Supporting the complete care of children and young people with life-threatening or life-shortening conditions, and their families: a mixed-method study of pastoral, spiritual and religious needs and support, and the role of chaplaincy services (The SPARK project)

Protocol
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1 General information

1.1 Funder acknowledgement and disclaimer

This study is funded by the National Institute for Health Research (NIHR) Health Services and Delivery Research Programme (NIHR128468). The views expressed are those of the author(s) and not necessarily those of the NIHR or the Department of Health and Social Care.

1.2 Key study contacts

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1.3 Protocol version history

Version	Date	IRAS Amendment number	Summary of main changes
1.0 (as funded)	07/08/20	n/a	Version of protocol as funded
1.1 (as submitted to HRA)	04/01/20	n/a	**WP1:** primary mode of survey completion changed to electronic. (*Decision based on consultation with NHS chaplains during survey development.*) **WP1:** respondent for children's hospice survey changed from chaplain to head of care. (*Decision based on consultation with NHS chaplains during survey development*.) **WP1**: greater distinction made between data collected from NHS Acute Trusts and children's hospices. (*Decision based on consultation with children's hospice spiritual care leads/chaplains during survey development.*) **WP2-4**: data collection may also occur via telephone/video calls. **WP2**: additional sampling characteristic: 'reach' of chaplaincy service into paediatric departments. (*Decision based on WP1 findings*)

			WP3: Recruitment process amended on advice of PAG:
			• sites distribute brief study information and expression of interest (EoI) form
			• EoI form offers two options
			  • request full information sheet via post
			  • request phone contact plus full information sheet via post
			WP3: On advice of PAG, addition of recruitment of parents and young people (16+ years) via social media
			WP3: Use of preparatory 'project workbook' posted to children/young people in advance of interview.

1.2	O4/08/2021 (REC approved: 21/10/201)	1	**WP3**: sub-sample B: addition of parents to the sample **WP3**: chaplaincy teams added as recruitment pathway for parents/young people>16 yrs who have self-referred/been referred to them and who they have supported in a substantive way. **WP4**: further specification of target sample.
1.3	22/11/2021 (Deemed non-substantial amendment: sponsor approval: 29/11/2021)	3	**WP3**: sub-sample C: maximum period of bereavement extended from 2 to 3 years.
1.4	18/03/2022 (Deemed non-substantial amendment: sponsor approval: 21/03/2022)	4	**WP3**: sub-sample A – young people • extended maximum age to 21 years

1.4 Non-substantial amendments

Amendment no.	Date	Summary of main changes
1	29/9/2021	Addition of PICs
2	18/10/2021	Revised versions of all study recruitment materials. Sponsor sign off.

1.5 Study Steering Committee

A Study Steering Committee will be appointed and will execute its responsibilities as set out in NIHR guidance:
https://www.nihr.ac.uk/documents/research-governance-guidelines/12154
The committee will meet on at least three occasions over the course of the project.

1.6 Advisory Panels

Separate Advisory Panels of young adults (18-25 years) and parents will be appointed. The Study Steering Committee will include Panel representatives. The budget includes funds for appropriate recompense to panel members as per INVOLVE guidelines. Advisory Panels will be closely involved in devising and reviewing recruitment strategies and materials, topic guides and facilitatory techniques, data analysis and interpretation, and refining the dissemination strategy and its delivery. The study will maintain a log of all PPI work and impacts of PPI on the study.

2 Background

This study falls under an area of interest specified by NIHR's themed call on End of Life Care, namely end of life care for infants, children and young people with life-limiting conditions. Its focus is the spiritual care of children and young people facing end of life, and their parents.

A life-shortening or life-threatening condition brings significant and unavoidable challenges. That death and dying cause suffering that goes beyond the merely physical is a central tenet of palliative care.[1, 2] Meeting spiritual needs is a core element of palliative care,[3-5] responding to the fact that people facing end of life find themselves needing to interpret, make sense of, and find meaning in what is happening to them and, perhaps, resolve things that have happened in their lives.[6-9] Some also seek, or draw on, religious, faith or spiritual beliefs as sources of hope or strength, or to assist decision-making. Whilst typically a positive resource, such beliefs may create dilemmas and raise critical questions.[10] Failing to address such needs increases suffering at end of life, and adversely affects the quality of life well-being of individual and their families.[11-16]

NHS England[17] defines spiritual care as "*care provided in the context of illness which addresses the expressed* <u>*spiritual*</u>*,* <u>*pastoral*</u> *and* <u>*religious*</u> *needs of patients, staff and service users. These needs are likely to include one or more of the following: ways to support recovery; issues concerning mortality; religious convictions, rituals and practices; non-religious convictions and practices; relationships of significance; a sense of the sacred; and exploration of beliefs*." (p5; our emphases) This definition draws on, and aligns with, an international consensus definition of spirituality.[3]

Chaplaincy services are identified as the key provider of "pastoral, spiritual and religious care" in the NHS.[17] This specification acknowledges that, regardless of religious belief, any patient/family may have pastoral or spiritual needs. Staffed by NHS chaplains and volunteers, chaplaincy is not affiliated to any specific religion and staff no longer need to hold a religious belief. Whilst traditionally viewed as separate from clinical services, in some NHS trusts chaplaincy services now sit within nursing directorates, acknowledging their role in direct patient care and experience. Whilst chaplaincy services are the key specialist provider in the NHS, patients may also seek pastoral, spiritual and religious support from other healthcare professionals. Supporting clinical colleagues in this is an important role for chaplaincy services.[18, 19]

Chaplains' willingness and ability to engage in conversations that health professionals may feel uncomfortable with, or do not have the time, confidence or skills to engage in, places them in a unique position in end-of-life care.[18, 20-24] They may also work to 'upskill' other healthcare staff to identify and/or respond to patients' pastoral and spiritual needs.[25] Clinical guidance also identifies chaplains as a possible resource when managing clinical issues, such as pain and agitation.[26] They may also facilitate conversations and/or advocate for patients/families in ethically challenging situations (e.g. withdrawal of treatment).[21] For those with religious beliefs, chaplaincy services can support them to practice their faith. The particular and significant role of chaplaincy within palliative care is reflected in NHS England guidance for a higher intensity of chaplaincy staff in these services.[17]

A Cochrane review of spiritual and religious interventions for adults at end of life [27] concluded that the NHS's broad approach to providing spiritual care aligns with existing (though weak) evidence supporting person-centred, non-judgemental, relational care rather than protocol driven interventions. However, it noted the quality of evidence was poor and described the need for research on spiritual care as "urgent"(p14), particularly given competing demands for resources for non-medical care.[27] A subsequent study of adult palliative care patients aligns with these conclusions, stating that 'human connectedness' (eg. compassion, empathy) and opportunities for conversations about existential concerns are key components of high quality spiritual care.[10]

Despite the importance placed on it by NHS policy[17] and clinical guidance,[4, 5] recent reviews of healthcare chaplaincy [21, 28, 29] show it is of poor quality and largely limited to the North American context. The most robust findings concern the value patients place on chaplaincy services.[30] An historic lack of research culture within the chaplaincy profession is acknowledged[8] and perhaps explains the absence of research investment. A handful of NIHR projects (older people's care, mental illness) refer to spiritual care/chaplaincy, but it was/is not the primary focus.

Pastoral, spiritual and religious care of children with life-limiting conditions

In England there are ~40,000 babies, children (0-18 years) living with a life-threatening or life-shortening condition (we collectively refer to these as life-limiting conditions (LLC) forthwith).[31] This represents a wide range of diagnoses including, for example, cancer, neurodegenerative conditions, kidney and heart disease, some chromosomal and metabolic disorders, and children with profound and global impairments. It also includes premature babies. Together, they cause of half of childhood deaths.[32] The illness trajectory of some conditions is predictable, for others there is great uncertainty. Some require intensive treatment whilst cure is attempted or efforts made to minimise the impacts of the disease or degeneration. In any year ~4000 children will die and, estimates suggest, ~10,000 will face death due to a medical crisis or inexorable deterioration.[26, 33]

Towards end of life, medical teams may involve specialist NHS paediatric palliative care services in caring for the child. They may also work with children's hospices (~45 in England) to provide end of life care and bereavement support. In addition to meeting the children's needs, are the needs of parents and other family members.

Existing evidence

There is a substantive body of work on the implications of cognitive and psychosocial development when considering the spiritual care of children and young people generally.[34, 35] Such work confirms that children and young people have such needs,[36] and also highlights the ways development affects the specific nature of such needs, how they are expressed and how to meet those needs.[37-42]

A recent qualitative meta-synthesis on studies investigating spirituality of children and young people with chronic (and including life-limiting) conditions drew the following conclusions.[43] The ways in which children and young people make meaning of their situation may differ to adults. Relationships and communication with others are key to this process. Religious beliefs may be an important coping resource. Access to spiritual care in healthcare settings was unusual. Finally, the authors note this body of evidence comes predominantly from North American studies. Others have observed the illness experience may cause either a regression or acceleration of maturity (including understandings of death), making the provision of 'developmentally appropriate' spiritual care complex and challenging.[44, 45]

A recent systematic review [46] on the symptoms, concerns and outcomes that matter to children and young people with LLC confirms the importance of acknowledging and attending to children and young people's spiritual needs. It found that spiritual/existential/religious issues were reported by over half of the included studies (n=37/68). Needs/issues reported included experiences of existential loss (e.g. loss of past ways of being in the world, loss of a future), existential vacuum (i.e. an inability to find or create meaning in life), not being at peace, longing, worry about the future and/or death, needing sources of hope and to be remembered. Other studies reported children, young people and parents' descriptions of feeling 'connected' to something larger than self, and this supported resilience. Again, the majority of these studies were North American, with just one from the UK.

A systematic review, drawing on a similar body of literature, specific to children and adolescents with cancer,[13] was carried out with the objective to inform the scope of the American Psychosocial Oncology Society's Standards for the psychosocial care in paediatric oncology.[47] It concluded that the quality of the evidence was sufficient to make a strong recommendation for spiritual needs assessments of children and families. Two further standards were therefore proposed for paediatric oncology within the US: systematic assessments of spiritual care needs, and "spiritual care offerings congruent with family belief systems during and after treatment".

Existing research also points to the specific and distinctive issues for children and young people facing death (and/or their parents) compared to adult patients. Their fragile mortality and the untimely nature of impending death are particularly distressing and challenging for (older) children and parents to reconcile [40, 48]. There are generational differences in the extent to which formal religion is seen as relevant to meeting spiritual needs, and beliefs held by children may differ from their parents.[48, 49]

Furthermore, parental bereavement is qualitatively different to spousal bereavement.[50-52] Evidence reviews, and more recently published research, on parents' needs identify spiritual support during end of life and bereavement as a dominant need and deficiencies in meeting such needs.[53-55]

These different bodies of work point to a potential challenge for chaplaincy services in terms of the skills and competencies of chaplaincy staff. Much of the writing on chaplaincy, including practice guidelines, pays limited attention to spiritual care and chaplaincy of children, young people and parents, the implications this has for practice and/or the unique issues they may be facing.[56, 57] Informal scoping work carried out in preparation for this bid suggests there may be differences between children's and general hospitals in terms of access to chaplaincy services and the extent to which chaplaincy services include staff with specialist training in providing spiritual care to children and young people. This raises questions both in terms of access to spiritual care for children and their parents, and also the adequacy and quality of that care.

3 Rationale

NICE guidance on end of life care of children[4] stipulates the spiritual needs of children and their families should be addressed, including during bereavement. However, evidence suggests such needs are among those most likely to remain unmet.[43,52-54,58]

In terms of research attention and investment, spiritual care is a relatively neglected aspect of palliative care, particularly for neonatal and paediatric populations.[43] In line with the requirements of the 2010 Equality Act, NHS England guidance on Chaplaincy Services highlights issues of equality of access to pastoral and spiritual care, regardless of religion or belief (or non-belief). Equally important is equity of access regardless of age. To achieve this, a more robust evidence base is required to ensure developmentally appropriate, high quality spiritual care and support is available to children and young people with LLC and their families. Another key barrier to children and young people with LLC facing end of life accessing spiritual care and support is health care professionals' lack of awareness and confidence with respect to identifying such needs, and a lack of understanding of the potential roles and contribution of chaplaincy services to holistic, end of life care.[21]

Existing evidence to inform commissioning and delivery of chaplaincy services for children and young people with LLC and their parents is minimal.[59] Most is non-UK and skewed towards certain faiths.[28, 43, 46] Differences between countries in degree of secularisation, religions practiced, the diversity of interpretation and belief within religions, and societal changes over time further constrain use of existing evidence.[60, 61] We also know little about how faith interacts with other aspects of a person's identity when used as an explanatory resource.[62]

It is, therefore, perhaps unsurprising that two research recommendations of the NICE guidance[4] speak to the issue of spiritual care and chaplaincy, namely:

- What emotional support do children with life-limiting conditions and their parents or carers need, and how would they like these needs to be addressed?
- What are children's and families' perceptions and attitudes about chaplaincy in neonatal and paediatric end of life care, and when would they like to access religious and spiritual support?

Spiritual care has also been identified as a key research topic in recent research prioritisation exercises. (We note that earlier exercises do not identify this, perhaps due to significant under-representation of children/young people and parents[63]). For example, within our Centre's research prioritisation work, non-clinical professionals and young people both identified this topic as top priority.[64] Similarly, a top priority of James Lind Alliance's recent teenage and young adult cancer priority setting partnership (What are the best ways of supporting a young person who has incurable cancer?) also speaks to this issue.[65]

This study will generate evidence to support evidence-informed change and practice in the provision of pastoral, spiritual and religious care, through chaplaincy services and other health/care professionals, to children and young people facing end of life and their parents.

4 Theoretical framework

The overarching theoretical framework for the research is the biopsychosocial-spiritual (BPS-S) model of healthcare.[66-68] This adds 'spirituality' as a further intersecting component to the biopsychosocial model[69] of health, illness and well-being which, over recent decades, has had a profound influence on healthcare including foundational concepts such as person-centred care and holistic care. Thus, as with biopsychosocial model, the BPS-S argues that the different component interact with and affect each other. Thus, intervening on one component may have impacts on others. Furthermore, all components are implicated in maintaining or achieving of a state of 'health' or 'wellness' A revised version of the model [66] accommodates the fact the individuals may differ in the extent to which the spiritual dimension is salient or important to them.

A further, separate point is that, as noted earlier, research on chaplaincy, spiritual and pastoral care, is relatively under-developed including theoretical frameworks by which we can understand how such care 'works' and the outcomes it achieves.[70] [71] One of the contributions of this study will be to further that understanding, particularly with respect to children and families, and the meaning of spiritual and pastoral care for children with very complex needs.

5 Research objectives

- To describe the organisation and delivery of NHS and hospice chaplaincy services, and identify differences in the nature of provision for children, parents & adult patients.
- To investigate equity of access to chaplaincy services for children and parents, and factors affecting access.
- To describe the spiritual needs of children and parents, preferences regarding sources of support, and their experiences of having those needs met or remain unmet.
- To understand the differences between providing chaplaincy services to children, parents and adult patients, and the implications for service provision and staff training.
- To describe children's and parents' attitudes, understanding and experiences of accessing and using chaplaincy services.
- To identify the (potential) roles of clinical teams in identifying and responding to the spiritual needs of children, young people and parents, and the barriers and facilitators to these roles being fulfilled.

6 Study design/methods

6.1 The study's definition of 'facing end of life'

This study was funded within NIHR's cross-programme end of life theme. It defined people at end of life as "people who are likely to die within 12 months". This is challenging to apply in the paediatric population. Many LLC diagnosed in childhood do not have predictable trajectories, thus determining when a child is at 'end of life' is problematic and there is insufficient evidence currently to use tools such as the "surprise question" with this population.[33, 72] In addition, spiritual needs associated with end of life may well arise (and need attending to) earlier in disease trajectory (e.g. at diagnosis, time of significant medical intervention, significant evidence of deterioration).[13, 73] Furthermore, evidence from the adult literature suggests the way such needs are attended to throughout the disease trajectory affects quality of life at the end stage.

For these reasons, for this study, children and young people 'facing end of life' will be defined as:

- children and young people who are 'actively' dying;
- children and young people definitively known to be at end stage (e.g. active treatment/ management has been withdrawn, palliative care only);
- children and young people who may die within the next twelve months, defined as having experienced one or more of the following within the past twelve months:
  - an acute life-threatening event associated with their condition or co-morbidities (e.g. chest infection requiring temporary tracheostomy)
  - awaiting treatment/intervention due to significant deterioration or stage in trajectory of the condition (e.g. kidney transplant)
  - currently being treated for cancer.

6.2 Overview of design

The lack of evidence demands an exploratory approach. The study comprises primary research, organised into four workpackages (WP):

- WP1: survey of NHS chaplaincy services and equivalent survey of children's hospices
  WP2: focus groups with NHS chaplaincy staff and staff assuming an equivalent/similar role in children's hospices
- WP3: interviews with children, young people and parents
- WP4: focus groups with clinical team/care team staff

Together, they address the research objectives (see Table 1).

Table 1: Contribution of work packages (WPs) to study objectives.

Objective	**WP(s)**
Describe the organisation and delivery of NHS and hospice chaplaincy/spiritual care services, and identify differences in the nature of provision for children, parents & adult patients.	1, 2
Investigate equity of access to chaplaincy services for children and parents, and factors affecting access.	1, 2
Describe the spiritual support needs of children and parents, preferences regarding sources of support, and their experiences of having those needs met or remain unmet.	2, 3, 4
Understand the differences between providing chaplaincy services to children, parents and adult patients, and the implications for service provision and staff training.	2, 3
Describe children's and parents' attitudes, understanding and experiences of accessing and using chaplaincy services	2, 3, 4
Identify (potential) roles of clinical team in identifying & responding to spiritual needs of children, young people and parents, and the barriers/facilitators to these roles being fulfilled.	2, 3, 4

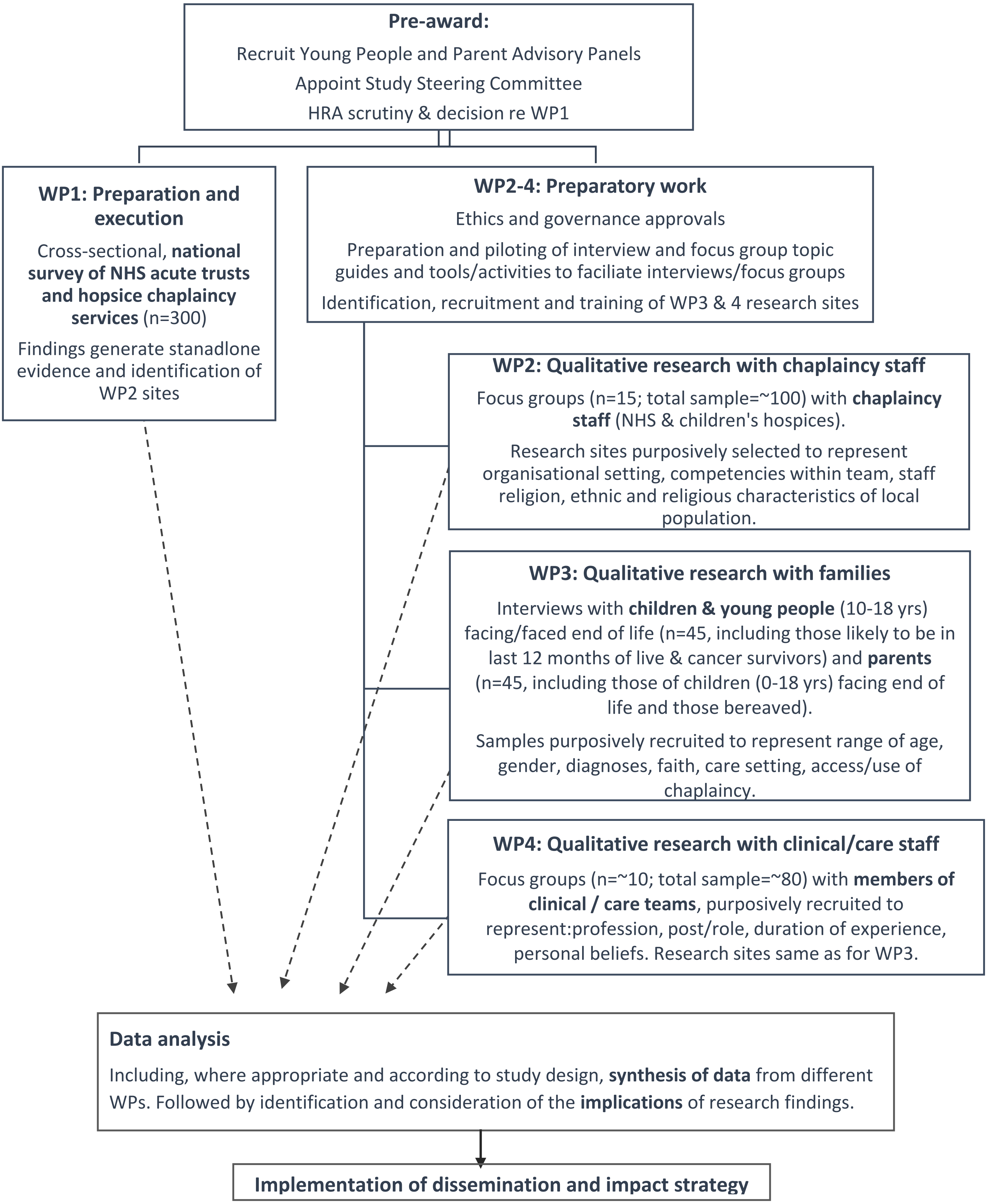
Design of the qualitative investigation (Work Packages 2-4)

The qualitative research is phenomenological in its approach. We will investigate the spiritual needs of children and young people facing end of life, and their parents, by triangulating a number of different sources of data.[74]

This does not, however, include the *direct* involvement of children and young people who are dying. This is because, from an ethical perspective and on the basis of existing evidence, we do not believe the case can be made for the imperative to seek the direct involvement of children at end stage. Our sources of data on the spiritual needs of children and young people facing end of life, and those of their parents, will therefore be drawn from data across the qualitative workpackages.

Specifically, the WP3 sample comprises children and young people (and parents) who either : i) who have survived cancer, ii) whose condition and health indicates they may die in the next twelve months; iii) have lost a baby, child or young person to a life-threatening or life-shortening condition. Some study participants recruited to WP2 and WP4 will have extensive experience of experience of caring for and supporting children and young people dying or facing death (including those who are very young, have complex needs and/or significant cognitive impairment).

6.3 Study flow diagram



Pre-award:

Recruit Young People and Parent Advisory Panels

Appoint Study Steering Committee

HRA scrutiny & decision re WP1

WP1: Preparation and execution

Cross-sectional, **national survey of NHS acute trusts and hopsice chaplaincy services** (n=300)

Findings generate stanadlone evidence and identification of WP2 sites

WP2-4: Preparatory work

Ethics and governance approvals

Preparation and piloting of interview and focus group topic guides and tools/activities to faciliate interviews/focus groups

Identification, recruitment and training of WP3 & 4 research sites

WP2: Qualitative research with chaplaincy staff

Focus groups (n=15; total sample=~100) with **chaplaincy staff** (NHS & children's hospices).

Research sites purposively selected to represent organisational setting, competencies within team, staff religion, ethnic and religious characteristics of local population.

WP3: Qualitative research with families

Interviews with **children & young people** (10-18 yrs) facing/faced end of life (n=45, including those likely to be in last 12 months of live & cancer survivors) and **parents** (n=45, including those of children (0-18 yrs) facing end of life and those bereaved).

Samples purposively recruited to represent range of age, gender, diagnoses, faith, care setting, access/use of chaplaincy.

WP4: Qualitative research with clinical/care staff

Focus groups (n=~10; total sample=~80) with **members of clinical / care teams**, purposively recruited to represent:profession, post/role, duration of experience, personal beliefs. Research sites same as for WP3.

Data analysis

Including, where appropriate and according to study design, **synthesis of data** from different WPs. Followed by identification and consideration of the **implications** of research findings.

Implementation of dissemination and impact strategy

7 WP1: Survey of NHS chaplaincy services and spiritual care provision in children's hospices

The purpose of WP1 is to describe current provision of chaplaincy services for children and young people with LLC, and their parents, within acute NHS trusts and equivalent provision in children's hospices (this may not be termed 'chaplaincy'), and to compare this to provision for adult patients and their families. Findings from WP1 will inform sampling for WP2.

7.1 Design

Cross-sectional surveys of heads of chaplaincy services in acute NHS trusts (n=~140) and heads of care of children's hospices across the UK (n=~50).

7.2 Data collection

Previous work mapping chaplaincy across all sectors[75] will inform survey content. Chaplains, including co-applicants (representing specialist children's and general NHS settings, and children hospices), will advise survey development and pilot the survey. Piloting will involve a member of the research team observing completion and the use cognitive interview techniques to ascertain clarity of language and instructions, meaningfulness, ease of completion and identify any relevant gaps in the data being collected. Any required revisions will be carried out prior to data collection.

The survey of NHS Acute Trusts will collect the following data:

- location within the organisation (e.g. nursing/patient care vs other directorate).
- staffing (e.g. salaried vs volunteers, duration in post of salaried staff, faiths represented);
- number of staff trained in working with children/young people (including nature of qualifications);
- clinical services/departments (e.g. wards, vs outpatient clinics vs emergency department vs community/outreach services) in which routinely work (e.g. have chaplaincy staff assigned);
- characteristics (e.g. age, condition, faith, ethnicity) of children and young people, and their families, whom support;
- relative use of chaplaincy services by children, young people & parents vs other patient groups;
- extent and ways in which chaplaincy services are used by paediatric vs adult healthcare staff, and relative use by these two staff groups;

The survey of heads of care of all UK children's hospices will collect the following data:

- number of post(s) within hospice with identified responsibility for spiritual and religious care;
- nature of above posts including: f.t.e., position of post in organisational structure (e.g. integrated into care team vs separate); scope of role (e.g. family vs staff

support; bereavement support), and characteristics of individual in post (e.g. faith, training etc.);
- any changes to posts/provision in past 5 years;
- nature of arrangements with local faith leaders to provide spiritual/religious care to families;
- faith profile of families using the hospice;
- data routinely collected regarding child/young person and parents' faith;
- inclusion of spiritual and religious care/support needs in routine needs assessment and advance care planning processes;
- type(s) of belief space/sanctuary offered;
- types and presence/availability of faith artefacts within hospice.

Desk-based research will identify contact details for service leads of all acute and children's NHS trusts chaplaincy services and children's hospice's heads of care. The primary mode of completion will be electronic (via *Qualtrics* survey platform) with postal completion also offered. Email and, if required, postal will support response rate. To support response, news of the study (including imminent distribution of the survey), will be cascaded out via chaplaincy networks and groups.

7.3 **Data analysis**

Data will be input (10% double-entered etc.) or downloaded (on-line completion) into SPSS. Most questions will be fixed response. However, a few will require a short, free-text response. These data will be subject to conventional content analysis[76] either to create codes/categories to transform responses into quantitative data, or to enable analysis and reporting of free text (i.e. qualitative) data. Quantitative data will be analysed using descriptive and comparative statistical techniques. Specifically, we will use univariate descriptive statistics to explore and describe categorical (e.g. location of chaplaincy service within organisation, faiths represented within chaplaincy service, settings in which routinely work) and numerical (e.g. number and full-time equivalent of paid and volunteer chaplaincy staff) data. Informed by our research questions, we will use cross-tabulation (and chi-square statistic) to describe and compare practices and provision of chaplaincy services staff, between child and adult patients and between organisational setting.

8 WP2: Views and experiences of chaplaincy staff

This work stream will generate qualitative evidence on chaplaincy staff's views and experiences of the spiritual needs of children and young people facing end of life, their parents and the staff involved in their care, and the ways chaplaincy (and any equivalent services in children's hospices) meets those needs.

8.1 **Design**

Cross-sectional qualitative study utilising focus group methodology.

8.2 Sampling

Using WP1 data, NHS research sites will be selected to ensure representation of the following characteristics:

- organisational setting: children's NHS Trusts vs general acute (no children's hospital) vs general acute (includes a children's hospital)
- staff qualifications/competencies (specialist training in paediatric chaplaincy or not)
- extent of 'reach' into paediatric departments, including provision/practices specific to paediatric setting
- chaplaincy staff's faith/religion
- faiths/religions represented in local population

Children's hospice research sites will be selected to ensure representation of:

- different models of providing spiritual and religious care as identified by WP1
- staff's faith/religion
- faiths/religions represented in local population

Focus group participants will be required to have a certain level of experience (duration, intensity/amount) of working in chaplaincy/spiritual care provision. Findings from WP1 will be used to further specify sampling characteristics and eligibility criteria.

In order to populate the sampling frame, we anticipateholding ~12 focus groups with NHS chaplaincy teams and three with children's hospice staff (including local faith leaders with honorary contracts) responsible for spiritual care/religious support. Focus groups with NHS staff will include salaried chaplains and chaplaincy 'visitors'. Size of the groups will range from 5-8 participants, thus yielding a total sample size of 75-120.

8.3 Setting

Focus groups will be held in hospital/hospice facilities or via video-conferencing (e.g. MS Teams, Zoom). For face-to-face focus groups with hospice staff, one hospice will host the focus group with staff in nearby hospices also attending.

8.4 Data collection

Focus groups will be conducted either via face-to-face meetings or via video-conferencing (e.g. MS Teams, Zoom). Focus groups are likely to vary in the relevant expertise/experiences of participants. For example, chaplaincy staff in general hospitals will have experience of working with adult patients and parents, and providing chaplaincy in a general hospital setting. However, based on work carried out in preparation for this bid, their experiences of working directly with children and young people may be quite limited. In contrast, chaplaincy staff working in children's hospitals and hospices will have greater experience of supporting children and young people, and their parents. However, they will not be able to compare these experiences with adult patients. Finally, chaplains and spiritual care leads/staff in children's hospices will have greatest experience of working with bereaved parents (certainly over the longer term) and, we anticipate, the most developed understanding of spiritual care of children with very complex needs.[41] Thus, topic guides will be tailored specifically to the characteristics of focus group participants.

We will use facilitatory activities (e.g. individual/pair exercises, small group work) to support articulation of views and experiences. Focus groups will last at least two hours. To secure the depth of information we require, focus groups with chaplaincy staff in children's hospitals/hospices will be of a longer duration (~ 4 hours). If logistically easier, this will be spread over two sessions.

A week or so prior to a focus group, participants will be sent succinct information about the objectives of the focus group and topics to be discussed and asked, if possible, to spend some time reflecting on these prior to the focus group. A 'notes to self' sheet will be provided should individuals wish to record thoughts and reflections. Participants will be encouraged to bring these to their focus group.

Views and experiences on the follow topics will be explored. The listing does not necessarily reflect the order in which they will be raised and not all topics will be relevant/dealt with the same depth:

- spiritual care and support needs of children and young people, and their parents facing end of life, and how these needs may be indicated or expressed;
- factors affecting needs experienced (e.g. age, beliefs, disease stage, complexity of need) and influencing likelihood of such needs remaining unmet;
- differences between child and adult patients, and parents vs other family members in terms of nature of spiritual needs;
- broad objectives, and outcomes sought, of chaplaincy services and how these are understood or operationalised with different patient groups;
- the ways spiritual care is provided to patients and their families by chaplaincy services, both generally and specifically in end of life situations;
- 'adjustments' to practice/ways of working when supporting children and young people and/or parents compared to adult patients and their families, and specific challenges;
- specific knowledge, skills and competencies associated with providing chaplaincy services in paediatric settings, and with respect to end of life care;
- other sources of spiritual support known to be used by patients and their families (e.g. the clinical team, other NHS professionals (e.g. ward nurses, informal and community sources);
- factors affecting the sources of support used or access to such sources of support;
- barriers (e.g. organisational, staff- or patient/family-centred factors) to meeting the spiritual support needs of patients and their families facing end of life; differences between paediatric and adult patients and within the paediatric population;
- existing and potential roles of other NHS staff in identifying and/or spiritual support needs, and factors which support or act as barriers to this happening;
- the ways clinical teams/MDTs currently use chaplaincy services (as staff members and/or in the management of a case), and factors this use;
- other potential contributions of chaplaincy to staff/clinical teams;

- actual and perceived potential roles re support to community faith leaders.

8.5 Data analysis

See Section 11.

9 WP3: Views & experiences of children/young people, & parents

The purpose of this WP is to hear directly from children and young people, and parents, about their spiritual care and support needs, sources of support, and their experiences of accessing and using spiritual care within NHS or children's hospice settings, including chaplaincy services.

9.1 Design

Cross-sectional qualitative study involving semi-structured, in-depth interview with 3 sub-samples of children and young people (n=~45) and parents (n=~45):

- Sub-sample A: children and young people who may die in the next twelve months but are not at end stage/dying, and parents of such children and young people;
- Sub-sample B: children/young people who have survived cancer and their parents;
- Sub-sample C: bereaved parents.

9.2 Sampling

We will purposively sample to ensure a range of faiths/beliefs (including non-religious), gender, use of NHS/hospice chaplaincy services, and age/developmental stage are represented in the overall samples of children/young people and parents. Inclusion criteria vary between sub-samples.

Sub-sample A
This sub-sample represents children and young people where the diagnosis and/or changes in their health indicate they may die within the next 12 months. Three types of life-limiting condition have been selected to represent different disease trajectories, likelihood of success of medical intervention, regularity of contact with clinical team/inpatient episodes, age at diagnosis, and impacts of LLC on everyday life. Target sample sizes are: children & young people: n=~25: parents of such children: n=~25.

Inclusion criteria:
Child/young person participants:

- ~10[1] – 21~~18~~ years
- diagnosed with:
    - relapsed cancer, or cancers, with 75% or less survival rate, (e.g. metastatic bone tumours, high-risk neuroblastoma, very high-risk leukaemias)

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[1] One purpose of piloting work will be ascertain the lower age limit

    - degenerative genetic, neurological or neuromuscular conditions (e.g. spinal muscular atrophy, Duchenne muscular dystrophy) and evidence of significant deterioration within past twelve months (e.g chest infection requiring hospitalisation)
    - kidney failure.
- does not have a significant cognitive impairment
- is aware of the (potentially) life-limiting nature of the condition.
- not at end stage/dying

Parent participants:

- parents of children (0-18 years) with above characteristics
- parents of children with above characteristics except
    - child has significant cognitive impairment
    - AND/OR child is unaware of (potentially) life-limiting nature of condition

Sub-sample B

The rationale for including this group is that having lived through a period of being acutely aware they may die, the elapse of time since then has facilitated a process of reflection and sense-making.[77] We believe, therefore, they will bring additional insights into the experience of facing death as a child or young person, and given their current state of health (and good prognosis), may be more able to explore these experiences very openly compared to sub-sample A. We will purposively sample for a range of age at diagnosis (5-17yrs), thus some recruited will be 19 years and older. Total target sample size: n=~20-25 (~10-15 children/young people; ~10-15 parents)

Inclusion criteria:

Child/young person participants:

- children and young people (12 – 18 years) and young adults (19- 24 years);
- have transferred to long-term follow-up (LTFU) within the past 12 months and within ten years of end of treatment. [Note: transfer to LTFUT is locally defined by Primary Treatment Centres and ranges from ~2-5 years post end of active treatment];
- cancer diagnosis occurred between ages of 5 and 17 years;
- does not have significant cognitive impairment

Parent participants:

- parent of child/young person as above
- child may have significant cognitive impairment

Sub-sample C

This sub-sample comprises bereaved parents, and they will be asked about their own spiritual needs (before and after death) *and* also their observations and reflections regarding their child's needs. This sub-sample is, therefore, one of our sources of data regarding children's/young people's spiritual care and support needs in the end stages.

Guided by previous research with bereaved parents [78], views of our Centre's PPI Family Advisory Board, and our own research experiences, we will seek to recruit parents whose child died no less than 3 months, and no more than 3 years previously. The ages of children and young people represented in this sample will be 0-18 years. Target sample size: n=~20

9.3 Research sites

Research sites will be clinical departments in NHS Children's Trusts and other children's hospitals, and children's hospices. There will be at least two NHS sites per 'diagnostic' group (relapsed cancer, degenerative neuromuscular, kidney failure, cancer survivors). Their location will ensure representation of different religious beliefs. For sub-sample C, neonatal and paediatric intensive care units will also be research sites.

9.4 Recruitment

Using the study's eligibility criteria, research sites will provide the research team with an anonymised list of potential study participants, detailing the sampling characteristics described above. We anticipate more than one member of the clinical team will be involved in this process, particularly so that there is confidence in the judgement made regarding child/young person's awareness of the life-shortening/threatening nature of their condition. The research team will review the anonymised list and use the study's purposive sampling frame to identify those individuals they would like to be approached regarding study participation.

Sites will distribute study recruitment packs, comprising covering letter from research site, brief information sheet, 'expression of interest' (EoI) form (i.e. consent to contact) and reply paid envelope. This may occur in clinic, on the ward/at the hospice, or via post. Where handed over directly, a member of the clinical/care team will briefly introduce the study. Individuals interested in taking part in the study will return the EoI form direct to the research team. The EoI form offers potential participants two options:

- request the full study information sheet plus response form be posted to them;
- request to be contacted by the research team by telephone, with the full study information sheet also posted to them.

The specific process will vary slightly according to the age of the child/young person:

- up to 15 years: parent(s) and child/young person jointly approached with separate versions of brief information sheet provided and joint EoI form
- 16 - 18 years: young person and parent(s) approached independently.

On receipt of an EoI or response form, a member of the research team will contact the respondent via their preferred means of communication (phone call, text, email), provide an opportunity to ask questions about the study and taking part and, if agreed, make arrangements for an interview.

In addition, chaplaincy teams in WP3 sites will also distribute study recruitment packs to parents and young people (16+ years) who have self-referred or been referred to them, and whom they have supported in a substantive way (e.g. conducting baby funeral; on-going visits/support during an extended NICU/PICU admission). They will liaise with clinical teams to ensure that potential participants are only approached via one recruitment pathway.

In addition, and on the advice of the study's Parent Advisory Group, we will also recruit via notices posted on social media platforms (e.g. Facebook pages/groups, charity websites) of relevant parent- and third-sector organisations. An on-line version of the 'Expression of Interest' form will also include brief screening information.

Recruitment packs will be translated into the languages represented in the sampling pool. We will work with our Advisory Panels to ensure the language and concepts used in recruitment materials are likely to be widely understood and meaningful. For example, phrases such as 'spiritual needs' may not be used. As well as written information, we will work with our Advisory Panels create two brief information videos (one for parents, one for young people) about the study. The hyperlink (and QR mark) to access these videos will be clearly indicated on information sheets.

9.5 Setting

Participants will choose to be interviewed face-to-face or via telephone or video call (e.g. MS Teams, Zoom). Face-to-face interviews will take place at hospital, home or a hospice according to the interviewee's preference.

9.6 Mitigating risk of distress or other negative impacts of participation

The particular vulnerabilities of the samples and the sensitive nature of the interviews means that a comprehensive strategy has to be in place from the outset of this work packpage, see Appendix 1. They are also described or referred to within the relevant sections within the description of this work package.

9.7 Data collection

In-depth, semi-structured interviews will be used and be conversational[79] in nature. Time and care will be taken at the start of the interview to establish rapport and the structure of the topic guide will be such that 'easier' (that is, more concrete and less sensitive) questions are used both at the beginning and end of the interview. We will be careful not to impose concepts and/or phrasing/language but rather respond to those used by the interviewee. The interviews will explore the experiences and concepts which concern or relate to spiritual needs and care but may not always be 'labelled' or articulated as such by individuals.

Topics covered in interviews, informed by existing research, will include:

- questions and concerns/worries generated by having the condition, and factors /situations which precipitate(d) or heighten such concerns;
- experiences of trying to resolve such questions or concerns, use of informal and formal sources of support within that process;
- experiences of needing/trying to make sense of what is happening, meanings which have been made, and the use of informal and formal sources of support within that process;
- needs for and/or sources of hope, comfort and strength; sources of support used and/or types/sources of support would like to have access to;
- impacts of having condition on feelings (e.g. hope, fear, uncertainty, worth and value, loneliness), strategies to manage negative feelings, sources of support;
- if practising a religion/holding a faith, impacts of situation on beliefs and impacts of beliefs on response to facing end of life;
- regardless of whether or not practising religion/faith, use of any 'religious' practices/rituals (e.g. prayer), and reasons for doing so;
- views on the role of the clinical team other hospital staff in relation to meeting spiritual needs;
- knowledge, understanding of, and attitudes towards, chaplaincy services;
- experiences using of chaplaincy services, and perceived impacts.

Interviews with parents will explore their own needs and experiences and, where relevant, their observations of their child's needs and experiences.

It is our and other researchers' experiences that providing children and young people with preparatory materials in advance of the interview is valued and helpful.[80-82] Prior to interviews we will therefore send child/young person participants a simple, age-appropriate, attractively designed 'project workbook' covering core topics of the interview with space, should they wish, for the interviewee to write or draw responses. The 'workbook' will then act either as an aide-memoire for the child/young person and/or a focus of conversation during the interview.

The interviews themselves will be tailored according to age/developmental stage and, in addition, to the 'project workbook', a range of participatory activities will be used. Such activities will act as 'entry points' from which sensitive or previously unconsidered, or unarticulated, issues can be explored, rather than being used to generate data *per se*. They also serve to 'normalise' the research interview and act as a point of focus thus reducing the need, should the child/young person prefer, for eye to eye contact. Examples of potential activities, widely used in participatory research with children/young people and/or by paediatric chaplaincy teams,[83-91] are set out in Table 2.

Table 2: Examples of potential facilitatory activities

Third person scenarios/vignettes depicted in pictures or simple stories;
Creating own painting/drawing (annotated if they choose) on topic suggested by researcher;

Creating an object/collage from a set of items to display/represent, for example, feelings/emotions, concerns and/or sources of support (e.g. making a bracelet from different colour beads, with each bead representing a different feeling, concern etc.; or different coloured leaves to create a picture of a tree);
Card sorting exercises (e.g. a set of cards each with a different picture/word/simple phrase relevant to a particular topic(s); for example, worries/concerns, feelings, sources of hope, sources of support) from which child/young person selects those true for themselves);
For sub-sample B (cancer survivors), to facilitate recall, sharing and discussing family photographs taken during active treatment.

All tools/activities will be piloted and, recognising that children and young people vary in their interests and preferences, we will ensure at least two activities can be used to explore a topic.

If both parents wish to take part we will offer joint or separate interviews. If a parent and child/young person from the same family take part, different interviewers will be used. All interviewees will have the choice of having a companion. For those preferring to be interviewed in a language other than English, we will use first-language interviewers, specifically recruited, trained and supervised by the research team. We have used this approach very successfully in another project.[92]

9.8 **Data analysis**

See Section 11.

10 WP4: Views & experiences clinical and care teams

The purpose of this workpackage is to generate qualitative evidence on: clinical teams' understanding, awareness and use of chaplaincy services, and their perceived impacts; their observations of the spiritual needs of patients, and their parents; and their roles (perceived or actual) in identifying and responding to these needs.

10.1 **Design**

Cross-sectional qualitative study utilising focus group methodology.

10.2 **Sampling**

This WP will use the same sites as WP3 (i.e. paediatric oncology, renal, neurology departments and wards, neonatal and paediatric intensive care units, children's hospices). One or two focus groups (depending on number of clinical teams involved) will be held in each Trust (n=~ 6). A further four focus groups will be held for hospice care/bereavement teams (hosted by different hospices and attended by staff from other hospices in the region). In total ~80 staff will participate in this WP.

We will purposively sample to ensure representation of relevant professions (medical, nursing, allied health) as well as setting (e.g. inpatient vs community; clinic/outpatient vs inpatient ward), duration of experience and faith/beliefs.

10.3 **Setting**

Focus groups will be held in hospital or hospice facilities or conducted via video-conferencing (e.g. MS Teams, Zoom).

10.4 **Data collection**

For this WP, in particular, it is important to pre-empt likely constraints on time of focus group participants, and the fact that we wish them to consider topics which may not necessarily have previously been reflected on or articulated. For this reason, a few days prior to a focus group, a brief introductory video (lasting no more than 2 minutes) will be shared with focus group participants which provides clear but succinct information about the objectives of the focus group and topics to be discussed. This video will be re-shown at the start of each focus group.

Topics covered in focus groups will include:

- experiences and observations of needs among patients/parent they care for which are relevant to, or which express the need for spiritual care and support;
- ways in which such needs are responded to;
- any routine practices regarding identification or assessment of such needs;
- perceived role and confidence in identifying and meeting such needs;
- views and practices regarding the inclusion of spiritual care in advance care planning;
- knowledge and understanding of chaplaincy services in relation to the care and support of patients/parents, for themselves, and/or for the clinical team and clinical decision-making;
- practices with respect to use involving chaplaincy services with respect to the care and support of patients/parents, for themselves, and/or for the clinical team and clinical decision-making;
- perceived outcomes of chaplaincy service involvement;
- barriers and facilitators to their involvement.

10.5 **Data analysis**

See Section 11.

11 Data analysis: WP2 – WP4

Audio-recordings of individual interviews and focus groups will be transcribed. For each WP, some data is discrete to that WP, and other data will be one of the sources being used to understand and describe children and young people's, and their parents, spiritual care and support needs.

The approach to data analysis will be thematic,[93] with the constant comparative method (internal/within interview, within a participant group, between participant groups)[94] used to support the analytical process. Throughout we will be careful to explore the nuanced influences of ethnicity and culture on spiritual care and support needs, preferred sources of support and experiences of using chaplaincy services. At the same time, we will not assume that these influences will play a more dominant role than other factors, including socio-demographic characteristics and past experiences. The Framework Method [95, 96] will facilitate systematic data management, data display, and data interpretation and ensure audit trails of the data management process and NVivo software will support the analytical process.

A senior researcher will lead and overview data analysis with respect to a particular study objective(s), with at least one other academic team member closely involved and clinical/practitioner team members actively contributing. We will meet with our parent and young people Advisory Panels at an early stage of the analytical process and again at the stage of drawing conclusions.

11.1 Development of the coding frameworks

A coding framework will be developed through an iterative process of reading, re-reading and comparing transcripts, in which the conceptual clarity and coherence of codes (and higher level themes/concepts), and the comprehensive of the coding framework, will be developed, refined and tested using all relevant data sources.

11.2 Coding, data extraction, data reduction and data synthesis

Once finalised, transcripts will be indexed using the coding framework. Next, indexed data will be extracted (text summaries, verbatim quotes, transcript page number) onto a series of thematic or conceptual matrices, one matrix per theme/concept. Each matrix comprises a series of columns (one column per code within that theme/concept), with the left-hand column carrying information pertaining to relevant participant characteristics. A single row in a matrix holds one participant's data. Thus a row contains all relevant data from a single study participant, and a column contains all data indexed to a specific code. (Multiple sources of data will be extracted into the same matrices).

11.3 Analytical writing and data synthesis

Analytical writings and visual displays[97] will be used describe the data (including where relevant, within and between group comparisons)[94] and to support development of theory/concepts and explanations. Again, this is an iterative and 'self-critical' process, both for the individual leading on the piece of writing and others in the team involved in data analysis. Iterations of analytical writing will be used build and test descriptive accuracy, conceptual coherence and explanatory power.

12 Ethical and regularity compliance

Before WPs 2-4 commence, a favourable opinion will be sought from an HRA REC for the study protocol, consent forms, recruitment materials and other relevant documents. Substantial amendments that require REC review will not be implemented until that review is in place.

13 Dissemination policy

Study findings will be published in academic journals (Open Access) and via practitioner, policy and public facing outputs. Findings will be presented at relevant national and international conferences. A dissemination strategy, detailing key audiences, project outputs and pathways to impact will be developed and signed off by the Study Steering Committee. It will be reviewed at subsequent SSCs. A ‘live’ dissemination log will record dissemination activity.

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15 Appendix 1: Strategies to manage risks associated with WP3

- Researchers will be highly experienced in researching sensitive topics with children and young people (and parents) who are vulnerable. They will be thoroughly trained, including input from young people and parents, and closely supervised by the CI.
- Interviewees can choose to have a companion with them during the interview.
- Clinical teams will only identify children/young person/parents aware of their prognosis. They can choose not to approach particular individuals due to concerns about vulnerability. (We will ask sites to record such decisions). We will explore only recruiting families where advance care planning has taken place. However, the way ACPs are implemented is highly variable so this would have to be considered in a site by site basis.
- We will use text and audio-visual participant information resources – we believe this will support greater understanding of the study and help individuals to discern whether they are ‘ready’ and/or able to take part in a study such as this. Our Advisory Panels will be closely involved in the development of these materials.
- All recruitment information and the consenting process will be clear that the individual can choose what they discuss and when to close the interview.
- Interviews will be structured so that there is a gradual progress to more sensitive topics and then a “lifting” of the interview towards the end by focusing on more concrete and general topics.
- Interviews will be “led” by the study participant in terms of what, and how much, they choose to talk about regarding the interview topic areas, with opening questions on each topic being quite neutral and high level.
- Researchers will be highly attuned and respond to verbal and non-verbal indicators of unease or early signs of upset. This may include steering the conversation to other topics or to a more neutral level, or gently reflecting they are observing unease/distress and asking the interviewee if they would like to pause, change direction, or end the interview.
- At the close of the interview, researchers will check with the interviewee about how they have found the interview and if any concerns raised.
- Evidence from existing research on sensitive topics consistently finds that, when carefully managed using strategies such as those set out above, research participants find benefit in taking part. However, it remains possible that a participant experiences significant distress. In these circumstances, the following approach will be taken:
  i) carefully reassure it is fine not to continue the interview;
  ii) identify with the interviewee preferred strategies to manage distress including available sources of immediate support;
  iii) if required, enable/support the interviewee to make contact/access sources of immediate support;
  iv) rehearse sources of support the interviewee (or parent) can contact in the next day or so (e.g. clinical team, hospice, chaplaincy service, support group, GP, faith community);

v) where agreement in place (e.g. clinical team, chaplaincy service) and interviewee requests, contact service on interviewee's behalf or alert that interviewee will be in touch;
vi) remain with the individual until satisfied distress has (sufficiently) eased;
vii) All such instances will be recorded, and reported and debriefed with the CI.