

Evaluating Derbyshire Community Health Services Trust Spiritual and Pastoral Care Provision 2015-16

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1. Introduction

This report addresses the question of the necessity for spiritual and pastoral care provision within the Derbyshire Community Health Services (DCHS) NHS Foundation Trust? It considers the current provision and seeks to bring staff and patient voices into the discussion, when evaluating services relevant to spiritual and pastoral care. The report examines the literature across a range of disciplines both academic and professional to contextualise thinking in the field. It provides empirical evidence based on patient and carer needs and a variety of staff reflections and makes recommendations for future consideration by the trust when making decisions about how best to provide spiritual and pastoral care across its services.

The Trust (hereafter DCHS) was created from a number of smaller separate Trusts within the county of Derbyshire and parts of Leicestershire and was first registered as DCHS on 31 March 2011. It employs nearly 4,500 staff and has 23 registered locations including its headquarters, based at Newholme Hospital in Bakewell Derbyshire. In addition its community based services number over 100. The trust delivers a variety of community services to approximately 1,100,000 people across Derbyshire and in parts of Leicestershire, with more than 1,500,000 contacts each year. Its services include community nursing and therapies, urgent care, rehabilitation, older people's mental health, learning disability, children's services, podiatry, sexual health, health psychology, dental services, outpatients and day case surgery (DCHS CQC Quality Report, 2014). More recently (in October 2015) DCHS took control of community-based services in the city of Derby.

Since 2011 DCHS has consolidated its position as a Foundation Trust and part of that extensive series of mergers with smaller trusts across Derbyshire and parts of Leicestershire has seen a steady reduction in the formal role of chaplaincy services in the trust. There are a variety of reasons for this, some of which can be attributed to smaller trusts' existing arrangements, which were often voluntary or ad hoc, and where they existed, often involved local personal connections with clergy. These arrangements were unsustainable as volunteers moved on or local clergy changed,

and contacts were lost. In the past some, but not all of DCHS' hospitals had chaplaincy arrangements. However as hospital chaplains have left their posts these have not been replaced and the current situation is that there is just one part time chaplain at one of the hospitals. The majority of DCHS' clinical service and sites have never had a chaplaincy arrangement. As services are increasingly delivered close to home, and often in the patient's own home, a new model for providing spiritual and pastoral care is being explored by DCHS.

This evaluative action research approach was commissioned by the Trust who engaged the services of The Multi-Faith Centre at the University of Derby to undertake the role and to examine existing services. This report follows from that commission and recommendations made will also involve additional support through updating staff resources in support of training needs and requirements into 2016 in consultation with DCHS.

1.1 Defining the Concepts: Religious, Spiritual and Well-being?

Concepts, such as religion, spirituality and well-being are often seen as uneasy bedfellows in NHS environments due to their fluctuating and often subjective modes of definition. It is important for this report however to identify some defining characteristics, insofar as these concepts are explained in the literature.

“Religion or religiousness is defined as participation in the particular beliefs, rituals, and activities of traditional religion” (NICE, 2004; NHS Scotland, 2009). Religious needs are couched in the language of religious traditions, and religion is seen “as a mode of spirituality but not considered to be synonymous with it” (Holloway *et al.*, 2011:18 [online]).

Spirituality is more basic than religiousness, explained thus:

It is a subjective experience that exists both within and outside traditional religious systems (Marie Curie, 2003, [online] in Holloway *et al.*, 2011 [online]). Spirituality relates to the way in which people understand and live their lives in view of their core beliefs and values and their perception of ultimate meaning. Spirituality includes the need to find satisfactory answers to ultimate questions about the meaning of life, illness and death (Puchalski *et al.*, 2010 [online] in Holloway *et al.*, 2011 [online])

Spirituality is difficult to tie down and has been variously acclaimed as a positive

connection with something greater than, or beyond the self, while at the same time identifying with the religious mode described above. A definition, or lack of, is sometimes seen as both help and hindrance in health care settings. Its strength however, may be in allowing for a subjective interpretation that allows for a nuanced approach to personal spirituality. In its broad sense it allows for a person centered model of care focusing on the individual, not tied into definitive limiting factors.

Well- being is another complex and complicated concept, explained thus:

At a basic level it is a subjective emotional experience that relates to the way in which a person perceives themselves to be, and to feel, within any given situation. Well- being is not a global concept. It is possible to have well-being in one aspect of one's life and not to have it in another... Both well-being and a lack of well- being can thus occur at the same time. (Holloway, *et al.*, 2011:18 [online]).

The importance of both religion and spirituality is that they provide a context in which people can make sense of their lives, explain and cope with their experiences and find and maintain a sense of hope, inner harmony and peacefulness in the midst of the existential challenges of life (Holloway *et al.*, 2011:18[online]). Equally, spiritual distress (discussed below) can bring negative emotions and anxiety to end of life care.

2. Spiritual and Pastoral Care: the contemporary Landscape

This report examines the contemporary literature as it reflects spiritual and pastoral care both from an academic and professional understanding of the conceptual models in place, with specific emphasis on end of life care. Practically, it aids to have comparable evaluation and assessment of provision across other service providers insofar as other trusts and health care providers are working in the arena of spiritual and pastoral care. There are learning opportunities through examining other service provision and taking into account policy, locally and nationally. Additionally, and conceptually, it is important to ground this work in the existing literature and to take account of the wider academic context when focusing on matters of spiritual and pastoral care. These are areas often framed around chaplaincy services within the healthcare sector and have developed in many instances through local arrangements, even though national structures exist to

support, advise and train chaplains in healthcare settings, and other types of provision.

2.1 Chaplaincy within the NHS

Historically, chaplaincy and the support it provides have a significant history through the association of religion with the sick. Certainly, the Christian church has always viewed this provision as core work for clergy and stems from monastic infirmaries in the Middle Ages. The creation of the NHS after the Second World War is marked by the embedding of Christian chaplaincy in the 1946 Act, which became effective in 1948, NHS “*a fact of life*”. Chaplaincy has continued its evolution through the many changes of policy and political striving, and is today part of an established NHS provision, which has a range of professional bodies addressing working practices; these include: College of Health Care Chaplains (CHCC) – supporting professionals in the United Kingdom; Association of Hospice and Palliative Care Chaplains (AHPCC) – a professional group supporting and working with people in end of life care; UK Board of Healthcare Chaplains (UKBHC) - a professional group which holds a voluntary professional register for chaplains; Health Care Chaplaincy Appointment Advisers – advising on professional appointments; Healthcare Chaplaincy Faith and Belief Group (HCFBG) – includes representation from nine world faiths and the British Humanist Association as observer.

There is a plethora of research and policy-related literature addressing the development of chaplaincy services and associated provision for health. Much of the developmental work and literature in the chaplaincy field has been shaped around contemporary ideas of ‘spiritual and pastoral care’ and how those concepts are understood and put into practice in Health Care (Roberts, 2012). The most recent NHS report on chaplaincy; *NHS Chaplaincy Guidelines 2015: Promoting Excellence in Pastoral, Spiritual & Religious Care* builds on the 2003 version and reflects not only good practice but creates a sense in which Health Care Chaplaincy is understood as a researched-informed profession. This idea comes out of academic responses to the professionalization agenda in line with aspirations for excellence across NHS environments. Research also comes from within healthcare itself, either through academic interests in health, social care, wellbeing, compassion and end of life care and/or from chaplain practitioners in the field, some of who are academics in their own right. This professionalization seen in the number of professional bodies

mentioned above includes the now more established multi-faith provision in support of Multi-Faith Healthcare Chaplaincy, (Healthcare Chaplaincy Faith and Belief Group) whose group have an established role, alongside more traditional church-based bodies and professional bodies, including: The Chaplaincy Leaders Forum (CLF) which was developed in September 2013 as an effective mechanism for dialogue between NHS England, and the wider chaplaincy associations listed above (Swift, 2015:3).

So what do we mean by chaplaincy? The Swift report says this:

Discussions have taken place over the years about the term 'Chaplaincy', its history and its meaning. The term 'chaplaincy' in the context of this guidance is not affiliated to any one religion or belief system. There have been changes in attitudes and contemporary language driven by changes in our communities. To that end modern healthcare chaplaincy is a service and profession working within the NHS that is focused on ensuring that all people, be they religious or not have the opportunity to access pastoral, spiritual or religious support when they need it.

This functional definition of what chaplaincy will do brings the question of affiliation into an inclusive arena driven by equality legislation (Equality Act 2010). It breaks with traditional perspectives based on a confessional Christian response to delivering 'religious support' only for Christians, and addresses the religious pluralism of contemporary societies and cultures. This appears to be distinct from pastoral and spiritual care. Of course, all three can and do overlap, however it helps to examine the terms in order to differentiate the types of provision made available and to whom might it appeal?

2.2 Chaplaincy: Religion, Belief and Spirituality

The question of inclusivity is unquestioned, and the nature of the religious and non-religious forming part of a wider secular society demands of chaplains, in paid roles and as volunteers increasingly complex social and cultural understanding as communities change demographically, culturally and in the context of their religion and belief (BSA Survey, 2013). Chaplains require an increased adaptability of skills and attributes that provides support or care in ways that may not always be clear to the chaplain or lay volunteer. For example, having the skills required to provide support in a non-religious context. These skills are embedded in the practice of listening, without judgement and supporting the spiritual, emotional, social,

psychological and cultural concerns of the patient, carers and/or their families, skills extended to the nursing profession who are seen as partners in delivering the spiritual well-being of patients.

In order to put patients first the NHS in England seeks to understand the rich variety of beliefs and values of the population in its care. Chaplains are an essential resource for achieving the ambition to provide high quality care for all and promote the protected characteristics of both religion and belief. It is important to note that chaplains are not alone in providing pastoral or spiritual care and the nursing profession has a long established role in supporting the spiritual well-being of patients (RCN, 2011; NHS England, 2013: 7).

The Chaplaincy Guidelines for 2015 define Religion and Belief as:

Religion or belief is as defined in the 2006 Equality Act: (a) “religion” means any religion, (b) “belief” means any religious or philosophical belief, (c) a reference to religion includes a reference to lack of religion, and (d) a reference to belief includes a reference to lack of belief (Swift, 2015:6).

The ‘religious’ aspect in the chaplaincy role works in the context of the straight forward and common sense meaning for those with a religious affiliation, commitment or faith and despite more obscure religious practice is, in the main, aimed at the World religions: Buddhism, Christianity, Hinduism, Judaism, Islam, and Sikhi as the majority proponents of these religions are supported demographically across the UK. Christian chaplains therefore commit to working with people of all faiths and none, and in some larger trusts minority religions are specifically catered for using chaplains from minority faiths. For example, a Muslim chaplain, or lay volunteers drawn from a particular minority religion, all of whom in principle will administer to the needs of people of all faiths and none. Chaplains and volunteers are, according to NHS England’s Business Plan 2013/14 – 2015/16, expected to provide “high quality care for all, now and for future generations”, (NHS England, 2013).

Spiritual and pastoral care may fall outside of traditional world faith provision and contextually could account for a range of beliefs. The professional body, ‘UK Board of Healthcare Chaplaincy’ acknowledges the professional role of chaplains today to manage diversity and difference and to “provide holistic care which recognises the vital relationship between spirituality and wellbeing” (ukbhc.org.uk [online]). There is within the latest guidance to trust Boards in the *NHS Chaplaincy Guidelines 2015* recognition of demographic need and local arrangements.

Spirituality can account for a diversity of views, beliefs or philosophical perspectives, but retains its meaning in accordance with the definition in the 2006 Equality Act as far as NHS England are concerned. The concept of the 'spiritual' is discussed at length by Singleton (2014) who suggests its usage in Western societies increasingly refers to an "alternative to religion", (2014:10). Recent scholarship implies its use as "both a part of religion, and something beyond religion" (2014:10). Consensually, there is academic evidence, which see spirituality and religion as separate things, and this is supported by the views of the general public in Smith and Denton's recent survey work in which "religion and spirituality can be different things" (2005:77). What then is spirituality, if it is both part of religion and something separate from it at the same time? Singleton explains this in relation to a "personal interior dimension" associated with spirituality, which has an "effective element" (2014:11) in which the individual finds accord with a practice or action stimulating a cognitive response. To make the leap to recognise spirituality outside of organised religion, Singleton also suggests, "spirituality is any enduring, meaningful experience or consciousness of something greater than the self," (2014:11). Sociologist Robert Wuthnow addresses both aspects and argues that:

spirituality can be defined as a state of being related to a divine, supernatural or transcendent order of reality or, alternatively, as a sense of awareness of a suprareality [sic] that goes beyond life as ordinarily experienced, (2001:307).

The claims by the UK Board of Healthcare Chaplaincy is that chaplains from different religion and belief groups come together in the "common focus of participation in the NHS" and require the skills and knowledge of the professional setting to address the accelerated spiritual diversity of UK society (ukbhc.org.uk [online]). These roles however extend beyond paid chaplaincy posts to volunteers, nursing staff and managers insofar as holistic care, of which religious, spiritual and pastoral care is a part as an inclusive offer to patients, carers and families accessing NHS services.

2.3 Chaplaincy Roles and Expectations in the NHS

The NHS Guidance for 2015 addresses the ideal provision associated with chaplaincy support, and within its recommendations there are a number of areas that trusts should be managing. These include best practice issues where chaplaincy departments are aligned to allied health professional or similar clinical

groups, ensuring staff are aware of how to access chaplaincy services, with an emphasis on the availability of non-religious pastoral and spiritual support. Additional administrative and reporting functions are also identified, including recording staff usage of services, annual reports, chaplains' wellbeing and appointments in line with guidance from the panel of professional advisers.

The provision of chaplaincy in the NHS has historically favoured facilities offering inpatient care. As the NHS undergoes a process of transformation with renewed emphasis on primary care it is important to address pastoral, spiritual or religious needs in these settings. This should be done in partnership and co-operation with the longstanding support offered by many local organisations of religion or belief (Swift, 2015:20).

Policy documents in relation to chaplaincy services should describe the service and what care those using it can expect to receive. Within that document or a separate document, a method for assessing belief, religious and pastoral needs will be evident. Staffing requirements are calculated according to formula identified in the (Swift, 2015) guidance document and reviewed annually. Chaplains and chaplaincy volunteers should "share the skills, knowledge, experience and insight to offer a comprehensive service" (Swift, 2015:12). Chaplaincy should be fully included in provider meetings to ensure that pastoral, spiritual or religious care is integrated in to holistic patient care. Workspace provision for chaplains will be made available and annual appraisals and development plans sought, accounting for different working arrangements, which may include Service Level Agreements. Chaplains supervise faith-specific spaces and those made available for non-religious beliefs, maintained to appropriate standards, including any multi-faith provision. Procedures should be in place for auditing the quality and quantity of chaplaincy services provided and supervision of chaplains one-to-one or in groups, including with their religion and belief group is advised. Staff have a right to access chaplaincy services. The guidance (2015) suggests that "chaplains trained in practice-guiding disciplines such as theology, philosophy and ethics as well as in interpersonal skills and pastoral counselling" (Swift, 2015: 11) is an expectation.

In order to have the information needed to provide excellent spiritual care it is essential that: "[a]ll NHS patients and service users should be asked if they wish to declare their religion or belief and to have this recorded" (Swift, 2015:11). It is widely known that this information is often limited or inaccurate, but is essential to fulfill the public sector equality duty, and should be verifiable, insofar as patients are made

aware that chaplaincy services are available to them. At the point of referral information should be recorded and action taken. Informed consent is essential and patients need to know how information will be recorded, used and shared, and their right to refuse to consent to such processing. Appropriate chaplaincy provision for a patient's needs should be sought wherever possible and prompt action taken by the provider.

Caring for patients, service users and staff is the primary role of health care chaplains. Providing that care always requires time for reflection, learning and improvement. Unless chaplains work to develop their skills and knowledge, as well as their own spiritual discipline, there is likely to be a diminishing return in their pastoral effectiveness. Chaplains need to learn from one another: through research; in their own religious or belief community; by reflective practice, and from the insights of colleagues in related disciplines (Swift, 2015:25).

Best training and development for quality pastoral, spiritual or religious care is achieved by: Annual reviews (including developmental needs and portfolios evidencing these), compliance with mandatory training in the NHS, and chaplaincy professional bodies and/or communities of religion and belief, awareness of professional research standards, and engagement with the wider community (to include Healthwatch, inter-faith groups and patient forums and those groups representing non-belief and non-religion). In addition:

Chaplains should be encouraged to draw on their wide contact with patients and service users to represent areas of concern to senior management. They may also have an appropriate role in supporting and encouraging members of staff to voice any concerns they may note in the course of their duties (Francis cited in Swift, 2015:11).

2.3.1 Volunteers

Volunteers are selected as trained members of a chaplaincy team in support of spiritual care. Volunteer roles should be documented, recruited in accordance with the providers best practice model and roles assigned which require ongoing supervision training and development. Volunteers should be recognised by the health provider and given a suitable agreement. These volunteers may, in the case of smaller catchment areas, come from locally sourced religion and belief groups to provide advice and support for those communities. Cooperation is required between voluntary services managers and chaplains in the recruitment of volunteers.

2.3.2 Community Care

Care outside of the NHS established inpatient and clinical spaces is a growing trend in patient care, which is expected to continue to grow. Increasingly, people prefer to be cared for in the home and with a rising elderly population the commitment to patients, their carers and families by the NHS and other agencies for care in the community and personalised support, is becoming a primary function. Religion and Belief groups historically have supported care in the community (November, 2014 [online]). Staff, many of who are lone workers should have access to chaplaincy services according to Swift (2015: 20) “This is both to support them in the day-to-day demands of caring and also to assist in their care for patients either by advice or attendance”. Access to chaplaincy services in community settings or private homes can lead to reduced isolation, and support by signposting to additional services. This creates increased resilience according to a recent study by Watkins, (2014) examining the role of emergency nurses meeting the spiritual care needs of patients, in which she reflects on the positive outcomes of chaplaincy support in the community on patient wellbeing.

Primary care and community care are increasingly connected, and with public health in local authority and community settings the increased potential for multi-agency support is seen as favourable for connecting chaplaincy services, even where those services may be made available through mental health and/or primary care trusts. There is a need to find synergies for chaplains in a variety of NHS settings who would and could link to community-based provision. Swift (2015) suggests a way forward in future care in the community may be for chaplaincy services to adopt pilot projects in telemedicine and the use of the Internet. The next ten years may see email, teleconferencing and/or telephone provision for community-based chaplaincy work for those receiving community care. The extent to which remote services becomes available is as yet unknown, but merit may be found in pooling resources locally and in regions if necessary to ameliorate the issues of isolated patients and service users who may value this type of support.

2.4 End of Life Care

Significant attention has been given to religious, spiritual and pastoral care in the care of the dying in the last two decades. There has been a rethinking of

developments in palliative care, and spiritual care and pastoral support have become integral to health care. In 2011 Holloway *et al* carried out a comprehensive review of the literature worldwide between 2000 and 2010, in support of the launch of the *End of Life Care Strategy* by DoH in 2009. The vast majority of sources however came from the UK and USA, with some from Australia. They addressed the question of spiritual care as a philosophy and model of care, thus:

Spiritual care is increasingly identified as an integral part of health care systems across the world. This is particularly so in palliative and end of life care where a holistic approach is established as both philosophy and model of care. Spiritual care has risen in visibility in health services over the last two decades, from a position where it was equated with religious care and regarded as the sole province of chaplains to one where a broad concept of spirituality is employed and spiritual care is recognised as having relevance for all sectors and to lie potentially within the remit of all health and social care workers (Holloway *et al* 2011:4).

Through the review it was identified that in their systematic approach to 248 separate sources, key areas for professionals working in end of life care could be developed in five key areas: 'disciplinary and professional contexts', 'concepts and definitions', 'spiritual assessment', 'spiritual intervention' and 'education and training'. Disciplinary and professional contexts produced 50% of the review of literature (25% from nursing and interdisciplinary studies respectively). Chaplaincy accounted for 14% and social work 10% of sources as the main contributors to the academic literature. All of the material examined showed a separate trajectory within each discipline. Nursing having responded as the nurturing influence for spirituality and spiritual care has also been criticised for "conceptual confusion and a lack of evidence for some of its claims" (Holloway, *et al.*, 2011:2). Chaplaincy has broadened its remit in a secular context and taking account of spiritual needs defined by humanistic interpretations "thus raising questions about what is unique about what they do [?]" (2011:2). Cautious responses by social work has opened up a debate about applying cultural sensitivities but the separation of psychosocial from spiritual care is as yet unanswered.

The literature continues to debate concepts of spirituality and its relationship to religion. Conceptually, 'well-being' has gained ground among scholars and its links to religious and spiritual variables have different meaning dependent on your understanding from either a British or North American perspective. The review however makes an effort to define spirituality, as both within and beyond religion,

but the lack of empirical data requires greater attention professionally and academically in this area.

Spiritual need produced the greatest response within the literature, but the differing perspectives in the USA and UK left the authors aware of a general UK-based skepticism, supported by practitioner consultations, about the efficacy and value of many of the tools designed to measure and rate spirituality in relation to individual need. This was summed up as follows, “*There is general agreement that identifying and responding to spiritual need is the responsibility of every worker, though there is growing support for competency models which differentiate levels of engagement*” (Holloway, *et al.*, 2011:3 [online]). What emerged in the UK were general questions and story-telling narratives in response to assessing spiritual needs. What was also apparent in the literature was, where spiritual care as an intervention in itself did happen, it was nearly always as part of an integrated model for end of life care, which was an embedded process or was in fact its starting point. There was very little evidence of evaluation of these approaches however.

Insofar as education and training are concerned relative to aspects of spiritual care, assessment and intervention, it is evident that there is a general paucity of material. Education and training outside of specific chaplaincy provision reveals a significant gap in the literature. The greater concern being that the need for education and training by far outweighed any actual evidence of education and training. The overarching recommendations from this review identify a good deal of evidence *for* spiritual care at end of life but not enough evidence *of* spiritual care in the context of end of life care. While practice models exist, too little evaluation of them has been undertaken and the need to improve education and training was, when published in 2011, heavily focused on translating the many academic concepts into accessible practice-based models for understanding and intervention. It appears from the work identified in this report to DCHS that improving education and training is important and reflects the findings of the literature review.

The national Institute for Health Research (NIHR) undertook its own review of evidence of end of life care and innovations within it and published them in *Better Endings: right care, right place, right time* (2015). Its recognition of the difficult

challenges presented for health care in supporting those dying with dignity, compassion and comfort, realistically tells us this is not easy to do (NIHR [online], 2015:4). The review reflects evidence from eighteen completed and twelve ongoing funded research initiatives assessing “recent evidence on the organisation and quality of end of life services” (NIHR [online], 2015:4) across a range of projects, programmes and work streams funded by NIHR since its inception in 2006 as the research arm of the NHS.

More people are dying older and the implications for care are reflected in the complexity of long-term conditions more commonly found in health care settings. General staff are providing care in the community or in hospitals in the final months of life and the report identifies a necessity to find time, training and support to do this well. Although general practitioners and community nurses too have significant roles in end of life care there is evidence of two or more unplanned hospital admissions in their last twelve months of life. Even though research points out that at least one third of patients may have palliative care needs not all hospitals provide managed end of life care (NIHR, [online], 2015: 5).

While evidence of specialist palliative care providing better opportunities exists across health care provision, services are not always tailored around need and the ‘Ambitions for Palliative and End of Life Care, a national framework for local action’ (2015 [online]) is seeking to address the rebalancing of tailored provision across the health service and in so doing address the concerns about equality of service and of opportunity of access through its acknowledgement of ‘right care, right place, right time’ (www.endoflifecare, 2015:6 [online]). ‘Right care’ includes: caring by general staff, accessing specialist palliative care, dementia and the very old. ‘Right place’ involves choosing where you live and die, joining up the care, and ‘right time’, addresses the question of getting care in time, and making the right decisions.

There is growing recognition across disciplines within health care professions and with patients, of the important role religious and spiritual beliefs have in adjusting to illness, death and bereavement and other forms of loss, physical, emotional and psychological. There is an emphasis that “discerning and assessing spiritual aspects or needs of individuals must be considered when providing end of life care,” (Holloway *et al* 2011 [online]). This is also true of life limiting conditions, and long-

term conditions as well as loss. This is not restricted to the bereaved, and includes those with conditions that affect capacity, like dementia, or managing life with disabilities, either as patients or carers. Increasingly all of these conditions have an impact in community settings as well as inpatient care, and will affect models of care.

2.4.1 Models of Care

Care extends to incorporate both integrated models and spiritual care models, according to the literature (Holloway *et al* 2011 [online]). Integrated care involves multi-disciplinary approaches in which consultation and co-ordination are important. This is underpinned by recognising all people as inherently valued and dignified regardless of 'health status or attention to spiritual needs'. It functions philosophically in relational aspects of humanity. Spirituality under this model is inclusive not something to be added as a discrete consideration. For successful outcomes this approach requires consultation and partnership with patients, families/carers as integral to the therapeutic approach. Implicit in all the models is the need for excellent communication and compassionate presence, lessening the burden of responsibility felt by families at the end of life through emotional support and education. In addition promoting physical comfort as well as control and decision making in patients families and carers is essential for quality end of life care (Holloway *et al* 2011 [online]).

Spiritual care models differ from integrated care models of end of life care, which incorporate spiritual care, in that the provision of spiritual care is the starting point for the model (Holloway *et al* 2011 [online]).

Spiritual care models aim to allow practitioners to apply theoretical ideas and concepts around spirituality, including spiritual need and spiritual distress in everyday care. Spiritual care models promote development and awareness of the spiritual integrated into the practice. It is still considered a concern that unmet spiritual needs may be under-diagnosed. It is not enough for a physician to understand the patients' beliefs and values but for all staff in multi-disciplinary environments. Patients have been able to get in touch with fears and anxieties through spiritual conversations, and the UK literature refers specifically to a preference for narrative accounts (spiritual conversations) and story-telling, almost in opposition to the more than thirty assessment tools and models of care

uncovered by Holloway *et al.*, (2011). This approach may help where patients in spiritual distress arising out of the loneliness of dying, or the struggle to accept the dying process may have been able to open up to a spiritual conversation. Spiritual distress can be compounded by feeling disconnected from self and others, and regular spiritual assessment and updating of care plans is seen as essential for good practice alongside other forms of assessment.

Despite the increasing emphasis on assessing spiritual needs, however, there are indications that these needs are not being met, through lack of spiritual awareness in the workforce generally, coupled with lack of confidence to broach spiritual issues (Holloway, *et al.*, 2011:24 [online]).

The literature is clear about additional education and training for staff, and while there is a paucity of material on community practice and religious and spiritual care, it is undoubtedly the case that community based staff like Health Visitors, District Nurses, Occupational Therapists and others who work in the community, are more, not less likely to require additional training and support in what are roles often defined by lone working arrangements.

3. Methods

In addressing methods developed within the research and evaluative framework for this project it is important to recognise the context around which an appropriate methodology could be developed, and effectively implemented against relatively tight timelines for completion. An action research model was seen by the researcher to be the most effective in bringing stakeholders and the researcher together in a solution focused approach. This model identifies a strategic necessity within the trust to understand how its stakeholders could voice their understanding and reflect on their personal and organisational position, in what would be a change process for the trust.

3.1 Commission

This project addresses the commissioning aspects and builds its method of action research and evaluation of the current religious, spiritual and pastoral care provision within DCHS from the original commission and the desire by DCHS to work with staff, patients, carers and families to find a solution to the need for and provision of religious, spiritual and pastoral care within the trust.

At the point of commissioning the trust was aware of the decline in previous chaplaincy services, and that former structures associated with the merger of a number of smaller trusts in 2011 (into the current organisation), identified many areas where spiritual and pastoral care had not in fact been in place. In taking into consideration the current model of working in the trust it was also aware of its expanding role in the city of Derby.

The most appropriate methodological approach for this evaluative work was one based on an 'Action Research' model. Action Research was first coined by Kurt Lewin in 1944 and developed in 1946 in his paper on *Action Research and Minority Problems*. Lewin broke new ground when he described action research as "a comparative research on the conditions and effects of various forms of social action and research leading to social action" (1946:36). Action research has two specific functions: 1) as a process affecting a 'community of practice' through which a reflective process is adopted which engages with workers and other stakeholders to develop problem solving progressively, and 2) as research initiated to solve an immediate problem. Lewin argues that action research uses "a spiral of steps, each of which is composed of a circle of planning, action and fact-finding about the result of the action" (1946:37)

In principle the methods adapted for the research and evaluation follow a model for change developed by Lewin (in social psychology) in the late 1940s. While it is a model of seventy years ago it resonates today as a direct consequence of organisational change models that have flowed from that early work, and the legacy that Lewin (1946, 1947) left to the fields of psychology and social psychology. Many of the current business models associated with change management have been formulated from these early developments. Action research through which a systems model for change was introduced and remains relevant today is testament to Lewin and his colleagues in that post war period in the USA.

An early model of change developed by Lewin (1958) described change as a three-stage process. The first stage he called "unfreezing". It involved overcoming existing "mind sets". At its extreme it is about organisational survival, and requires the bypassing of defensive attitudes to change. In the second stage the change occurs.

This is can be typically a period of confusion and transition. We are aware that the old ways are being challenged but we do not have a clear picture as to what we are replacing them with yet. This model reflects the decision by DCHS to examine the existing provision for spiritual and pastoral care in the trust and to look for alternative solutions driven by the evaluation, albeit the exact changes were unknown at the point of commissioning. The third and final stage he called "freezing". Here the new mindset crystallises and a level of comfort returns to the organisation. The model is presented below at figure 1.

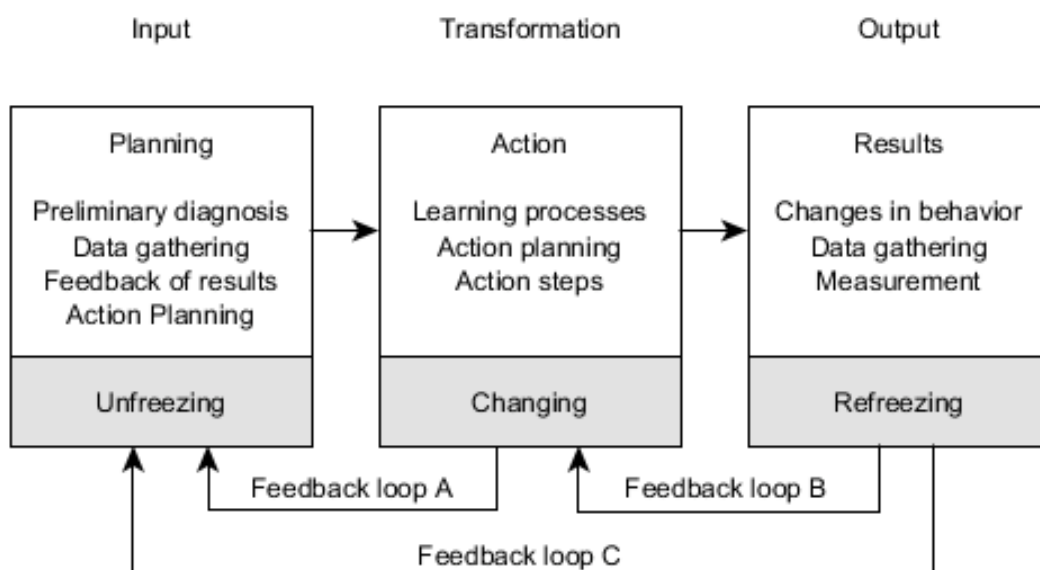


Figure 1. Lewin (1958:201) Systems Model of Action Research Process

There are two types of action research: 'participatory action research' and 'practical action research'. Actively participating in change within an organisation while simultaneously conducting research is reflective of the former, and working with large organisations or institutions to assist as a researcher in improving working practices and knowledge within that environment is reflective of the latter.

Denscombe (2010: 6) suggests, "an action research strategy's purpose is to solve a particular problem and to produce guidelines for best practice". The model adopted here addresses the improvement of strategies, practices and knowledge in support of a solution focused approach from within the organisation and its stakeholders, out of which a co-created process of change could impact on the community's ability to improve its work practices. In short, to identify where stakeholders feel, religious

spiritual and pastoral care should be in place within the trust, and recommend possible solutions to address that need, both at a personal and organisational level.

3.2 Research questions

The research questions developed to take account of the commission can be established under the aim to:

‘evaluate spiritual and pastoral care provision in DCHS Foundation Trust; report on the findings and recommend future developments.’

Questions to be addressed include:

- How does the existing provision for religious, spiritual and pastoral care (in the trust) reflect best practice under national guidance?
- What do patients, carers and families expect when accessing services related to religious, spiritual and pastoral care?
- How do staff and volunteers understand the role of religious, spiritual and pastoral care within the trust?
- After evaluation within the trust are there potential models for delivery of religious, spiritual and pastoral care that can be recommended?

3.3 Research Design

The evaluative action research was undertaken over a period of three months between October 2015 and January 2016. The research design sought to engage patients, carers and families as service users, as well as staff and volunteers within the trust. In order to do this a series of ‘engagement meetings’ were scheduled across the county and the city, specifically catering for staff and volunteers and patients, carers and families. DCHS communications department supported the delivery of these meetings, and arrange spaces to hold them in, as well as promoting them by advertising across staff and patient carer contact lists that they were taking place, with between four weeks and six weeks notice of the engagement events.

The research adopted a mixed methods approach using qualitative data collection from focus groups, geographically spread north and south of the county of Derbyshire. In addition a quantitative research instrument was developed in the form of a survey questionnaire, which was posted via a web-based platform and was

made accessible to respondents, promoted by communications within DCHS and via the Multi-Faith Centre e-bulletin, which reaches over six hundred individuals and groups across the county of Derbyshire.

The focus groups were convened with staff and volunteer groups at Chesterfield's Walton hospital where a group of nine staff were involved. At Ilkeston Hospital a group of five staff met, and at London Road Hospital in Derby city, where a group of four staff members met in the focus group. There were eighteen participants in total, all staff members with various roles. The gender divide identified fifteen females and three males. The age ranges of the females between twenty-four and sixty-four years of age. Male age range was between thirty-eight and sixty years. Roles varied from in-patient nursing, to occupational therapy, specialist nurses, administration, management, community nurses and therapists.

Staff were not asked directly if they held a personal faith or belief, but were content in the main to identify themselves with religion or belief in their personal lives or understanding, or if they were atheistic, agnostic or in another way non-religious in the traditional sense of a commitment to a world religion or its worldview.

Organisational affiliation was not discussed and was only realised in the context of what staff were prepared to disclose in the focus group setting. A review of the focus groups identifies seven females with a faith-connection/personal commitment, seven (five females and two males) with no traditional faith connection or commitment, and two females who were non-religious but sympathetic to the needs of those with religious or spiritual concerns in their lives.

Engagement events were also sought with patient, carers and families, at Walton and at Newhall in South Derbyshire, however both venues failed to see anyone turn up for the focus group sessions. The timing for these was close to the Christmas break and that may have had an impact. However there were three patients at the London Road engagement meeting. Additional patient, carer, family focus groups were established at Treetops Hospice on two separate occasions in January 2016 and at Ashbourne at the support group which meets in Café Connect in support of the bereaved.

The focus groups convened at Treetops consisted of four groups on day one with

fifteen participants, and on day two there were three focus groups made up of ten participants. They were loosely defined according to where clients at the hospice were located in the open plan rooms and where it was possible to hold these group conversations together. The researcher moved around the rooms during his time there to create the group arrangements according to participants' immediate access to each other and a willingness to participate. Not everyone was willing to participate, but many did. As a number of the Treetops clients had impaired mobility it seemed to be the most appropriate method to form focus groups within the potential client groups on site, without trying to physically move people around unnecessarily.

For the purpose of identifying speakers in the Treetops focus group sessions the participants have been numbered from 1 to 15 on day one, and from 1 to 10 on day two. Where participants were in agreement or talked about aspects of the research in similar ways they can be grouped by number around a particular theme or idea. Where they had something to say that reinforced a point or made a significant contribution their *verbatim* response is captured. The participant groups at Treetops are described as; 'in end of life' day care and the population distribution of the groups was split across genders approximately 60% female, 40% male on both days. Age ranges were between 60 and 92 years of age.

With a few exceptions all those who participated had experience of DCHS services in different parts of the county, before and during their time in day care services provided by Treetops. The focus group at Ashbourne's Café Connect consisted of eight people who had all been bereaved, all of whom had experience of DCHS services as a family member or close friends of those who had died, and had personal experience in most instances, as patients in in-patient care, outpatient and community-based services, including district or community nursing support. The gender split among this group was six females and two males, ages ranging from mid thirties to late eighties. The total number of participants in the patient, carer and family focus groups was thirty-three. The focus group data was recorded via digital recording in staff and volunteer engagement meetings and some patient, carer, family meetings. These recordings were transcribed *verbatim* and focus group evidence appearing in the report is coded with a letter according to site where it took place (w = Walton, i = Ilkeston, l = London Road) and a designated number to

identify the person speaking. For example, w1 reflects a person designated by that number in the Walton focus group. Where more than one focus group took place at the same location the prefix number relates to the session. For example, 213 = session 2 at London Road person number 3 speaking). In the context of the hospice setting and bereavement support group the conversations with participants were recorded by contemporaneous note taking, as neither setting lent itself to recording information in digital format. The same coding process exists for identifying place and speakers; a letter t = Treetops (1t and 2t), and a = Ashbourne, with appropriate numbers identifying the speaker and retaining their anonymity, outside the group itself.

Focus groups interviews were conducted using a semi-structured questions, a schedule, can be found at appendix1 of the report. Focus group data was analysed and coded according to themes presented in the research and the findings identify key themes, which feed into recommendations in this report at section 5.

The quantitative survey was developed as a research instrument to ask ten direct questions of patients, carers, families and DCHS staff. It uses a combination of likert scale questions measuring importance of aspects of spiritual and pastoral care, both in its reach and scope, choice of possible types of provision and confidence levels of staff in dealing with end of life care and life limiting conditions. It also uses open qualitative questions to assess the experiences of respondents and possible future thoughts about what provision they would like to see. The survey can be found in appendix 2 of this report together with a summary of the data analysis. Sixty-four respondents completed the survey (n=64), the results of which are explored in the findings section in section 4 below. The survey data was analysed using the web-based platform software analysis and interpreted in the findings below.

3.4 Ethical Considerations

Ethical approval was agreed with DCHS in the context of evaluation of services for staff and volunteers and DCHS promoted the research to patients, carers and family members. Non-DCHS staff was approached to obtain informed consent directly. This was obtained from all participants and organisational links to those people prior to taking part in any focus group interview, and in the introduction to the survey questionnaire. Anyone who took part was made aware, in advance, of the nature of

the research, that consent was required, that they could withdraw at any time and/or choose not to have their input included in the report if they so desired. In addition, participants were made aware they would remain anonymous in the process of reporting the findings from the research, and should they wish to seek support or advice, to contact DCHS Communications, particularly if they needed authentication or verification of the research and its legitimisation. In a focus group setting anonymity from within the group and its participants is difficult, dependent on the situation. However, all participants recognised this and were content with the in-group dynamics, as long as external to the group anonymity was maintained in the reporting process.

4. Findings and Analysis

The following section will address the findings from the research in three areas. First, it will examine the staff engagement across sites (identified above), second, develop patient, carer and family contributions and finally, explore the quantitative and qualitative aspects of the questionnaire survey which has both staff and patient input embedded within it. Analytically the combined findings will be drawn from the themes identified from interviews and questionnaires and evaluated in response to the literature (previously discussed) from which conclusions and recommendations can be drawn.

The findings from the research can be summarised under eight themes, as follows: Defining concepts for religious, spiritual and pastoral care; The Importance of spiritual and pastoral care; Staff confidence, training, awareness and up skilling; The religious and non-religious dynamics; Space - its availability and use; Elevating the conversation internally within the trust; Volunteers – their roles and potential; Models for spiritual and pastoral care.

Analytically, questions relative to the research findings are discussed in light of current thinking within the trust from a staff and patient/carer perspectives, identifying how barriers and bridges could be reflected in recommendations and an examination of what has been discovered and where it sits with existing research. This is particularly relevant for that which affects end of life and life limiting conditions, which opens a door to how recognition and discerning approaches can

impact, what organisational and environmental conditions exist and how is workforce development affected and effecting the challenges presented in the research.

4.1 Staff and volunteer engagement

Staff engagement sessions reflected across all aspects of the themes identified above and drew on the considerable experience of participants in the focus groups all of whom had worked with previous trusts before the development of DCHS in 2011 which merged many of them under one umbrella. The staff from London Road engagement sessions in Derby city had only just moved across to DCHS in October 2015, and was still effectively transitioning into their new environments.

4.2 Defining Concepts

Across all staff group engagement there was both a concern and an inquisitiveness to better understand the concepts of spiritual and pastoral care. There was also some confusion about what those terms mean, and a readiness in many instances to accept that they would like to find them defined clearly for them in their working environment in order to better be prepared to work with ideas, structures and functions that could/would enhance the nature of spiritual and pastoral care within the trust.

Defining the terms 'religious' and 'religions' was seen as less problematic than 'spiritual or pastoral'. Staff made the everyday reference to mainly Christian churches, recognising the distinction, in the main, between Protestant and Roman Catholic models, although few knew of any real differences other than the different sacraments, and that came essentially from staff with a personal Christian faith. Staff saw Christianity as denominational (for the most part) again with little sense of the distinction beyond the labels.

These groups associated 'religious care' in a healthcare setting as support in matters of religion and belief and as the domain of a minister of religion, including a chaplain from a Christian perspective. They did however acknowledge that with more knowledge to signpost and basic understandings of some traditional religious ideas that they could, if called upon, find support or a means to access it if it was required. This included and was limited to, access to local vicars or priests within

Christian churches, and essentially the first response was to find the patients existing links to those external services. This approach was seen as a possibility for inpatient and community care, the latter having potentially more difficulties associated with it, contingent on a range of factors, including family /carer support and local knowledge and time /capacity issues, using their own time often to make it happen. However, if the patient had no particular external connection with religious and or belief groups, most staff said they would struggle to know where to start when it came to making contact. Some suggested local voluntary services, or line managers as a starting point.

When asked to give thought to their understanding of the concepts, 'spiritual and pastoral care' the following ideas were expressed:

It's the essence of what we are, it's different for each individual (w3). Faith has massive meaning for a lot of our patients. It's also a person's creativity and their connection to nature (w2). It's a thing historically where people used to turn to the church for help advice and whatever (w4). A lot of young people don't recognise that now (w3).

In addition it was recognised that there are distinctions between what is described as spiritual and what is understood as pastoral care/support. This was explained by w5, who suggested:

What you are talking about is the spiritual perspective. For me I think it is about pastoral care. I think the work we do, [pause] you get impacted quite deeply by things you see and know, and we are a caring organisation, but actually do we care for ourselves? Do we help ourselves or each other to recover from traumatic experiences?

Spirituality was raised as an idea that is akin to religion but it could be different from it, and may be about what we see in our efforts to make existential sense of our lives or connect with nature, or forces beyond us we may struggle to explain. It could be a God or Gods but is not necessarily so. It may be about transcending normative experiences in different ways. There are those in the focus groups who saw this connected to music, to prayer, to natural phenomena that has a power we are unable to harness, tame or manage, such as earthquakes, volcanoes, animal or plant life and the wonders of the sea or space. There were few attempts to define spirituality as distinct from religion or pastoral care and the one attempt was to think about the spiritual outside of specific religious traditions, explained thus:

Spirituality for me comes inside and outside of [religious] tradition. If you have spiritual wellbeing it makes for a better recovery. It should not just be aimed at patients either, I think it's carers that should be included or families because they may have a specific or denominated religion or some sort of alternative idea and they might need help coming to terms with their love one, their condition or whoever. Minority religions should still be acknowledged, its not just an umbrella thing – we've got nothing else, just have this [Christianity] for now, which is not very helpful (2L1).

There was a general agreement independently across all the focus groups that the necessity to address patient care holistically was not being met in the way that spiritual and pastoral care was understood or being applied. In all the focus group settings it was agreed that the trust dealt with the physical and psychological needs of patients well, but was less good at dealing with their spiritual needs, and that had an impact on spiritual and emotional wellbeing and potential recovery rates. The exception to that general consensus being in end of life care, where it was, according to the groups interviewed, still questionable in terms of its efficacy and implementation, but was seen to be given greater consideration.

Pastoral care distinctions were focused around personal wellbeing and were seen as not bound by a formal faith, and having everyday considerations at its heart. The Ilkeston focus group, explained it, saying:

I'd like to see more pastoral care for staff not so much religious care (i4). Pastoral care is about support for your wellbeing, your needs, and is designed to help you [staff], and patients (i3). Pastoral care is not bound by a formal faith its about supporting people in daily life (i2).

The lack of adequate training and hence lack of understanding were cited as a possible cause for concern and will be addressed in the section on staff confidence and training later, in section 4.5 .

4.3 The Importance of religious, spiritual and pastoral care

There was another general consensus across focus groups in relation to the question of how important was religious, spiritual and pastoral care to those interviewed, and their perspective on where it should sit within the trust.

Overwhelmingly, the participants in interviews referenced the caring profession and the necessity to care for spiritual and pastoral wellbeing as part of the holistic provision being offered. At the same time accepting that spiritual and pastoral care needed more work and specific training to facilitate confidence to deal with it. They

also acknowledged that those with no particular faith or spiritual source of affiliation should be provided with an offer of alternative support in a more secular sense, be that about befriending, companionship or active and deep listening. The in principle ideas were about providing an inclusive service to address the majority Christian faith group, minority faiths and those of no religion or the non-religious, but spiritual. A participant at London road said: “ you cant do this at all if you don't have the human to human contact and relationship building, before any question of religious spiritual or pastoral care” (1L3).

The question of who would provide such a service identified a couple of people who were annoyed at the lack of a formal chaplaincy presence within the trust. One of who was passionate about chaplaincy support without compromise, the other being prepared to consider other ways to facilitate spiritual and pastoral care without formal chaplaincy roles within the service. Others however, more generally, had a sense of a changing landscape in DCHS and recognised, while provision was for them necessary and important, inpatient care was shrinking across the trust. A greater proportion of the trusts emphasis and energy therefore was focused in the community and directly in many cases at people in their own homes. The question of how best to facilitate community support through the majority of services in the trust became a more difficult topic to address than the inpatient provision, for which there are historic models, mostly designed around a chaplaincy model.

The importance of visiting inpatients or those in community settings did not diminish the fact addressed by W5, who said: “it is hugely important in life’s difficult times, which can be traumatic, to have spiritual support. It makes a huge difference to the people we deal with who have real difficulties in life”.

There was also reference to the nature of multi-faith and multicultural settings in which the trust had little spiritual or pastoral provision, outside of staff being active enablers of their own support, which generally means finding or accessing through signposting to services outside the trust and linking patients and carers with spiritual or pastoral care provision. A similar cord was struck by W2 who said:

I think it is important as clinicians to deliver high quality care to all patients, children, older people, to meet everyone’s needs through holistic care, but we are not very good at delivering the spiritual aspect of that care. We are great

at DCHS at having things like 'Resolve'¹ but spiritual care is nothing to do with going on your record, you don't have to make an appointment for spiritual support if we have something in place you can just turn up. We need something reliable and confidential. We can have a new model, but we definitely need something, I really believe it is important.

In consideration of providing models for spiritual and pastoral care these are covered in section 4.7 to follow. Staff in London Road who had responsibilities for community services in the city and beyond, also recognised the importance of spiritual and pastoral care. Managers of services recognised their own roles as having a pastoral care elements in supporting staff during difficult work/life issues, suggesting that the role was only limited by what people were prepared to share with others. They also recognised the importance of pastoral support for patients, and talked about a compassionate response to others on a human level, that did not necessarily require a formal response to religion and belief, or indeed alternative forms of spirituality.

The perspective of the trust was considered when assessing care packages or patient needs on admission or in community settings. It was discussed that the question required of all patients relates to initial assessments and asks if individuals have any religious beliefs? It talks about the social importance but not separately about the particular belief system or religious or spiritual dimension. In other words, staff were concerned that patients were being asked the question in most instances, but even if they said they did identify with a religion or belief tradition or group, no further exploration took place about the group and what that might mean for their care. 1L1 suggested, "we often ask if they [patients] need anything to help with recovery but don't include the spiritual".

There is little dispute about the importance given to spiritual and pastoral care by staff interviewed in the focus groups, but there remains some concerns about the lack of formal spiritual and pastoral care structures across DCHS and that in some places there are existing connections with local parishes or other services and in others there are none. The piecemeal way through which staff addresses spiritual and pastoral care appears to be defined by local circumstances in inpatient provision and in communities' through connectivity with other services or agencies

¹ Resolve is a service for staff in the trust where they can receive Counselling, and support.

that might signpost or provide support. None of which is being formally identified currently by the trust.

4.4 Staff confidence – awareness, training and up skilling

Probably the most significant aspects associated with the evidence from the focus groups relates to staff confidence to deal with the spiritual and pastoral care of patients, their peers and the desire to see more training awareness raising and greater skills development as part of their existing roles.

Staff are conscious of the lack of a public conversation about personal religion and belief and even at initial assessment they suggest that patients too often feel embarrassed to discuss it, and defer to a default, 'put me down as C of E' (Church of England) even if they are not. This creates a twofold dilemma, not wanting to embarrass patients further by exploring their religious and spiritual life, knowledge of which could assist clinicians later, when managing their care. In addition, feeling that to pursue the questions about religion, spiritual or pastoral care may lead to a situation where the staffs' own lack of knowledge or understanding could lead to them responding inadvertently in inappropriate ways which then causes offence. Conversely there is a fear that the non-religious patient may take offence at questions about religion and belief, and challenge staff to provide resources that they cannot access.

Focus group members at Ilkeston, Walton and London Road highlight these issues. London Road and Walton groups raised a historic question about staff training, particularly nursing training, suggesting many years ago nurse training dealt with the importance of spirituality and faith in a much more vocational manner, whereas today in a more academic training programme there seems to be a lack of vocational outcomes to help nurses address the spiritual care of their patients. There is also evidence from all three groups of a lack of any structure in support of provision for spiritual and pastoral care outside any already extant local arrangements. Community staff are expected to assess for religion and belief and explore spiritual needs, but there is nowhere to access those particular needs for patients, and most would, it seems, start by identifying through the patient, carers or family any existing connections and if none are apparent then they would need to proactively source them through voluntary services support or local area

coordinators (in the case of Derby city) or through colleagues or other staff members. A participant at Ilkeston summed up the position for community service workers saying,

“I would have to do the legwork to find someone, I don't know where to signpost to. There is nothing on the intra-net and no staff training that I am aware of.”

In London Road, 1L2 said,

“in thirty years working for the NHS I have never seen anyone offer spiritual care or support outside a chaplaincy model, and certainly never heard it offered to staff”.

At the Ilkeston engagement meeting, staff acknowledged that there were no structures in place, nor were there any structures in support of multi-cultural or other faith provision, and they felt there was not just a lack of awareness of religion and belief issues, but also of ethnic and racial identity issues too. A staff member said,

We don't get any training in Counselling but we are often asked for advice in the community and I am always living with self-doubt, asking, did I give the right advice? I once rang Resolve to see if the advice I had given was ok (i4)

Staff suggested that they have commonsense and life experience, at least those that have been employed in their roles for some time, but would value training in these areas.

We don't deal directly with end of life care but we do manage those with life limiting conditions, and many of the patients we see will go on to end of life care. We informally support them but if we had specific training we could help prepare them for when they move into end of life care packages.

There was equally a concern that the lack of training and awareness left staff feeling defensive and in fear of making mistakes in dealing with religious, spiritual or pastoral care matters, and as a consequence they would do nothing rather than get it wrong. As a consequence it was felt colleagues could not blame them. A staff member in the London Road meeting suggested, “colleagues don't have religion or belief in their lives so don't really know about it” (2L1). The question of pastoral support for staff was also raised and it was generally felt that even good managers who had made time beyond supervision for staff with pastoral care needs were saying there is no longer space or time to fit it into existing working models.

This led to discussions across all focus group settings about staff confidence to deal

with spiritual and pastoral care in their roles. Generally there was a feeling, that with a few experienced exceptions around the trust, most staff had no confidence at all to address these issues. There was also a question about whether managers were feeling confident and it was highlighted that spirituality is not the subject of any master-class topics or leadership training programmes. Managers in the focus groups said it was their responsibility to support staff and to find effective ways to signpost into services where they existed.

Confidence is a significant issue and potential barrier to staff's abilities to connect spirituality with themselves and their patients. Some staff feel embarrassed by putting the question to patients about having a religion or belief. It seems this stems from the lack of a public conversation or discourse about religion and belief and that they may not have a personal faith themselves and so feel awkward asking others if they do.

In end of life care the Derbyshire life tool kit, a specific spiritual care assessment tool seems to have gone largely unnoticed according to w5, who raises the implicit question in the statement, "nobody's heard of it and nobody's using it"... further discussion reveals,

it's so important it's opening a door and a window to learning more about your patient, what there needs are and thoughts and wishes and preferences. This involves how they want to be treated, how they want to die. These are things we should embrace if we are brave enough but most of our staff are not brave enough

End of life care was acknowledged as a specialist provision but was also held up as a flagship area and staff wanted insight into the support provided in end of life care to help support their own confidence to deal with matters related to spiritual or pastoral care.

4.4.1 Suggestions for staff training and awareness raising

Focus groups in all locations came up with suggestions for improving training and raising awareness of staff in the trust, including:

- A designated link worker on wards or within community teams or GP teams with additional training so that they could advise and support colleagues on decisions around religious, spiritual or pastoral care.
- Ambassadors with experience who are brave enough to tackle these areas and are confident to support other staff, particularly with patients with life

- limiting conditions who may not be able to achieve independence.
- Half day umbrella training on religion and belief matters and the production of cards with the top ten tips for nursing and other staff to keep in their pockets based on needs in care.
- Resources uploaded to the intranet to give religion and belief issues greater clarity within the trust, and confidence that they are being taken seriously as a consequence.
- Culturally sensitive training, (face-to-face preferably).
- Develop a list posted on the intranet of where to seek help.
- Send out newsletter to service users identifying link workers in the trust.
- Campaign – ‘it’s ok to ask about religion or spirituality’ – badges could be worn by confident staff who could advise and support patients carers, families and other staff members.
- Key skills training in communication, listening, problem solving through solution focused questions.

4.5 Religious, non-Christian and non-religious dynamics

The current provision for spiritual and pastoral care in the trust is seeking a response to the lack of formal chaplaincy arrangements in inpatient care and the necessity to facilitate the needs of patients through staff engagement in community settings. Current provision has only one part time chaplain attached to the trust and informal arrangements with the Diocese of Derby at Newholme. The Christian model seems to be the default position as far as staff in the engagement focus group meetings is concerned. In that sense staff are inclined to connect with existing Christian groups, churches etc., in community settings. These arrangements are at present informal and individually accessed by staff in community settings.

There is however an overwhelming sense that with the exception of the Derby city staff newly migrating over to DCHS few, if any of those spoken to as part of this research and evaluation have any idea about accessing non-religious service provision or those of a secular nature that would still address wellbeing and provide support for patients in community or inpatient care.

In addition there is equally a dearth of ideas or knowledge among participants about who and how to contact those in other faith provision, be they from the world religions: Buddhist, Hindu, Jewish, Islam, Sikh, or more obscure expressions and less well known, such as Baha’i, Chinese traditional religions, Neo-Pagan or other alternative spiritualities. There was also a concern about a lack of knowledge to facilitate access to denominational Christian groups, Methodist, Baptist,

Pentecostals (including Black majority churches), 7th day Adventists, Jehovah's Witnesses, or Society of Friends (Quakers).

It was acknowledged by w6 that there was more to the question of spiritual and pastoral care than a religious non-religious dimension,

I believe there's more to it, any denomination you go to, they have set skills, caring support, being non-judgmental, good listening, just happy to step in. They can support anyone if religious or not. I wonder if other faiths have a need? I don't know much about the Muslim community.

The discussion at Walton agreed that some people as patients or carers wanted nothing to do with religion, and if religious provision was made available even if they were only supporting in a befriending manner, it may be that there could be an objection. Equally the alternative would be based on the need and what the person requesting was seeking? Participants pointed out that they had experience of people in end of life care who did seek a spiritual and or religious level of support, and sometimes the mortality question raises doubts and fears in people out of which they may seek solace or even redemption from a religious and/or spiritual perspective.

At Ilkeston too there was a sense that catering for the non-religious in whatever form did not create any easier solutions than seeking religious spiritual or pastoral support. In both settings those participants in the focus groups agreed that they would appreciate more knowledge of other cultures and religions and sensitivities associated with them. They also accepted that other faith communities were part of the need for more cultural awareness and training and accessing Hindus or Sikhs as spiritual support was something they had no experience of or any idea where to begin their exploration.

4.6 Space - availability and use?

The question of the kind of spaces currently in use and how they were being used was posed to all three staff focus groups. At Walton there was recognition of specialist units like Riverside and how there were significant efforts there to work with the issues of dementia, which had allowed a creative visual response to help support patients with that condition, and others that affect capacity.

This also raised questions of dignity and privacy in the use and function of multi-faith spaces and or separate rooms as either quiet spaces or specific for prayer, reflection meditation with a religious or spiritual dimension associated with that idea. One participant w6 felt very strongly about the need to adopt both spaces that could function as multi-faith provision and those that were designated as quiet spaces. This also raised the idea of embarrassment sometimes experienced by those who feel they want to ask for a room. The trust has very few spaces and so if asked staff have to try to find one, which in the current situation is less than ideal. There is also the difficulty of some wards not even having any quiet space on them. The Riverside example was cited as having resourced itself with equipment, including: DVDs, music free access to art, and the fact that although off sick currently the Diocese of Derby has made a local minister available to Riverside. The work there is seen as good practice and has been presented to students in Sheffield, and to care homes and others.

The Walton focus group agreed with the London Road and Ilkeston groups about supporting ambassadors or linked workers to address some of the issues being experienced in the trust currently. One such request came from the Walton group:

It would be really great if someone in DCHS, I'm not sure who it is, but someone to network with vicars, priests, rabbis or imams, whoever – [pause] people who may not be able to find a way to contact DCHS. People like [name] could be ambassadors for the trust. Care homes around the county need support DCHS could provide it, it could be cost neutral for the trust. This is as important as mental health and we are a big organisation surely there is a resource to fund this, it should not be diminished (w4).

Cases of Muslim doctors accessing spare rooms or other convenient spaces was discussed, as were the staff zones as possible places of access for materials where link workers or ambassadors could act as support staff for those who want to know more. There was also a suggestion of designated quiet rooms around the trust for quiet reflection by staff and patients, carers, families.

It was suggested that facilities for prayer or other form of ritual use including equipment to facilitate prayer, reflection, meditation, like for example: DVDs or music CDs, prayer mats, deity or image, candles, could be stored in cupboards and made available when needed. The potential to keep things out of view unless patients or staff was using them appealed to focus group members at Walton,

Ilkeston and London Road, not least as it retained a multi-functioning purpose for the room, and was not deemed a big pull on precious resources.

4.7 Elevating the conversation internally in the trust

There was, among all four staff engagement focus groups a feeling that the prominence of the debate about spiritual and pastoral care needed elevating to become a trust-wide, more publicly oriented conversation. It was recounted thus:

I would like to see the leaders of DCHS give pastoral care and spiritual care an eminent position” (w5). Just a simple thing like the trust speaking out and supporting publicly the idea that it is committed to pastoral and religious care support for patients and staff (w7).

There was a feeling also that more meaningful engagement with people [including staff] involved valuing patients insofar as their spiritual and pastoral needs was concerned. It was felt this should be valued across the trust, and the trust should embrace a cultural shift to make spirituality valued, and to embed it in training. Ilkeston group member (i1) noted that:

There is no advertising of spiritual and pastoral care provision or training or support on the intranet for the trust, and yet as a quality issue and an indicator of the trusts equality and diversity provision and end of life support these things should be embraced (i1).

In line with ideas of a cultural shift in the organisation it was also suggested that using experienced staff to talk to others about the options for pastoral and spiritual care, is reflected in the comments:

staff don't seems to be tuned in and don't seem to realise an investment of time at one end will pay dividends at the other, it will help with greater cooperation with patients and families. It is much easier then through the use of open questions, affirmation and reflection to tap into where patients are at

As a general sentiment from the focus groups there seems to be a desire to see the trust promote spiritual and pastoral care as an element in the life of the trust manifest in peoples lives - staff patients, carers and families. It was even suggested that such an approach could be a business opportunity especially to develop community models of engagement where community practitioners and patients could be seen to function in replicable ways for the benefit of other trusts

4.8 Volunteers – roles and potential

Volunteers are a resource considered by the focus groups as potentially important

for the support they could provide and do provide for the spiritual wellbeing of patients in inpatient care and for the potential to create community based functions around which volunteers could have a role. Churches rely heavily on volunteers to act as pastoral visitors to the sick, the housebound and those with other needs. It was acknowledged that volunteer roles in the trust vary and there are still some ward visitors who act as befrienders and thereby have a pastoral function in support of patients.

There is also evidence of young people in universities in Sheffield and Derby that are interested in the isolation issues of older generations and it is a possibility that if the trust had a recruiting drive for volunteers for befriending support that it might attract younger people into its ranks. Of course while these ideas are suggestions there would need to be a good deal of practical application to make it work.

The challenge for volunteers is identified in the necessity to embrace them as part of teams with whom they are working and to provide proper welcome and induction and task them and supervise them appropriately to get the best for the volunteer and the organisation. Volunteers would need to be fully embraced by the trust and valued within teams if they are to feel empowered to function in the setting where they are being asked to give support to others.

In addition, volunteers, not unlike staff require training and managing, and can be deterred by formal training delivery. It may be appropriate to change the language to develop volunteer support sessions and move away from the language of formal training. Focus groups at London Road, Ilkeston and Walton all support the idea of volunteers working in support of spiritual and pastoral care within existing teams and would like to see progress to pilot work with them in community settings to.

4.9 Models of Religious, Spiritual and Pastoral Care

Previous historic offers of core funded chaplaincy services are not the only model to provide spiritual and pastoral care in NHS trust settings. It was raised at Walton by the focus group that:

Community hospitals over the years saw chaplains coming in as they were part of the town in which, mostly inpatient care was being provided. The model is changing now that beds are dwindling. The focus was around wards but this is only 5 to 10% of the trusts work, such a lot more is out there in the community. Churches are out there and we should perhaps remind them that

we are doing work with similar intent to them, that is to bring people to a place of wellness, including caring for their wellbeing and spiritual wellbeing is part of that model. We should work together with churches not in isolation from them, particularly as many patients are also parishioners (w2).

It appears that resourcefulness, flexibility and models that promote self enabling and support of others, may be need to be given greater consideration. For example, (w3) asks, “if the local vicar doesn't turn up for a session then have a back up plan, put the music on and see if you get what I got, which was four ladies signing and enjoying themselves.” Local parish links do already exist and it would not be too difficult to create more links across parishes in the county and the city where DCHS has a footprint.

Churches, Mosques, Gurdwaras and Temples all have a pastoral supportive role for members of particular religion and belief groups and will if approached feel their moral and civic duty as well as kinship ideals of brother and sister hood to act if they can. The trust can embrace diversity of religious practice with some little effort to connect with these organisations formally, albeit through things like memorandum of understanding or even service level agreements. It is therefore evidently more than a possibility with some networking and discussion to forge links across these places of worship.

There were those in focus groups (Walton and London Road) that felt if the model of chaplaincy was no longer part of the trusts ideas for the future there must be an alternative model put in place. When discussing churches and possible linked work, there were questions raised in the Ilkeston focus group about the capacity of smaller parish churches who may have the best of intentions and seek to support care but fail to do so due to too few volunteers available to cope with the demands. These of course are strategic questions that should be addressed in light of any firm ideas about local community places of worship collaborating with the trust.

There were discussions at Ilkeston about the type of model that could be adapted and be effective. It was felt that as long as it was a person recruited in the correct way it wouldn't matter if they were necessarily formally trained as long as they had the skills, for the role. When asked if they thought volunteers could do it they agreed that they could if they had the necessary skill set. The skills should include

communication skills, being non-judging, able to feedback and administer appropriately to the official body. Listening, and empathy, compassionate and emotional awareness; these were all seen as attributes and skills. Fundamentally the concern was that anyone taking on lay roles should be recruited properly and managed appropriately. They should be fully embraced by the trust and given status through their role.

There would, in any model being adapted for use within the trust, be a need to offer extended training to those working in end of life care and even those working with people with life limiting conditions. Specialising in these areas would require that those providing support were part of the team engaging through the end of life care plan. They would need to be fully embedded in the team and proven in their application of spiritual and pastoral care to work in that setting.

Community based models could equally rely on volunteer support by recommendation or through a process of vetting for the role including DBS checks and working alongside community teams, where references could be sought from local faith community leaders (across all faith provision). Community matrons and care coordinators would then be able to task pastoral care support volunteers in their own areas. They would be subject to similar working arrangements as other community team members and would probably team up with other team members initially to quality assure provision.

4.10 Barriers and Bridges

Summarising the focus group engagement meetings brings into relief where barriers may exist and provides potential bridges to overcome them.

End of life care would require specialised support and training, which currently is in place through the Derbyshire life tool kit, and would be implementable with team support for those bringing spiritual and or pastoral care to the package.

Scoping exercises are necessary to see where recognised institutional forms of religion in Churches, Mosques, Gurdwaras and Temples are willing and able to support DCHS. Some of the more denominational Christian groups too fall into this scoping exercise, and ultimately all faith-based and secular provision in the city and

the county should be sourced and lists made of material, access and contacts through which networks can be established, relationships built and support achieved.

Much of the skill set required many people already possess, and training to enhance skills would be part of the opportunity being created. Non-religious support seeks to walk a journey with patients, carers and their families, in similar ways to those with a faith affiliation, with a fundamental difference, the reference to transcendental or supernatural being(s). There are of course overlaps in philosophical, practical, ethical and human interaction terms that can be mapped in training for both approaches. Indeed with the exception of specialist religious knowledge, either candidate could work across religious and non-religious divides. This is true of life limiting conditions and end of life care. The mundane needs of everyday life are still fundamental to contact and support alongside spiritual and pastoral care.

There is a lack, it would seem, according to our respondents of spiritual and pastoral support for patients, carers and families. There seems to be a similar lack for staff too and a lack of training also.

DCHS and Derby hospitals trust will need to agree integrated working where an overlap and a shared service through city based chaplaincy may be an option, and the use of space, like the chapel at London Road a possibility.

Dedicated spaces and staff in support of spiritual and pastoral care across inpatient and community settings may be a positive move towards addressing the needs of patients and staff. Part of this involves management and the trust embracing a cultural shift in the previous functions to embed spiritual and pastoral care provision in patient and staff environments, thereby dispensing with hierarchical tensions between managers and staff that may not lead to open disclosure. A more trust wide embracing may support staff resilience and increase better working relationships, less sickness, and better productivity.

Intranet resources are not currently available, and this needs to change in support of awareness raising, up skilling of staff, and future training provision. These should include cultural as well as religion and belief resources for greatest impact.

4.11 Patient, Family and Carer engagement

Focus groups established at Treetops Hospice providing day care for end of life clients and at café connect with a bereavement support group raised a range of topics in relation to the experiences of religious spiritual and pastoral care in the lives of those forming the groups that were interviewed. These included, defining ideas around religious spiritual and pastoral care; the importance to them of religious spiritual and pastoral care (as patients/carers/family members), support; community contact; and end of life care.

4.11.1 Defining Concepts

The ideas of religious, spiritual and pastoral care were discussed in sessions at Treetops Hospice on both occasions when focus groups were convened and at Ashbourne with the support group there (groups 1t, 2t and A). In 1t, participants 4,5,8, and 11 talked about their sense that religious care in hospitals was about seeing a vicar or someone from a church. They did not use the word chaplain or refer to a chaplain. All four individuals said they had not seen anyone on either of their last inpatient visits that offered any religious support or contact. They had all been in inpatient or outpatient care within the previous 2 years. Those specific participants were unable to recall if they were asked about their own religious connection or affiliation on admission, and seemed to think in general they may not have been asked the question.

There was also a wider conversation about participants' thoughts on spiritual or pastoral care. In 1t the responses varied from not understanding what was meant by the terms spiritual and pastoral (1t 5,6,7,9,11,12,) to questions about how spiritual care could take place, by suggesting staff in inpatient settings helped to encourage recovery and sometimes connected the patient with the spiritual, in the context of conversations about the weather, reference to flowers in bloom and to the quality of the landscape and the views. 1t4, said:

I think staff do a wonderful job, they should pay them more if you ask me. The nurses used to talk to us about the lovely views when we couldn't get up out of bed, and about all kinds of things like natural surroundings, they were very kind, I think that's a spiritual thing, it certainly makes you feel a bit better.

In the 2t focus group, participants did reference the idea of a chaplain as associated with inpatient care but many said that they had not received in patient care for a number of years, or if they had it was not recalled in their experience that they had any real connection with chaplains. Two participants however (2t 4 and 8) had both received a visit from voluntary services and had discussed with them their religious connection, and that they were both Christian and involved in parishes in their home locations.

I remember voluntary services, a lady from there came to see me and she asked if I had a church or someone at home who was coming in to see me. We talked about my work in the parish for some years, and she told me all about her voluntary work and visiting people in her parish. I think she was from Matlock. I was pleased to see her and she came twice while I was in (t4).

Yes I had a visitor too and she was lovely we talked about the local church and the vicar there she said he came to the hospital, I didn't see him though. I probably would have if I'd stayed longer, she probably could have arranged it (t8).

In t2 the ideas associated with spiritual care were interpreted as, in one case, about spiritualism, and in a number of others about a lack of understanding of what the terms pastoral or spiritual really meant (2t 1,2, 4, 7, 8 9 and 10). One participant did suggest that pastoral care was likened to his experiences in the army, saying:

I can remember the pastor in the army he used to come and see us, offer services, communion that sort of thing. Mostly we had to go if the CO said so, you know what I mean? But [pause] ...he was all right the pastor, he didn't over do religion. He was happy that you turned up at his service that was probably enough for him. I suppose hospitals get that support too from a local fella, a vicar or whatever?

In the Ashbourne group (a) there were a number of people who had experienced themselves or their loved ones who had a previous connection with a local parish church, and who had found a good deal of support from local people either as lay visitors, who knew they were in hospital and came to see them, or were prayed for in their church when they were ill. One participant a3 explained, "I'm 66 and had no carers and no one came to see me for six weeks." There was a qualifying conversation through which it was established that phone calls from careline were the nearest thing to a visitor that he received, albeit the participant was grateful for those calls.

The general sense of the concepts surrounding the 'religious and spiritual' was to associate them both with formal traditional religious practice. For the most part these referred to denominations associated with, the Church of England, Roman Catholic and Methodist churches locally in Ashbourne, and for one participant just outside Derby. With reference to St Oswalds hospital in Ashbourne, a7 explained, "there is an associate priest who takes communion there [St Oswalds], once a month I think it is, the local clergy co-ordinate it... I think its churches together in Ashbourne".

4.11.2 The Importance of Religious, Spiritual and Pastoral Care

On the question of 'how important do people feel spiritual and pastoral care is in a healthcare setting or when being supported by health professionals at home?' There was a feeling among the group that spiritual aspects in their lives were essentially connected to ritual and sacrament and were related to their personal contact with places of worship. The expectation seemed to be that they understood that pastoral visitors existed and they (the visitor) would get out to see people in their homes, coordinated through Churches Together locally in Ashbourne, and that such a visit could extend to local inpatient care. It was however seen as the responsibility of the churches to undertake this role and support the local hospital, as opposed to any sense of the hospital having a responsibility to provide spiritual or pastoral care or support.

The same question about the importance of spiritual and pastoral care was explored in the groups making up t1 and t2. Across the groups a majority expressed firm support for how important the meeting of spiritual and pastoral needs could be. There were references to 'how lucky people felt' at having been supported in the past and finding the care in the hospice setting a great social and emotional boon to them. The hospice was praised for its consistency each week, the sense of community within the various groups of people who attended and who have got to know each other, and in the kindness and quality of the care they received. A very important point made by the majority of those interviewed across the groups was epitomised in what 1t9 said, "people here are so caring, staff and volunteers and nurses, they are so kind, so helpful and so friendly".

The idea of friendly caring staff and volunteers was explored further, and reference made to care at home in the community and in inpatient care. Those who had an

experience of spiritual or pastoral care at home suggested that they thought the qualities of compassion and caring were to be found in their experiences of district nurses or occupational therapists, and that in inpatient settings they had found very caring individuals who provided care for them. In many cases the idea of kindness and caring attitudes and behaviours were for the participants comforting and supportive, although not many referred to this approach as pastoral care or support, but recognised the genuine human to human contact that was essential to their feeling well, or better or being cheered up in a time of difficult emotional and physical strain, or even distress for some. 2t10 was the exception saying: "I think it's important to have pastoral support, that someone cares, not just about the medical side, but about you".

Participants were asked what pastoral support related to for them? There were a range of answers, reflecting caring attitudes, spiritual care through ritual, such as prayer or conversation with someone who was not necessarily connected to their home church or traditional religious or spiritual group but a friendly face with whom to interact at a difficult time (1t 2, 3, 5, 7,8 and 2t 4, 8, 9, 10). This was suggested by 1t6 who said:

It's probably just on a network level of support. Everyone likes to have a friendly face, its like people in here, we are a small community in a community... we just want to see a friendly face (it6).

Reference was made to the local vicar attending Treetops on a Friday, and he was described as a very friendly man, who has a laugh and tells participants jokes (1t 3,4,5; and 2t 7, 9, 10). A great deal of store was put into the notion that friendly caring attitudes were supportive and helped with wellbeing and that making people feel comfortable and providing safe space to communicate in was an important part of an individual's confidence in their care and the care provider (1t 1,2,3,6,7 and 2t 3,4,6, 8, 9).

Community care, where district nurses are visiting participants at home was discussed, and participants in most cases said that they had never had a conversation about their spiritual care with district nurses or occupational therapists. But there were those who had discussed with district nurses that they were church attendees or had a local contact with a church group in their area. On participant (2t 5) had always asked local clergy to pray for her and with her when she was visited,

and even though that may not be reflected in her experience of DCHS settings she said she would appreciate contact with a local vicar or priest for prayers if it were available to her through DCHS. Participant 1t 3 talked about having a carer, and that he was aware that health visitors did offer a range of support and would talk to you about spiritual care if you asked about it. Participant 1t7 also talked about spiritual care in community settings and said she had never thought to ask for spiritual support from health professionals who visited her. But was clear,

the District Nurses are wonderful, if I wanted some help with spiritual matters I am sure they would help me if I asked them.

Friendly conversation was acknowledged by 1t 6 as essential to his own sense of wellbeing and he identified where he saw that in relation to formal religious practice, saying:

You know I don't really need religion to be part of my care, I recognise some people do, but I know that pastoral care is more than that, its like having an extension of the family, like when I come here. For me it's enough to have people to talk to, simple as that, I am happy to talk about religion but I don't need it I just need someone to talk to.

Participants 1t 12 and 13 talked about their spiritual and religious connection with the Roman Catholic Church. They both agreed that spiritual care was essential for them when at home or in day care. 1t 12 explained:

It's a great comfort to me to know that in places like this I have a connection with others who believe that coming to the end of your life is a time when you make your peace, put your house in order and look to God.

They both understood pastoral care and the importance of people to talk to. They had visits from local people in their church when at home and they would appreciate being able to speak to a Priest, especially if it meant being able to go to confession or take communion.

Participants were asked if the conversation about religious, spiritual and pastoral care needs came up when talking to NHS staff, carers in the home or inpatient settings or with the hospice staff. For the most part participants said that it didn't occur, and if it did it was only occasionally and was triggered inadvertently, as opposed to a direct request from them, or an offer from a staff member. Participant 2t 9 said she felt:

it was a bit embarrassing really, but if I wanted to I could ask people I

suppose? They would help me in some way...[pause] most people are very helpful. I have someone come in every day, I get a shower and they bring food, and help me before bed if I need it, especially if my son cant get to see me. It's difficult with his work he sometimes can't get...

Members of the Ashbourne focus group commented on the importance of pastoral care or support in inpatient care and spoke of the local church connections and the volunteer network of lay supporters. There was a feeling that lay visitors would be a good thing if there were no chaplains within the hospital and this was felt to be a positive model for community-based work too. Participant a7 talked about local support saying:

we have a lot of support locally in Ashbourne I think it would be good to look at lay visitors too, there is always someone available to go to visit sick people at home, the people here are very caring and always seem ready to help.

Two other participants both talked about when you might need support and why that was important. One participant (a2) suggested that if you were religious then these issues would matter to you depending on how long you were in hospital, or if you were at home and already had connection with a local church group. The second participant (a6) made it clear that even though people may not be particularly religious, they may still find great value in the contact or befriending in the home. A conversation followed about the religious non-religious dimension in people's lives and across social groups more broadly. The consensus was that regardless of your leaning or otherwise towards a particular religion of belief there was undoubtedly merit in human connection, which was supportive and people with health issues would likely benefit from such contact.

The experiences of the Ashbourne participants was discussed where there was actual or potential contact with pastoral or spiritual care in health. This was also extended to their loved ones and family. The participants spoke about caring individuals and their support in a pastoral sense. These were mainly associated with nursing staff in hospitals or health visitors, district nurses and occupational therapists in community settings. The message was generally positive and there were a number of occasions cited where kindness was an important and compassionate aspect of a persons care. There was however still confusion about how to access spiritual and pastoral care or support in inpatient care, unless a lay visitor, voluntary services or a local parish visitor was involved. There was also an

acknowledgment that in their experiences and those of family members in relation to care in the community, there was no formal discussion about spiritual or pastoral care provision by practitioners with whom the group came into contact.

4.11.3 How should spiritual and pastoral care be delivered?

Participants were asked about how they would like to see spiritual and pastoral care delivered, both in inpatient care and through care in the community. In groups 1t and 2t the message was strongly in favour of spiritual and pastoral care and support being offered to everyone and people being given the chance to accept the offer or refuse it. There was also a feeling among some (1t 4, 9, 10, 11, 15) that it should be discussed more openly and more often, not confined to a process of questions among many other questions on admission, when it is likely be forgotten. The frequency of raising the idea that support is available and then explaining just what that means was also raised, and 1t 15 suggested:

It's easy to forget what you are told when you are admitted or if a nurse comes out to see you. It would be nice if people knew they could access something and someone told them what that was.

Others agreed in group 2t and there were aspects of the delivery of care raised, which included staff offering support for patients' spiritual well being regularly throughout any given treatment period, and at the very least when patients were undergoing treatment and when being discharged to assure there was a community link available. This was seen as beneficial too as it would alert those returning into community care to explore the possibilities with the community practitioner.

The Ashbourne group registered some surprised that more was not made of spiritual well being and support within existing health structures and some agreed with what was being put forward by groups 1t and 2t, that if more information was readily and openly available more people would access the services This was reflected by both a6 and a1 who had relied on local church-based support but were not aware that there was any other internal provision available within DCHS. A1 remarked:

There was no offer from anyone when I went in St Oswalds but my church knew I was there so someone came to see me, the staff were fine with that, but it would be good to know that someone could come to see you, no one told me that.

A6 talked about her hospital stay, saying:

I was in hospital but got no services, no one came to see me and there was no chaplains around as far as I can tell. I didn't get asked on the ward. I think [lay] visitors are important and I would like it if they came on the wards to see you.

The community setting revealed a similar lack of information and this was pointed out by a4 who said:

I don't worry about spiritual needs, even though there was no conversation about my needs when I was seeing the Occupational Therapist, but I get communion every month. A man I know and his wife take me to church and that's good enough. I know a lay reader too that keeps in touch. These are people who could help others in the community, but I doubt DCHS knows they are there.

In exploring the kinds of service provision focus group participants would like to see, there was a general agreement that existing parishes of all church denominations had some capacity to support healthcare, specifically where patients are discharged into the community. All three groups saw merit in examining the relationship of DCHS to the local church infrastructure around the county to see if that was a solution to support, through lay visitors and/or ordained ministers. Those who supported that idea were by far the majority within the focus groups.

Where however there were participants of no particular faith, there was a mixed response to what they thought was the necessity to address spiritual care needs, and who should do it. In group 1t, participant 14 raised some concern that the Christian model did not work for everyone, and there was a wider non-Christian and growing non-religious section of society which should not be ignored. He suggested the following:

I don't have a faith, I don't know if I ever had one, although I was brought up a Christian. What I need is the best care staff can give and they are able to make my life as comfortable as possible. I have no objection to Christian visitors or chaplains or anything like as long as they are not trying to convince me about God. [pause] I would be happy just to see someone who would chat about how you feel, and what's going on and make sure there is somewhere you can go if you need help at home, or whatever. I don't see hardly anyone anymore, if it wasn't for health visitors I probably would be very much on my own. I value their help and company, I only wish there was more of it. It's very difficult when you can't get around anymore and you don't have much of a family to help you. That's why this place is invaluable to me.

In other cases where a secular or atheistic/agnostic response was received there was a sense that most people want communication and are supportive of lay people

or ministers being available to give it, as long as it was about being a friendly face and not about delivering a specific religious or spiritually determined message.

There was little opportunity to examine with patients, carers or relatives how people felt about ethnic minority spiritual or pastoral care, as the focus groups did not provide a diverse ethnic mix. However when asked about other faiths and if people were aware of their needs most people who were able to comment suggested there must be some support for other religions from within community groups that represented them. Only one individual (2t 8) ventured to suggest that, Muslims, Hindus and Sikhs had religious structures around them and thought their community groups would provide that kind of support if it was needed.

On the question of spaces that people would like to see in inpatient settings, most people thought a quiet space was a good idea, but not one that should create an undue burden for staff. It was more about the opportunity to access a quiet area if one were available. In consideration of ritual activity many agreed that ritual could take place in a quiet space formally or informally depending on the need. The general concern was if there could be an offer of communion in inpatient care, providing an ordained person was available to administer it? There were no objections to the idea that volunteers could support people in inpatient care with their spiritual or pastoral needs, and that could be through lay visitors who gave up their time to talk to patients on wards. This was also echoed in the community setting, suggesting volunteer help could be very empowering and good for individual wellbeing by visiting at a time when the health and emotional support was important to people.

4.11.4 End of Life care

End of life care identified a general sense for many of connection with a spiritual aspect of life, and most had already taken steps to take care of their estates, and were committed to a plan that involved decisions about resuscitation, and ritual rites of passage. There were those that suggested the initiation of end of life care should raise the question of spiritual and pastoral support as early as possible. There were concerns that if not discussed openly it could become a burden for those in end of life who felt they were not able to settle their own peace of mind or felt they had left things undone.

The question of choice remains a significant area of concern. Those that saw end of life support as not necessarily adopting religious or spiritual support elements, were very committed to them being able to control what end of life care could mean, and they saw the hospice as the perfect solution. Here companionship and community on a regular basis was actually fulfilling their pastoral needs, without a specific requirement to address the religious or spiritual. There was however very little knowledge of the process adopted in DCHS to support end of life care, but welcomed any kind of support that involved appropriate conversations, no matter how difficult to address their needs.

Participants t1, 4, 5, 7 had made plans and were happy with them, this they saw as part of their hospice care. Participant 2t 2, 3, 6 all agreed that activity based approaches like the art and craft provision in the hospice were very positive, but only if the outputs were tangible and they could see value in what they were creating. In other words, art for arts sake as a distraction was not what they were looking for, but more of a reason for the art, practically and/or aesthetically.

Most of the participants who were happy to discuss end of life suggested there was always the difficulty of coming to terms with the prognosis initially, and it was at that point that they valued specialist nurses or carers that had the experience to support them. The majority also saw value in being at home and having community-based care and support. They agreed that care plans were a part of that provision but were unsure often what exactly was in the plan, for the most part they needed to know that there was support available, but the detail was not always immediate in their minds. Family and carers were a very important consideration and finding a way to live as normative a life as was possible equally a concern. As 1 t3 suggested:

I don't want to be a burden on anyone, not family, my wife, no one... I know the people who are caring for me are doing the best job they can, I am grateful for what people do here it is marvelous. I have everything in there [referring to a bag], if I have a heart attack I am not to be resuscitated. Plans have been made; I want to get on with life with what time I have and get the most out of it. I'm not a very religious person, but I value the support, everyone needs someone to be around for them don't they?

4.12 Quantitative survey findings and analysis

The survey instrument reflects data gathered from 64 respondents (n=64) and can be summarised here based on the ten questions it asked across staff, patient carer and relative responses.

Question 1 asked: ‘Do you think spiritual and pastoral care is important for your patients/service users?’ Sixty respondents answered the question (n=60). Of those, 8 (13%) said that it was not very important; 4 respondents (6%) thought it was quite important; 16 (27%) that it was important; 16 (27%) that it was very important and 16 (27%) that it was essential. Overall 81% of respondents saw it as important, very important or essential. Only 13% of the population in the survey saw it as not very important. The table below at figure 2 reflects this.

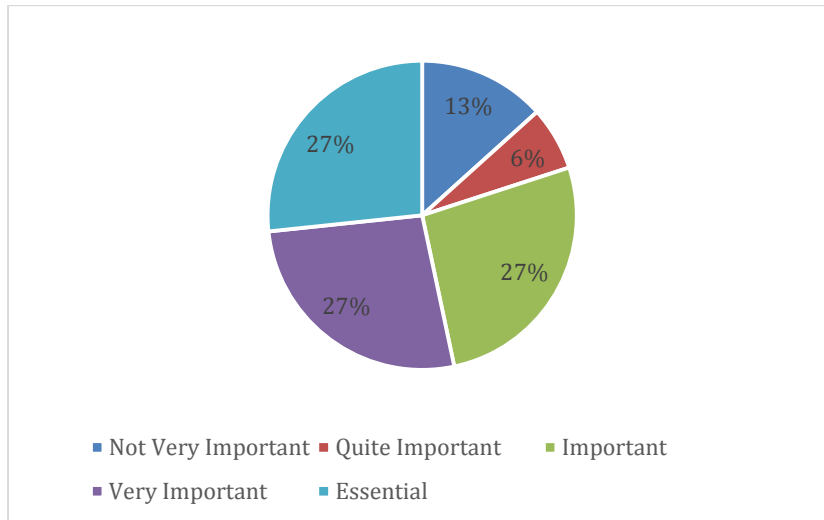


Fig. 2 Is Spiritual and Pastoral Care Important for Your Patients/Service Users?

Question 2 asked: ‘How important is it for those providing spiritual and pastoral care support in DCHS to support all faiths and none in their work?’

Sixty-two respondents answered the question (n=62). Of those, 7 (11%) thought it was not important; 18 (29%) said it was important and 34 (55%) that it was essential. Overall 84% of respondents considered the support for all faiths and none as important or essential. The table below at figure 3, reflects this.

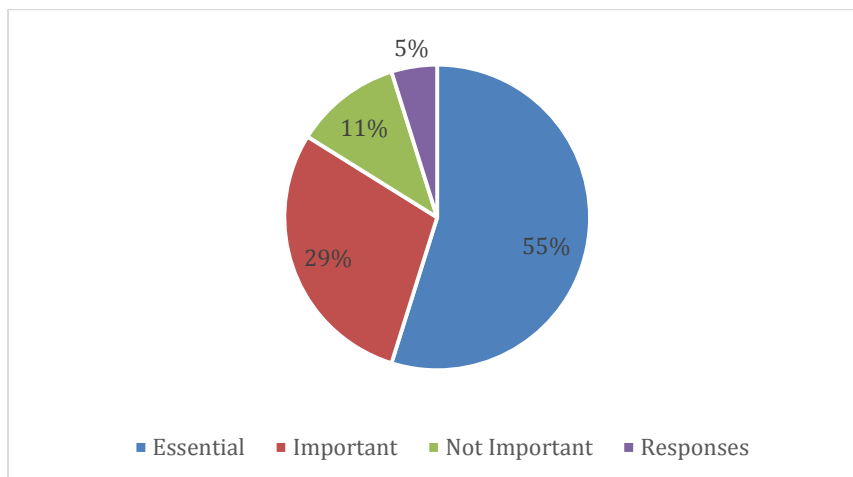


Fig. 3 How important is it to Support All Faiths and None?

Question 3 asked: ‘How should spiritual and pastoral care be provided in DCHS?

Rank your choice in order of the most important to you (1 is first choice 3 is last choice)’. The choices that were provided were: ‘By developing links to local faith communities’; ‘Using the knowledge and skills of DCHS staff to discuss spiritual and

pastoral needs with patients/service users’; and ‘by developing volunteer roles from the local community’.

The highest first ranked response was: ‘by developing links to local faith communities, which received 23 first ranked votes, which is 40% of the population.

The highest second ranked answer was, ‘by developing volunteer roles from the local community’, which received 24 votes, which is 43% of the population. The

highest third ranked answer was, ‘using skills and knowledge of DCHS staff to discuss spiritual and pastoral needs with patients/service users’, which received 21 second rank votes, which is 38% of the population. The outright first choice was ‘by developing links to local faith communities’. This response is similar to many of the staff and patient/carer focus group sessions. The table below, figure 4 reflects the ranked responses.

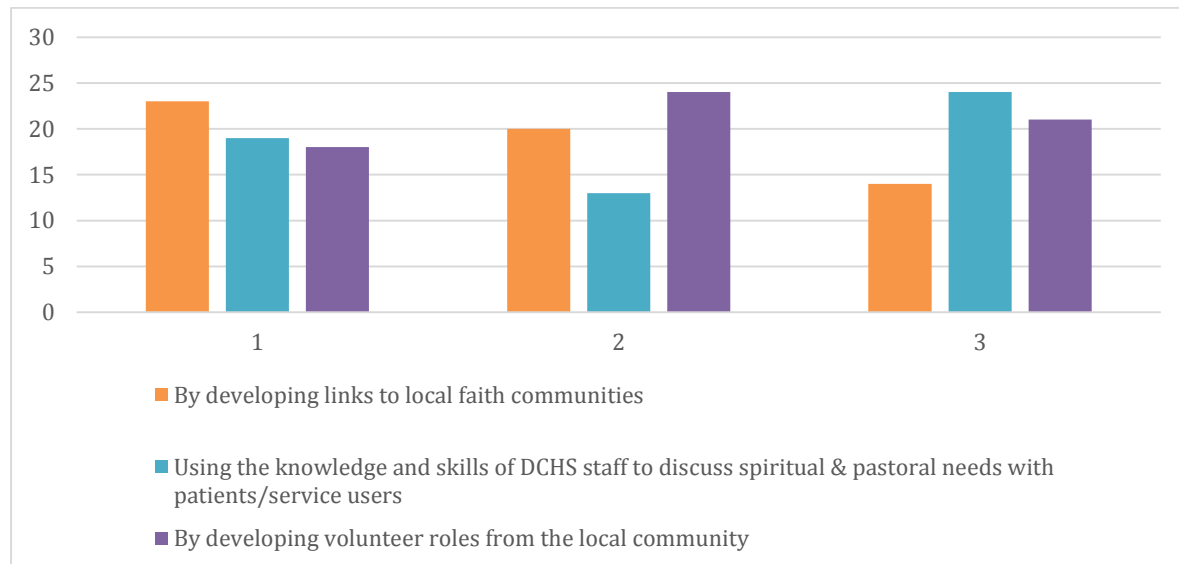


Fig. 4 How Should Spiritual and Pastoral Care be Provided in DCHS?

Question 4 asked: ‘Thinking about your first choice answer above in Q.3, would you write a few lines explaining how you think your first choice would work best?’

There were 63 written responses to this question (n=63). What follows is a selection

of comments associated with the answers, (the full list of answers can be seen in the survey summary at appendix 1).

The responses are summarised across three themed areas: 1)'contacting various local faith communities for advice, support and practical responses', 2)'staff training and support' and 3) 'volunteers and how best to work with them'. These were key feature of the comments form respondents and are reflected below:

Comments on contacting local faith communities include:

By contact with local faith communities and inviting volunteers to undergo training. Patients in the Nottingham University Hospitals Group, where such an arrangement is in practice, find this works very well for them.

Local groups have in-depth knowledge of a wide range of local cultural, social & historic issues, Such groups often have either "paid" professional clergy or people with vast experience & life skills who could be used to support clinical staff in their caring role of patients

Talk to churches and ask parish priests to link up with hospitals or other services.

By encouraging religious leaders of all persuasions to visit in and out patients.

Getting to know about the many cultural beliefs and their impact upon life.

It does not matter what faith or none we are all the community of Derbyshire.

I have found when patients are on the ward who ask for pastoral care they are very often and an active member of their own church and I believe they would benefit more from receiving pastoral services from their own vicar / church ministers.

Discovering what is already available in the faith community to support people and building on that

Having local communities involved would provide already trained personnel probably known to many individuals.

Calling a meeting of all faiths to discuss the future of the service would provide a list of contacts that could be offered to patients.

Staff training and support for staff is seen by respondents as an essential aspect of developing a system that has the greatest benefit for both patients and staff, who cannot be discounted in the context of the structure of a deliverable outcome in support of spiritual and pastoral care. Comments on staff training and support can be found below:

Giving staff the necessary skills because staff are on hand 24 hours a day

It would need staff to consider their own beliefs.

Some emotional intelligence from all staff would be a start!

They are on the front line and would have better Intel about what kind of needs each person requires

Discussing with the patient and clearly explaining the possible prognosis of their condition having ascertained their ability to cope with the situation.

To discuss with the family and patient and determine what their exact needs are on assessment when their religion is obtained

It is DCHS staff who have the main contact with service users. Having said that, many (most?) staff are woefully ignorant of faith matters and the requirements that faith imposes, and possibly would be obstructive where faiths other than the norm present.

Staff should undergo training in dealing with the spiritual and pastoral care of patients/service users. They should be shown how to use volunteers who may be more able to offer the required support for service users, recognising that some staff may not have interest or expertise in these areas. They should know how and where to find expertise.

Staff need robust and regular training and support to offer and understand patients spiritual needs but if all staff are fluent and skilled then this will be an every day matter that is addressed often and continually for everyone. We need to stop assuming spiritual needs are the same as religious needs, they might be but they may well not be and we need to educate people to understand this.

If staff think this is something other people can deal with they will never take responsibility for including this as part of their duty of holistic care.

The DCHS staff would be on hand to speak to patients / pray with them etc., but also they would understand the organisation, procedures and policies which may be causing fear and apprehension in patients/ colleagues/ visitors.

As a patient I do not want to discuss my spiritual and pastoral needs as I would be ill. Volunteers might be sympathetic to ones needs at the time.

*1. Building links to faith & spiritual leaders is essential for DCHS staff to develop a trusting relationship and to learn a little about that belief.
2. Ultimately the patient will need spiritual & practical support upon return to the community. 3. The faith leader can then organise, if appropriate, voluntary support.*

Because local faiths may know the individuals and understand properly. Staff automatically provide pastoral care, especially at end of life, but the

responsibility must lie with an overstretched clinical team.

provide relevant information in pamphlet

I would be concerned about religious bias, especially against people of no faith, from representatives of any specific faith communities.

I think paid spiritual advisors are a waste of good public money. If organised religions want to do this kind of thing, then they should fund it themselves

Helping carers more

Volunteers have been identified as knowledgeable in the local community, as potential support for patients and as available to train to provide advice and support and to consider those without a specific faith through British Humanist Society. The comments below reflect these ideas:

Approaching the person in charge to encourage them to find volunteers

Volunteers have knowledge of local community & can liaise with local faith centres

By liaising with patients & matching them with someone from their particular faith or spiritual belief system.

By having recognised trained spiritual /pastoral providers in the main faiths and notifying them of any identified and agreed patients/clients needs .

Because this should be the role of the community not expensive so-called professionals

Via charities such as British Humanist Association.

By recognition of the importance of a hospital Chaplain and the need for his services followed by prompt response

Question 5 asked: 'What would you like to see provided by those delivering spiritual and/or pastoral care in DCHS?' There were 62 responses to this question (n=62). The question was framed around three specific answers: 1) spiritual care, helping with life changing issues, 2) general companionship, walking beside me on the journey, and 3) addressing spiritual/religious or non-religious needs (advice, support, ritual)?

Respondents were asked to rank on a likert scale their answer based on a scale

across the following: 'not very important', 'moderately important', 'Important', 'very important' and 'essential'. Responses identified 31% (19 individuals) who saw spiritual care helping with life changing issues as essential. General companionship /walking the journey was seen as essential by 29% of respondents (18 individuals), and addressing spiritual/religious or non-religious needs saw 23% of respondents (14 individuals) who suggested that was essential. Combining 'very important' and 'essential' variables however shifted the focus to 'General companionship /walking beside me on the journey', having the greatest weight, being identified as having the greatest importance to the respondents with 61% (38 individuals) combining. In second place was 'spiritual care helping with life changing issues', which polled 57% of responses (35 individuals) when combining the variables, and in third place of overall importance was 'addressing spiritual/religious or non-religious needs' which had a 46% combined response (28 individuals). The table below (figure 5) reflects the likert scale responses and the figures broken down in tabular form can be seen in appendix 1.

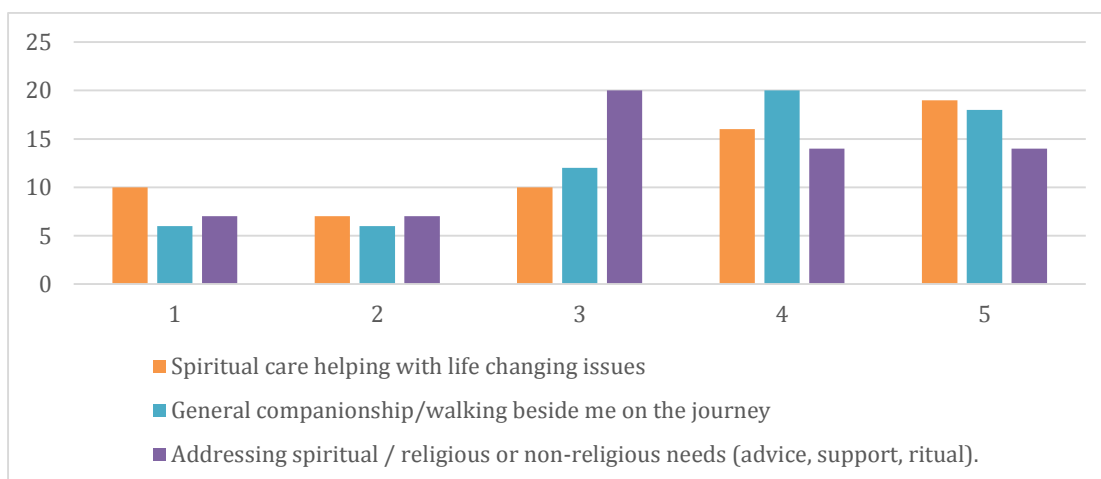


Fig. 5 What Would You like to See Provided by Those Delivering Spiritual and/or Pastoral Care in DCHS?

Question 6 asked: 'Choose from the models presented below. Rank your answer in order of importance to you (1 is first choice 3 is last choice)'. The three models to rank against included: 1) co-operation with local faith communities in localities close to DCHS; 2) referral into other services outside DCHS; and 3) support form staff within DCHS? Respondent numbers varied slightly; there were 56 responses to question 1 (co-operation with local faith communities in localities close to DCHS), 58 responses to question 2 (referral into other services outside DCHS) and 60

responses to question 3 (support from staff within DCHS). The overall response rate was 60 (n=60), therefore four respondents did not offer a ranking for question 1, and two did not offer a ranking for question 2. In spite of this minor variation in overall responses, question 1 (co-operation with local faith communities in localities close to DCHS) was ranked the highest, with 48% of respondents (27 individuals) ranking it first. Question 3 (Support from staff within DCHS) was ranked second with 35% of respondents (21 individuals) ranking it so, and question 2 (referral into other services outside DCHS) coming in third place with 45% of respondents (26 individuals) ranking in the highest order in the votes for third place. The table below (figure 6) reflects ranking for each question.

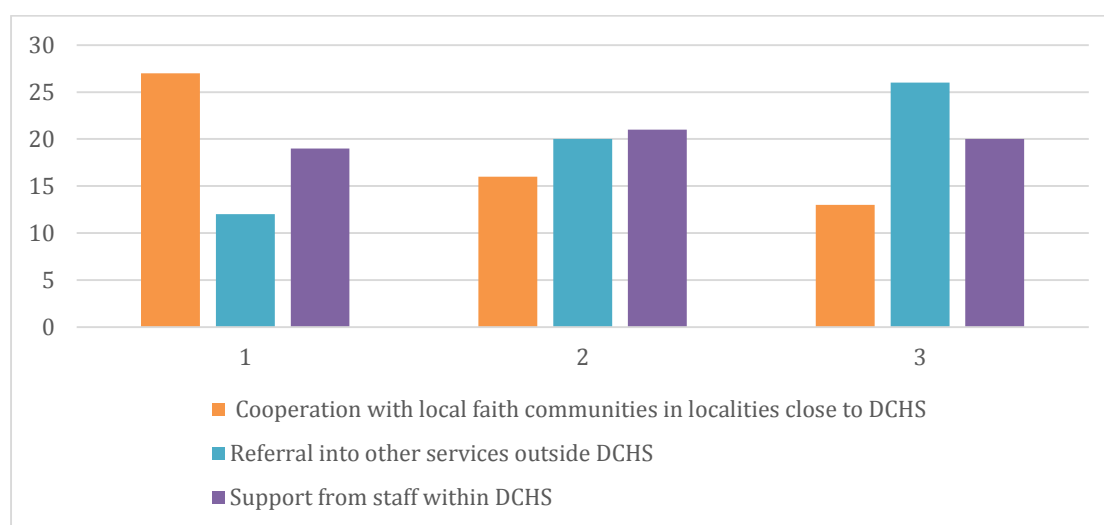


Fig. 6 Choose From the Models Presented: Rank in Order of Importance to You.

Question 7 asked: 'If you have experience of spiritual and/or pastoral care in DCHS settings please tell us about it'. There were only 24 responses to this question (n=24). The numbers who responded were low compared to other answers in the survey, what was interesting was the number of respondents who said they had no experience of spiritual and pastoral care in the trust or marked the question with an x as a non-response. In total 10 respondents didn't have experience to comment on or chose not to, and 14 respondents did comment to the open question. The answers can be seen below cutting across 'solace and comforting experiences', concerns at 'a lack of empathy or support' and 'experiences of chaplains/ ministers and volunteering'.

Comforting and seeking solace can be seen in the comments below:

The comfort and chance to sit quietly and reflect with a staff member in the middle of the night following the death of my father.

Yes - many years ago due to neo natal death of my firstborn. It was appropriate.

I don't have first hand knowledge but my sister had really good support when she lost her baby.

I have used the chapel at the Royal Chesterfield Hospital to pray and have some quiet time when my grandma was terminally ill in hospital.

My son was christened and circumcised in ICU as a very ill baby.

Concerns at a lack of empathy or support are reflected in the comments below:

Recent spells in hospital has [not sic] reinforced the feeling that staff forget they are dealing with humans who are possibly unprepared for hospitalisation.

I have experience that any basic empathy is sadly lacking.

Comments on ministers/chaplains and volunteering can be seen below, and reinforce earlier answers to question 4 about seeking support for spiritual and pastoral care from local churches and other minority groups.

I used to line manager the hospital chaplains and, whilst they used to do an excellent job, this did not allow for multi-faith beliefs of our patients. However, we operate a monthly Sunday service at the hospital, where ALL local churches take their turn, regardless of faith.

In the past our locality had a contact who would approach the relevant religious group in the area on our behalf and ask them to visit our patient.

The C of E Reverend used to come to the wards at St Oswalds and deliver Holy Communion, this was really important for some of the patients.

At Walton Hospital the main Christian faiths had Chaplains who visited regularly.

When I asked a local minister to come in and carry out a weekly service and communion on a dementia ward, still going 5 years later. Called a Shaman from Chesterfield when a Buddhist patient died but it wasn't very easy as we had no guidance.

I have come across chaplains and local ministers who are willing to be called on - very often these people already know patients who belong to faith communities.

As a Home from Hospital volunteer I try to be a good listener & offer practical advice & help when needed.

Question 8 asked: 'Please tell us what you would like to see from DCHS in providing spiritual and pastoral care'. There were 40 responses to this question (n=40). This open question elicited responses that can be themed across 'staff training and engagement with patients and each other', 'community focus and older patients', 'consigned outside DCHS', 'volunteers' and 'ease of approach'. Staff training and engagement can be seen in the comments below:

People who have the relevant skills being in place and this will need on-going training.

Staff trained to respond to requests from patients and know how to refer these requests to the appropriate party (chaplaincy department)

I think death should be discussed openly and freely. Possibly sympathy and holding hands if the person would like it. Sometimes it can be creepy.

Staff trained to be good listeners and who are non judgemental.

Staff to be trained to be knowledgeable about and sympathetic to spiritual needs.

A Spiritual and Pastoral Care lead to develop the necessary expertise and tools across the Trust.

To be included in the Resolve staff support services, and to be a key part of all clinician interactions (it is a fundamental part of respect and compassion for the patient).

First contact (clinical) staff being confident, unembarrassed and relaxed when responding to patients more general psychological and spiritual needs, rather than generally avoiding this as many do at the moment.

*More visits from appropriate staff for patients on wards or at home
Pastoral and spiritual care would be good for the workforce as well as the Service users.*

Better liaison between clinicians and those providing spiritual pastoral care with training opportunities to bring both closer together & develop understandings.

Opening conversations with patients about their feelings, if nothing else, shows them that YOU care about them as individuals and not just as the condition i.e. The Stroke patient.

Ask the patient if they would like to see someone. Be able to access such a person.

Making this accessible to patients as they need

To bring the pastoral care in line with the medical care - both are key to a patient's recovery.

all religious leaders to be made welcome throughout the DCHS.

By adopting a spiritual and pastoral care will benefit the care system and bring comfort.

Community based support and specifically working with older patients and carers was seen as important for future developments within the trust, as can be seen in the comments below:

Community based

More knowledge of what is available within the community

Good liaison with community faith leaders. Someone who is a named person for each individual needing the service.

Chaplains would be preferable but probably difficult to achieve

Access to advice, support and hands on assistance.

Ability for patients and staff to have access to this care at any time free of charge.

Acknowledgement that older people, and in particular, those with dementia, will most likely have been brought up with traditional "religious" values (of whatever faith).

Helping older people to adjust to life without long standing partners or life changing illness (long term conditions or those that are life limiting). Meeting the spiritual needs of those who may struggle to verbalise their needs e.g. stroke, learning disability

Some respondents see spiritual and pastoral care as consigned to a place outside the role of DCHS, or want to see it removed and comment below:

Personally I don't think I would require it.

less of it

not in the role of DCHS. they need to focus on medical issues and leave religion to the churches

Volunteers are seen as integral for some respondents who also see a multi-faith

dimension being possible in securing good voluntary service:

Using a volunteer based service would allow access to multi-faith disciplines.

I believe these issues should be dealt with by the professionals in whatever faith plus appropriate volunteers as it is important to maintain the integrity of any communications

Ease of approach and style are expressed in the comments below, where individuals are seeking support which can bring comfort:

Easy going, relaxed non-missionary style, where rather than 'pushing' 'religion' is there to talk/ comfort and guide.

Easy access to non -judgemental listening ear and emotional support

Someone who can help in times of trouble, make you feel comforted. It helps even when you are not suffering life-threatening treatment.

Question 9 asked: 'As a staff member of DCHS how confident are you in': 1) 'supporting the general spiritual and pastoral care needs of patients/carers/families?' 2) 'providing support for patients/carers/families in life changing circumstances?' 3) managing end of life care which involves the spiritual and pastoral needs of patients/carers/families?' or 'not applicable in my role?' Responses were low compared to other questions in the survey, and only saw 28 respondents answer the questions (n=28). The question was designed as a likert scale across a range of five answers, starting at: 'not confident at all'; 'moderately confident', 'confident with support'; 'confident without support'; 'very confident'.

Overall there were only 5 respondents (18%) 'very confident' in managing end of life where it involves spiritual and pastoral care, and less, only 4 (14% respondents), who were very confident in supporting general spiritual and pastoral care needs, and in supporting those needs in life changing circumstances. Across the same three questions 'confidence without support' was identified by 3 respondents (11%) in end of life care, 1 respondent (4%) in life changing circumstances and 2 respondents (7%) in general spiritual and pastoral care needs. At the other end of the scale evidence of 'not being confident at all', is reflected by 5 respondents (18%) who are involved in general support for spiritual and pastoral care; 6 respondents (21%) involved in support of life changing circumstances and 10 respondents (36%) who were not confident at all in managing end of life issues, which involve spiritual and

pastoral care. The table below (figure 7) reflects the level of confidence from no confidence at all at 1 to very confident at 5. 'Not applicable in my role' is reflected in the 19 responses (79%), who declared it did not apply at 1.

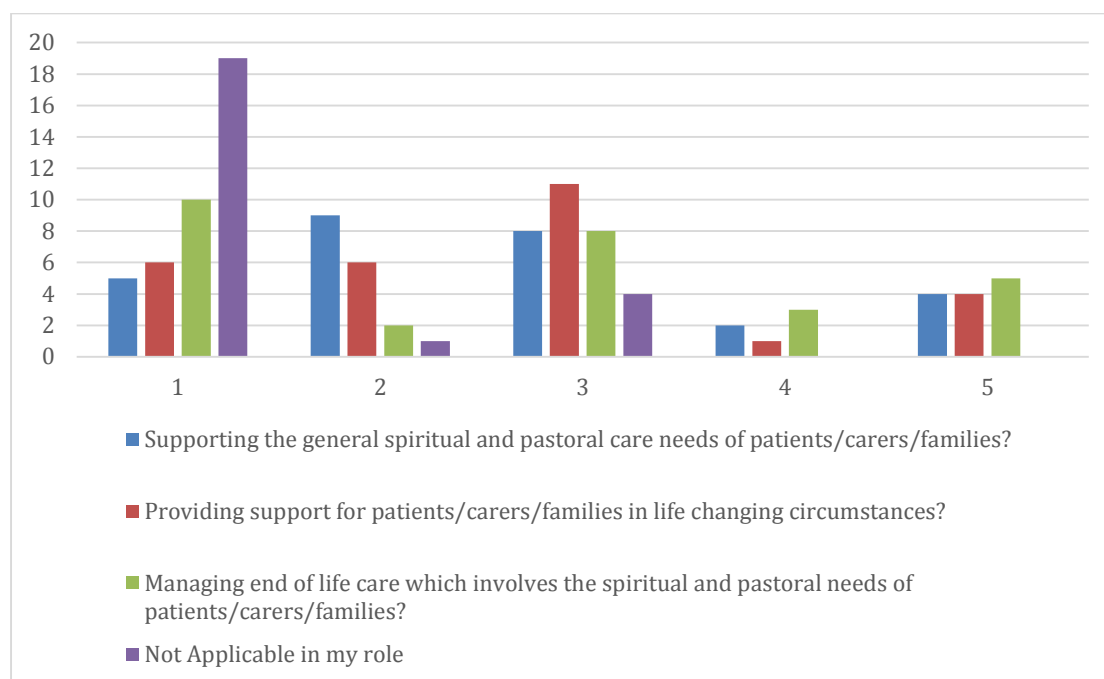


Fig. 7 How Confident Are You in Providing Support: In General Spiritual and Pastoral Care; In life Changing Circumstances; In Managing End of life Care?

Question 10 was designed to allow participants to leave their details if they wanted too, and not a question requiring an answer.

4.12.1 Summary findings from quantitative analysis

The quantitative survey in many ways reflects the findings from the focus groups analysed earlier. Significantly, the importance of spiritual and pastoral care stands out among respondents to the survey with 81% seeing it as important, very important or essential. The importance of supporting all faiths and none also secures a very high percentage when combining 'important' and 'essential' variables, where 84% of respondents are in favour.

Spiritual and pastoral care was assessed against ranking scores in order of importance and the idea of developing links to local faith communities came out as the first ranked and top priority of respondents. This kind of support was also underpinned by open questions and narrative responses by respondents who were

keen to see a link with local parishes in sites across Derbyshire. There was also a strong sense of connecting with a range of faith communities and their leaders, encouraging them to visit DCHS sites. An emphasis on multi-cultural learning and multi-faith encounter was also voiced. Staff training was highlighted by a number of respondents who suggested it should be robust and continuous, that patients should be assessed for their spiritual and pastoral needs and that staff should not assume that spiritual and religious needs were the same thing. It was noted also that staff have a responsibility for assessing spiritual and pastoral care and not believing someone else may take on the role when dealing with patients holistically as part of their care. There were also a complaint of a lack of empathy and a warning to beware religious bias in dealing with holistic assessments of spiritual and pastoral needs. There was a critique raised of the value of paid chaplains in the role, and also a clear secular influence challenging the need at all for spiritual and pastoral care? Community support was raised, part of which looked at volunteer help. Volunteers were given serious consideration as they could act as links between DCHS and community groups of religion and belief, where there may be trained providers of spiritual and pastoral care.

In the survey consideration was given to future provision and respondents were asked to think about what they would like to see provided by those delivering spiritual and pastoral care. The three options that they were given included: helping with life changing issues, addressing spiritual/religious and non-religious needs. The one that featured as the priority choice was 'general companionship walking beside me on the journey', which respondents supported above the other choices, with 61% of the population seeing this as very important or essential. The desire for companionship and support taking priority over a more specifically religiously motivated model.

In considering models for future application within DCHS respondents ranked three options. Cooperation with local faith communities came out on top with 48% of the responses followed by 'support from staff within DCHS' and 'referral into other services outside DCHS'.

When asked to think about existing spiritual and pastoral care services in DCHS, respondents were given an open question with which to provide a narrative response. There was evidence of individuals who had sought solace and/or comfort

by talking to staff about a bereavement both adult and children and in two cases with babies. There was evidence of ritual support in inpatient care and a bemoaning of the lack of a chaplain, and a critique of a lack of staff empathy and support. The latter two were however in the minority. In addition an open question about what people would like to see from DCHS raised a number of significant issues, including staff engagement and training, and seeking people with the right skills for the work of delivering spiritual and pastoral care, including good listening, knowledge and empathy, better liaison between clinicians and those delivering spiritual and pastoral care. There was a request by several respondents to make care more available to patients in inpatient and community settings, and to make those older patients who had grown up with religious values, or those with dementia and potential communications difficulties a priority. There was also a concern to see more volunteers, and to find an easy access non-judgmental support system.

On the question of staff confidence it was apparent that very few staff had the confidence to deliver spiritual and pastoral care, either in a general sense, in support of life changing or life limiting conditions or as end of life care where only 18% of respondents said they were very confident, and 36% said they were not confident at all.

5. Conclusions and Recommendations

This report brings a diversity of views from staff patients' carers and families for consideration in the challenge to deliver religious, spiritual or pastoral care for a trust with barely five years service to its public since its inception. The merging of small trusts within which a host of cottage hospitals, and community-based services existed has taken time to bring to the vision of the organisation the necessity to provide continuity and consistency of approach and provision to spiritual and pastoral care across the trust. The lack of an extant chaplaincy service, and increasing trends towards greater community engagement away from inpatient provision is adding to the difficulties of creating strategic responses to spiritual and pastoral care. Communities vary demographically in their diversity, ethnically, religiously and in socio-economic status, in addition to a geographic area, which ranges over such a wide area extending from the northern peaks touching south of Manchester, to the southern lowlands into east Staffordshire and parts of

Leicestershire. The demographic diversity has extended the reach of the trust further during the period within which this research was undertaken, as the transfer of staff and services from Derby Hospitals Trust has substantively adjusted the ethnic and religious affiliations for the trust in the city of Derby.

5.1 The backcloth to spiritual and pastoral care in DCHS

The considerations before the trust are predicated on a requirement to provide spiritual and pastoral care services for staff and patients. Legislatively the protected characteristics of the Equality Act 2010 in so far as religion and belief is concerned extend to equality of opportunity to practice your religion or belief and a non-discriminatory response which embraces it, and creates the right for staff employed by the trust not to be discriminated against on the grounds of religion or belief.

The current model of spiritual and pastoral care has an inconsistent approach in as much as inpatient services are concerned as they have a varied and to some extent ad hoc relationship to accessing support for spiritual and pastoral care services. In the city and county the community based teams and services are similarly unable to seek a consistent resource to spiritual and pastoral care provision. In most cases where there is a request or an obvious need local support invariably is sought through the patient's own faith community, or local support accessed via essentially Christian provision sought by the staff member closest to the patient (in service terms) in most instances.

Anecdotally and informally there is a suggestion from community matrons that awareness of spiritual needs among trust staff is low. That coupled with low End of Life audit scores for 'social and spiritual support' at the end of 2014/15 presents a weakness in the provision, but is reflected in an improving picture in 2015/16 up to the end of quarter three. This area is generally strong otherwise. The examination of current and alternative models in support of spiritual and pastoral care has provided a potential opening in as much as responses to community service provision for spiritual and pastoral care is concerned. There is little evidence in the literature of how extensive community networks are supporting spiritual and pastoral care and the report will recommend possible options and further evaluation in support of gathering data towards a successful community-based model.

5.2 What do we know?

The importance of spiritual and pastoral care is recognised by staff and patients alike. There are concerns for staff at the lack of a policy framework around which to source spiritual or pastoral care, and yet there is guidance in *NHS Chaplaincy Guidelines 2015*, but DCHS does not have a model of chaplaincy support within its services, unless they are in place through local arrangements. Increasingly the shift to more care in the community and ultimately the home requires investigation to find and provide a service to community-based patients, the reality being that few community referrals do not suggest a lack of a need but more likely a lack of an offer.

Training and confidence go hand in hand insofar as the requirements of a properly trained workforce would inevitably reduce the lack of confidence that exists among staff, with the exceptions of those who work with patients' with specific needs, like dementia and care for the older patient. Here there is it seems, less of a stigma attached to talking openly about religion and belief and peoples' needs. However that demographic group while on the increase generally only makes up a small proportion of specialist services in the trust. What is apparent however is the ageing population will increase the burden of community staff who will be required to work with more patients across wider geographic boundaries in order to satisfy the demands on the services.

There is evidence of a great deal of ingenuity and a willingness to progress the spiritual and pastoral care provision among staff who have experience and have developed their own roles with some support, often sought out at a personal and not institutional level. These staff will continue to want to see good practice extended in the trust and are in many cases willing to support other staff on that journey. There have been suggestions that such people could become ambassadors for spiritual and pastoral care, and be a supportive conduit to training and links to ministers of religion from a variety of faith communities. The qualities that have been referenced by patients and other staff in the course of this research are in keeping with ideas of compassionate action and to enhance pastoral care. This is often understood at the level of human to human interaction and involves simple acts of kindness and going out of one's way to help support patients in inpatient or community settings.

Staff have however universally asked for support with training around spiritual and pastoral care, material on the intranet, and additional support in relation to equalities and end of life care. These aspects will, it is anticipated, make for a better equipped workforce, with greater confidence and would, if the evidence of the literature is to be accepted, increase patient wellbeing and aid recovery, potentially shortening time spent in hospital or community care. To strategically drive the push to greater effectiveness of trained staff the trust is asked to consider a higher profile for spiritual and pastoral care, which it could make more visible publicly by advertising the credentials of staff support throughout the trust. In addition spaces, where they are available in inpatient settings, could with little or no cost be set aside for quiet reflection, meditation or prayer, without the symbolic representation of formal institutional religions, or indeed the alternative or minority communities of faith. Such spaces can be designated quiet rooms and can in that sense be inclusive. Where there is a willingness to retain and use religious artifacts they would need to be managed locally, and stored out of site in quiet spaces, in cupboards to be used when needed and put away after use. This raises a question of managing the space, but may fall within the willingness of potential ambassadors to take that responsibility.

Models of spiritual and pastoral care are many and various, and where there is a largely Christian demographic, most of those spoken to in the course of this research implied a form of primacy likely to be mainly Christian across different denominations. The extension of that idea was to inclusively connect with all known religion and belief leaders/groups in a specific area and seek their willingness to engage with patients and staff in a networked model, which could be formally facilitated with memorandums of understanding with the trust, and endorsed by authority figures within churches, via diocese or elder groups and committees, or through Mosque, Gurdwara or Temple committees in minority faith communities. Additional support for alternative religions and even new religious movements could be sought by ambassadors or designated staff where a list of providers for use in hospitals and in community settings could be accessible to all staff via the intranet. This is not to discount where there are patients who have a faith and seek support from their own communities that too should be made available to them through local arrangements.

The secular nature of the landscape should take into account the non-religious, as atheist or agnostic, and those who take a specific humanist or secular humanist response. The British Humanist Society could be a source of befriending care, or those within existing settings may feel content to be pastoral ambassadors for the religious and non-religious. There should be every effort to take a patient centred response to assessment of spiritual and pastoral care needs, and not to conflate or confuse the religious with the spiritual or the pastoral. Assessing for spiritual and pastoral care should be an on-going provision and if circumstances in care provision change the extent to which spiritual and pastoral support is available may also change. It is not enough to ask for a self designation of religious or spiritual identity, but if an identification is made with a faith or secular area, it would be appropriate to enquire how the patient might like to see support specifically for their needs should that be a choice they intend to take up. Staff will overcome the embarrassment of asking questions about religion and belief with supportive training, and will put patients at ease too, many of whom also find a faith-based or secular non-religious conversation difficult to do and confine it to their private world. This move to a more open conversation, and one in which end of life care should be constituted will overcome the lack of formal questions about spiritual or pastoral needs referenced in this report.

In addition the newly developed model for working within the city of Derby should take account of its links to existing chaplaincy services through Derby Hospitals and formally agree integration approaches to spiritual and pastoral care with Derby Hospitals Trust, as existing provision at London Road (now a DCHS site also) has a chaplaincy team attached to it and chapel space on site.

End of life care has become well established in the NHS and tools in support of it deployed, there are however gaps it seems in the way spiritual and pastoral care are accounted for in this provision and additional support and training may alleviate that gap. There is often a desire for solace or a redemptive quest at the end of life and staff should be able to manage the needs of patients and carers faced with those challenges, for themselves and their loved ones.

Volunteers are a feature of life in the trust, but current provision does not proactively seek volunteer support for spiritual and pastoral care. Those that are still engaged in

ward visiting for example, have been doing so for some considerable time, and their numbers are dwindling. Voluntary services exist and there could be a great deal of synergy in connecting visitor volunteers, as either 'on ward visitors' or 'at home visitors' in support of staff and patients in inpatient and community care. These too could be connected to other services of voluntary support, the likes of which the diocese of Derby is supporting in its drive to extend lay chaplaincy into industry and public services. Any volunteer however should be properly recruited into a role with a designated description, be supervised regularly and supported and embraced as part of the enhanced model for existing teams in pastoral or religious care provision. This is an essential element to a quality service and will be a necessity for volunteers working as part of existing teams in the community.

5.3 Recommendations

1. **The importance of meeting patient and staff needs** for spiritual and pastoral care require a refocusing of provision and the development of local networked support from existing religion or belief groups/organisations at the level of Christian denominations and across wider minority faith communities and the secular environment for the non-religious (referred to above in conclusions at 5.2). Staff and patient need for spiritual and pastoral care is an essential aspect of quality of service provided by the trust. It has implications for equality and diversity and has legal and best practice requirements. Every effort should therefore be made to adopt a trust wide model of working that allows for and provides spiritual and pastoral care support in the absence of an extant chaplaincy model.
2. **Community Care** is catered for implicitly through the recommendations in this report and should be read in each recommendation as applicable and necessary. In terms of the provision of spiritual and pastoral care in community settings it is an underdeveloped area both in the literature and practically. To adopt a networked model to work in communities is breaking new ground and will serve to inform future good practice in the trust and beyond. The networked model being suggested here however, would seek to do three things constructively: 1) Scope volunteer support through existing provision in Christian denominations including the Church of England through the Diocese of Derby. 2) Link up ambassadors/champions for spiritual and pastoral care in community teams with volunteers from within the current voluntary services or externally from lay visitors connected with denominational Christian churches and in minority faith settings (via support from the

Multi-faith Centre). And 3) train current and future community teams to provide them with confidence and knowledge to provide support in communities, developing appropriate lists of potential providers of spiritual and pastoral care support across the county and city (these can be hosted on the intranet service).

3. **Local network support** exists and the Multi-Faith Centre team has reached out to minority faith provision in the city of Derby, and the county of Derbyshire to develop links, which it will provide for the use of the trust. Multi-Faith Centre in consultation with Derby City Chaplaincy (a volunteer group) with a footprint across the county will support the development of a network and act as a conduit to provide the contact information in order to facilitate the needs of practitioners in communities. This service has wider Diocese of Derby support and extends a model of volunteer lay and ministerial chaplaincy to good effect in developing it to support DCHS. The next stage for this would be to broker arrangements and pilot provision to test the model in communities across the county. The author commends this model to the trust and recommends it be developed to support DCHS with spiritual and pastoral care across the county and the city.

4. **Developing staff confidence** should be a priority for the trust and training which involves basic religious literacy, cultural familiarity and interpersonal support are all aspects that would strengthen staff confidence and work to provide patient support in a more proactive and universally recognised way. Training resources are extant and could be transferable into DCHS settings. One six module programme from NHS Wales developed around volunteer pastoral care visitors could be adopted; *Spiritual Care for Volunteers: a training resource* (2010) and can be found at: [http://www.wales.nhs.uk/documents/Spiritual%20Care%20Volunteers%20A%20Training%20Resource%20Binder\(4\).pdf](http://www.wales.nhs.uk/documents/Spiritual%20Care%20Volunteers%20A%20Training%20Resource%20Binder(4).pdf)
Additional resources include *Better Endings, D of H End of Life Review, NHS Chaplaincy Guidelines 2015*, Religious Diversity and Anti-discrimination training (The Belieforama Project/Multi-Faith Centre). Weller P (2007) *Religions in the UK : A Directory* (Multi-Faith Centre). These resources can be hosted on the DCHS intranet and in the case of specific training provision the NHS Wales volunteer programme, and Religious Diversity and Anti-discrimination experiential training (RDAD) - delivered via the Multi-Faith Centre may be worthy of consideration, given the practical hands on nature of both. Planning the educational needs of the DCHS workforce will be the next stage in development including additional support for end of life care (see below at recommendation 7).

5. **Quiet Spaces:** the current inpatient provision within DCHS has seen a general reduction in numbers of beds in the last two years. There are therefore some spaces that could be adopted without incurring any significant costs to provide quiet space for staff and patients/carers/families. These would not require a great deal of management and would be supported on each site by those with an interest to see the use of a quiet space as enhancing the DCHS offer to patients and staff, by providing a place for quiet reflection, meditation or prayer. Where there is a willingness to adopt artefacts that act as symbols for particular religious practice these could be stored in cupboard space out of sight and only used as needed and put away again after use. Volunteer staff as ambassadors for such provision could have overall care of the space and see that its use is regulated, with a very light touch.

6. **Raising the profile of spiritual and pastoral care:** the feelings of staff and patients reinforce ideas about a better and more visible profile for spiritual and pastoral care within DCHS. This would be enhanced by senior staff adopting and supporting the necessity to address the spiritual and pastoral care of patients and staff in inpatient provision and across community-based services. Making the case for visible support for this provision is not difficult to reconcile, better patient wellbeing reduces recovery time and leads to greater cooperation and satisfaction with the services being provided.

7. **End of Life Care** is part of a national specialism service adopted across NHS England sites and recommended through national guidance. DCHS has the end of life *Priorities for care when patient is in the last days of life handbook* (2014) and a toolkit for establishing spiritual care needs at www.dchs.nhs.uk/end-of-life-care The link however is not currently working and the handbook makes only a cursory response to spiritual needs assessment. It would seem to require greater emphasis and in light of low confidence levels among staff as evidenced in the survey data (referred to earlier) a more robust approach to end of life and more broadly, in relation to assessment of spiritual and pastoral needs, should be addressed in training. The necessity for an open conversation, unimpeded by a lack of confidence will assist in getting the right support for the patient and carers. The assessment should be continuous and managed according to changes in circumstances in a care package. The Multi-Faith Centre would need to take up an additional work phase to develop resources to meet the needs of different faith groups in end of life care.

8. **Volunteers** can bring greater social and emotional capital to both the organisation and the people in its care. Embracing volunteers, as team members, properly recruited and supervised as either pastoral visitors 'on wards' and/or 'in homes' would enhance the offer for spiritual and pastoral care within DCHS and this could be aided through networks external to the trust where support for spiritual and pastoral care is likely to be piloted. Staff with empathy and a desire to see a broader more universally understood service across the trust could act as champions or ambassadors for spiritual and pastoral care and link up with existing sites or community teams and the potentially adopted networks of Christian denominations and/or minority faith communities (through Derby City Centre Chaplaincy). Volunteers as 'pastoral visitors' can also link to existing volunteer groups within the Trust and coordinate support with external providers of spiritual or pastoral and secular providers of care.

9. **Strategic responses to spiritual and pastoral care** should form part of the policy relating to issues of culture and be included in the health and wellbeing strategy within the trust, equality and diversity legislation and guidance, and ultimately may form part of a newly developed policy document for religious spiritual and pastoral care to be published at the conclusion of any ongoing training or evaluation. This will allow future evaluations to form research and service evaluation functions to add to the trust's portfolio.

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Appendix 1 - Semi-Structured Interview Schedule

How do you understand Religious, Spiritual and Pastoral Care?

Is it Important? If so why?

How does pastoral care affect the non-religious or spiritual?

Can you say something about your experiences of religious spiritual or pastoral care?

How would you like to see spiritual and pastoral care offered in your workplace/ hospital or community setting?

Do you know of links to local providers of spiritual and pastoral care?
Can you explain what they are?

Should spiritual and pastoral care extend beyond Christian provision?
What else should be included?

Would you comment on staff confidence in matters of spiritual and pastoral care?

As a staff member what would you need to help with confidence?

Would you comment on your experiences of spiritual and pastoral care?
How well was it delivered? Where there any barriers?

What ideas for models of care can you think of, or would you like to see in communities and in-patient settings?

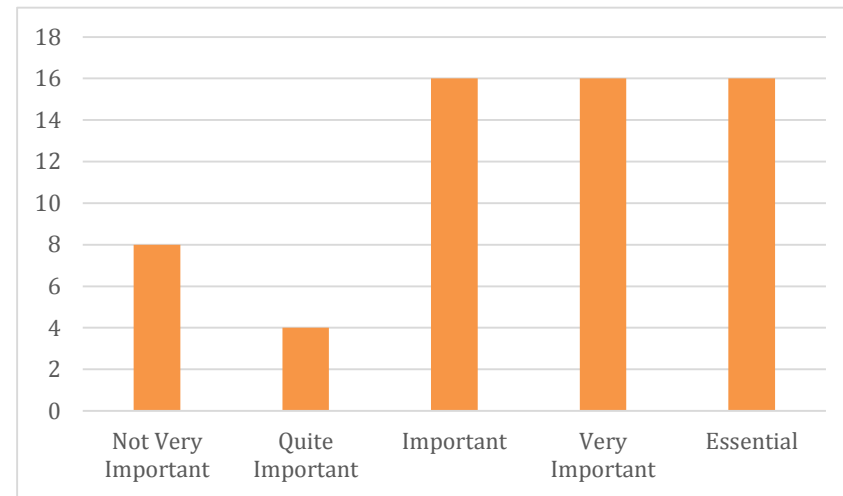
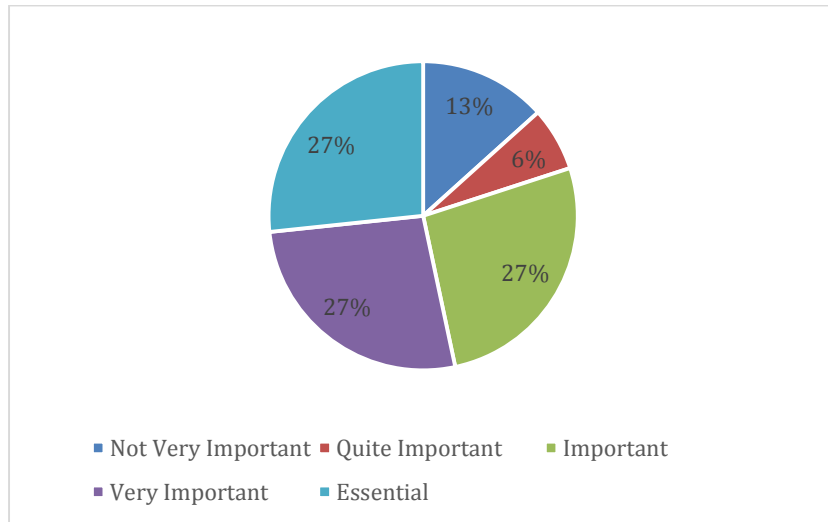
What are the barriers/challenges to delivering/receiving spiritual and pastoral care?

What are the positive enablers for supporting spiritual and pastoral care?

Appendix 2. Survey: Experiences of Religious and Pastoral Care in DCBS

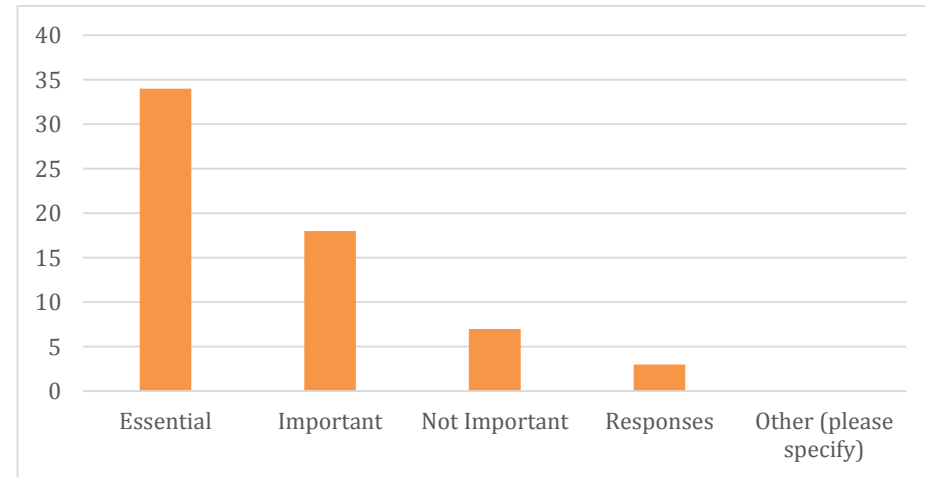
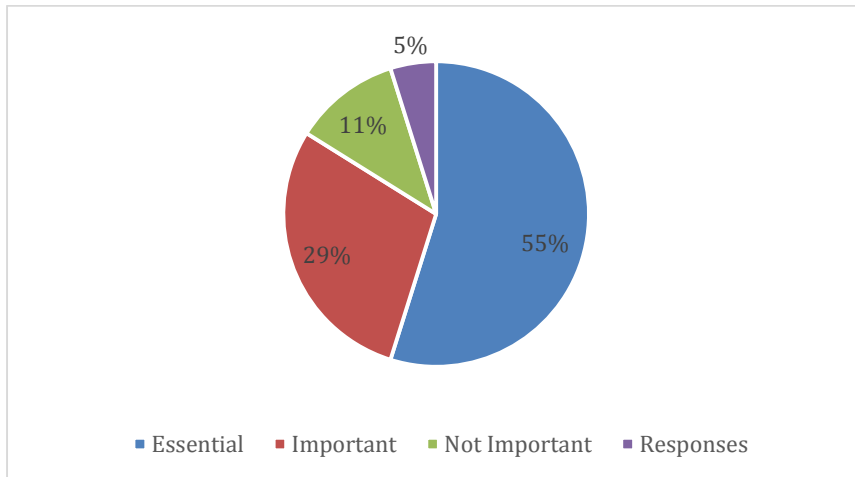
Q1 Do you think spiritual and pastoral care is important for your patients/service users?

	Not Very Important	Quite Important	Important	Very Important	Essential	Total	Weighted Average
(no label)	13.33% 8	6.67% 4	26.67% 16	26.67% 16	26.67% 16	60	3.47



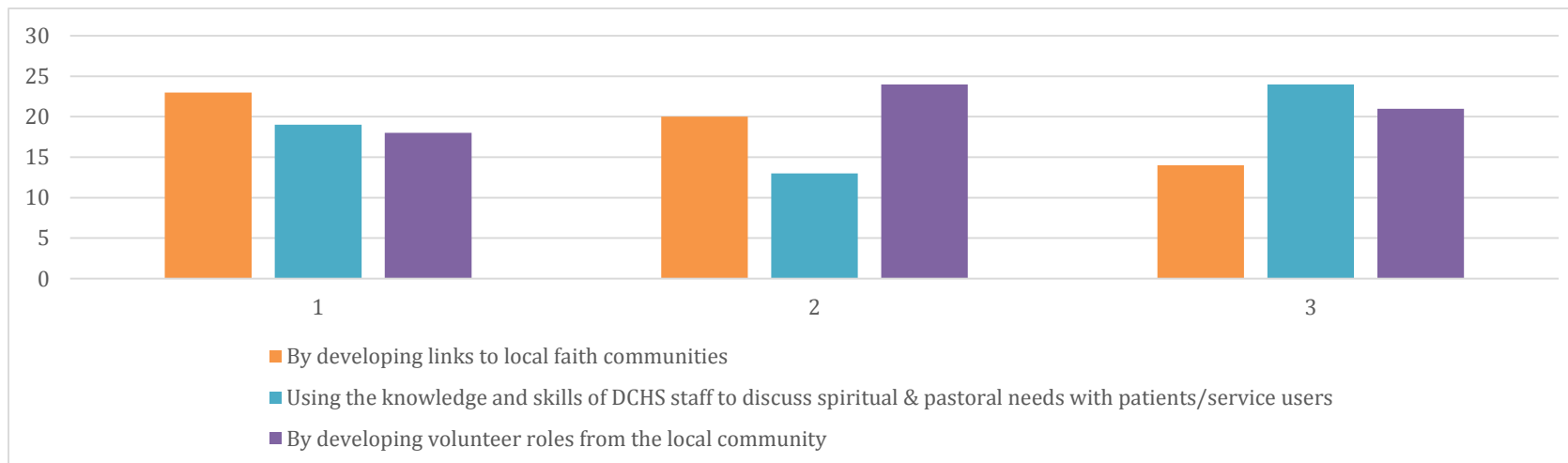
Q2 How important is it for those providing spiritual and pastoral care support in DCHS to support all faiths and none in their work?

Answer Choices	Responses
– Essential	54.84% 34
– Important	29.03% 18
– Not Important	11.29% 7
– Other (please specify)	4.84% 3
Total	62



Q3. How should spiritual and pastoral care be provided in DCHS? Rank your choice in order of the most important to you (1 is first choice 3 is last choice).

	1	2	3	Total	Score
— By developing links to local faith communities	40.35% 23	35.09% 20	24.56% 14	57	2.16
— Using the knowledge and skills of DCHS staff to discuss spiritual & pastoral needs with patients/service users	33.93% 19	23.21% 13	42.86% 24	56	1.91
— By developing volunteer roles from the local community	28.57% 18	38.10% 24	33.33% 21	63	1.95



Q4. Thinking about your first choice answer above in Q.3, would you write a few lines explaining how you think your first choice would work best?

(63 responses)

Giving staff the necessary skills because staff are on hand 24 hours a day

12/15/2015 9:47 AM [View respondent's answers](#)

It would need staff to consider their own beliefs.

12/13/2015 5:09 PM [View respondent's answers](#)

the people involved can be very useful in being able to develop pastoral care continuously both as in-patients and in the community

12/7/2015 4:02 PM [View respondent's answers](#)

provide relevant information in pamphlet

12/3/2015 7:42 PM [View respondent's answers](#)

By contact with local faith communities and inviting volunteers to undergo training. Patients in the Nottingham University Hospitals Group, where such an arrangement is in practice, find this works very well for them.

12/3/2015 3:21 PM [View respondent's answers](#)

Discussing with the patient and clearly explaining the possible prognosis of their condition having ascertained their ability to cope with the situation.

12/1/2015 3:01 PM [View respondent's answers](#)

I think paid spiritual advisors are a waste of good public money. If organised religions want to do this kind of thing, then they should fund it themselves

11/29/2015 12:26 PM [View respondent's answers](#)

Some emotional intelligence from all staff would be a start!

11/28/2015 7:02 PM [View respondent's answers](#)

Approaching the person in charge to encourage them to find volunteers

11/28/2015 12:16 PM [View respondent's answers](#)

By encouraging religious leaders of all persuasions to visit in and out patients.

11/28/2015 12:06 PM [View respondent's answers](#)

Getting to know about the many cultural beliefs and their impact upon life. Faith and belief are a major personal choice.

11/28/2015 11:36 AM [View respondent's answers](#)

They are on the front line and would have better Intel about what kind of needs each person requires

11/27/2015 8:32 PM [View respondent's answers](#)

By recognition of the importance of a hospital Chaplain and the need for his services followed by prompt response

11/27/2015 7:24 PM [View respondent's answers](#)

By liaising with patients & matching them with someone from their particular faith or spiritual belief system.

11/27/2015 6:51 PM [View respondent's answers](#)

There already links in local faith communities. As a patient I do not want to discuss my spiritual and pastoral needs as I would be ill.

Volunteers might be sympathetic to ones needs at the time.

11/27/2015 5:10 PM [View respondent's answers](#)

Calling a meeting of all faiths to discuss the future of the service would provide a list of contacts that could be offered to patients.

11/27/2015 4:22 PM [View respondent's answers](#)

Because this should be the role of the community not expensive so-called professionals

11/27/2015 4:14 PM [View respondent's answers](#)

To discuss with the family and patient and determine what their exact needs are on assessment when their religion is obtained

11/27/2015 3:49 PM [View respondent's answers](#)

Helping carers more

11/27/2015 1:54 PM [View respondent's answers](#)

1. Building links to faith & spiritual leaders is essential for DCHS staff to develop a trusting relationship and to learn a little about that belief. 2. Ultimately the patient will need spiritual & practical support upon return to the community. 3. The faith leader can then organise, if appropriate, voluntary support.

11/27/2015 1:15 PM [View respondent's answers](#)

Volunteers have knowledge of local community & can liaise with local faith centres

11/27/2015 11:03 AM [View respondent's answers](#)

It is DCHS staff who have the main contact with service users. Having said that, many (most?) staff are woefully ignorant of faith matters and the requirements that faith imposes, and possibly would be obstructive where faiths other than the norm present.

11/27/2015 10:38 AM [View respondent's answers](#)

By having recognised trained spiritual /pastoral providers in the main faiths and notifying them of any identified and agreed patients/clients needs .

11/27/2015 10:36 AM [View respondent's answers](#)

Appointing a lead on spiritual and pastoral care to direct ways in which the care can be actioned

11/27/2015 9:49 AM [View respondent's answers](#)

A good role for lightly screened volunteers

11/27/2015 9:06 AM [View respondent's answers](#)

Peer support is a valued way to underpin knowledge

11/26/2015 10:52 PM [View respondent's answers](#)

By having people in hospital or other services made known to local faith communities if that is possible

11/26/2015 10:04 PM [View respondent's answers](#)

Because local faiths may know the individuals and understand properly. Staff automatically provide pastoral care, especially at end of life, but the responsibility must lie with an overstretched clinical team.

11/26/2015 9:08 PM [View respondent's answers](#)

Having local communities involved would provide already trained personnel probably known to many individuals.

11/26/2015 8:23 PM [View respondent's answers](#)

It has no place in Community care

11/26/2015 8:17 PM [View respondent's answers](#)

By inviting them to take part in a piece of work or consultation together

11/26/2015 7:48 PM [View respondent's answers](#)

A holistic evaluation of a persons needs should at least recognise that a patient may have spiritual needs - so those working for the organisation should be the primary port of call

11/26/2015 7:28 PM [View respondent's answers](#)

I would be concerned about religious bias, especially against people of no faith, from representatives of any specific faith communities.

11/26/2015 7:20 PM [View respondent's answers](#)

A person centred approach used by staff would hopefully enhance their own wellbeing and self esteem and thus assist the patient more holistically.

11/26/2015 6:56 PM [View respondent's answers](#)

People who are not paid in my opinion will have a bigger impact and they will probably be able to give the patient all the that maybe required

Discovering what is already available in the faith community to support people and building on that

11/26/2015 6:01 PM [View respondent's answers](#)

Local groups have in-depth knowledge of a wide range of local cultural, social & historic issues, Such groups often have either "paid" professional clergy or people with vast experience & life skills who could be used to support clinical staff in their caring role of patients

11/26/2015 5:55 PM [View respondent's answers](#)

Voluntary agencies in the local community to each DCHS site can be requested to provide a visitor service which can be offered to patients who might be in need of spiritual support.

11/26/2015 5:49 PM [View respondent's answers](#)

Staff should undergo training in dealing with the spiritual and pastoral care of patients/service users. They should be shown how to use volunteers who may be more able to offer the required support for service users, recognising that some staff may not have interest or expertise in these areas. They should know how and where to find expertise.

11/26/2015 5:26 PM [View respondent's answers](#)

The DCHS staff would be on hand to speak to patients / pray with them etc., but also they would understand the organisation, procedures and policies which may be causing fear and apprehension in patients/ colleagues/ visitors.

Via charities such as British humanist association.

11/26/2015 5:19 PM [View respondent's answers](#)

It does not matter what faith or none we are all the community of Derbyshire.

11/26/2015 5:12 PM [View respondent's answers](#)

independent and knowledgeable

11/26/2015 10:28 AM [View respondent's answers](#)

This individual could have lists of local religious groups/contacts that represent the different faiths who may be available to visit patients in hospital when required.

11/26/2015 9:49 AM [View respondent's answers](#)

I have found when patients are on the ward who ask for pastoral care they are very often and an active member of their own church and I believe they would benefit more from receiving pastoral services from their own vicar / church ministers.

11/26/2015 9:34 AM [View respondent's answers](#)

less likely to be entrenched in certain ways of thinking, generally demonstrate compassion by the nature of them volunteering, and less drain on clinical intervention time

staff need robust and regular training and support to offer and understand patients spiritual needs but if all staff are fluent and skilled then this will be an every day matter that is addressed often and continually for everyone. We need to stop assuming spiritual needs are the same as religious needs, they might be but they may well not be and we need to educate people to understand this.

11/26/2015 9:18 AM [View respondent's answers](#)

If staff think this is something other people can deal with they will never take responsibility for including this as part of their duty of holistic care.

11/26/2015 9:14 AM [View respondent's answers](#)

Because they are available 24/7. Spiritual/pastoral needs don't fit into certain times!!

11/26/2015 8:46 AM [View respondent's answers](#)

There are people within the Service and therefore who know the Service and our users with a deeper understanding: we are already there, on the front line.

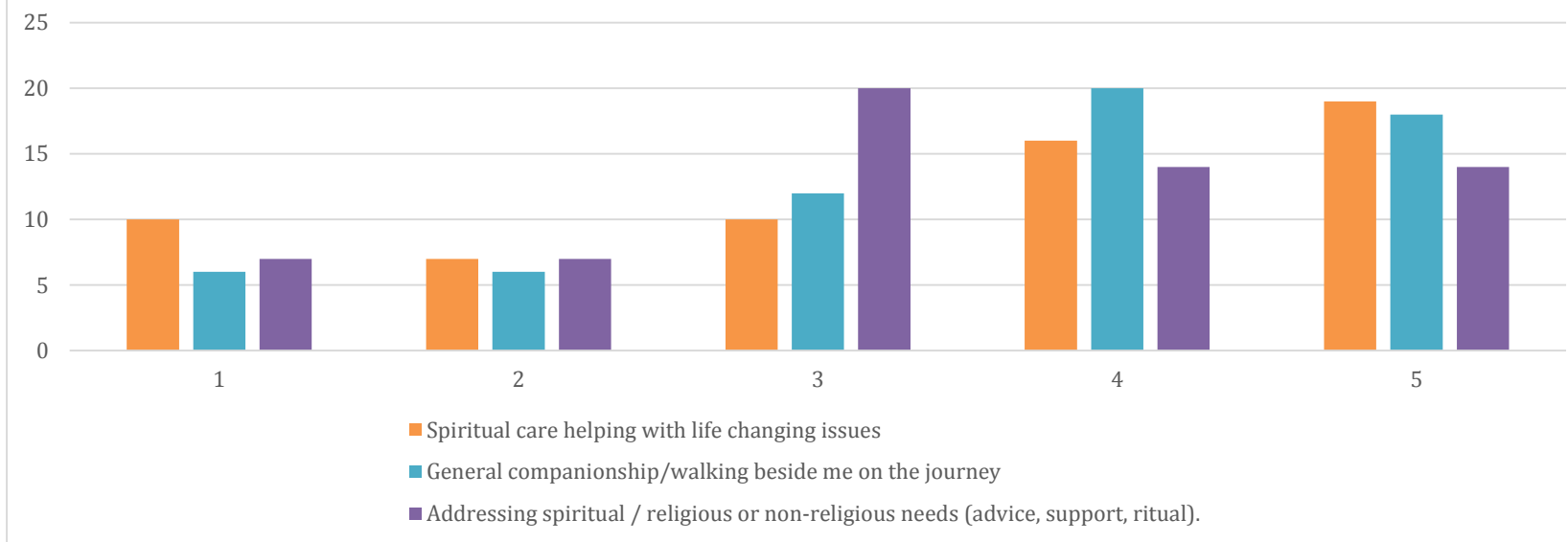
11/25/2015 6:21 PM [View respondent's answers](#)

Talk to churches and ask parish priests to link up with hospitals or other services.

11/18/2015 10:32 PM [View respondent's answers](#)

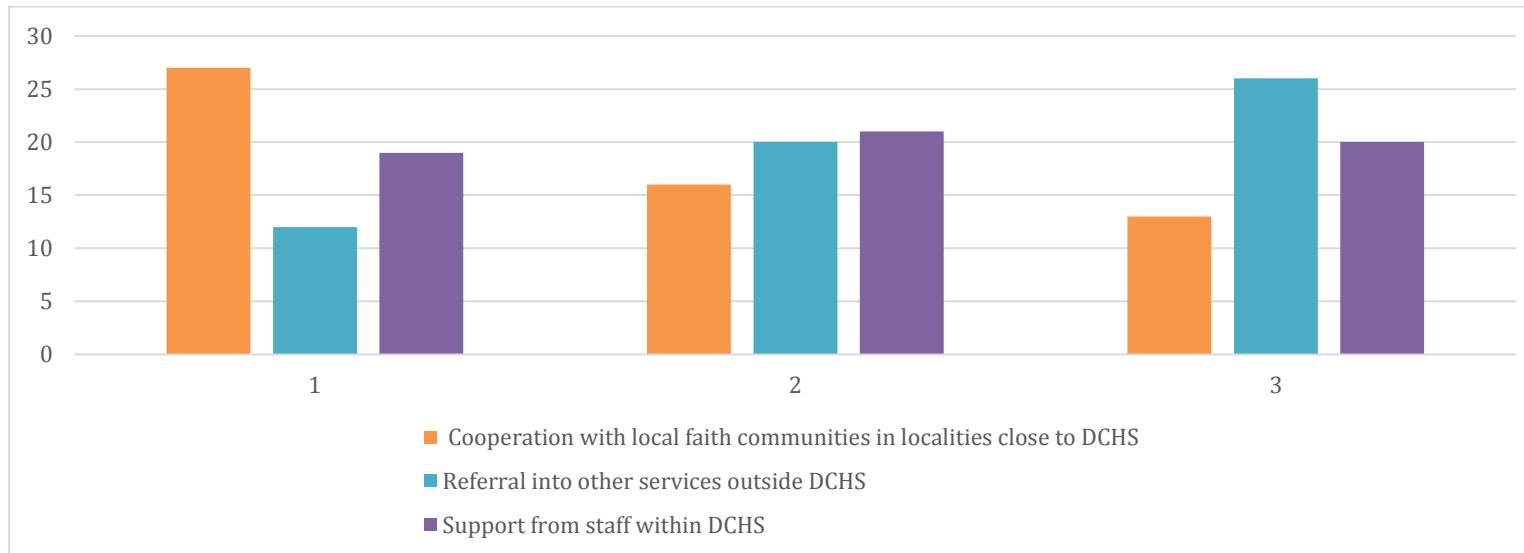
Q5. What would you like to see provided by those delivering spiritual and/or pastoral care in DCHS?

	not very important	moderately important	important	very important	essential	Total	Weighted Average
Spiritual care helping with life changing issues	16.13% 10	11.29% 7	16.13% 10	25.81% 16	30.65% 19	62	3.44
General companionship/walking beside me on the journey	9.68% 6	9.68% 6	19.35% 12	32.26% 20	29.03% 18	62	3.61
Addressing spiritual / religious or non-religious needs (advice, support, ritual).	11.29% 7	11.29% 7	32.26% 20	22.58% 14	22.58% 14	62	3.34



Q6. Choose from the models presented below. Rank your answer in order of importance to you (1 is first choice 3 is last choice).

	1	2	3	Total	Score
—	—	—	—	—	—
Cooperation with local faith communities in localities close to DCHS	48.21% 27	28.57% 16	23.21% 13	56	2.25
Referral into other services outside DCHS	20.69% 12	34.48% 20	44.83% 26	58	1.76
Support from staff within DCHS	31.67% 19	35.00% 21	33.33% 20	60	1.98



**Q7. If you have experience of spiritual and/or pastoral care in DCHS settings please tell us about it.
(24 responses)**

The comfort and chance to sit quietly and reflect with a staff member in the middle of the night following the death of my father.

12/15/2015 9:51 AM [View respondent's answers](#)

When my wife was a patient in the Derby Royal and asked for a visit from the chaplain - no-one came.

12/3/2015 3:24 PM [View respondent's answers](#)

I have experience that any basic empathy is sadly lacking.

11/28/2015 7:04 PM [View respondent's answers](#)

My son was christened and circumcised in ICU as a very ill baby.

11/28/2015 12:08 PM [View respondent's answers](#)

Kind RC nun at the QMC. As a Quaker I just talked to her.

11/27/2015 5:12 PM [View respondent's answers](#)

As a Home from Hospital volunteer I try to be a good listener & offer practical advice & help when needed.

11/27/2015 11:09 AM [View respondent's answers](#)

no experience

11/27/2015 10:40 AM [View respondent's answers](#)

At Walton Hospital the main Christian faiths had Chaplains who visited regularly.

11/27/2015 10:40 AM [View respondent's answers](#)

When I asked a local minister to come in and carry out a weekly service and communion on a dementia ward, still going 5 years later. Called a Shaman from Chesterfield when a Buddhist patient died but it wasn't very easy as we had no guidance.

11/26/2015 9:11 PM [View respondent's answers](#)

none

11/26/2015 8:18 PM [View respondent's answers](#)

I have come across chaplains and local ministers who are willing to be called on - very often these people already know patients who belong to faith communities

11/26/2015 7:30 PM [View respondent's answers](#)

Yes - many years ago due to neo natal death of my firstborn. It was appropriate . Recent spells in hospital has not reinforced the feeling that staff forget they are dealing with humans who are possibly unprepared for hospitalisation.

11/26/2015 6:59 PM [View respondent's answers](#)

N/A

11/26/2015 5:58 PM [View respondent's answers](#)

n/a

11/26/2015 5:50 PM [View respondent's answers](#)

I have used the chapel at the Royal Chesterfield Hospital to pray and have some quiet time when my grandma was terminally ill in hospital.

11/26/2015 5:29 PM [View respondent's answers](#)

None

11/26/2015 5:28 PM [View respondent's answers](#)

n/a

11/26/2015 10:30 AM [View respondent's answers](#)

I used to line manager the hospital chaplains and, whilst they used to do an excellent job, this is did not allow for multi-faith beliefs of our patients. However, we operate a monthly Sunday service at the hospital, where ALL local churches take their turn, regardless of faith.

11/26/2015 9:55 AM [View respondent's answers](#)

In the past our locality had a contact who would approach the relevant religious group in the area on our behalf and ask them to visit our patient.

11/26/2015 9:53 AM [View respondent's answers](#)

None

11/26/2015 9:23 AM [View respondent's answers](#)

The C of E Reverend used to come to the wards at St Oswalds and deliver Holy Communion, this was really important for some of the patients.

11/26/2015 8:48 AM [View respondent's answers](#)

Not within DCHS, but externally.

11/25/2015 6:24 PM [View respondent's answers](#)

I don't have first hand knowledge but my sister had really good support when she lost her baby

11/18/2015 10:38 PM [View respondent's answers](#)

x

11/16/2015 6:03 PM [View respondent's answers](#)

Q8. Please tell us what you would like to see from DCHS in providing spiritual and pastoral care (40 responses)

People who have the relevant skills being in place and this will need on-going training

12/15/2015 9:51 AM [View respondent's answers](#)

Not on staff

12/13/2015 5:12 PM [View respondent's answers](#)

Staff trained to respond to requests from patients and know how to refer these requests to the appropriate party (chaplaincy department)

12/3/2015 3:24 PM [View respondent's answers](#)

Not funding it! Enabling organised religions to be approached - at the behest of patients, not by them approaching patients

11/29/2015 12:27 PM [View respondent's answers](#)

Ask the patient if they would like to see someone. Be able to access such a person.

11/28/2015 12:18 PM [View respondent's answers](#)

all religious leaders to be made welcome throughout the DCHS

11/28/2015 12:08 PM [View respondent's answers](#)

By adopting a spiritual and pastoral care will benefit the care system and bring comfort.

11/28/2015 11:38 AM [View respondent's answers](#)

I think death should be discussed openly and freely. Possibly sympathy and holding hands if the person would like it. Sometimes it can be creepy.

11/27/2015 5:12 PM [View respondent's answers](#)

Staff trained to be good listeners and who are non judgemental.

11/27/2015 4:24 PM [View respondent's answers](#)

less of it

11/27/2015 4:15 PM [View respondent's answers](#)

Community based

11/27/2015 1:56 PM [View respondent's answers](#)

Opening conversations with patients about their feelings, if nothing else, shows them that YOU care about them as individuals and not just as the condition i.e. The Stroke patient.

11/27/2015 1:16 PM [View respondent's answers](#)

More knowledge of what is available within the community

11/27/2015 11:09 AM [View respondent's answers](#)

Good liaison with community faith leaders. Someone who is a named person for each individual needing the service.

11/27/2015 10:40 AM [View respondent's answers](#)

Staff to be trained to be knowledgeable about and sympathetic to spiritual needs.

11/27/2015 10:40 AM [View respondent's answers](#)

A Spiritual and Pastoral Care lead to develop the necessary expertise and tools across the Trust

11/27/2015 9:51 AM [View respondent's answers](#)

help in securing appropriate support for individual patients

11/27/2015 9:07 AM [View respondent's answers](#)

Ongoing support

11/26/2015 10:55 PM [View respondent's answers](#)

chaplains would be preferable but probably difficult to achieve

11/26/2015 10:08 PM [View respondent's answers](#)

Access to advice, support and hands on assistance.

11/26/2015 9:11 PM [View respondent's answers](#)

Ability for patients and staff to have access to this care at any time free of charge.

11/26/2015 8:24 PM [View respondent's answers](#)

not in the role of DCHS. they need to focus on medical issues and leave religion to the churches

11/26/2015 8:18 PM [View respondent's answers](#)

Making this accessible to patients as they need

11/26/2015 7:30 PM [View respondent's answers](#)

To bring the pastoral care in line with the medical care - both are key to a patients recovery.

11/26/2015 6:59 PM [View respondent's answers](#)

I believe these issues should be dealt with by the professionals in what ever faith plus appropriate volunteers as it is important to maintain the integrity of any communications

11/26/2015 6:24 PM [View respondent's answers](#)

Acknowledgement that older people, and in particular, those with dementia, will most likely have been brought up with traditional "religious" values (of whatever faith)

11/26/2015 6:05 PM [View respondent's answers](#)

Better liaison between clinicians & those providing spiritual pastoral care with training opportunities to bring both closer together & develop understandings

11/26/2015 5:58 PM [View respondent's answers](#)

Personally I don't think I would require it.

11/26/2015 5:50 PM [View respondent's answers](#)

Easy going, relaxed non missionary style, where rather than 'pushing' 'religion' is there to talk/ comfort and guide.

11/26/2015 5:29 PM [View respondent's answers](#)

People knowing where to find the correct support from those with expertise in spiritual or pastoral care.

11/26/2015 5:28 PM [View respondent's answers](#)

Helping older people to adjust to life without long standing partners or life changing illness (long term conditions or those that are life limiting). Meeting the spiritual needs of those who may struggle to verbalise their needs e.g. stroke, learning disability

11/26/2015 10:30 AM [View respondent's answers](#)

Using a volunteer based service would allow access to multi-faith disciplines.

11/26/2015 9:55 AM [View respondent's answers](#)

As above

11/26/2015 9:53 AM [View respondent's answers](#)

Easy access to non judgemental listening ear and emotional support

11/26/2015 9:24 AM [View respondent's answers](#)

To be included in the Resolve staff support services, and to be a key part of all clinician interactions (it is a fundamental part of respect and compassion for the patient)

11/26/2015 9:23 AM [View respondent's answers](#)

First contact (clinical) staff being confident, unembarrassed and relaxed when responding to patients more general psychological

and spiritual needs, rather than generally avoiding this as many do at the moment.

11/26/2015 9:17 AM [View respondent's answers](#)

More visits from appropriate staff for patients on wards or at home

11/26/2015 8:48 AM [View respondent's answers](#)

Pastoral and spiritual care would be good for the workforce as well as the Service users.

11/25/2015 6:24 PM [View respondent's answers](#)

Someone who can help in times of trouble, make you feel comforted. It helps even when you are not suffering life-threatening treatment.

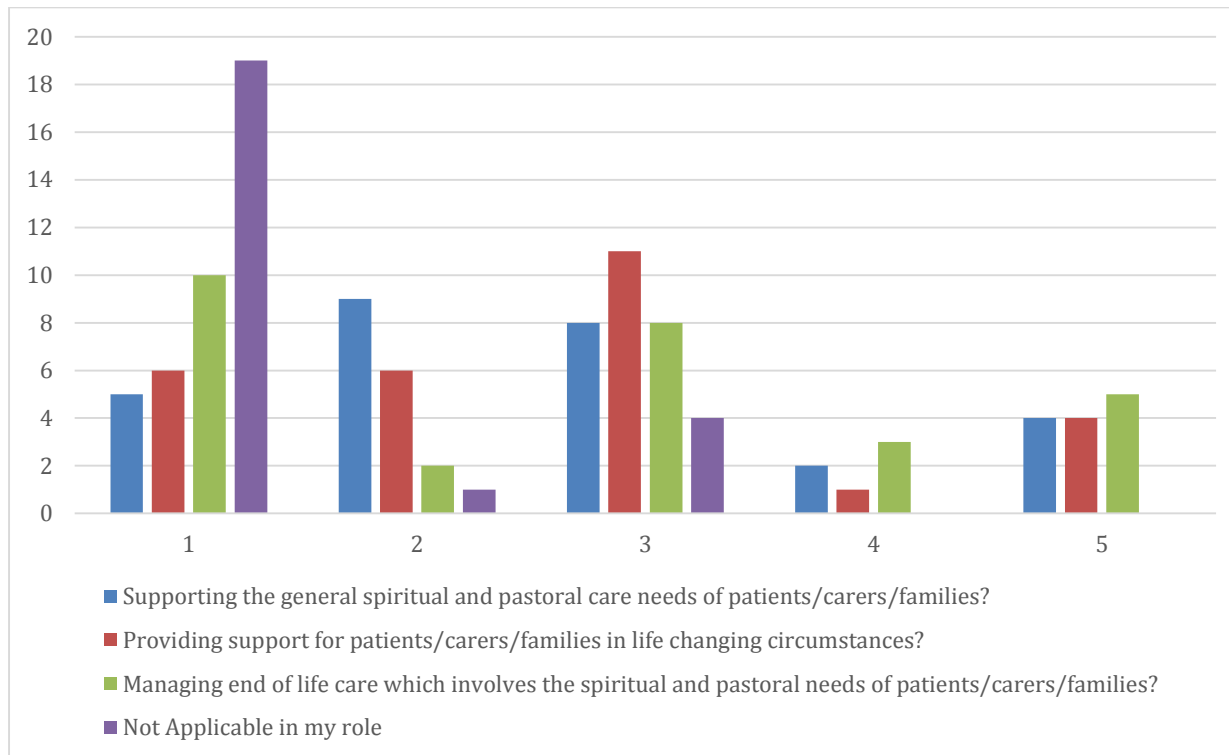
11/18/2015 10:38 PM [View respondent's answers](#)

x

11/16/2015 6:03 PM [View respondent's answers](#)

Q9. As a staff member of DCHS how confident are you in:

	Not Confident at all	Moderately confident	Confident with support	Confident without support	Very confident	Total	Weighted Average
–	–	–	–	–	–	–	–
– Supporting the general spiritual and pastoral care needs of patients/carers/families?	17.86% 5	32.14% 9	28.57% 8	7.14% 2	14.29% 4	28	2.68
– Providing support for patients/carers/families in life changing circumstances?	21.43% 6	21.43% 6	39.29% 11	3.57% 1	14.29% 4	28	2.68
– Managing end of life care which involves the spiritual and pastoral needs of patients/carers/families?	35.71% 10	7.14% 2	28.57% 8	10.71% 3	17.86% 5	28	2.68
– Not Applicable in my role	79.17% 19	4.17% 1	16.67% 4	0.00% 0	0.00% 0	24	1.38



If you would like to leave your preferred contact information please insert in the box below. It would help if you could include your role, locality and the service you provide? Thank You!

Answered: 17 Skipped: 47

Redacted for reasons of anonymity

Appendix 3: DCHS Sites Map

