

Study title: Informing staff support interventions and practices in children's hospices: a mixed methods study

Study team:

Dr Jo Taylor, Department of Health Sciences, University of York (Project Lead)

Professor Bryony Beresford, Social Policy Research Unit, University of York

Dr Jan Aldridge, Martin House Children's Hospice

Dr Lorna Fraser, Department of Health Sciences, University of York

Dr Andrew Papworth, Department of Health Sciences, University of York

Study duration:

18 months (01/01/2019 – 30/06/2020)

1 Study aims and objectives

This study will increase understanding about the work-related stressors and rewards experienced by children's hospice staff, with an aim to identify staff support systems and organisational practices that offer the most potential to prevent staff burnout and enhance wellbeing at work, which is associated with the quality, safety and costs of patient care.^{1,2}

The study has the following objectives:

1. adapt existing measures of paediatric oncology work-related stressors and rewards for use with children's hospice care teams;
2. test the psychometric properties of the adapted measures;
3. describe the work-related stressors and rewards experienced by UK children's hospice care team staff;
4. describe the well-being of UK children's hospice care team staff;
5. map the different ways UK children's hospices support their staff;
6. identify organisational, service delivery, role and employment factors which moderate or mediate the impact of work-related stressors and rewards on staff wellbeing;
7. identify the implications for staff support systems and organisational practices in children's hospices;
8. effectively disseminate the findings and learning from the study.

2 Background and rationale

Concern about the wellbeing of the health and care workforce is widespread.^{3,4} It stems from increasingly robust evidence of relatively high levels of burnout and mental health difficulties among staff, high rates of sickness absence and staff turnover, and an observed association between staff wellbeing and the quality, cost and safety of patient care.^{1,2,5} Evidence on how to prevent these negative outcomes is weak,⁶ and what does exist is limited to particular settings or sections of the workforce.⁷ Although it is recognised that a core set of work-related stressors are found in most workplaces, it is also evident that specific jobs have their own unique challenges and, conversely, rewards.⁸ To inform selection of appropriate interventions for new occupational groups and settings, it is therefore essential to first identify what the distinct factors are that affect staff wellbeing for these.

In the UK, the children's hospice sector has become increasingly concerned about levels of work-related

stress and the need to review and develop staff support systems and practices to enhance staff wellbeing and reduce the risk of occupational burnout.⁹⁻¹¹ Children's hospices are a key provider of paediatric palliative care, supporting children and young people with life-limiting and life-threatening conditions from diagnosis through end of life and their families in bereavement.^{12,13} The important role of the staff working in this specialty has been acknowledged in numerous reviews and guidelines internationally,¹⁴⁻¹⁷ and educational standards and staff competencies are now being developed.¹⁸ However, relatively little consideration has been paid to the specific challenges of the work, and studies highlight the limited organisational and emotional support available for staff.^{9,19}

There are some suggestions in the literature that children's hospice staff may experience lower levels of stress and burnout when compared to those working in similar settings.¹⁹ However, there is no robust evidence about levels of burnout in children's hospice staff and little understanding of what the key work-related stressors are or what works to modify these for staff working in this important setting.¹⁹⁻²¹ Our own (JT and JA) case study in one children's hospice identified a range of potential stressors relating to the direct work of caring for children and their families, team functioning, organizational factors, and individual circumstances.^{10,20} This study also found that many staff were worried about their wellbeing but did not always feel confident to discuss this at work. All participants in the study valued the informal support from colleagues and the provision offered by the organisation; however, opportunities for this were limited and many staff identified unmet needs for support.

The results of our earlier study have been shared widely with other children's hospices in the UK,^{22,23} and they too expressed concerns about staff wellbeing and the limited evidence base from which to develop effective staff support systems and improve organisational practices. Workforce issues have previously been identified as a research priority, and again emerged as a key area for research in the research prioritisation exercise conducted by the Martin House Research Centre.²⁴ This study aims to address this gap in evidence by examining the wellbeing of children's hospice staff and understanding the work-related stressors and rewards they experience in order to identify organisational, role and employment factors, which may moderate or mediate the impact of work-related stressors and rewards on staff wellbeing. The study is underpinned by an organisational model of occupational stress that recognizes the interplay between role, employment and organisational factors in contributing to work-related stress and staff wellbeing.²⁵⁻²⁷ Knowledge generated from this study will provide an important evidence base from which to identify staff support systems and organisational practices that offer the greatest potential to improve staff wellbeing in children's hospices and its associated outcomes.

3 Methods

To conduct this study we will adapt scales developed by the University of York (co-applicant BB) for measuring work-related stressors (WSS-PO) and rewards (WRS-PO) (see Appendix A and B respectively) and validated in paediatric oncology multi-disciplinary teams.^{8,28} These are self-report measures of the frequency and intensity of stressors/rewards experienced by an individual during the previous 6 months. The scales include items that are recognised as potential stressors and rewards across many occupational settings as well as items that are specific to working with children and young people who are seriously ill. Although paediatric oncology has a pathway that is focused primarily on remission and cure²⁹ there are many similarities with paediatric palliative care and the stressors and rewards experienced by staff.^{20,28} In the children's hospice case study we assessed the feasibility of adapting the scales for care team staff; the scales were reported as acceptable and relevant, and feedback from staff using focus groups and written

comments showed that minimal revisions to the validated scales are required.¹⁰

For this study we will use a mixed methods exploratory design³⁰ comprising two phases:

Phase one – A literature review to identify role and organizational characteristics that influence staff wellbeing and a qualitative study with children’s hospice care team staff to develop and refine work-related stressors and rewards scales for children’s hospice settings

Phase two – Cross-sectional survey of children’s hospices and care team staff in the UK to examine work-related stressors and rewards, identify role and organisational factors that mediate or moderate the impact of these on staff wellbeing, and explore provision of staff support.

3.1 Study population

The WSS-PO and WRS-PO were developed for the paediatric oncology multi-disciplinary team. Although children’s hospice settings are likely to have some characteristics that are different to paediatric oncology settings, the intensity and nature of the work, and team-based approach to caring for children and their families is similar.¹⁹ We will therefore include all employed members of the care team regardless of their professional or occupational background (e.g. clinicians, nurses, allied health professionals, nursery nurses and those without a specific occupation or profession) as long as their main role is to provide direct care to children and their families.

3.2 Phase one

In phase one we will:

- i. conduct a literature review to identify role and organisational characteristics that may influence exposure to and/or the impact of exposure to work-related stressors and rewards;
- ii. adapt the WSS-PO and WRS-PO for use in children’s hospice settings using the approach taken in other research that has adapted scales for different settings and populations.^{10,20,31}

3.2.1 Rapid review of literature

The aim of the review is to identify job role (e.g. community/hospice-based, clinical/non-clinical), staffing (e.g. numbers, team structure) and organisational (e.g. service provision, size, management, support structures) characteristics which have been identified as being associated with staff well-being and/or reported levels of exposure to work-related stressors or rewards. Findings of the review will inform the purposive sampling strategy in the phase one qualitative study and selection of items to include in the phase two observational survey, and will also help to contextualise the main study results.

We will use rapid review techniques to ensure we identify the most relevant studies and extract data from which to identify key characteristics. This will include relying on existing systematic reviews as the main source of evidence, narrowing the timeframe for article inclusion, limiting dual review for study selection and extraction, and eliminating formal quality appraisal.³²⁻³⁴

Search strategy: We will conduct searches of the academic literature in Medline, PsycINFO and CINAHL to identify systematic reviews that:

- 1) focus on the topic of staff wellbeing, engagement, stress, burnout and support;

- 2) relate to settings that provide palliative care to children and/or adults (e.g. intensive care, oncology, hospices, community nursing teams, neonatal units);
- 3) identify role, staffing and/or organisational characteristics that influence exposure to and/or the impact of exposure to work-related stressors and rewards.

We recognise that systematic reviews on this topic may be limited. We will therefore also conduct a targeted search of the grey literature (through web searches) and consult with clinical and research experts in palliative care to identify key studies which are specific to children's hospice settings.

We will only include studies /reviews published from 2000 onwards, carried out in developed countries (using OECD membership³⁵ to determine inclusion).

Screening: One reviewer will screen the search results, first by title and abstract to remove studies that are not relevant and then by full text to identify eligible studies. Uncertainties will be discussed with a second reviewer, and a second reviewer will also assess all studies identified as eligible to ensure they meet the inclusion criteria.

Data extraction and synthesis: The role and organisational characteristics identified in each study will be extracted into Excel along with the study ID, year of publication, study aim, population and setting to provide contextual information about their relevance to the children's hospice setting. Using data displays, the study team will assess the relevance of each characteristic for the children's hospice setting and remove items that the whole team agree are not relevant. The study team will work together to merge the remaining similar and overlapping characteristics, and to group characteristics into overarching categories.

3.2.2 Adaptation of the WSS-PO and WRS-PO

Using an iterative approach involving input from children's hospice staff at each step we will:

- i. develop draft versions of the Work-related Stressors Scale-Children's Hospices (WSS-CH) and Work-Related Rewards Scale-Children's Hospices (WRS-CH);
- ii. assess the content validity and acceptability of items in the draft WSS-CH and WRS-CH and identify new items that are missing from the scales;
- iii. refine the draft WSS-CH and WRS-CH and assess the content validity of amended and new items;
- iv. conduct initial testing of the new scales using cognitive interviews.

3.2.2.1 – Develop draft versions of the WSS-CH and WRS-CH (version 1)

Drawing on feedback from the original case study which examined the acceptability and appropriateness of the WSS-PO and WRS-PO for children's hospice staff,¹⁰ we will develop draft CH scales which include all items from the validated oncology scales but with wording appropriate to the setting (e.g. replacing patient with child; using care team rather than multidisciplinary team).

3.2.2.2 – Assess content validity of WSS-CH and WRS-CH version 1

The WSS-PO and WRS-PO contain 60 and 35 items respectively.⁸ In order to obtain feedback on the relevance of all items to the children's hospice setting and the comprehensiveness of the item list, we will use survey methods and invite care team staff to provide individual feedback on the draft CH scales. Children's hospices will be selected for participation in phase one according to key characteristics

identified in 3.2.1. We expect that six hospices will be required to ensure sufficient variation in these characteristics is achieved. All care team staff will be invited to take part in each setting.

Participants will be asked to rate the relevance of each item for staff working as part of a care team in a children's hospice, and asked to add important missing items. The draft CH scales will be presented using the same format as the WSS-PO and WRS-PO and the original scales' response options (*how often* and *how rewarding*) will be changed to allow an assessment of relevance (*relevant; relevant but needs re-wording; not relevant*). Space for new items will be added. Participants will have the option of completing this task online (in Qualtrics³⁶) or on paper to maximise response rates. Each participant will be asked (after completing the task) if they wish to take part in a focus group or follow-up interview for steps 3.2.2.2 and 3.2.2.3 below.

Responses from 3.2.2.2 will be aggregated for all participants (% relevant; % not relevant) to investigate relevance across all members of the care team, and with respect to two broad subgroups based on whether the staff provide medical and/or nursing care:

- i. Clinical (consultants, GPs, paediatricians, registered nurses)
- ii. Non-clinical (allied health professionals, nursery nurses, psychologists, other)

A content analysis of new items proposed by participants will be carried out to identify distinct stressors and rewards that are not represented in the draft scales.³⁷

We will remove items that ALL participants in each staff group rate as not relevant; re-word relevant items that the majority (more than 50%) of participants believe require this; and draft new items based on the content analysis above.

3.2.2.3 Assess content validity and comprehensiveness of WSS-CH and WRS-CH version 2

We will conduct a series of focus groups³⁸ (3-6 in total) with children's hospice care team staff to refine version 2 of the WSS-CH and WRS-CH. These will focus on assessing and refining content validity of re-worded and new items, and identifying any further missing items to ensure comprehensiveness of the measures.

Two focus groups will initially be conducted in different participating hospices, each consisting of 6-8 participants reflecting the diversity of the care team where possible. The draft measures will be provided to focus group participants in advance and participants will be asked to discuss the relevance and meaning of new and re-worded items, and to identify stressors and rewards that they agree are not represented in the measures.

Focus groups will be audio recorded, transcribed intelligent verbatim by a professional transcription company and anonymised for analysis. Content analysis will be conducted to identify distinct stressors and rewards that are not already included in the draft scales, and to revise wording of new or re-worded items.³⁷ The results will be used to refine the draft WSS-CH and WRS-CH.

Additional focus groups (with participants from a different hospice) will be conducted to discuss wording of new and revised items and assess comprehensiveness until no further revisions and additions are required.

3.2.2.4 Assess content validity and comprehension of WSS-CH and WRS-CH version 3

Cognitive interviews with up to 10 participants, and representing all staff groups, will be conducted and audio-recorded using the ‘think-aloud’ technique and concurrent verbal probing to confirm that the existing response format is appropriate and make a final assessment of content validity, comprehension and acceptability of the adapted measures.³⁹ After five interviews, audio data will be transcribed and extracted into a participant-by-item matrix using directed content analysis.³⁷ This will be synthesised into a further matrix summarising key findings across participants for each item to inform any final refinements of the WSS-CH and WRS-CH.

The remaining interviews will test the refined scales, and data saturation will be monitored to determine final sample size (i.e., where no new feedback is obtained from subsequent participants data collection will stop).⁴⁰ The analytical process will be repeated for the second phase of interviews (if required) to identify any final refinements of the WSS-CH and WRS-CH.

3.2.3 Exploring role, staffing and organizational characteristics

To supplement the review findings (section 3.2.1), focus group participants (section 3.2.2.3) will also discuss role, staffing and organisational characteristics that they think influence exposure to and impact of work-related stressors and rewards. Findings (from the content analysis) will be assimilated into the list of characteristics developed in 3.2.1. This information will be used inform decisions regarding what data is collected on organisational and staff characteristics in phase two.

3.3 Phase Two – Cross-sectional survey of children’s hospice staff

In phase two we will conduct a cross-sectional observational survey of children’s hospice care team staff in the UK to:

- 1) examine work-related stressors and rewards and staff wellbeing;
- 2) identify organisational and individual characteristics that mediate or moderate exposure to or the impact of these factors on staff wellbeing and associated outcomes;
- 3) collect information about staff support provision in children’s hospices.

3.3.1 Sample

All children’s hospices in the UK will be invited to take part in phase two, which for this study we are defining as those organisations that are categorised as a children’s hospice and provide direct care and support to children with life-limiting and life-threatening conditions and their families. Together for Short Lives identifies 53 children’s hospice services in the UK.⁴¹ Recent studies show that these vary significantly in the services that are offered, the number and composition of staff, and the children and young people supported.^{42,43}

All care team staff (as defined in section 3.1) in participating children’s hospices will be invited to take part in the staff survey. The latest mapping of children’s hospices carried out in 2011/2012 identified 1632 whole-time equivalent direct care team staff working in the 43 hospices taking part.⁴³ Based on NHS workforce statistics the total headcount is likely to be around 15% higher than this.⁴⁴ Taking into account the increased number of children’s hospices since 2012, the study population is likely to be around 2000.

Based on earlier work in this area and preliminary consultation with local children’s hospices, we estimate

that around 30 organisations are likely to participate in this research, and we hope to achieve a response rate of around 65-70% in the staff survey.^{8,10,45} This would yield a minimum sample size of approximately 750 participants. This is more than sufficient to conduct the validation study,^{8,46} and will enable us to include multiple variables (i.e. job role, organisational and individual characteristics) in the regression analyses, including those that may be important but less frequently observed.^{47,48}

Although a smaller sample would be sufficient and allow some exploration of the relationship between organisational characteristics and exposure to / impact of stressors and rewards and wellbeing, the aim of this study is provide the children's hospice sector with evidence to inform the development and/or modification of staff support structures and organisational practices. To maximise the potential impact of the study for improving staff wellbeing and associated outcomes (e.g. quality, safety and cost of patient care), it is important that we offer all children's hospices an opportunity to participate in this research, and we will aim to produce individual reports for participating hospices on their own organisation in addition to reporting the main study findings. This approach offers significant value for money (the cost of including more hospices is minimal) and enhances our pathways to impact for the study.

3.3.2 The survey of senior representatives

A questionnaire (the Children's Hospice Organisation and Management (CHOM) questionnaire) will be developed to collect information about hospice organisational and staffing characteristics, and staff support strategies and practices. Content will be informed by the phase one literature review and focus groups, and developed in consultation with the Martin House Research Centre team and project advisory board (see Section 9). The questionnaire will also be piloted with two to three hospices and modified according to feedback received. A senior representative will be identified in each participating hospice to complete this questionnaire, either online or via a structured telephone interview. This person will also act as study lead for the hospice.

3.3.3 The survey of care team staff

A survey of care team staff will comprise a suite of questionnaires collecting the following data (the final selection of measures and content of study-specific questions will be informed by phase one findings and potential participant burden):

- a) demographic, role and employment information;
- b) work-related stressors and rewards using the WSS-CH and WRS-CH;
- c) participants' access to and uptake of staff support provision;
- d) burnout: the Copenhagen Burnout Inventory will be used. This is a 19-item scale with items rated on a 5-point scale, assessing three aspects of burnout – personal, work-related and client-related.⁴⁹
This measure is recommended over the more commonly used Maslach Burnout Inventory,⁵⁰ which has been subject to a number of methodological criticisms and is only commercially available, therefore having implications for the feasibility of hospices conducting any future evaluation of staff support structures that are developed;⁵¹
- e) engagement: we will use two questions from the National NHS Staff Survey 2017⁵² that measure job satisfaction (8 items rated on a 5-point scale from 1 (*very dissatisfied*) to 5 (*very satisfied*)) and job motivation (3 items rated on a 5-point scale from 1 (*never*) to 5 (*always*));

- f) intention to leave: a measure of Intention to Quit⁵³ will be used which comprises two questions 1) how often do you think about leaving the job? rated on a 5-point scale from 1 (*rarely or never*) to 5 (*very often*) and 2) how likely are you to look for a new job within the next year? rated on a 5-point scale from 1 (*very unlikely*) to 5 (*very likely*);
- g) management standards: the UK's Health & Safety Executive (HSE) management standards indicator tool^{54,55} will be used to provide an indication of how staff believe that the organisation they work for is managing the risks associated with work-related stress. The HSE tool is a 35-item measure with items rated on a 5-point scale.

The questionnaire will be piloted with 5-10 children's hospice care team staff. Feedback on participant burden, format and acceptability of measures will be used to refine the questionnaire.

Staff will be invited to take part in the survey jointly by the participating organisation and the research team. A participant information sheet will be provided to explain the voluntary nature of participation and the confidentiality and anonymity afforded to participants.

To maximise response rates, we will incentivise staff using a prize draw with several prizes offered to reflect the size of the sample (e.g. tablets, high street vouchers). We will also produce a short video for participating hospices to promote the study, ask hospices to display posters and leaflets in shared staff areas and using staff pigeon holes, and recruit a staff champion who is a member of the care team in each participating hospice (where possible) to engage colleagues in the study.

The survey will be available to complete online or on paper. The online survey will be designed and administered using Qualtrics, a secure web-based survey platform. Paper questionnaires will be returned direct to the research team using pre-paid envelopes. Completed paper questionnaires will be entered into Qualtrics in preparation for analysis. The complete survey data will be downloaded into Excel and cleaned in preparation for analysis.

3.3.4 Data analysis

For each participating hospice, eligibility, recruitment and response rates will be reported. The analysis will progress in several stages with different foci aligned with research objectives 2 to 6. In all analyses descriptive statistics will be presented for continuous (Mean, Median, SD) and categorical (category frequencies) variables, according to STROBE guidelines.⁵⁶ Missing data will be reported as a separate category for descriptive analyses. Data inclusion/ exclusion will be presented with flow charts and the final strategy to deal with missing data will depend on their pattern and amount.

A more detailed statistical analysis plan will be produced during the design of the phase two survey (i.e., when the study variables have been selected) to ensure that a priori hypotheses can be tested and appropriate statistical tests are used to explore associations and relationships between categorical and continuous variables. An overview of the plans for analysis is provided below:

3.3.4.1 Study objective 2

Exploratory factor analysis will be used to determine whether the dimensionality of the scales are the same as the WSS-PO and WRS-PO, and to identify item sets to take forward for psychometric testing. Rasch analysis will be used to assess the validity and reliability of the WSS-CH and WRS-CH, following the process used to validate the WSS-PO and WRS-PO.^{8,57}

3.3.4.2 Study objectives 3-5

Descriptive statistics will be used to describe the work-related stressors and rewards and well-being of UK children's hospice care team staff (as a whole and by subgroups, e.g. clinical, non-clinical), and to identify the different ways children's hospices support their staff.

These statistics will also be produced for each participating hospice for the purpose of targeted dissemination (see section 7 Dissemination).

3.3.4.3 Study objective 6

Multiple regression models will assess the relationships between individual (e.g. role, demographics) and organizational characteristics (e.g. size, care team structure), work-related stressors and rewards, and wellbeing and associated outcomes; and to identify role, staffing and organizational factors that mediate or moderate exposure to and the impact of work-related stressors and rewards.

4 Ethical considerations

We will obtain ethical approval for the study from the University of York's Department of Health Sciences Research Governance Committee. For this study, specific consideration will be given to the process of informed consent, confidentiality and anonymity, dissemination of findings, and participant burnout.

Informed consent: We will gain overall permission to conduct the study from a senior representative of participating children's hospices, and in doing so, gain access to their staff. Therefore, to ensure that staff do not feel pressured to take part they will be invited in writing jointly by the research team and the organisation, and provided with comprehensive information about the study, why it is being carried out, and how their information will be used.

Confidentiality and anonymity: To maintain anonymity, a generic link to the survey will be provided to all staff and paper questionnaires will be placed in shared staff areas with prepaid envelopes to be returned directly to the research team. No personal details about participants will be collected and role characteristics will be grouped in all reports to ensure individuals cannot be identified.

The personal details of participants in phase one and all study data will be stored securely on the University of York servers and will only be accessed by the study team. Participants' personal details will be deleted at the end of the study period because it is not required during the reporting and dissemination phase. Study data will be kept for 10 years in line with University requirements.

Dissemination of findings: All participating children's hospices and their staff will be provided with summary findings of the overall study. Each participating hospice will also be provided with a summary report which presents some of the findings for their own organisation to inform the development/modification of staff support structures and organisational practices. We will aim to ensure that the level and type of information shared about individual organisations is appropriate and (where possible) this is shared with the team in addition to senior management. We will work closely with the study lead in each participating hospice to negotiate this.

Participant burnout: It is likely that a small number of care team participants may be experiencing high levels of burnout, which cannot be followed up in the study because of the anonymous nature of the staff questionnaire. To ensure that support is available, participant information sheets will be localised for each

hospice to include the name and contact details of an appropriate individual (e.g. psychologist, care team manager, human resources manager) who individuals will be able to contact in confidence.

5 Public involvement

We will collaborate with Together for Short Lives and consult regularly with the children's hospice sector and its staff to ensure that the knowledge we produce can be used by children's hospices to improve staff wellbeing and its associated outcomes. This will include, for example, obtaining feedback on the phase two survey before administering it, consulting with hospice study leads and champions on the study findings, and working with participating children's hospices to ensure that the summary reports we produce contain the right level and detail of information to inform future practice.

We will also consult with the Martin House Research Centre Family Advisory Board, which has 15 parent members, and meets three times each year to provide input and ideas for the Centre and its research. Although children and their families are not direct beneficiaries or participants of the research, we will work with FAB members to ensure that the summary findings we produce are accessible and shared with relevant service user groups/ organisations in addition to participating hospices.

6 Planned outputs

- Academic paper reporting adaptation and validation of CH stressors and rewards scales;
- Academic paper reporting results of observational study;
- Academic paper reporting key findings and implications for staff support systems and organisational practices;
- Study summary of key findings and implications for practice for children's hospices and other relevant stakeholders;
- Summary reports for participating hospices to inform their own development of staff support structures and organisational practices.

7 Dissemination and impact

We will disseminate outputs to likely beneficiaries (direct and indirect) of the research, including:

- children's hospice organisations and their staff both in the UK and internationally;
- NHS and non-NHS settings that provide palliative care to children and young people and their families;
- organisations responsible for standards of training of professionals who work with this population;
- children, young people and their families who have prioritised supporting staff as an important area for research;
- organisations that represent the sector (e.g. Together for Short Lives, Hospice UK);
- NICE guideline development group;
- NHS England;
- Royal College of Paediatrics and Child Health;
- the research community.

We will develop innovative strategies for different audiences using formats they are most likely to engage with, supported by the wider Martin House Research Centre (MHRC) team and parent advisory panel. We expect to use a combination of written reports (including academic and clinical articles, summary findings), oral presentations, professional networks, websites, and social media. We will also work in partnership with Together for Short Lives and Hospice UK to ensure effective dissemination of the key findings from the study.

Each participating hospice will receive a confidential summary report describing the stressors and rewards experienced by their staff and levels of staff wellbeing. To maximize the utility of this output to inform future practice, these will be presented alongside key findings from the main analysis about the role, staffing and organisational characteristics that are associated with work-related stress and staff wellbeing for children's hospice staff.

To maximize the potential impact of the study findings for the children's hospice sector we will consult with hospice study leads and champions to help with interpretation of study findings and inform the format and content of study outputs intended for participating organisations. If appropriate, we will seek additional external funding to produce a web-based implementation and evaluation tool for children's hospices and other similar organisations. We will design this in collaboration with the hospice sector and the organisations that represent hospices and their staff. We will also make available the measures and questionnaires developed for the study as well as key findings to inform the development and subsequent evaluation of staff support structures and organisational practices.

8 Study team and management

Dr Jo Taylor (JT) will lead the project, supported by Professor Bryony Beresford (BB), Dr Lorna Fraser (LF) and Dr Jan Aldridge (JA) all of the Martin House Research Centre, and Dr Jan Boehnke (JB) of Dundee University. Dr Andrew Papworth, a research fellow, has been appointed to work on the project under the supervision of JT, to assist with literature reviewing, development of the CH scales, designing and administering the survey, and cleaning and preparing data for analysis.

Jo Taylor is a mixed methods researcher with experience of conducting research in the area of paediatric palliative care for 11 years, and led the earlier case study exploring stressors and rewards in one children's hospice, working with Jan Aldridge.^{10,20} Bryony Beresford brings significant expertise in paediatric palliative care research and qualitative methods, and led the earlier work in paediatric oncology.^{8,25,40} Bryony will contribute to the scale development and survey design, and assist with fieldwork and analysis where required. Lorna Fraser is an epidemiologist with a background in clinical paediatrics and brings paediatric palliative care and statistical expertise to the project. Lorna will oversee the phase two analysis. Jan Boehnke is a psychologist by background and brings expertise in scale development and psychometrics, and has kindly offered to provide psychometric support to Jo for the validation analysis in phase two. Jan Aldridge is a clinical psychologist at Martin House and has been instrumental in pushing forward the agenda for supporting children's hospice staff. Jan will bring topic and clinical expertise and experience of implementing staff support structures in a children's hospice setting. Andrew Papworth is a mixed methods researcher with experience of conducting research with NHS staff.

JT will be responsible for the project's timely completion, the quality of the work, adherence to ethical standards, and effective dissemination and impact. JT will meet with BB, LF and JT monthly, although

frequency of meetings will be driven by the needs/stage of the study and will vary over its duration. JT will seek input from JB as and when needed during the project.

The Centre's Management Committee will review project progress (including budget profiling) when it meets (every two months). The Centre's Advisory Board (which includes several children's hospice representatives holding different positions and research experts in palliative care) will act as the Project Advisory Board and provide independent oversight. A report on progress will be given at the bi-annual meetings of the Centre's Advisory Board and meetings will also be used to discuss the project and gain expert input when required. A report on progress and spend against budget will also be reviewed by the Centre's Partnership Committee (jointly occupied by representatives from Martin House and the University of York).

9 Project timeline

Phase 1 – Development and testing of children's hospice (CH) scales

Months 1 to 3

Scope children's hospice literature to identify characteristics to sample for in phase 1 Ethics approval (University of York)

Promote study to children's hospice sector and recruit hospices for phase 1

Months 4 to 9

Feedback from individual staff on scales and development of draft CH (months 4-5) Focus groups with staff and refinements of CH scales (month 6-7)

Cognitive interviews and final refinements of CH scales (months 7-8)

Phase 2 – Cross-sectional (observational) study of children's hospice staff

Months 8 to 10

Recruit children's hospices to the study

Collect organisational data from participating hospices

Develop and pilot staff survey

Months 11 to 13

Administer staff survey and clean data

Months 14 to 18

Validation of CH scales (month 14)

Descriptive and regression analysis of study data (month 15)

Study write-up and dissemination (months 16-18)

See Appendix C (page 21) for detailed project Gantt Chart.

10 Reference List

1. Dawson J, West M. Employee engagement, sickness absence and agency spend in NHS trusts. Leeds: NHS England, 2018.
2. Hall LH, Johnson J, Watt I, Tsipa A, et al. Healthcare Staff Wellbeing, Burnout, and Patient Safety: A Systematic Review. *PLOS ONE* 2016; **11**(7): e0159015.
3. Sizmur S, Raleigh V. The risks to care quality and staff wellbeing of an NHS system under pressure Oxford: Picker Institute Europe, 2018.
4. NHS England. Next steps on the NHS Five Year Forward View - Strengthening our workforce. 2018. <https://www.england.nhs.uk/five-year-forward-view/next-steps-on-the-nhs-five-year-forward-view/strengthening-our-workforce/> (accessed 22/04/2018).
5. Dawson J, West M. Employee engagement and NHS performance. London: The King's Fund, 2012.
6. NHS Employers. Evaluating health & wellbeing interventions for healthcare staff: Key findings. Nottingham: Zeal Solutions, 2014.
7. Ahola K, Toppinen-Tanner S, Seppänen J. Interventions to alleviate burnout symptoms and to support return to work among employees with burnout: Systematic review and meta-analysis. *Burnout Research* 2017; **4**: 1-11.
8. Mukherjee S, Beresford B, Tennant A. Staff burnout in paediatric oncology: new tools to facilitate the development and evaluation of effective interventions. *Eur J Cancer Care* 2014; **23**(4): 450-61.
9. Goodrich J, Harrison T, Cornwell J. Resilience: A framework supporting hospice staff to flourish in stressful times. London: Hospice UK; 2015.
10. Nicholson J, Aldridge J. Exploring the Support and Development Needs of Children's Hospice Staff - A Case Study. York: J N Research, 2012.
11. Hospice UK. Transforming hospice care: A five-year strategy for the hospice movement 2017 to 2022. London: Hospice UK, 2017.
12. World Health Organization. WHO Definition of Palliative Care for Children. 2017. <http://www.who.int/cancer/palliative/definition/en/> (accessed 10/05/2017).
13. Knapp C, Woodworth L, Wright M, Downing J, et al. Pediatric palliative care provision around the world: a systematic review. *Pediatr Blood Cancer* 2011; **57**(3): 361-8.
14. Craft A, Killen S. Palliative Care Services for children and young people in England. An Independent review for the Secretary of State. London: Department of Health; 2007.
15. Steering Committee of the EAPC task force on palliative care for children and adolescents. IMPaCCT: standards for paediatric palliative care in Europe. *Eur J Pall Care* 2007; **14**(3): 109-14.
16. Scottish Children and Young People's Palliative Care Executive Group. A Framework for the Delivery of Palliative Care for Children and Young People in Scotland. 2012. <http://www.gov.scot/resource/0040/00408254.pdf> (accessed 27/10/2017).
17. National Hospice and Palliative Care Organization. Standards of Practice for Pediatric Palliative Care and Hospice. Alexandria, Virginia: National Hospice and Palliative Care Organization; 2009.
18. Downing J, Ling J, Benini F, Payne S, et al. Core competencies for education in Paediatric Palliative Care. Milano, Italia: European Association for Palliative Care; 2013.
19. McConnell T, Scott D, Porter S. Healthcare staff 's experience in providing end-of-life care to children: A mixed-method review. *Palliat Med* 2016; **30**(10): 905-19.
20. Taylor J, Aldridge J. Exploring the rewards and challenges of paediatric palliative care work - a qualitative study of a multi-disciplinary children's hospice care team. *BMC Palliat Care* 2017; **16**(1): 73.
21. McConnell T, Porter S. The experience of providing end of life care at a children's hospice: a qualitative study. *BMC Palliat Care* 2017; **16**(1): 15.
22. Aldridge J, Taylor J. Hospice staff: well-being at work. Hospice UK Annual National Conference. Liverpool, England; 2015.
23. Aldridge J, Nicholson J. Exploring the Rewards and Stressors of Working in Paediatric Palliative Care 6th International Conference on Paediatric Palliative Care. Cardiff, Wales; 2012.
24. Booth A, Maddison J, Wright K, Fraser L, et al. Research prioritisation exercises related to the

care of children and young people with life-limiting conditions their parents and all those who care for them: a systematic scoping review. *Palliat Med* UNDER SUBMISSION.

25. Sharma SS. Model of organizational stress for use within an occupational health education/promotion or well-being of members of the organization. *Ind Psychiatry J* 2009; **18**(2): 135-6.
26. Sharma J, Devi A. Individual Differences and Stress at Workplace. *Asia Pacific Business Review* 2011; **7**(3): 198-207.
27. Marcatto F, Colautti L, Larese Filon F, Luis O, et al. The HSE Management Standards Indicator Tool: concurrent and construct validity. *Occup Med (Lond)* 2014; **64**(5): 365-71.
28. Mukherjee S, Beresford B, Glaser A, Sloper P. Burnout, psychiatric morbidity, and work-related sources of stress in paediatric oncology staff: a review of the literature. *Psychooncology* 2009; **18**(10): 1019-28.
29. Harris MB. Palliative care in children with cancer: which child and when? *J Natl Cancer Inst Monogr* 2004; **32**(32): 144-9.
30. Creswell JW. *Designing and Conducting Mixed Methods Research*. Thousand Oaks, California: SAGE; 2007.
31. Ellis-Smith C, Evans CJ, Murtagh FE, Henson LA, et al. Development of a caregiver-reported measure to support systematic assessment of people with dementia in long-term care: The Integrated Palliative care Outcome Scale for Dementia. *Palliat Med* 2017; **31**(7): 651-60.
32. Ganann R, Ciliska D, Thomas H. Expediting systematic reviews: methods and implications of rapid reviews. *Implement Sci* 2010; **5**(1): 56.
33. Tricco AC, Antony J, Zarin W, Strifler L, et al. A scoping review of rapid review methods. *BMC Med* 2015; **13**: 224.
34. Haby MM, Chapman E, Clark R, Barreto J, et al. What are the best methodologies for rapid reviews of the research evidence for evidence-informed decision making in health policy and practice: a rapid review. *Health Res Policy Syst* 2016; **14**(1): 83.
35. Organisation for Economic Co-operation and Development (OECD). Members and partners. 2017. <http://www.oecd.org/about/membersandpartners/> (accessed 08/05/2017).
36. Qualtrics. Qualtrics Research Suite. 2016. <https://www.qualtrics.com/research-suite/> (accessed 25 May 2016).
37. Hsieh HF, Shannon SE. Three approaches to qualitative content analysis. *Qual Health Res* 2005; **15**(9): 1277-88.
38. Morgan DL. *Focus Groups as Qualitative Research*. 2nd ed. Thousand Oaks, CA: SAGE; 1997.
39. Peterson CH, Peterson NA, Powell KG. Cognitive Interviewing for Item Development: Validity Evidence Based on Content and Response Processes. *Measurement and Evaluation in Counseling and Development* 2017; **50**(4): 217-23.
40. Francis JJ, Johnston M, Robertson C, Glidewell L, et al. What is an adequate sample size? Operationalising data saturation for theory-based interview studies. *Psychol Health* 2010; **25**(10): 1229-45.
41. Together for Short Lives. Children's Hospice Services. 2018. <http://www.togetherforshortlives.org.uk/wp-content/uploads/2018/01/FamRes-Childrens-Hospice-Services-Factsheet.pdf> (accessed 23/03/2018).
42. Hunt A, Coad J, West E, Hex N, et al. The Big Study for Life-limited Children and their Families: Final research report. Bristol: Together for Short Lives; 2013.
43. Devanney C, Bradley S, Together for Short Lives. Count Me In: Children's Hospice Service Provision 2011/12. Durham: Durham University School of Applied Social Sciences, 2012.
44. NHS Digital. NHS Workforce Statistics. 2018. <https://digital.nhs.uk/data-and-information/publications/statistical/nhs-workforce-statistics> (accessed 04/04/2018).
45. Beresford B, Gibson F, Bayliss J, Mukherjee S. Preventing work-related stress among staff working in children's cancer Principal Treatment Centres in the UK: a brief survey of staff support systems and practices. *Eur J Cancer Care (Engl)* 2018; **27**(2): e12535.
46. Guilleux A, Blanchin M, Hardouin JB, Sebille V. Power and sample size determination in the Rasch model: evaluation of the robustness of a numerical method to non-normality of the latent trait. *PLOS ONE* 2014; **9**(1): e83652.

47. Bowden MJ, Mukherjee S, Williams LK, DeGraves S, et al. Work-related stress and reward: an Australian study of multidisciplinary pediatric oncology healthcare providers. *Psychooncology* 2015; **24**(11): 1432-8.
48. Knofczynski GT, Mundfrom D. Sample sizes when using multiple linear regression for prediction. *Educational and Psychological Measurement* 2008; **68**(3): 431-42.
49. Kristensen TS, Borritz M, Villadsen E, Christensen KB. The Copenhagen Burnout Inventory: A new tool for the assessment of burnout. *Work and Stress* 2005; **19**(3): 192-207.
50. Maslach C, Jackson SE. Maslach Burnout Inventory Manual. 3rd ed. Mountain View, CA: Consulting Psychologists Press Inc.; 1996.
51. Chambers CN, Frampton CM, Barclay M, McKee M. Burnout prevalence in New Zealand's public hospital senior medical workforce: a cross-sectional mixed methods study. *BMJ Open* 2016; **6**(11): e013947.
52. NHS. National NHS Staff Survey 2017. 2017. http://www.nhsstaffsurveys.com/Caches/Files/ST17_Core%20Questionnaire_v2.pdf (accessed 20/04/2018).
53. Karantzas GC, Mellor D, McCabe MP, Davison TE, et al. Intentions to quit work among care staff working in the aged care sector. *Gerontologist* 2012; **52**(4): 506-16.
54. Brookes K, Limbert C, Deacy C, O'Reilly A, et al. Systematic review: work-related stress and the HSE management standards. *Occup Med (Lond)* 2013; **63**(7): 463-72.
55. Cousins R, MacKay CJ, Clarke SD, Kelly C, et al. 'Management Standards' work-related stress in the UK: practical development. *Work & Stress* 2004; **18**(2): 113-36.
56. von Elm E, Altman DG, Egger M, Pocock SJ, et al. The Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) statement: guidelines for reporting observational studies. *Lancet* 2007; **370**(9596): 1453-7.
57. Tennant A, Conaghan PG. The Rasch measurement model in rheumatology: what is it and why use it? When should it be applied, and what should one look for in a Rasch paper? *Arthritis Rheum* 2007; **57**(8): 1358-62.

APPENDIX A:**The Work Stressors Scale - Paediatric Oncology (WSS-PO)**

This scale looks at situations and events which paediatric oncology staff report encountering at work.

For each statement please tick [✓] the box (on the left) that best describes how often you have encountered this situation or event during the past 6 months. **Then** tell us how stressful this has been for you by ticking [✓] 'Not at all', 'A little' or 'A lot' (on the right).

How often have you encountered this situation?			During the past 6 months:			How stressful have you found this?			
Rarely	Sometimes	Often		Not at all	A little	A lot			
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Working in an environment where there's lots of stress, sadness, and anxiety	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>			
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Having to answer parents' questions during the end of life stage	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>			
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Other members of the multi-disciplinary team not responding to my requests for help	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>			
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Other staff being quick to find fault with me	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>			
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Talking to children about distressing subjects	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>			
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Feeling my skills are not recognised	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>			
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Watching a child deteriorate day-by-day	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>			
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	A parent getting upset	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>			
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Other departments not prioritising our patients	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>			
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	When a child deteriorates very quickly	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>			
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Containing my emotions after the death of a child	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>			
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Supporting the family after the death of their child	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>			
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Dealing with a lot of deaths in a short space of time	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>			
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Families becoming dependent on me	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>			
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Not feeling sure how much parents have understood what I've told them	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>			
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Not knowing after a child dies whether we chose the wrong approach	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>			
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Working to targets set by managers	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>			
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	A parent not letting me talk to their child alone	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>			

During the past 6 months:						
How often have you encountered this situation?				How stressful have you found this?		
Rarely	Sometimes	Often		Not at all	A little	A lot
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Parents not supporting what I'm doing with their child	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Periods when I only see patients who are ill	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Families being aggressive towards other members of the multi-disciplinary team	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Having a family on my caseload who is in desperate social circumstances	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Staff being obstructive	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Not being able to do my job to the standard I would like	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	A parent not being happy with the care I am providing	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Lots of very sick children on the ward at once	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Having to be positive with a family when I know the outcome will not be good	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Feeling my work is being closely monitored by managers	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Senior managers placing unfair demands on me	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Giving a parent bad news	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Supporting parents who feel guilty about treatment decisions	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Being involved in telling parents their child's diagnosis	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Dealing with parents who are in conflict with each other	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Not having time when a family asks for help	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Having to respect a parent's wishes when I don't agree with them	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Parents expecting me to do things that are not part of my job	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Not agreeing with how a parent is behaving towards their child	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Parents not understanding the importance of adhering to medical regimes	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Feeling that members of the team don't value each other's opinion	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Feeling that patient care is being compromised	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

During the past 6 months:						
How often have you encountered this situation?				How stressful have you found this?		
Rarely	Sometimes	Often		Not at all	A little	A lot
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Being interrupted when I am talking to a family	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	When we come to the end of the treatment we can offer	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Being expected to take on a wide variety of tasks	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	A protracted death	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Feeling responsible for a child's distress	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Working in an environment that is very noisy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	A family expecting things to be done within an unrealistic timeframe	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Staff not passing on the information I need to do my job	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Finding that I don't switch off properly after I have finished work	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Parents thinking they know better than me	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Difficulty establishing a relationship with a family	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Working with a team member who isn't pulling their weight	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Having to adapt what I say to parents to cater for their level of understanding	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	A parent asking me what I would do in their situation	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Being involved in a consultation where parents are told the prognosis is worse than we thought	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Feeling parents are being pushed into agreeing to treatments	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	A parent demanding more and more support from me	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Feeling that I can't keep up with requests from other team members	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Being responsible for controlling the symptoms of a dying child	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Feeling like everything I do can have major consequences for a patient	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

APPENDIX B: The Work Rewards Scale - Paediatric Oncology (WRS-PO)

This questionnaire describes situations and events which paediatric oncology staff report encountering at work.

For each of the following statements please tick [✓] the box (on the left) that best describes how often you have encountered this situation or event over the past 6 months. **Then** tell us how rewarding this has been for you by ticking [✓] 'Not at all', 'A little' or 'A lot' (on the right).

During the past 6 months:						
How often have you encountered this situation?				How rewarding has this been for you?		
Rarely	Sometimes	Often		Not at all	A little	A lot
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Feeling that I've made a difference to a child	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Knowing how to help	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Knowing that we are providing a good service	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Helping a child cope with their situation	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Knowing that I am doing something really useful	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Seeing children at follow-up when they're well and thriving	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Having a chance to develop my role	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Families valuing my opinion	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Doing something that makes a child feel better	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Feeling I'm respected by other members of the team	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Getting thanks from parents	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Knowing that other members of staff need my help	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Feeling I've contributed to a child returning to a normal life	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Being able to work creatively in my role	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Being able to identify what I can do about a problem	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

During the past 6 months:						
How often have you encountered this situation?				How rewarding has this been for you?		
Rarely	Sometimes	Often		Not at all	A little	A lot
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Seeing a family develop the ability to cope	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	The feeling that I'm doing my job well	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Sharing the high points with a child and their family	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Seeing a child get better	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Working with people who enjoy the same sort of work as me	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Being involved in both the medical and psychosocial aspects of the child's care	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Knowing I'm making the situation easier for families and for children	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Being able to get a child to interact with me	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Being involved with the child and family from the beginning to the end of treatment	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	A family getting to know me	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Other staff appreciating my contribution to a child's care	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Developing new skills and gaining knowledge	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Feeling that I am working in an expert team	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Being one of the people that parents and siblings feel they can open up to	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Developing long-lasting relationships with families	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Families are pleased to see me	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Seeing a family move on with their lives	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Working in a supportive team	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Working in a team that is committed to the patients	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Seeing a patient further down the line	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Appendix C: Project Gantt Chart

Staff Support Project GANTT CHART	M1	M2	M3	M4	M5	M6	M7	M8	M9	M10	M11	M12	M13	M14	M15	M16	M17	M18
	Jan-19	Feb-19	Mar-19	Apr-19	May-19	Jun-19	Jul-19	Aug-19	Sep-19	Oct-19	Nov-19	Dec-19	Jan-20	Feb-20	Mar-20	Apr-20	May-20	Jun-20
Team meetings																		
Project advisory group meetings																		
Phase 1 – Develop children’s hospice (CH) scales																		
Rapid review to identify organisational characteristics																		
Ethics application and approval (Uni York)																		
Recruit hospices for phase 1																		
Survey feedback on CH scales v1																		
Focus groups to refine CH scales v2																		
Cognitive interviews to refine CH scales v3																		
Phase 2 – Cross-sectional study of children’s hospice staff																		
Recruit children’s hospices to the study																		
Collect organisational data from participating hospices																		
Develop and pilot staff survey																		
Administer staff survey and clean data																		
Validation of CH scales																		
Descriptive and regression analysis of study data																		
Study write-up and dissemination																		