Wigan and Leigh Hospice
'Hospice in Your Care Home' Project Evaluation

Final Report

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June 2017

Executive Summary

In late 2015, Wigan and Leigh Hospice were funded to establish a Hospice in your Care Home team to deliver a multi-component intervention to improve palliative care provision in 8 care homes and address hospital admissions. The project comprised three key elements: responding to urgent referrals, advance care planning and monitoring and the provision of on-going support in the form of educational training, role-modelling and working alongside staff. Educational approaches and expertise underpinned all that was delivered. An evaluation was undertaken in early 2017 to evaluate the process and outcomes of the project since its start in November 2015.

A responsive approach to evaluation was adopted, that considered both the process and outcomes. This comprised two strands: 1) an analysis of secondary service provision data collected by the care homes, HiYCH team and other external bodies, and 2), focus group interviews with care home managers (n=6, plus 1 individual interview), care home staff (n=11) and the HiyCH team (n=6). Some preliminary analysis of cost in terms of time and finance was also undertaken. Analysis was carried out using descriptive and inferential statistics on the secondary data and framework analysis was used to structure the qualitative data analysis. Ethical approval was granted by the Lancaster University Research Ethics Committee.

Since November 2015, nine care homes have been involved in the study (one care home withdrew in September 2016 and, one joined in November 2016). All secondary data analysis was undertaken on the seven facilities present throughout the project and the qualitative interviews also included care home staff from the seven facilities present during all the project and the most recently joined care home.

The process of delivering the HiyCH project was successful in terms of meeting its own aims. The provision of timely responses to urgent referrals was addressed: 34 referrals (of which 29 were appropriate referrals) were received until February 2017, all with responses within 24 hours. Advance care planning was supported by resident status meetings in each facility, with 4479 residents discussed at 217 meetings. On-going support was provided through thee educational programmes: a formal 12 week course, clinical skills workshops and ad-hoc training at the hospice and in care homes. The cost of this education delivery was high in terms of care home staff time, (approximately 2421 hours), equating to a cost of just under £30,000 for care home staff attendance.

The key finding regarding outcomes concern the 25% reduction (from 234 to 176 admissions in a comparable 6 month period between 2015 and 2016). This was statistically significant, even when an outlier with a high reduction in admissions was removed from the analysis. There was also a significant relationship between hospital admissions and amount of training received per staff in a care home. Nursing home resident deaths in the care home were overall at 69% across the seven facilities for the duration of the project. The number of advance care plans written in seven care homes increased from 13 to 31 by January 2017,

with 108 residents being offered the opportunity to write a plan. Nine residents died with an advance care plan in place in this period.

The qualitative accounts of the care home managers, staff and HiyCH team members identified a process of initiation, assimilation, and everyday running. Within each of these stages there were key actions undertaken to develop and establish the project by the HiyCH team and care home managers and staff who worked with new practices and knowledge in their own setting.

An important outcome for staff and also the care home organisations was increased confidence in their own skills and ability to care for residents with palliative care needs. Not objectively measured, this nevertheless identified a key outcome that could be considered further in the future. The approach of the HiyCH team was a key facilitator mechanism by which participation in the project was positively described by participants. The team's flexible approach to delivery of the project components and trust building through their support and work with staff led to reported and evidenced changes in practice regarding communication, symptom management, end of life care and hospital admissions. Few barriers to the project were described, but those that were reflected the ongoing challenges within the care homes sector regarding staffing levels and release of staff to attend training.

The model developed here has the potential to be more clearly formalised and expanded in this locality and others.

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1. Background

Care homes for older adults are an increasingly important location for palliative and end of life care delivery. In England, 22.6% of people died in care homes (End of Life intelligence Network 2015). In the Greater Manchester, Lancashire and South Cumbria Strategic Clinical Network (GMLSCSCN), the percentage of deaths in older people ranges from 7.5% in the 65-74 years range, 18.5% for 75-84 year olds to 36.3% for the over 85 year olds (End of Life intelligence Network 2015). However, these figures for not reflect that for many residents who live in care homes they end their lives in hospital. The ONS (2012) calculated that an additional 3,000 people within GMSCSCN normally resident in a care home have died elsewhere (Wigan and Leigh Business Case 2015).

Deaths in care homes often have multiple causes, with a higher rate of non-cancer conditions than any other care setting (ONS 2012). An ageing population will further exacerbate this situation which emphasises the need for investment in care homes as a site for palliative and end of life care delivery. The ever-increasing complexity of medical conditions faced by residents present a challenge for care home staff which can result in older frail patients presenting at Accident and Emergency Departments, often followed by lengthy hospital admissions with many people then dying in unfamiliar surroundings.

Whilst some admissions are unavoidable and appropriate, evidence suggests that emergency admissions from care homes are often unnecessary and preventable with the appropriate support and a skilled workforce in the home (Thomas & Lobo, 2011). It is proposed that in many cases, inappropriate admissions could be prevented with the right education and support from specialist services such as a hospice.

1.1 Care homes and palliative care development

The specialist palliative care sector, including hospices, has been proactive since the mid-1990s in engaging with the provision of palliative care in care homes (Froggatt 2001). In 2008, the English End of Life Care Strategy identified and promoted the provision of palliative care in care homes, recognising the importance of the setting as a place where palliative care was needed and could be provided (DH 2008). Supported by a national End of Life Care programme, three tools were specifically promoted to support palliative care provision: an organisational programme (Gold Standards Framework), use of an end of life care pathway (Liverpool Care Pathway) and advance care planning (Preferred Priorities for Care plan) (DH 2008).

Alongside these tools and frameworks a number of initiatives have been developed nationally and internationally to increase staff preparedness to deliver palliative care in care homes (Froggatt and Reitinger, 2013). Initiatives are often multi-faceted (van Riet et al, 2015) and integrate different educational approaches within their approach (Anstey et al 2016). Educational approaches adopted include: educational toolkits (Cox et al 2017), a

train the trainer model (Mayrhofer at al 2016), e-learning and workshops (Farrington 2014), role modelling (Finucane et al 2013). Care home support teams, based in hospices, delivering education, have also been used (Locker and Collins 2014), in some cases, for example St Christopher's Hospice, Sydenham (Kinley et al 2014) supporting the delivery of other established frameworks such as the Gold Standards Framework, end of life pathways and advance care planning tools. Other activities delivered include clinical fora (Locker and Callin 2014) and system changes with respect to competencies and staff appraisals (Lansdell and Mahoney 2011).

Throughout this engagement between palliative care services and care homes a number of ongoing challenges shaping the effective delivery of palliative and end of life care in care homes have been documented. These include:

- Increasing complexity of residents' needs and the subsequent difficulty of diagnosing/recognising when someone is dying particularly for residents dying from multiple co-morbidities;
- A lack of confidence amongst care home staff to communicate with patients and families about end of life issues;
- Lack of staff knowledge about symptom control, the appropriate medication available and the accessibility of drugs, particularly out of hours;
- Lack of confidence in using syringe drivers for delivering symptom management;
- Workforce issues, including minimum numbers of staff, the rapid staff turnover in some care homes and different cultural approaches to death and dying with multicultural workforces;
- Pressure from carers and families to send deteriorating end of life residents to hospital in the hope that curative treatments may be available (Seymour & Froggatt, 2008).

With the ongoing pressures on care homes regarding changing population needs, care delivery and workforce instability there is an ongoing need to develop local initiatives to ensure high quality palliative care for residents living and dying in care homes.

1.2 Wigan and Leigh Hospice in your Care Home

The Hospice in your Care Home (HiyCH) project was launched by Wigan and Leigh Hospice in November 2015. The rationale for the development of the service was to: '*Respond to the education and training needs of nursing home staff in relation to end of life care, and provide a role model approach to support, empowering staff to embed the 5 priorities of care into their everyday routine*.' (Wigan and Leigh Hospice Business Case, 2015).

The Hospice in your Care Home education and training model was based upon a project carried out at St Christopher's Hospice, London, which began in 2008. The St Christopher's 'Care Home project' involves a team which provides high facilitation incorporating the role

modelling of advance care planning and symptom management, whilst promoting collaborative working via monthly coding (resident status) meetings and reflective debriefing sessions. The primary focus was the provision of formal theoretical education, opportunistic training and role modelling for staff within the nursing home environment, supporting the management of residents expected to die within 6 - 12 months.

Building upon the St Christopher's Hospice model, of direct engagement by the hospice with care home organisations, the Wigan and Leigh Hospice established the Hospice in Your Care Home team (HiyCH team), as an educational team, to address needs in their locality. The team had a different skill mix to the St Christopher's project, using a health care assistant and staff nurse alongside senior educators with extensive experience and skills in education. This project aimed to offer a service model that provided 3 key elements: responding to urgent referrals, advance care planning and monitoring and the provision of on-going support in the form of educational training, role-modelling and working alongside staff (Table 1)

Table 1: Key elements of HiyCH project

Key elements	**Activities**
Responding to urgent referrals	Telephone referrals followed by a response within 24 hours Identification of urgent learning needs
Advance care planning and monitoring	Resident status meetings (monthly) Identification of ACP needs Support with ACP conversations – role modelling and meetings with family Staff reflective practice sessions Integration with GSF GP meetings if necessary
On-going support	Rolling education programme: Principles of Palliative and End of Life Care Clinical skills workshops Other identified educational needs (see urgent referrals) Nursing Home Managers meetings (monthly) Role modelling Working alongside care home staff

The project formally commenced in November 2015 and was initially offered to eight nursing care homes from the Wigan and Leigh district. In September 2016, one care home withdrew and replaced with a further care home which joined the project in November 2016.

A small scale evaluation was commissioned at the end of 2016 to consider the HiyCH and its work to date.

2. Aims and Objectives

2.1 Aim

To evaluate the process and outcomes of the 'Hospice in Your Care Home' initiative.

2.2 Objectives

- To determine the impact of the 'Hospice in Your Care Home' initiative upon the following outcomes:
    a. Hospital admissions
    b. End of life care practice within care homes
- To establish the cost (both time and financial) of delivering the 'Hospice in Your Care Home' initiative.
- To identify the facilitators and barriers and to the implementation of the 'Hospice in Your Care Home' initiative and its sustainability.

3. Evaluation Methods

As the aim of the project was to evaluate the processes and outcomes of the 'Hospice in your Care Home' initiative, a responsive approach to evaluation was adopted (Stake and Abma 2005). This allows both process and outcomes to be considered. Developed for use in educational contexts, this approach allows for multiple perspectives within the evaluation drawing on personal experience to make judgements of worth and quality of the programme.

First, the extant service activity data that had been collected throughout the lifespan of the project to date, and secondary sources that relate to the initiative, were collected and analysed. Second, qualitative data that specifically addressed the processes and outcomes was collected directly from three perspectives – the care home managers, care home staff and Hospice in Your Care Home team members.

The following sections will detail the approaches that were taken to collect and analyse these different types of data.

3.1 Analysis of secondary data

3.1.1 Service activity data

Service activity data was derived from both the Hospice in your Care Home team records and also external data from relevant sources, such as hospital admission data from the local Trust (where possible). HiyCH have collected service activity data that reflects the processes

of delivery of the project and outcomes arising from the HiyCH team's work since commencement in November 2015 (Table 2).

Table 2: HiyCH secondary data

Data Focus	Information Included
Clinical Skills Workshop	Date; Time; Venue; No. Attendees; Facilitator
Formal Education Programme	Date; Time; Venue; No. Attendees; Topic; Facilitator; Attendee role breakdown
Ad. Hoc Training Sessions	Date; Time; Venue; Topic; No. Attendees; Name of Attendees
Resident Status Meeting[1]	Date; Venue; Time; Care Home Staff Present; No. Residents Discussed; No. Green Residents; No. Amber Residents; No. Red Residents
Hospital Admissions and Deaths	Care Home; No. Hospital Admissions; Date (Month); No. Deaths in Care Home; No. Deaths in Hospital
Deaths	Nos. Place and preferred place
Advance care plans	Nos. offered; Nos. completed
Urgent referrals	Nos. received; No. days from death

Data analysis

Descriptive and inferential statistics were used to analyse the levels of change in activity before and through the delivery of the project to date. Analysis was only conducted on the seven nursing homes which were in the project from November 2015 to February 2017.

3.1.2 Costs and cost data

Both time and financial costs of the following activities have been calculated based on:

- Care Home staff attendance at education activities (formal education programme; clinical skills workshops)
- HiyCH staff involvement in the delivery of the project:
    - Education activities (formal education programme; clinical skills workshops)

Cost of care home staff time has been worked out using average salaries based on salaries obtained from http://www.payscale.com/research/UK (including NI and pension). Salaries of HiyCH team were used to allocate costs per person.

3.2 Qualitative interviews

Data on the experience of participation in the project and views on the barriers and facilitators for the work were obtained through qualitative interviews using focus groups

[1] This is a staff meeting at which residents are discussed individually to consider their status. They are coded green, amber or red depending on their end of life/palliative care need.

methods. Focus groups were selected as the means to capture the three perspectives – Care Home managers, Care Home staff and Hospice in your Care Home staff team respectively. Focus groups are qualitative method, a 'form of group interview that capitalises on communication between research participants to generate data' (Kitzinger 1995: 299). Focus Groups allow attention to be paid to the group interaction and are ideal for exploring people's knowledge and experiences, in this case their experience of the Hospice in your Care Home initiative.

A topic guide was used to structure the focus group and interviews which explored: becoming involved in the project; the processes of engaging with the HiyCH project; the outcomes of the project; the barriers to participation; and the facilitators to participation. In addition, a demographic form that recorded gender, occupation, length of time working in the field and organisation, was completed by each participant.

3.2.1 Care Home Managers

The managers from each of the eight care homes were invited to focus group interview by letter. Participant information sheets were also sent to provide background about the evaluation.

Of eight managers invited, six staff in managerial roles attended. The outstanding two care home managers were contacted to take part in a face-to-face interview at a time when they were available to participate. Of these two care homes, one had a new manager come to post the week previous to contact (and hence had no experience of the Hospice in Your Care Home initiative); the other agreed to participate in a face-to-face interview with one researcher, which was conducted successfully. As such, seven of eight care homes contributed some data from the management perspective. Six women and one man participated and other demographic details are presented in Table 3. This was an experienced workforce with at least 12 years' experience in the care home sector.

3.2.2 Care Home Staff

Staff from each of the eight care homes were invited to a focus group interview by letters distributed via their managers. Participant information sheets were also sent to provide background about the evaluation. The inclusion/exclusion criteria for staff participants were as follows:

- Nurses and care assistants who have worked in the nursing home since the Hospice in Your Care Home initiative was started.
- Staff that work day shifts
- Staff that have a more than 0.5FTE contract

Table 3: Care home management demographic details

Role	Age Range[2] (years)	Time in Care Home Sector (years)
Clinical Manager	50+	41
Manager/nurse	50+	30
Manager	41-50	20
Lead RGN	41-50	14
Manager	50+	43
Manager	50+	30
Deputy manager	31-40	12

Due to the number of participants recruited, the staff were split into two groups according to role, each of which was facilitated by one researcher. A total of 11 care home staff contributed their perspectives (Table 4).

Table 4: Care Home Staff demographic details

Role	Gender	Age Range[3] (years)	Time in Care Home Sector (years)
Senior Care Assistant	Female	41-50	Unknown
Lead Senior Support Worker	Female	41-50	25
RGN	Female	50+	15
Nursing Assistant	Female	31-40	7
RGN	Female	50+	12
RGN	Female	31-40	6
Support Care Worker	Female	50+	10
Support Worker	Female	31-40	18
Senior Carer	Female	50+	14
Nursing Assistant Practitioner	Female	21-30	11
Carer	Female	21-30	8

All participants were female and again experienced in working in the care home sector with an average of 12 years' experience, ranging from six to 25 years.

[2] The ages of this group ranged more specifically from 32-59 years
[3] The ages of this group ranged more specifically from 26-62 years

3.2.3 Hospice in Your Care Home Staff Team

Each of the six staff members from the Hospice in Your Care Home team were invited to focus group interview by letter. Participant information sheets were also sent to provide background about the evaluation. The inclusion/exclusion criteria for staff were as follows:

- Member of the Hospice in your Care Home team working in the nursing homes participating in the project

The demographics of this group are shown in Table 5.

Table 5: HiyCH team demographic details

Role	**Gender**	**Age Range[4] (years)**	**Time in Hospice Sector (years)**
RGN	Female	50+	6
RGN/Manager	Female	41-50	15
RGN	Female	31-40	12
RGN	Female	50+	18 months (16 years in care home sector)
HCA	Female	31-40	18 months (20 years in care home sector)
RGN	Female	50+	14

This was an all-female team with varying experience of working in the hospice, but those members with less experience working in hospices had extensive experience in care homes.

3.2.4 Data handling and analysis

The focus group and one-to-one interviews were audio recorded and transcribed using an encrypted digital device; supplementary notes were made by a second facilitator during the focus group sessions with the care home manager and HiyCH teams.

Framework analysis (Ritchie & Spencer 1994) was used to analyse all the data. The analytical process involves the following stages: familiarization; identifying a thematic framework; indexing; charting; mapping and interpretation. Atlas.ti qualitative data software was used to assist in coding and analysis of the data.

3.2.5 Ethics

Full ethical approval was received from the Lancaster University Research Ethics Committee in February 2017 prior to the start of the evaluation. The ethics committee was then

[4] The ages of this group ranged more specifically from 34-56 years

approached to approve an amendment to invite outstanding care home managers to a one-to-one interview. This was granted in March 2017.

As the study did not involve patients, the main ethical issues considered here included consent, confidentiality and anonymity and the potential for emotional distress. Each participant received a participant information sheet and gave written consent before the focus groups commenced. The right of participants to refuse participation, or withdraw, without providing a reason was communicated.

Neither confidentiality nor anonymity could be maintained during the focus group itself, but was maintained following data collection. The transcriber signed a confidentiality agreement and each participant was assigned an anonymised code which was used throughout the analysis and presentation of the results (e.g. direct quotation). No ethical concerns arose during any of the focus group or interview sessions.

4. Findings

Findings from the evaluation are presented in this section according to the type of data and analysis. An overview of the participating care homes is presented, followed by the findings from the secondary analysis of service activity data and other related material. The accounts arising from the focus groups are then considered.

4.1 Care Home Demographics

For the duration of the HiyCH project since November 2015, nine care homes have participated (Table 6). All care homes were dual registered providing nursing and personal care to residents over 65 years plus, with dementia and some residents with mental health needs.

Five care homes were part of not for profit groups, three for profit organisations, and one was not identifiable at the time of writing the report. The facility size ranged from 42 to 180 beds. Staffing levels varied and all reported the use of agency staff.

4.2 Secondary data analysis

The data analysed for this section was drawn from the seven care homes that were in the project from November 2015 until now, so the service data from the care home that withdrew and the care home that joined later has not been included. One care home (CH6) had markedly higher changes in the hospital admissions outcome, so analysis has also been undertaken without this outlier to see if the results were still significant.

4.2.1 Processes

As presented in Table 1, the three key areas of activity concerned responding to urgent referrals, advance care planning and monitoring and on-going support through education and role modelling. These activities are considered below.

Table 6: Care Home overview

Care Home	Owner	No. Beds	Status	Total no. staff	RN	RMN	HCA
CH1	For-profit (small company - 6 homes)	81	Dual registered	77	7	0	70
CH2	Not-for profit chain (250 homes)	57	Dual registered	51	6	1	44
CH3	Not-for profit chain (279 homes)	180	Dual registered	97			
CH4	Not-for profit group (5 homes)	72	Dual registered	112	6	1	105
CH5	For-profit (family-run company - 18 homes)	46	Dual registered	41	1	3	37
CH6	Not-for profit chain (250 homes)	42	Dual registered	32	7	2	23
CH7	For-profit (small company - 2 homes)	62	Dual registered	49	5	1	43
CH8[1]	Not-for profit chain (250 homes)	46	Dual registered	54	1	11	42
CH9[2]	For-profit group (19 homes)	51	Dual registered	19	3	0	16

1. Started November 2016 2. Left September 2016

Response to urgent referrals

Until February 2017, the HiyCH team received 34 referrals, of which 29 were deemed appropriate. All were responded to within 24 hours. All residents referred died in the care home, with two referrals onto the hospice nurse specialist. Urgent referrals led to ad-hoc training sessions as described below.

Advance care planning and monitoring

A key activity that supported advance care planning within the care homes was the establishment of resident status meetings (monthly) in each care home. Since December 2015 until the middle of February 2017, the HiyCH team have facilitated 217 resident status meetings discussing 4479 residents (Table 7). The number varied by facility ranging from 9 meetings over the 15 months period to 65 meetings.

Table 7: No. of resident status meetings held

Care Home	No. resident status meetings	No. residents discussed
CH1	40	740
CH2	35	630
CH3	44	1148
CH4	65	722
CH5	10	282
CH6	9	354
CH7	14	603
Total	**217**	**4479**

The number of resident status meetings did vary by care home, which reflected the number of residents to be discussed in each facility (Figure 1). In larger facilities, reviews were undertaken in ward units for smaller groups of residents. Generally, meetings were facilitated by one member of the HiyCH team, except in 26 instances, where 2 staff were present and in one instance three staff were present.

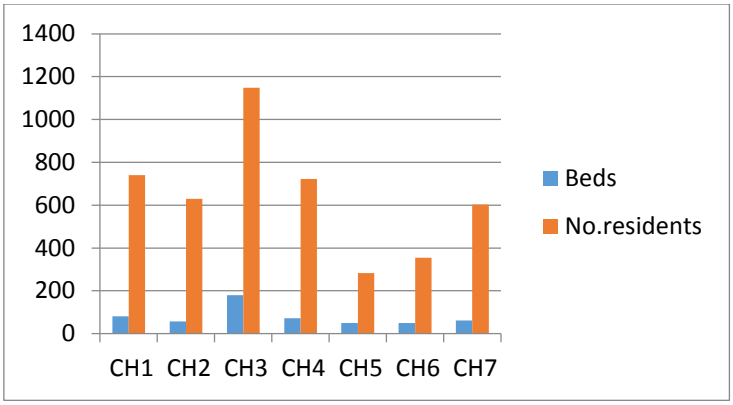

Figure 1: No. residents discussed compared with the no. of beds

On-going Support

Three types of education were offered: a 12 week training programme, clinical skills workshops and ad hoc sessions.

Formal training programme:

1809 staff from six of the care homes attended 113 formal training sessions (Table 8). The number of sessions attended ranged from 3 to 31 per care home; the number of attendees ranged from 19 to 439 per care home. Sixty-eight staff completed the full training programme from the seven care homes.

Table 8: Attendance at formal training programme, cohorts 1 to 5

Care Home	No. sessions attended	No. attendees	No. staff completed 12 week programme
CH1	29	360	4
CH2	3	19	4
CH3	0	0	9
CH4	30	439	9
CH5	16	173	1
CH6	31	426	37
CH7	20	392	4
Total	**129**	**1809**	**68**

The cost of delivering and attending the formal training for Cohorts 1 to 5 was £24,242.90 (Table 9):

Table 9: Cost of delivering the formal training programme (Cohorts 1 to 5)

	Care Home staff	HiyCH staff
Number of hours attendance	1809	113
Cost per hour	£12.11	Varied by grade
Total cost	**£21906.99**	**£2335.91**

Clinical Skills Workshops

Attendance at the 43 clinical skills workshops similarly varied, with attendances per care home ranging from 3 to 47 (Table 10) and a total of 204 staff attending a workshop.

Table 10: Attendance at clinical skills workshops

Care Home	No. workshops	No. attendees
CH1	9	47
CH2	4	18
CH3	8	40
CH4	7	34
CH5	2	3
CH6	5	30
CH7	8	32
Total	**43**	**204**

The cost of delivery of the clinical skills workshops was £4668.42, covering both care home staff time for attendance and HiyCH team time to deliver the training (Table 11).

Ad-hoc training

A further 16 ad-hoc training sessions were offered to the seven care homes, 11 sessions at the hospice and five in different care homes, to a total of 147 staff. Issues addressed included: comfort care round, syringe driver training, dementia and pain, palliative care emergencies and clinical decision making.

Table 11: Cost of Clinical Skills Workshop delivery

	Care Home staff	**HiyCH staff**
Number of hours attendance	306	102
Cost per hour	£12.11	Varied by grade
Total cost	**£3705.66**	**£962.76**

The cost of delivering the ad-hoc training for care home staff attendance was £4347.49 for 359 staff hours of training. 35.5 hours of HiyCH staff time was used, but costs are not available for this time.

In total therefore, the costs of care home staff time to attend the formal training programme, clinical skills workshops and ad-hoc sessions was £29,960.14. The costs of the HiyCH team time to deliver the formal training programme session and the clinical skills workshops was £3298.67.

4.2.2 Outcomes

Three outcomes are presented here: hospital admissions, deaths and advance care planning activity.

Hospital admissions

A 25% reduction in hospital admissions is identified across the seven care homes (Table 12) between July – December 2015 and the same period in 2016, from 234 to 176 (Figure 2). This is a highly significant difference ($p=0.01$) using a paired t-test. When the outlier (CH6), which had a greater reduction in the number of admissions than for the other care homes, was removed there was still a significant difference. Therefore it is possible to conclude that there was a significant reduction in hospital admissions as a result of the Hospice in your Care Home initiative.

Table 12: Hospital Admissions 2015 and 2016

Care Home	**Hospital Admissions July - December 2015**	**Hospital Admissions July - December 2016**
CH1	45	40
CH2	27	18
CH3	76	69
CH4	8	3
CH5	17	10
CH6	41	20
CH7	20	16
Total	**234**	**176**

The relationship between training and hospital admissions was analysed. The number of costed hours of training divided by number of staff in the care home was used as a proxy measure for this. The more training care homes had the more likely they were to reduce admissions in this time period - this was also highly statistically significant (p=0.002). However, when the outlier care home was removed the results were non-significant. The relationship between the review meetings and admissions was also analysed. This had the same effect but this alone showed no additional benefit and no difference was identified (p=0.51).

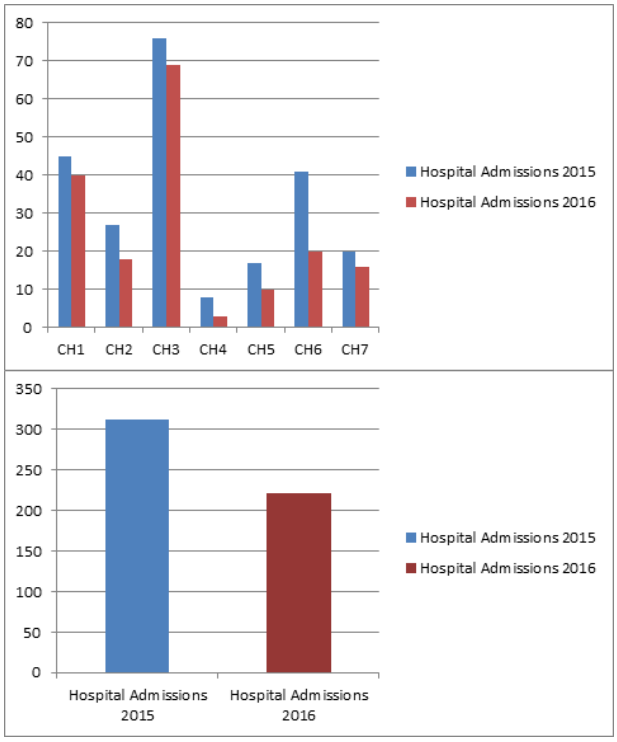

Figure 2: Hospital admissions Pre and Post Intervention

Nursing Home Resident Deaths

Based on data from the last 6 months of 2016 (Table 13), 69% of death occurred in the care home. For all care homes over 50% of resident deaths occurred in the facility, but care needs to be taken as in some care homes there were few deaths recorded. There is also insufficient data on cause of hospital admission, cause of death or resident preference for place of death to assess the appropriateness of the place of death.

Advance care planning

The number of advance care plans in place for residents at the start of the project was low with only 13 recorded across the seven care homes (Table 14). Throughout the project's duration December 2015 to January 2017, 108 residents in seven care homes were offered the opportunity to write an ACP and 31 active ACPs were written.

Table 13: Place of death

Care Home	Deaths in care home N (%)	Deaths in hospital n (%)	Total deaths
CH1	16 (59.3)	11 (40.7)	27
CH2	12 (66.7)	6 (33.3)	18
CH3	26 (66.7)	13 (33.3)	39
CH4	21 (87.5)	3 (12.5)	24
CH5	5 (71.4)	2 (28.6)	7
CH6	5 (62.5)	3 (37.5)	8
CH7	4 (66.7)	2 (33.3)	6
Total	**89 (69)**	**40 (31)**	**129**

Table 14: Advance Care Plans

Care Home	No. residents with ACP September 2015	No. residents offered an ACP discussion December 2015 – January 2017	No. residents with ACP December 2015 – January 2017
CH1	0	24	6
CH2	1	8	2
CH3	0	22	3
CH4	10	19	8
CH5	0	3	0
CH6	2	24	11
CH7	0	8	1
Total	**13**	**108**	**31**

4.3 Experiences of participation

These findings will be structured as per the topics covered by the focus group schedule that was developed specifically to capture data about processes and outcomes. The qualitative approach allowed more detailed accounts to be elicited that complement the material available from the data in the previous section; along with factors perceived to act as facilitators and barriers to the initiative. The findings will be presented next alongside quotes as examples.

4.3.1 Processes

The processes of the project's establishment and running described by the three groups encompassed three distinct phases:

- Initiation
- Assimilation
- Everyday running

Initiation - Much of the initiation processes were explained by the HiyCH team who devised the initiative and selected eight care homes to participate; specifically, those that were deemed to have greatest need based on factors such as hospital admission rates. The HiyCH team approached these Care Homes to recruit and informed the wider community of the project's initiation through a launch event. A 'Terms of Engagement' document was used to outline the level of engagement and practice standards expected by the Care Home's to be involved.

From the Care Home's perspectives, the initiative was very welcome and all participants communicated that their initial perception of the project was very positive at both managerial and staff level. The response to the invitation was described as a *'no brainer'* (Interview, Care Home Manager) i.e. the opportunity was clearly desirable. This was the perception reflected by the Care Home Managers focus group too who indicated that it was *'only a positive'* (FG1, Care Home Managers).

Overall, the same positivity was described by the Care Home Staff when advised they would be participating:

> *'The management came to us. And said they were piloting this scheme with the hospice at home, and I thought it was a fantastic idea' (FG2, Care Home Staff)*

Assimilation – The enthusiasm for the initiation of the project communicated by the Care Home managers and staff in the focus groups, overlooked a crucial phase in the process – assimilation. The HiyCH team identified a precarious period at the outset characterised by relationship building between the two agencies. This phase involved a transition from 'before' to 'after' where the Care Home shifted from a position of isolation and limited skills/confidence with palliative care; to becoming a competent partner in the provision of this type. The HiyCH team, and some of the Care Home Managers identified the 'before' status as characterised by a level of insecurity and apprehensiveness on the part of the Care Home who were accustomed to working in relative isolation from other health care agencies and with limited recognition/appreciation.

> *'Her job [HiyCH Team Member] is to come in and work on the floor with the staff and initially staff were a little bit wary […] they think they are being spied on. Or someone is trying to catch them out, but as they have got used to the process and the training […] they have realised they are not trying to catch them out they just trying to help make sure that they doing it right, and it it's not been as hard as what they thought it would be. The staff are suspicious of strangers coming in watching them do stuff. You know so they were worried about that but now they are not.'* (FG1, Care Home Managers)

Following the assimilation period, characterised by relationship building and increased trust the Care Home's relaxed and could proceed to engage with working with the HiyCH team to develop their end of life care practices.

Everyday running– This refers to the day-to-day processes that are a requisite part of engagement in the HiyCH initiative, rather than the new end of life practices which have developed as a result of involvement with the HiyCH. Section 4.1 indicated the diversity of training delivered and the staff time invested engaging in the programmes. The participants of the focus groups from all three perspectives, perceived Syringe Driver Training to be particularly helpful as staff have limited opportunity to engage in this facet of practice regularly:

> '*I think syringe driver training was an important factor for me as well. Because the nurses in the care homes are not doing it sort of every day [so] nobody was really confident enough to set a syringe driver up before so we wanted sort of more thorough training and regular updates for the staff so they had confidence to do it*.' (FG1, Care Home Managers)

There was discussion about the format of training, currently each cohort runs for six weeks at two hours of training per week. This was perceived to be more favourable than the original twelve week/one hour per week format. This was supplemented by 'role - modelling', ad-hoc training sessions and clinical skills workshops along with specific practices (new to many Care Homes) such as regular resident status meetings.

Mainly however, the care home participants focussed less on the formal training sessions and 'role-modelling' and highlighted more the ongoing general support received from the HiyCH team-this was a central theme in the material about 'processes' and was highly valued:

> *'It helps you every day, the hospice team. We know they are there for support whenever we need it. We only have to pick up the phone […] I think it's a really good idea because at end of day we have all got residents best interests at heart. And it's all about making them comfortable. And having that extra support'* (FG2, Care Home Staff)

The deployment of various practice tools was also perceived to be a welcome addition to the Care Homes, such as the 'comfort tool':

> *'I think it's really good because it's all on one sheet so that when the carers are delivering the care […] as nurses we can have a look at the sheet, 'cos at the bottom if they have noticed anything they come and tell the nurse and you initial it, so it's all there, it's all in the documentation. You can look at it you know at a glance'* (FG2, Care Home Staff)

The HiyCH Team spoke more about the specifics of the initiative including the concept of 'role modelling,' which was clearly experienced by the Care Home staff too, but not spoken about in the same terms:

> '*It's not just the clinical and practical things […] and role modelling, it's the communication side of things as well. One of the units I go on they were very concerned about discussing the family and the life issues, getting a DNA CPR in place. And they had some trouble with a family before and I've met with family and with one of the carers and […] had a difficult conversation and it was successful*.' (FG3, HiyCH Team)

In addition, the comments about 'process' were frequently in relation to the specific approach of the HiyCH team (See section 4.2.4.)

The findings in this section offer a flavour of some of the processes that comprise the HiyCH initiative, many of which could also be perceived to be 'outcomes' especially in cases where the 'process' was new to Care Home practice. More of the specific outcomes are discussed in the next section.

4.3.2 Outcomes

Many diverse outcomes were mentioned across the three groups who participated. Indeed, the impacts of the project ranged from 'measurable' such as hospital admissions and prevalence of Advance Care Plans; to clinical skills; to personal emotional development. The key outcome spoken about most from all perspectives, Care Home Managers, staff and the HiyCH Team, was improved confidence in end of life and palliative care practices and in communication. The increased confidence underpinned all the other outcomes discussed as it meant that trained staff were better able to make clinical and care decisions and to initiate conversations with residents, families and other agencies. This was in turn was perceived to result in, for example, fewer hospital admissions, and a better resident and family experience:

> '*More confident - it's like speaking to relatives, obviously if you have got somebody dying, I think a lot of staff are a bit scared to approach people as they don't know what to say. So all that's taught on the course. They're more confident, they don't shy away, they are more likely to approach them now and be a bit more proactive. And we certainly had a couple of deaths where relatives can't praise us enough. 'Cos of how the staff have been with them*' (FG1, Care Home Managers)

> *'And the staff they more comfortable asking for certain things, and disagreeing with the GPs as well and saying 'No we don't want that person to go to hospital. If you do*

X Y and Z we will be able to keep them.' (FG1, Care Home Managers)

It was also reflected how residents, families and other agencies, including GPs, had more confidence in the Care Homes because of their involvement with the hospice:

> *'The families were much more confident with us nursing them having had the conversations with [HiyCH Team] and a few others. […]. Like you say […] they just think that it's better that we have got involvement with the hospice.'* (FG2, Care Home Staff)

Congruent with the data from Section 4.2.2, and reflected in some of the above quotes, all the participant groups reflected that hospital admissions have been reduced, for example:

> *'I think its reduced its hospital admission really 'cos as we have said we would challenge a GP now if they just, we want to shove somebody straight in if the issue was pain control then that's something that we are all well-equipped and competent to cope with in the home. So it's unnecessary to send that patient to hospital. So, it would prevent any admissions for pain control.'* (FG1, Care Home Managers)

In addition, other time and cost savings were identified in the form of reducing district nurses visits as a result of Care Home being able to, for example, manage syringe drivers independently:

> *'P1: With the syringe pump training, we have now got six out of the eight homes who are managing their own syringe pumps now instead of the district nurses having to come in.*
> *P2: But there is a cost saving for the health economy. It was taking a lot of time from district nursing services previously and they were there was an agreement that homes would be charged if the district nurses came to manage the situations. So, there is an expectation that they should be doing this themselves. So yes, they are a lot more independent of that now.'* (FG3, HiyCH)

This ability to be more independent in practice was complemented by processes being better organised regarding palliative and end of life care; and the Care Homes being more prepared for end of life:

> *'P1: We are just better prepared now. Just better prepared it's as simple as that really, we are just better prepared.*
> *P2: So, it means you are not acting in an emergency.*
> *P1: Yes, proactive.'* (FG2, Care Home Staff)

The three groups highlighted how significant changes in practice have been made in the Care Homes specifically regular resident status meetings; ACPs and DNACPRs administration as standard; and monthly manager's meetings. Ultimately these outcomes were perceived to impact positively on the key beneficiaries of the Care Home environment – residents and their families:

> *'I mean one impact it has with me is if I go to do an assessment at the hospital I am now having those conversations if they have got capacity about DNA's CPR's and advance care plans, and then I'm writing that on my assessment that it's been discussed and this person may or may not wish to complete an advance care plan. Once they come to us. So, that that is as soon as somebody is admitted. And I said I would like to go back twelve months and look at how many DNA CPR's we had in place, I would hazard a guess at probably out of thirty-nine residents probably about four or five, we have now got eight residents that haven't got one.'* (FG1, Care Home Managers)

Many of the outcomes, overlapped with the processes; for example, the Resident Status Meetings and the Monthly Managers Meetings were part of the terms of agreement for the initiative the 'every-day' processes but they were also new to the Care Home and a valued outcome of the engagement with HiyCH. In addition, the outcomes (and processes) of the initiative were arguably much further reaching than the Care Homes. Indeed, one Care Home Manager identified the HiyCH Initiative as '*surpassing expectations*' for delivering support for palliative and end of life care in Care Homes, recognising the formation of new professional networks in health and social care across the locality; and benefits to all residents regardless of their 'status.' For this reason, they described they rejected the concept of the HiyCH initiative as a discrete entity and described it instead as a '*movement*' that was much more wide reaching than expected or insinuated by their name (Care Home Manager, Interview).

4.3.3 Facilitators

The approach of the HiyCH team was considered an important facilitator with respect to the success of the project. This was extensively discussed by all focus group members. The characteristics of this approach included: Supportive-ness; collaboration; non-judgmental; tailored to individual home need; approachability; transparency; honesty; trust; inclusivity; being non-hierarchical. The responsive-ness and collaboration was exemplified with regards to the format of the training programme, as mentioned in the previous section:

> *'Initially it was twelve weeks of training and it was at set times during the afternoon, then after that we have sat down at the meetings and had discussions about: was those times working? was it over twelve weeks? And we reduced it to six weeks. At different times, they did evening sessions for the night staff. So it was all about us*

coming together and seeing what worked.' (FG1 Care Home Managers)

The care home staff and managers perceived other aspects of the HiyCH approach in such terms:

> *'It's just been really valuable I think that the input that they give us is very individualised as well. So we needed quite a bit of reflective practices as there was some issues that we needed to address and they dedicated loads of their time and I think it's down to the team themselves. And their personalities really. The staff are really eager to get on the training, they want to learn and they respect them [HiyCH Team] and I think it's how they come across that makes it easier and more accessible.'* (FG1 Care Home Managers)

The HiyCH Team reflected how this approach was thoughtfully and deliberately executed, and the characteristics they were aiming are exemplified as follows:

> *'We didn't want to go in and take over us like we know it all. We wanted to go in and work at the level of the staff within that home. The level varies according to the different homes. We didn't want to be like a big brother watching you we wanted to be there as a genuine team that cares passionately about palliative and end of life residents.* (FG3, HiyCH Team)

> *'I think that was very much we had to keep in mind that we were going into the care homes and we are role modelling. We are not going in to actually do that job for them. We need to be aware what our boundaries are that we don't overstep them into that clinical practice because our aim is to role model yes, facilitate and then to develop their skills. Not to go in and do the job for them.'* (FG3, HiyCH Team)

They characterised also how they approached Care Homes when struggling to engage:

> *'So we are not going to say to them 'Right you are not toe-ing the line so you are out.' We will hopefully try and sort of be flexible with them, try and identify what the issues are so that we can maybe help them. So we went to this particular home, sat with the manager and the deputy manager tried to identify what the issues were and so we did come up with a strategy that we said we would review after three months and we really bent over backwards to try and accommodate them and do things in a different way.'* (FG3, HiyCH Team)

Another manager described how the hospice had worked with them and been flexible to confer sustained participation - arranging a pause in their engagement with the training programme whilst they tackled some internal logistical issues (Interview, Care Home Manager)

They also transformed other barriers that presented into fruitful learning opportunities:

> *'Sometimes the care staff in home experience a problem. In one of the homes there were having a problem with the resident who was at risk of a palliative care emergency which they had no experience of. And because they were experiencing that problem that then led to us initiating a palliative care education session. Which was then delivered to all the homes. So all the other homes then benefited from the experience.'* (FG3, HiyCH Team)

This approach was also experienced and valued within the HiyCH Team, making for a very fulfilled and positive workforce:

> *'I like as well like how our opinions and views are valued. Because I've been in a situation where those in the management and at the top they make the decisions and then everybody else has to follow. Whereas I think with [our managers] we all get our chance to put our views across and we make like a decision as a team. Which I think is brilliant.'* (FG3, HiyCH Team)

The 'status' of the hospice was also an important facilitator to the success of the project and was co-opted by the Care Homes to some extent through their involvement with HiyCH:

> *'Families are more confident because a lot of the families when they get to end of life or they deteriorating they expect them to go into hospital. But now they know especially if you say that we have got the hospice you know helping advising us it they are quite happy for their relative to stay. Knowing that we can now deal with most things*.' (FG1, Care Home Managers)

When asked specifically about 'facilitators' the two care home sample groups responded with discussion about the award ceremony that the hospice hosted. This was perceived to be very inspiring and valuable, providing recognition for the Care Home staff that was typically absent:

> *'We had an award ceremony and that were really good. 'Cos, you don't really get much thanks. I don't think anybody does. I've never known any but yes, just for like going up for the awards and it were really good.'* (FG2, Care Home Staff)

The positivity of this experience, and the comparison with other schemes, led some to suggest that accreditation would be beneficial:

> *'I think as well that recognition should be some sort of recognition you know like the GSF for instance. If they have financial recognition as well [like] the fact that you were a GSF home I think that it would be nice if we, although we have got recognition with the awards ceremony that went that was lovely, but I think it would*

be nice probably nationally. To have some sort of recognition.' (FG1, Care Home Managers)

4.3.4 Barriers

As evidenced by the quotes in the last section, the initiative was perceived extremely positively overall by all groups. It was a challenge to elicit any disadvantages in the focus group discussion. The main barrier to participation of the Care Homes in the HiyCH initiative was care home constraints, particularly staffing levels which in turn was linked to financial constraints. Thus, releasing staff to participate in the training could be difficult and many staff also had to attend on days off. This factor was identified across all the three focus groups:

'It's easier when it's in your own home. But when in it's somebody else's its they have had a look at your off duty to release. Or persuade them to go on the day off. So, it's that your staff management.' (FG1, Care Home Staff)

This led to the HiyCH team making programme changes to try and best accommodate these issues:

'We decided to try it trial it on full day with the homes coming here. 'Cos, we found we was getting to some homes and they couldn't release staff. So, that that was a problem really it was just a waste of a morning or an afternoon.' (FG3, HiyCH Team)

General issues of organisational capacity also impeded most effective participation. Indeed, one home had withdrawn from the initiative for this reason and another had taken a brief hiatus, stressing that the HiyCH initiative was not responsible but instead that internal logistical issues were proving prohibitive. The size of the care homes, the size of the workforce, managerial changes, embargoes on admissions – factors such as these all limited capacity to best engage. For example:

'It's been quite difficult to get numbers and volumes to go into the cohorts cos for quite a long time we didn't have any admissions and we couldn't take in admissions on a regular basis which means our staffing levels have now kind of quite tight. So, for us releasing them has been a bit of a tricky.' (FG1, Care Home Managers)

There were also some practical barriers such as training space and transport to venues as follows:

'A lot don't drive. They live very close to the home. So they live within walking distance. So, to go to [ANOTHER CARE HOME] it's quite a long way. So it was us getting used to planning, somebody putting people on because of cohorts so there was always a driver. Or making

sure I hadn't booked an appointment so that I could take them. There was somebody there to take them pick them up. So, that was quite difficult.' (FG1, Care Home Managers)

However, overall the discussion about barriers was limited.

Appendix 1 presents further examples of the outcomes identified by care home and HiyCH staff.

5. Discussion

The findings show that through the HiyCH project hospital admissions have been reduced. It is not possible to identify exactly what elements of the project led to this change regarding the attention to urgent referrals, advance care planning activity and the on-going support primarily through the educational provision. This multi-component approach reflects that most initiatives to implement palliative care have multiple components often including educational strategies as one element (Van Riet Paap et al 2015).

The complexity of the project is also seen in the way in which elements of the project were both a part of the implementation process but also an outcome. For example, the resident status meetings were an activity introduced in the project to aid advance care planning, but also became a 'new' practice (outcome) for care homes. Similarly, monthly manager's meetings were a part of the 'process' and an expectation of participation in the project laid out in the terms of engagement, but also resulted in a valued and supportive network an 'outcome.' The identification of three stages of establishing the project (initiation, assimilation, and everyday running) proves a useful framework for future work with the expansion of this project or in new initiatives elsewhere.

A focus on hospital admission raises questions about the appropriateness of such transfers, which are linked to the resident's particular health needs, alongside their preferences for care. Collating these different elements in acute situations is challenging and responses to such changes will reflect ongoing relationships within and external to care homes with primary care providers (Gage et al, 2012). There are assumed cost savings to the local health economy in resident deaths in a care home rather than in hospital, but the extra cost to care homes and those supporting them, e.g. hospice, is not always addressed in commissioning.

The impact of this project has gone beyond the service outcomes. The confidence of staff and therefore the organisation and their place in the local health and social care economy was reported to increase. Care home staff and managers described themselves before the HiyCH initiative as being isolated. They now described feeling supported and allied to other services. Interestingly this also led to greater independence in care. An example of this was the accounts of situations where they had avoided district nurse call outs for syringe driver management. Underpinning this was the valuing of care home staff by the project as exemplified by the awards ceremony. This had the effect of raising the profile of care homes more generally within the locality.

The increased confidence, described by staff, was built though the approach of the HiyCH Team as much as via the skills taught and the information received. This facilitative approach was both a part of the delivery of the project and an outcome. The importance of facilitation in ensuring the effective delivery of interventions into care practice cannot be underestimated and has long been acknowledged in the literature (Kitson et al, 1998). Specifically in the implementation of palliative care with care homes, the impact of high levels of facilitation has been demonstrated (Kinley, 2014). This facilitation approach that had most impact upon implementation was called 'being present' and required skill and mastery by the facilitator to work with care home staff.

Barriers, although hard to elicit, for all care homes lay in in the sector's structures leading to on-going issues regarding staffing levels and therefore availability for training. The 'status' of the hospice and what that conferred to the care homes participating was important and helpful. However, in the longer term, if the project expands there is the potential to confer risks for the hospice of their reputation. It is worth considering if their reputation could be compromised and/or unreasonable expectations of the care homes and their delivery of palliative care. Care home staff raised this issue in terms of accreditation being a way to ensure standards, but this has costs attached to it, which may be inappropriate.

The crude costing work undertaken demonstrates that there are costs to both the hospice as a provider of this project, and also to the care homes in terms of their participation with respect to staff time and ultimately salary. However, some of these costs were underwritten by staff themselves as they attended in their own time. Further work could be done to determine these costs more accurately.

Finally, the concept of the initiative as a 'movement', as described by participants rather than a discrete activity seems appropriate due to its wide-reaching impact and uniting of health and social care workers across the locality. This has the potential to link into other wider movements such as compassionate communities (Kellehear, 2005), whereby the health and social care sector works with the public and other third sector organisations to create a community which can address palliative and end of life needs in whatever context.

5.1 Limitations

The limitations identified with the evaluation concerned primarily the quality of the data and assumptions made in cost calculations. The data collected regarding service provision and outcomes and in the qualitative interviews had its limitations, owing to the different sources used to ascertain figures. The service provision data relied on the quality of care home supported by HiyCH records. The data sources external to the project, for example regarding hospital admissions was also inconsistent in its availability.

With respect to the qualitative interviews the sample reflected the population working in care homes and hospices. There was therefore limited diversity in the sample of people who participated in the empirical research. All participants were female (except one) from an older population (mainly at least 50 years old). This workforce was also predominately established workers in their respective sectors. The evaluation was undertaken in one locality and through the project a close network was being established. Consequently here may have been a social desirability bias in reporting their experiences. Not all care homes were equally represented. For example, one home manager not spoken to at all due to staff change-overs;

It is also acknowledged that the costing figures are an underestimation of care home staff costs, as they we based on the care assistant salaries not registered nurse or manager salaries. The figures also do not include travel time for care home staff or HiyCH team members to training venues. The cost saving to the hospitals of increased deaths in the care home are also not identified.

6. Conclusions and recommendations

This small scale evaluation has provided an overview of the ways in which the Hospice in your Care Home project has made a difference to the provision of palliative care for residents and their families, living in some of the care homes within the Wigan and Leigh locality. The success of this project is based on the objective measure of reduced hospital admissions, increased advance care planning and the reported benefits to care home managers, staff and their residents, The change in outcome measures reflects the educational expertise, qualities and processes of the HiyCH team and their ability to engage with staff in a supportive and flexible way. Identifying these key attributes and the phases of project initiation, assimilation, and everyday running offers a model that has the potential to be expanded and delivered in other locations.

6.1 Recommendations

For Wigan and Leigh Hospice

- Maintain the champions meetings and develop into a wider network to include other professionals and build upon developing relationships within the health and social care economy;
- Maintain the current ethos and approach and find ways, if the scale increases to avoid compromising the flexibility of the team; this includes building upon the success of the awards ceremony;
- Consider accreditation of some description to formalise the status of care homes involved;
- Consider how the terms of engagement contract offers a tool to ensure sustainability as managers change and how it might link into any accreditation process;

- Develop information/terms about the early stages of the project (initiation stage) for residents/families (more public information) to raise the profile and manage the expectations of what type of service delivery could be expected.

Future research

- Develop audit mechanisms to collect ongoing data in a consistent way
- Look in more detail at confidence as an outcome of this model, both qualitatively and also objectively
- Consider more detailed costing of the activities to give more accurate figures for the project and where costs lie

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Appendix 1

A reflection on the change in skills and confidence of care home staff in dealing with End of Life from before to after the training.

We had some consultants […] doing some other research […] and they wanted to speak to a couple of people who had been involved in end of life care and they were having this conversation. It was dead confident and I kind of kind of stood back and I thought, wow. You know in five years it was like 'will you come and help me with this? I can't have this conversation[…] I can't talk about that.' And I was kind of astounded. I was kind of taken aback really because although we have been trying for so long to embed it they actually well it was just wonderful to hear (FG1, Care Home Managers)

A reflection on the outcomes of the HiyCH Initiative

There is nothing better than a relative coming to you, I mean I had a lady who went to a funeral last week and I had not seen obituary in the paper but one of my staff said to me, 'Have you seen it?' I said 'No', and they had put in it [the obituary] that she died in her home. And that all I want […] I mean I have quite a few that said recently 'She couldn't have died in a better place.' That's all you want, just that recognition that yes, you have got it right. (FG1, Care Home Managers)

An example of a care home staff member dealing with resident family further to HiyCH training

I think it helps you to deal with it bit better especially with the families because I struggled with families especially on the end of life, because families can ask you tough questions like 'Is she going to be here tomorrow? Is she going to be here next week? 'Has she got an hour to live?' and obviously, you can't answer that question. We had a tough one a couple of months ago, and she was on the end of life and the son was totally devastated. She was eighty six, and she was definitely end of life. She just had the syringe driver put in so that she was more relaxed and not restless but the son was still in a bit of denial as in she could perk up or she could get better. And if anything happened 'I want you to resuscitate her I want her to come back.' And obviously with the help of the hospice team, they were fantastic. We have resident status meetings every month where they help us with the families, to chat to the families and I must say I feel a lot more confident talking to a family member knowing that what I've learnt I can pass on to them, and I'm not saying the wrong things[…]. And it can be hard but I do feel a lot more confident in that respect with the families, and feel confident that I know what I'm talking about […] and helping them plan for end. (FG2, Care Home Staff)

An example of a 'good death' attributed to the HiyCH support

We had a really positive experience. It was Christmas Day and a lady, she actually passed on Christmas Day. But the family had said it was so nice cos they even bought a Christmas tree

up and everything. She had a nice room and they said it was such a lovely experience with her because it was like being in her home. And they had the children and it was it was a nice for them so that was really positive that we were able to do. Cos she was initially in hospital. She had gone in with something and then they kept her in but the family were pushing because they knew that we had the hospice supporting us [so] the family were pushing for her to come out and she came out. I mean she only came out for a couple of days but they actually said it was so much better for them because it wasn't clinical and lovely so that was good experience for them and us. (FG2 Care Home Staff)

A 'before and after' – improved confidence with clinical practices and communication about end of life

I think one which has helped me personally a lot, and speaking to the staff, is about when you should give anticipatory medication especially midazolam and diamorphine. And I have to hold my hand up in the past years ago, I've given it when I've not necessarily wanted to give it, and I've given it because the family have put me under a lot of pressure to give it. And that is a very difficult issue to deal with, because it's very difficult to tell a family, 'I'm not going to give that because I don't think they [THE RESIDENT] need it.' But they are saying 'But they are restless' or 'They are in pain'. And I think one thing [that] the nurses [HiyCH Team] being with the team have made us realise it's to be […] confident and not to be bullied. And asking them to leave the room. Like we used to always be always thinking What shall we do? We need to give them pressure relief for the family. We don't want to tell them to go, but then again we don't want to do everything in front of them. And it's been nice to sort of say, 'No' [and] ask them to leave the room like you would with anything else, and just have that confidence to think that dealing with death doesn't mean that they have got the absolute ultimate decision, it still has to be something that we are dealing with when you are giving those sort of medications. I've done it loads of times [before]. Should I? I don't think so. But go on I will give the lowest dose because the family is hovering behind me. (FG2, Care Home Staff)

An example of a tool implemented by the HiyCH team

I think the other thing […] that we sort of have been very keen to bring in and maintain in the homes is that sense of dignity and respect as well, and we have a sign which we use which we call our dignity signal don't we. It's a lovely sunset, a very serene sunset and we ask the staff to use that when somebody is dying, approaching the end of their life and it's a symbol for all the staff to know that in this particular area there is a family in vigil or there is somebody dying and please be dignified and respectful in this area. And that's working quite well, or likewise if they need to have a discussion with the family in another room if they can put that on the door it signified that there is a conversation here please do not disturb. You know and again, we're beginning to see that it being used a lot more. (FG3 HiyCH Team)

An example of needs-led training delivery

A gentleman in one home who had a cancer that was at risk of […] having a major bleed in the cancer because it was near his carotid artery and they didn't know how to manage that. They didn't actually know that somebody could have a catastrophic haemorrhage from a cancer. So, that was an example of where we said 'Right, we will put some training on around that' but we opened that up to the other homes as well. So yes, if there is things that they want us to do we will try and accommodate them. (FG3 HiyCH Team)

An example of supporting staff to undertake ACP in all situations

Just an example of the advance care planning process which we do- I was in one of my homes last week and one of the health care assistants [….]. There was a lady with capacity of her completing the ACP but she's had a very severe stroke and was unable to verbalise. And this care staff who looks after her has a very intimate relationship with this lady and really understands her and can communicate with her. So we talked about the ACP and she'd offered the lady the opportunity and the lady agreed, and the care staff said to me beforehand 'I'm not very good at doing this 'cos I can't spell very well and can't write very well.' So I said 'well don't worry about that we'll sort it out.' And her ability to communicate with the lady through her eye movements and her facial features was tremendous, and she actually completed the care plan with this lady […] I was almost tearful with the way that she approached the questions and it was the first one she'd ever done. You know and to me it's so important to acknowledge and to nurture that.
(FG3 HiyCH Team)

A reflection on the experience for the residents' families

We had a family come only two weeks ago, from this unit, a mental health unit. The team were involved in supporting the residents in there that were dying and role modelling with staff. And the family came into the hospice about two weeks ago, with a donation and they were just overjoyed with the fact that the hospice team had been involved. (FG 3, HiyCH Team)

Examples of the responsiveness and needs-led approach of the HiyCH Team

During FG1 with the Care Home Managers, one participant raised that she would like training or guidance around Organ Donation. It was immediately confirmed by the other managers that this had been arranged and someone was due to come and talk with them about this issue at the next Managers meeting. Also, during FG2, one of the HCAs advised that they had a problem getting through on one occasion to the HiyCH Team regarding how to arrange Last Rites for a resident. During the course of the session, it also transpired that this had already been addressed by the HiyCH Team. (Researcher Fieldnotes)