develop PROMs. This paper describes its instigation, scope and function. The primary goal of PROMIS is to build item banks and short forms that measure key health outcome domains that are manifested in a variety of chronic diseases which could be used as a &quot;common currency&quot; across research projects. It is entirely disease centred and as such may have limited direct relevance to chaplaincy, which is not. However, the process of PROM development and utility is highly salient.</td>
</tr>
<tr>
<td><strong>(Morgan &amp; Farsides, 2009)</strong></td>
<td>This study shows the development of a scale for ‘meaning in life’ from initial construct analysis to questionnaire. The process of development of this measure from construct development through theoretical development to validity testing is</td>
</tr>
</tbody>
</table>
### Bibliography of methodological issues: how have other comparable or relevant PROMs been developed?

<table>
<thead>
<tr>
<th>Source</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>McDonald et al., 2010</td>
<td>This paper develops a potential PROM for muscular dystrophy from aspects of existing scales. It suggests that there is currently no link between clinical outcome measures and patient well-being. By comparing validated clinical outcome measures with subscales of well-being measures this study found significant correlations between certain subscales and outcome. These subscales therefore have potential as PROMs. As there are no PROMs for chaplaincy our study is in a similar position and could therefore integrate salient aspects of subscales from existing measures in a similar manner.</td>
</tr>
<tr>
<td>Nicklin et al., 2010</td>
<td>Describes the construction of a PROM for rheumatology utilising patients to construct the language of it. They used interviews to analyse experience of RA and incorporated this analysis into a draft PROM. They then tested this draft for comprehension. This process strengthened face and content validity. Relevant to the development on spiritual care PROM as the process utilised in this study mirrors our approach to the extent that we developed themes from the literature and then piloted the draft in a similar manner.</td>
</tr>
<tr>
<td>Luckett &amp; King, 2010</td>
<td>This paper gives practical advice on ‘how to choose a PROM’. This is broken down into six specific principles, all accompanied by exemplars. It is cancer specific, but is designed for novice researchers to ensure they get the right PROM for their particular study. The six principles may be pertinent beyond the cancer literature. That is, some of the cautions raised in other papers presented here are consistent. So although chaplaincy is conceptually distant from a disease base approach, the process of self reported measurement may be relevant. The six principles are: 1. Always consider PROMs early in the design process within the context of other methodological decisions 2. Choose a primary PROM proximal to the specific cancer 3. Identify candidate PROMs on the basis of scaling and content 4. Appraise the track record of the candidate PROM in similar studies 5. Look ahead to practical concerns 6. Take a minimalist approach to ad hoc items</td>
</tr>
</tbody>
</table>
| Palmer & Miedany, 2009 | Palmer and El Miedany discuss PROMS in standard rheumatology practice and describe how it is ‘all about patients’ (p190). Short analytic They make an interesting point about how poor physicians are at identifying issues of importance to the patient. While clinicians focus on numbers of affected joints, hand }
### Bibliography of methodological issues: how have other comparable or relevant PROMs been developed?

<table>
<thead>
<tr>
<th>Reference</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Palmer &amp; Miedany, 2010</td>
<td>Cross sectional study of 102 RA patients using the mRAI developed in the paper above. The modification included a ‘self helplessness’ index. They found self helplessness to be correlated with other psychological and functional status measures. Although disease specific to RA, the acknowledgement and integration of self helplessness as a correlational disease factor adds credence to the claim that this is a factor to be targeted within an intervention. Chaplains may address this issue, and if so there is a measure here.</td>
</tr>
<tr>
<td>Barham &amp; Devlin, 2011</td>
<td>Overview of history of PROMs and relevance to health services in UK. States that thousands of different PROMs are available that refer to different diseases or parts of the body. Suggests PROMs have 4 functions: 1. Informing patient choice 2. Measuring and rewarding performance 3. Informing spending decisions 4. Regulating quality</td>
</tr>
<tr>
<td>Chen et al., 2010</td>
<td>Systematic literature review undertaken to identify PRO measures used in oncologic breast surgery patients. Ten measures underwent development and psychometric evaluation in an oncologic breast surgery population. Overall, two key limitations were noted: 1) surgery-specific issues of breast-conserving surgery patients were not well represented and 2) measures were largely developed without the aid of newer psychometric methods that may improve their clinical utility. Reliable and valid PRO measures in breast cancer patients exist, but even the best instruments do not address all important surgery-specific and psychometric issues of oncologic breast surgery patients. Raises the issue of practicality whilst remaining quantitative. Suggests that if a PROM was likely to be clinically useful as well as epidemiologically then clinicians may be more likely to engage (p595). Utilised Item Response Theory, which the authors claim creates more clinically meaningful psychometric instruments. They suggest the benefits of this extend to patients, as they feel they are providing more pertinent information and receiving better outcomes. In other words, the measure becomes a therapeutic tool.</td>
</tr>
<tr>
<td>Whiteing &amp; Cox, 2010</td>
<td>Clinically focused article on the utility of PROMs in practice. Describes the importance of choosing a PROM fit for purpose, focusing this discussion on GI disorders. Contains useful list of questions to be asked of PROMS. Further illustration of the disease focused nature of PROMs, highlighting the necessity to specify and correlate the PROM with the intervention in order to connect the outcome meaningfully to that intervention. Important for chaplaincy as the intervention rather than the outcome has historically been the focus. The questions opposite remain relevant however.</td>
</tr>
<tr>
<td><strong>Bibliography of methodological issues: how have other comparable or relevant PROMs been developed?</strong></td>
<td></td>
</tr>
<tr>
<td>---------------------------------------------------------------</td>
<td></td>
</tr>
<tr>
<td><strong>(Winters &amp; Thomson, 2011)</strong></td>
<td>Short introductory paper describing the need for specific PROM related to breast reconstruction outcomes.</td>
</tr>
<tr>
<td><strong>(Mertens, 2010)</strong></td>
<td>Philosophical paper introducing the ‘transformative paradigm’ as an approach to conducting research into issues related to social justice. The transformative paradigm serves as an umbrella for research theories and approaches that place priority on social justice and human rights. It is essentially ‘mixed’ in its methods, but differs from other mixed methods by prioritising axiology (ethics) as opposed to ontology (world view).</td>
</tr>
<tr>
<td><strong>(McClimans, 2010)</strong></td>
<td>Theoretical paper discussing the underpinning philosophy of PROMs as a meaningful measure. Analyses the consequence of <em>not</em> considering this issue and concludes that the questions that make up any such measure should be coherent with their purpose. If the outcome is complex then the measure should reflect this.</td>
</tr>
</tbody>
</table>
### Appendix 3: Chaplain referral record

<table>
<thead>
<tr>
<th>Date of Referral</th>
<th>Mode of Referral (please tick)</th>
<th>Hospital / Ward / Community Setting</th>
<th>Reason for Referral</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Staff</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Self-Referral</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Significant Other</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Other (e.g. chance encounter)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Name &amp; Address of Person Referred</td>
<td>Status of Person Referred (please tick)</td>
<td>Contact Phone Number</td>
<td>Faith Belonging</td>
</tr>
<tr>
<td></td>
<td>Patient</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Significant Other</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Name of Chaplain</td>
<td>Number of Visits</td>
<td>Other Relevant Details</td>
<td>Project Identification Number (office use only)</td>
</tr>
<tr>
<td>Description of Spiritual Care Episode(s)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Chaplain’s Personal Assessment of Outcome</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Appendix 4: PROM Presentations


Appendix 5: Spiritual Care Patient Reported Outcome Measure (PROM)

This survey is designed to gain a broader understanding of the impact of Spiritual Care support in NHS Scotland.

You recently received the support of a chaplain or member of the Spiritual Care Team. We would very much appreciate you answering the following questions about that support.

Section One

<table>
<thead>
<tr>
<th>Please indicate your gender</th>
<th>Male</th>
<th>Female</th>
<th>Other</th>
</tr>
</thead>
<tbody>
<tr>
<td>Please state your age</td>
<td>16-25</td>
<td>26-40</td>
<td>41-55</td>
</tr>
<tr>
<td>How long were you in hospital?</td>
<td>Between one week and one month</td>
<td></td>
<td>Between one month and three months</td>
</tr>
<tr>
<td>How many times have you seen the chaplain?</td>
<td>once</td>
<td>twice</td>
<td>three</td>
</tr>
<tr>
<td>How many different chaplains have you seen in the last year?</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>On the last visit how long were you with the chaplain?</td>
<td>&gt;15min</td>
<td>15-30</td>
<td>30-45</td>
</tr>
<tr>
<td>Prior to this last visit how would you describe your relationship with the chaplain?</td>
<td>Not seen before</td>
<td>Seen them around</td>
<td>Met previously</td>
</tr>
<tr>
<td>How did you get to see the chaplain?</td>
<td>Chance encounter</td>
<td>Self referral</td>
<td>Staff referral</td>
</tr>
</tbody>
</table>
Section Two

During my meeting with the chaplain I felt …

<table>
<thead>
<tr>
<th></th>
<th>Not at all</th>
<th>Seldom</th>
<th>Some of the time</th>
<th>Most of the time</th>
<th>All of the time</th>
</tr>
</thead>
<tbody>
<tr>
<td>I was NOT listened to.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>We focused on decisions about my/my relative’s/friend’s health care.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I was able to talk about what was on my mind.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>My situation was NOT understood and acknowledged.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>My faith and/or beliefs were valued.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I could NOT have spoken to any other professional about what we talked about</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Section Three

After meeting with the chaplain I felt …

<table>
<thead>
<tr>
<th></th>
<th>Not at all</th>
<th>Seldom</th>
<th>Some of the time</th>
<th>Most of the time</th>
<th>All of the time</th>
</tr>
</thead>
<tbody>
<tr>
<td>I could be honest with myself about how I was really feeling.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>My levels of anxiety had lessened.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I had gained a better perspective on my health/the health of my relative/friend</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Things seemed under control again.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>A sense of peace I had not felt before.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Section Four

In the last seven days I have felt…

<table>
<thead>
<tr>
<th>Statement</th>
<th>Not at all</th>
<th>Seldom</th>
<th>Some of the time</th>
<th>Most of the time</th>
<th>All of the time</th>
</tr>
</thead>
<tbody>
<tr>
<td>I could be honest with myself about how I was really feeling.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>My levels of anxiety have lessened.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I had gained a better perspective on my health the health of my relative / friend.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Things seemed under control.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>A sense of peace.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Section Five

Please add any further comments you wish to make about how the conversation with the chaplain affected you
Dr Austyn Snowden
Snowden & Snowden Ltd

1 Knockdhu Place
Gourock
Scotland, UK
PA19 1DP

tel : 07010 021403
email : austyn@snowdenresearch.co.uk
web : www.snowdenresearch.co.uk