

VOICES – HOSPICE

Phyllis Tuckwell Hospice Care



Phyllis
Tuckwell
Hospice Care

...because every
day is precious

Reporting period
April 18 – July 18

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SUMMARY

Key findings

- ❖ The PTHC VOICES – HOSPICE Survey 2018 achieved a response rate of 46%.
- ❖ The care across the In-Patient Unit and the Community (Care at Home) was rated as exceptional or excellent by 98% of respondents.
- ❖ For those who had discussed and expressed a preference with their relative/carer, just under two thirds (63%) said they would like to die at home with 35% saying the Hospice.
- ❖ The most commonly recorded place of death was at Phyllis Tuckwell Hospice 49%.
- ❖ Pain was relieved well – more so in the hospice setting than at home.
- ❖ 99% of respondents said they would recommend PTHC to friends and family if they were in need of similar support.

Summary - findings

Phyllis Tuckwell Hospice Care (PTHC) is committed to the delivery of high quality care and to a process of continuous service improvement. Seeking the views of people that use the service is vital in achieving this. Within the setting of palliative care, response rates are often low – PTHC are pleased to report a response rate of 46% in this year's VOICES survey.

When asked about the support the patient received with financial, spiritual and family matters more respondents (particularly for patients that had been on the In-Patient Unit) than in 2017 indicated that this was required, where this was a need the results show that it was well met. Again more felt that emotional support was a need and this too was reported as being well met.

The relatives/carers were asked about the information and support that they had received. The vast majority said that they were always or usually kept informed. Emotional support for them was also an area of high satisfaction.

In reference to the In-Patient Unit (IPU) - respondents were asked if there had been enough nursing care and help available - all agreed. The care received from both doctors and nurses was rated very highly with 99% in the exceptional or excellent category. The high rating continued when asked if the patient was treated with dignity and respect with 96% reporting 'always'.

In the home setting most respondents felt that the patient saw the nurse as often as needed, with 89% saying that this was always the case. The care the patient received from PTHC Care at Home Team was rated very highly with 95% in the exceptional or excellent category. When respondents were asked, overall had they and their family got enough help and support, 89% agreed that this was the case.

Support with symptoms and pain relief

Respondents reported that patients received good support with symptoms other than pain, this was managed better than last year on the IPU, slightly less so in the home setting. Pain was generally managed well although the results indicate not as well as last year across both settings (see graphs on the next page, the results from 2017 are also included).

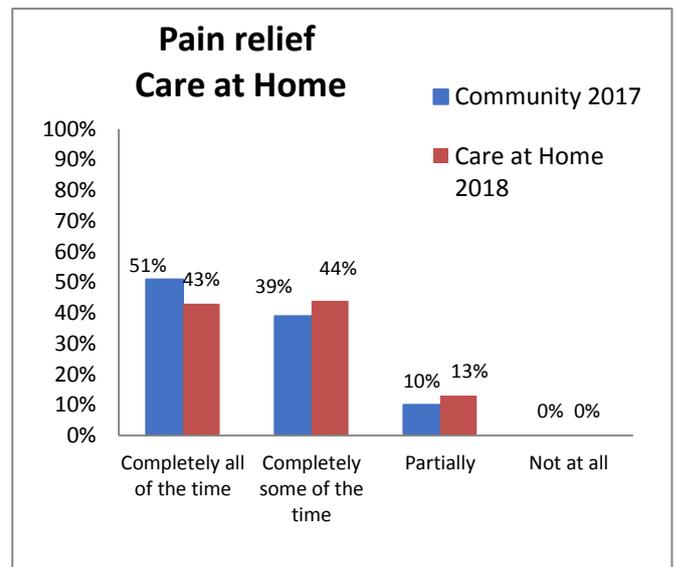
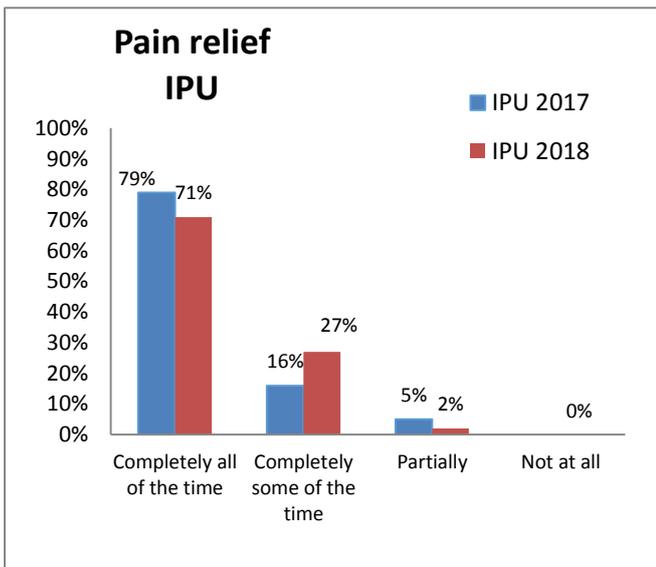


Figure 1a & 1b

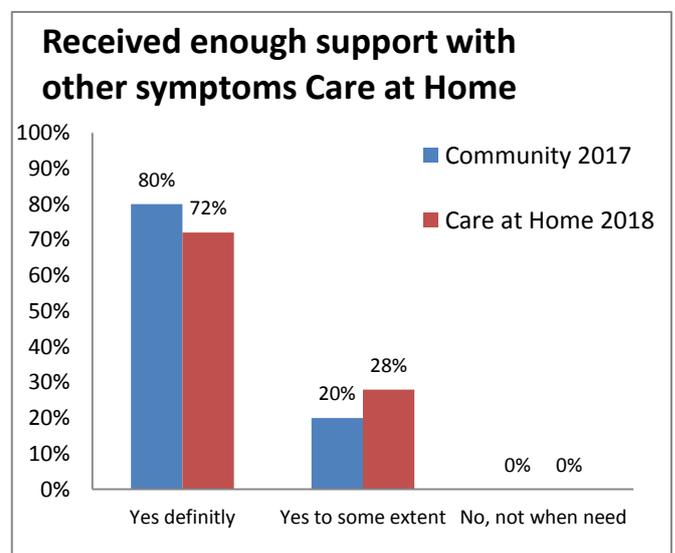
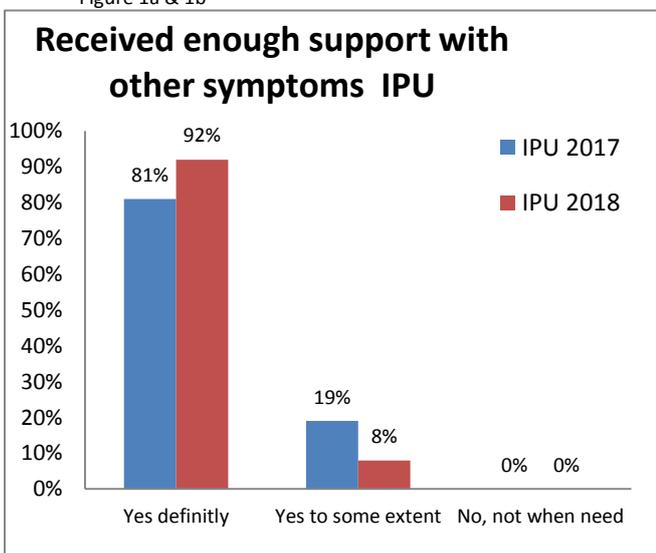


Figure 2a & 2b

The graphs use the responses where this was relevant i.e. excluded 'does not apply' and 'don't know' responses

Circumstances surrounding death

Most patients had expressed a preference about where they would like to die - 63% wanted to die at home. The survey also provided information on where the patient actually died - 38% of patients (n=32 total sample 84) died in their home and 49% (n=41) died in the Phyllis Tuckwell IPU. The proportion of people dying at home and in the Phyllis Tuckwell IPU has reversed from last year (2017, IPU = 35%, Home = 45%). The number of patients dying in hospital has decreased to 6% compared to 15% in 2017.

NB This is based on the data from returned surveys and may not be truly reflective of all patients and their families that had accessed PTHC services in the months leading up to their death in this survey period.

Although less people died at home than wanting to, the vast majority of respondents, that expressed a view, thought that 'on balance' the patient had died in the right place (96%).

Over half (60%) of the respondents said that they didn't want to talk about their feelings surrounding the patient's death. Those that did talked to a bereavement counsellor or nurse. Most respondents, who received the literature produced by PTHC about bereavement services found the information helpful.

Summary – implementation

The VOICES survey was run over a three and a half month period with 181 surveys sent - the response rate was good (46%). The data was collated and entered on to a database, it was then interpreted and a report written. The whole process was completed by the project lead. In terms of feedback the quantitative and qualitative data provides PTHC with a good sense of how its services are meeting the needs of the community. The data will also feed into service improvement and development.

The project has demonstrated that the VOICES – HOSPICE survey provides a validated method of measuring the impact and outcomes of hospice care. It is being used by a number of hospices and so there may also be an opportunity for benchmarking.

SECTION 1

Introduction

This report presents the findings of the VOICES - HOSPICE survey conducted at PTHC over a three and a half month period in 2018. (The survey is a validated service evaluation and quality assurance tool for use in hospices). Its aim is to evaluate what bereaved relatives think about the quality of care provided by a hospice to patients and families before the patient's death, and to themselves in bereavement.

The central domains of measurement include:

- Inpatient care
- Care at Home (all services delivered in the home i.e. nurses, therapists, doctors)
- Living Well (Including Day Hospice, group sessions and Outpatients)
- Care provided at end of life
- Bereavement care

The VOICES survey was conducted for the fourth time in 2018 and provided valuable information about the service patients and carers receive - both quantitative and qualitative. This was reviewed by the clinical teams and used in the continuous improvement and development of services. The Senior Clinical Team reviewed the use of the tool itself and the data it generated and agreed to incorporate it as a regular tool in the governance and performance measurement structure.

The survey was developed jointly between the Southampton University School of Health Sciences and St Christopher's Hospice, London. It is based on the National Bereavement Survey – VOICES conducted by the National Office of statistics.

Method

Surveys were sent to 181 bereaved relatives of patients cared for by Phyllis Tuckwell Hospice Care over a three and a half month (fifteen weeks) period.

Patients

A list of deceased patients was taken from the PTHC electronic patient system and the data from patients that died in the set period collated. To be included in the final sample patients needed to have been receiving care and/or support by PTHC in the four months before their death and would have needed to have had at least one episode of face-to-face contact.

Relatives

The notes of the deceased patients were examined and a survey sent to the next of kin or main carer (often one and the same). For the next of kin or carers to be included they needed to be over the age of 18 and have the ability to complete the survey. The survey was sent twelve weeks post bereavement.

The surveys were formatted in A4 colour booklet style (appendix 4) and sent with a covering letter and with a freepost stamp address envelope included.

SECTION 2

Response rate

In all there were 315 deceased patients, known to PTHC, in the set period.

After examining the notes the final recipient sample (those relatives sent a survey) was 181.

181 surveys were sent out, 84 were returned = 46%

Completion

There were various levels of completion with some questions unanswered. Some had whole sections unanswered – this happened most frequently with the home care setting. This may have been due to uncertainty as to who they had seen and from which provider.

NB the project lead had allocated a number to each survey - allowing additional information i.e. which service had been accessed, to be gathered.

Respondents

Most commonly respondents were the spouse of the person that had died (64%), followed by daughter.

Service areas accessed - IPU/Care at Home/ Living Well

82% (n=69) of the patients accessed Care at Home

56% (n=47) of the patients accessed the In-Patient Unit

29% (n=24) of the patients accessed the Living well

Most had accessed more than one service. A quarter (21) had accessed both the IPU and Care at Home, 10 (12%) had accessed Care at Home and Living Well, 3 (4%) had accessed the IPU and Living Well and 11 (13%) had accessed all three services.

This confirms that patients are requiring different levels of support throughout their journey and that the flexibility and range of services provided by PTHC is providing patients with more choice about where they want to be supported and cared for.

SECTION 3: Findings – In-Patient Unit Care

Of the 84 patient sample 47 received care on the IPU. This equates to 56% (38 in last year's survey).

Of the 47, 21 had also been cared for at home and 3 had accessed Living Well and 11 had access Care at Home and Living Well in addition to being an inpatient.

Two respondents had not completed this section despite their loved one having been a patient on the IPU. The following information will refer to the information obtained from the 45 completed.

Of those who had been on the In-Patient Unit over half (60%) had stayed between 24 hrs and two weeks. Of the others, 31% had stayed 2-4 weeks, and 5% had stayed over four weeks. Only 4% had stayed for less than 24hrs (10% in 2017), indicating that there may be greater understanding of the dying phase and that referrals to the IPU (particularly from hospitals) are being made before the patient is actively dying.

NB Percentages in the following sections are based on the questions completed. Some free text comments are included.

Help and support available (Q3 &4)

Respondents were asked to consider the amount of personal and nursing care available and the adequacy of the general environment and bed area in providing privacy. With reference to personal and nursing care 72% 'strongly agreed' and 28% 'agreed' that there was enough personal and nursing care available, a slight reduction in the number 'strongly agreeing' than in 2017. In terms of the privacy provided 78% 'strongly agreed' with a further 20% saying that they 'agreed', 2% neither agreed nor disagreed, this has improved since 2017.

Respondents were asked to consider the amount of support that was available. When asked if there was enough emotional support 84% said 'yes definitely', 7% said 'yes to some extent', 2% (n=1) said 'no not when needed', 2% said that 'this type of help was not needed', 5% answered that they didn't know.

More respondents than in 2017 felt that there was a need for religious and spiritual support with only 35% said that this was not needed (54% in 2017). When asked if these needs were met ('not needed' and 'don't know' responses excluded) 63% said 'yes definitely' the remaining answered 'yes, to some extent'.

In reference to support dealing with family concerns again more respondents felt there was a need for this kind of support with only 39% saying that this was not required (50% in 2017). When asked if these needs were met ('not needed' and 'don't know' responses excluded) 92% said 'yes definitely', the remaining replying 'yes, to some extent'.

Support dealing with financial and practical matters was reported as not needed by 68% of respondents, 21% said there was 'definitely' enough support, 2% stating 'to some extent', the remainder didn't know.

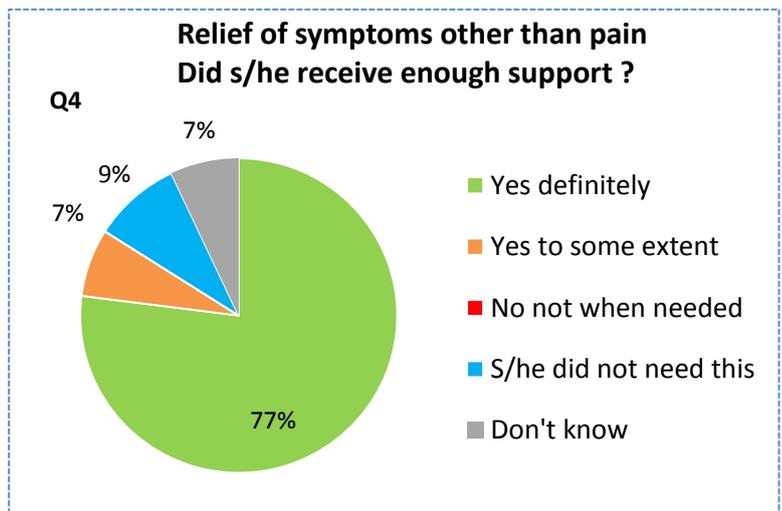
"The assistance, care and support was wonderful. My wife died in my arms which is what she wanted. The Hospice and staff were wonderful-help when needed and privacy when required."

"I can't think of a better place for my mothers last days to be spent. The care they have for the patients is second to none. I would say to anyone, if you were lucky enough, to be offered a bed there, take it."

Care and Treatment (Q4)

When asked about whether they received enough support in the relief of symptoms, other than pain, all, for which the question was relevant, answered positively.

Figure 3



In reference to the care they received from both nurses and doctors the results were very good. (Q13)

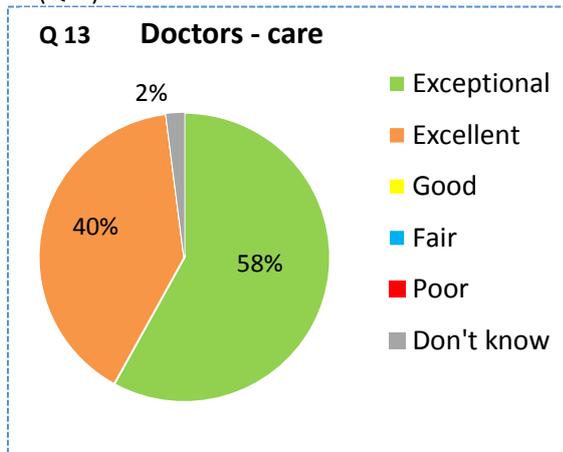


Figure 4a

Figures 6 a & b

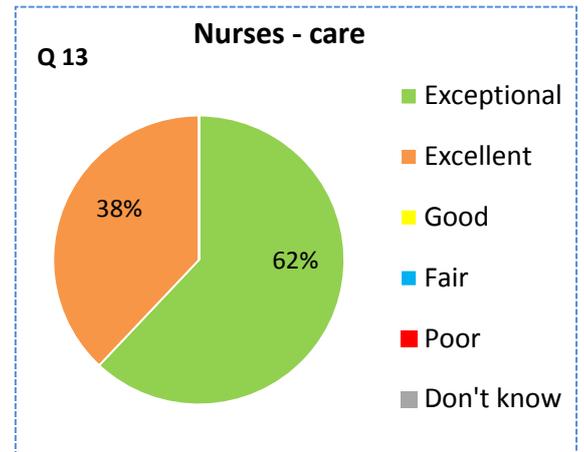


Figure 4b

When asked “How much of the time was s/he treated with respect and dignity by doctors and nurses”? (Q9). The results were again very positive:

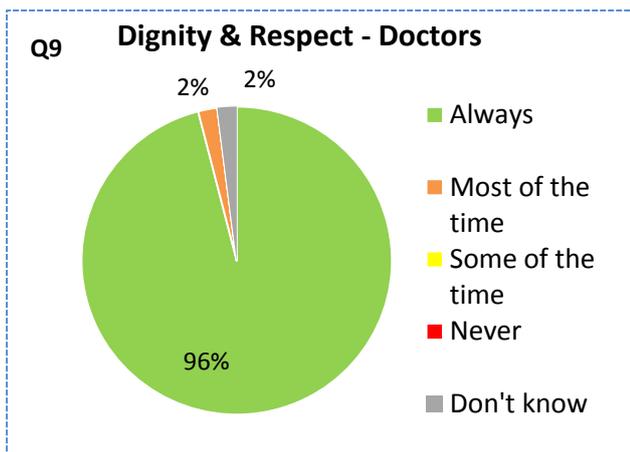


Figure 5a

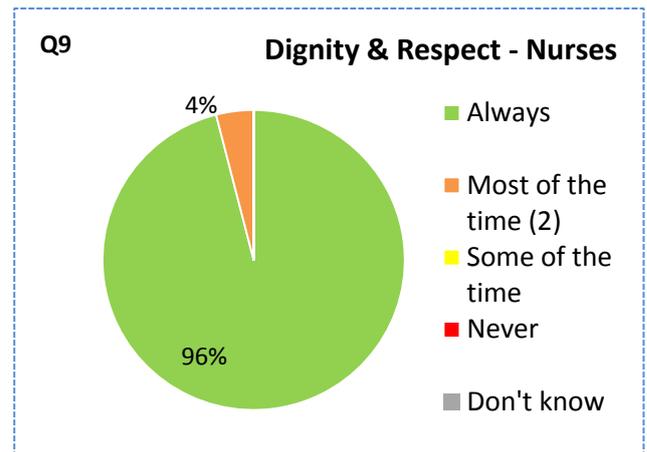


Figure 5b

Respondents were asked how well the patient’s pain was relieved (Q5).The results were generally positive.

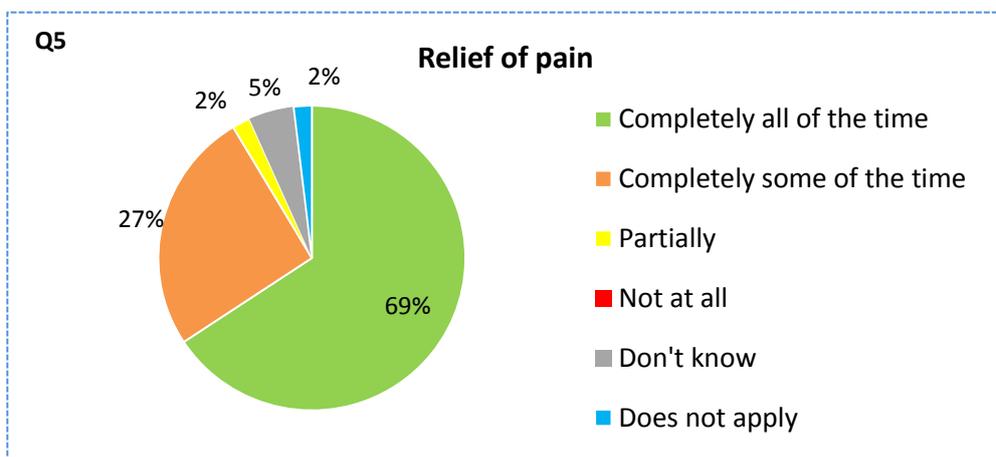


Figure 6

Communication and involvement (Q8 & Q10)

When asked “were there any decisions made about his/her care or treatment that s/he would not have wanted” 11% didn’t know, all the remaining (89%), answered positively with a ‘no’.

In reference to whether the Phyllis Tuckwell worked well with the patient’s GP and other services - most thought that this was the case with 67% saying ‘definitely’ (55% in 2017). This suggests stronger relationships and increased collaborative working. No-one thought they didn’t work well together, 20% said ‘yes, to some extent’, the remainder (13%) didn’t know.

Food and comfort (Q14)

68% of respondents, who rated the food given to their relative, reported it as either ‘exceptional or ‘excellent’, with the remainder, 32%, saying ‘good’.

Environment

Question 15 asked about the comfort and pleasantness of different areas the Hospice. The answers were as follows:

Room	Excellent 76%	Good 24%	Fair 0%	Poor 0%	Don’t Know 0%
Bathroom	Excellent 55%	Good 23%	Fair 0%	Poor 0%	Don’t Know 18%
Communal areas	Excellent 60%	Good 36%	Fair 2%	Poor 0%	Don’t Know 2%
Coffee Lounge	Excellent 53%	Good 42%	Fair 0%	Poor 0%	Don’t Know 5%
The Garden	Excellent 80%	Good 20%	Fair 0%	Poor 0%	Don’t Know 0%

There was an increase in the number of respondents reporting the facilities as excellent than in the 2017 VOICES Survey.

The survey also asked whether the patient was in a single room or a four bedded bay. 58% had stayed in a side room, 18% in a four bedded bay (24% had stayed in both).

“Everyone at Phyllis Tuckwell made the place comfortable and special rather than frightening, sterile and crowded. Everyone is amazing. As a family and the patient we were very lucky to have Phyllis Tuckwell Hospice Care and will do all we can to support it.”

“Phyllis Tuckwell did an amazing job in trying to make it home from home.”

Support and communication (direct question to relatives/carers) (Q6 & Q7) & (Q12 & Q11)

When asked if the explanations about treatment and tests were easy or difficult to understand, of those that answered, 84% said ‘very easy’, 14% ‘fairly easy’ with 2% (n=1) saying fairly difficult.

They were also asked if they and/or other family members were kept informed about the patient’s condition, 84% said ‘always’ with the remaining reporting ‘usually’.

When asked about whether they themselves received enough emotional support from the Phyllis Tuckwell team there was a very positive response, with 85% saying ‘yes definitely’, and the remainder saying ‘yes, to some extent’.

When asked about staying in the IPU/relatives room overnight, 41% had stayed.

SECTION 4: Findings – PTHC Care at Home (defined for the purposes of the survey as :- ‘Clinical Nurse Specialists’(CNS), ‘Community Doctors’, ‘Hospice Care at Home team’, ‘Community Therapists’ and the Patient and Family Support team.)

Of the 84 respondents who completed all or part of the survey, 63 stated that the patient received care from the PTHC Care at Home Team. The true figure was 69, as 6 more had also received support at home, but had not completed the section. This may be due to respondents being unsure as to who had provided the care due different health care professionals from other providers contacting or visiting the home.

Overall 82% of the patient sample had been supported in their homes – much the same as in 2017 VOICES survey.

Of the 69, 21 had also been on the In-Patient Unit, 10 had been supported by Living Well and 11 accessed all three services.

Most had been supported by either the CNS team (60) or Hospice Care at home (45) – many by both (39). The majority had received support from multiple clinicians e.g. doctors, therapists and a Psychologist. Only (6) had received care from HCAH without CNS input, a small number (3) had been supported by only clinicians other than CNS and HCAH.

The following information will refer to the information obtained from the 63 completed surveys.

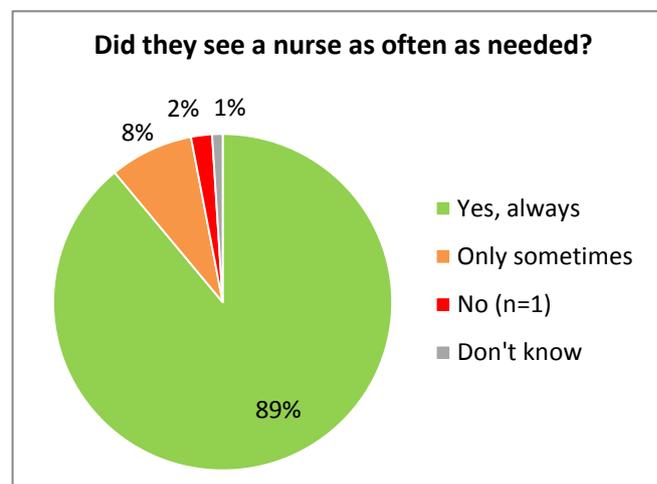
NB Percentages in the following sections are based on the questions completed. Some free text comments are included.

Help and support available (Q17)

Respondents were asked “Whilst receiving care from the PTHC Care at Home Team, did s/he see a member of the team as often as it was needed?”

The majority thought that their relative did see a member of the team as often as needed. One said ‘No’.

Figure 7



Respondents were asked to consider the amount of support available for their loved one. In terms of emotional support - 71% said ‘Yes definitely’, 18% ‘yes to some extent’, 8% said that ‘this type of help was not needed’, 3% didn’t know.

“Wonderful team, best care for my husband, great care and consideration for me too”

For religious and spiritual support 66% said that this was not needed, 22% agreed that there was support, the remaining 12% didn’t know. The results were similar when asked about support with financial matters, with 67% saying that it was not needed, 26% agreed that there was support, the remaining 7% didn’t know.

When asked about support with family concerns 47% said that this type of help was not required, 31% felt that the patient definitely received enough support, 12% stated 'yes to some extent', 3% (n=2) said 'no not when s/he needed it', 7% didn't know.

"We were extremely fortunate to have such an incredible resource in our locality. We thank you for all your support from diagnosis to mums passing. We are SO grateful"

When asked about receiving help with urgent problems in the evening and at night many reported that this had not been required, 44% & 39% respectively. If only looking at cases where help was needed i.e. excluding 'not needed' and 'don't know', regarding the evening time 81% said 'yes definitely', 8% said 'yes to some extent' with only 11% (n=3) saying 'no not when needed'. For night time 72% said 'yes definitely', 14% said 'yes to some extent' with 14% (n=4) saying 'no not when they needed'.

The results indicate that patients' needs are generally being met outside of 'regular hours' NB Locally care provision overnight involves Phyllis Tuckwell Hospice Care at Home and out of hours community nursing, social care services and medical services.

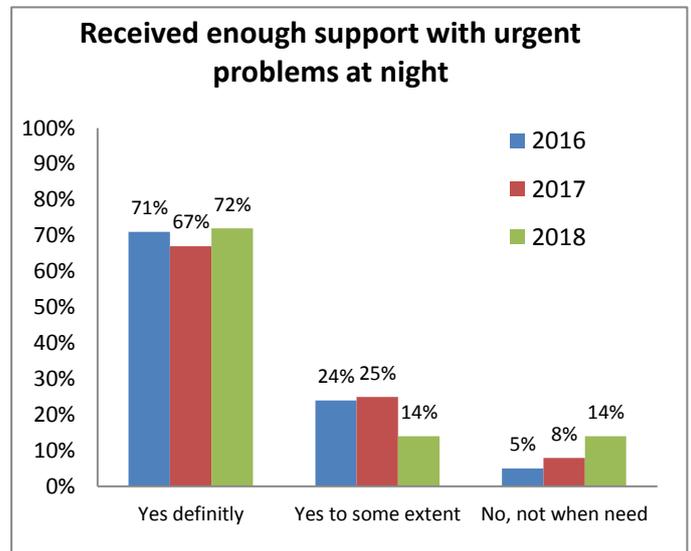
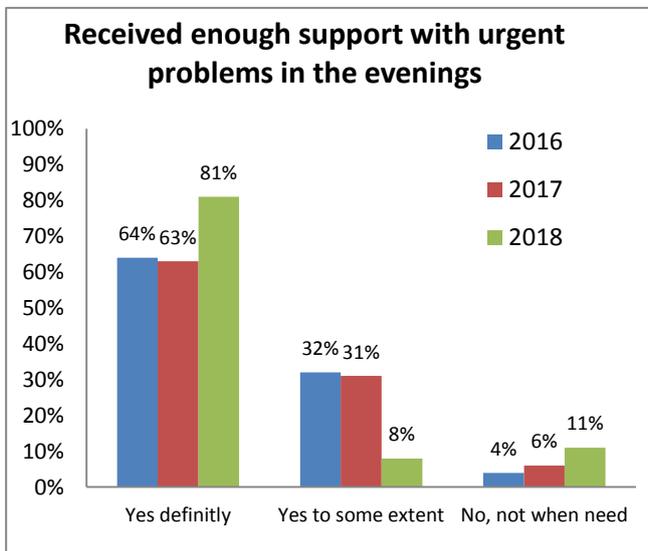


Figure 8a & 8b

Care and Treatment (Q19)

In terms of relief of symptoms, other than pain - all respondents, that reported this as a need, answered positively.

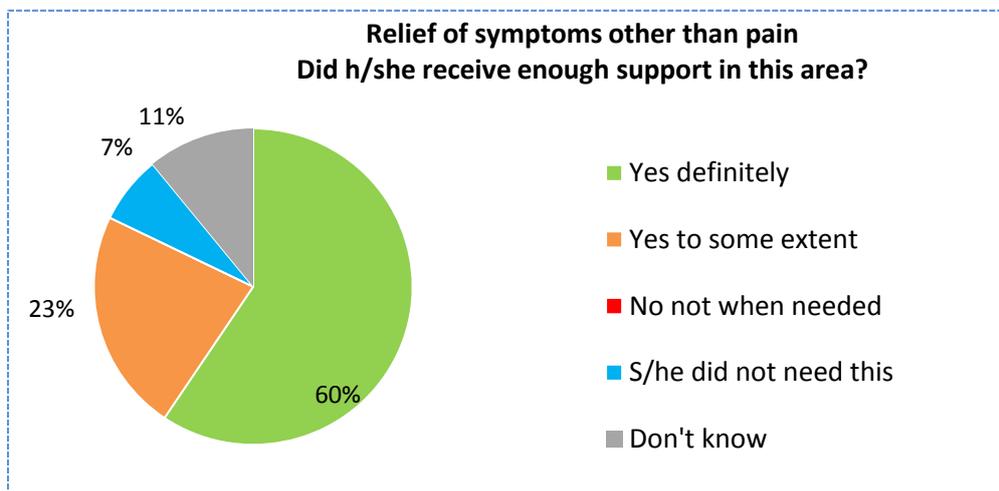
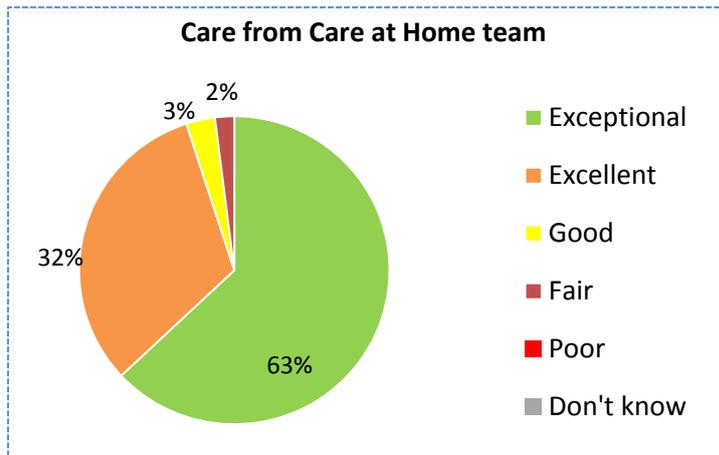


Figure 9

When relatives/carers were asked what they thought about the care the patient received (Q24) - the results were extremely good with 95% saying it was 'exceptional' or 'excellent':-



“Still finding it tough without mum, however the care mum received was truly exceptional. We referred to you all as angels and I will always feel blessed to have had the team help mum.”

Figure 10

When asked “How much of the time was s/he treated with respect and dignity by the Phyllis Tuckwell Care at Home team”? (Q18). The results were again very positive:

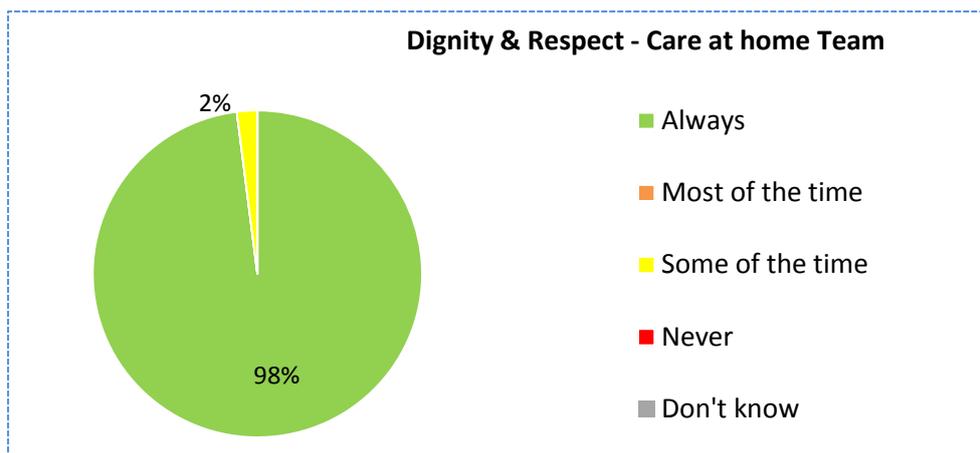


Figure 11

Respondents were asked how well the patient’s pain was relieved:-

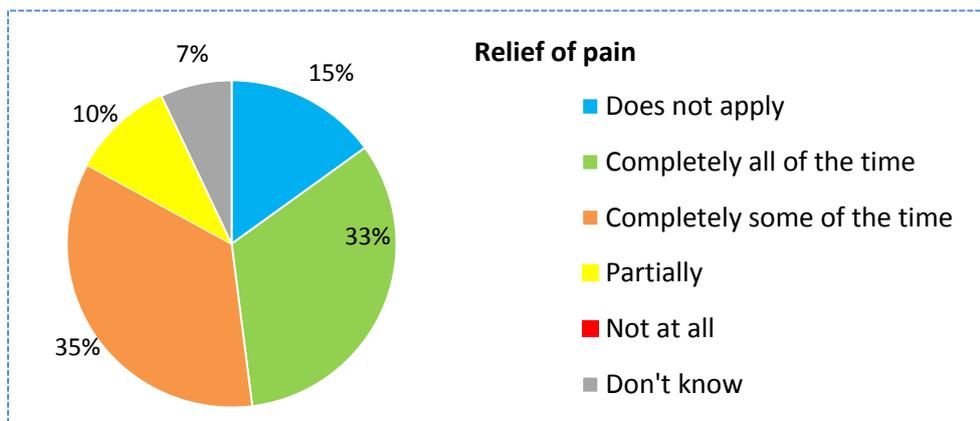


Figure 12

These results for how well pain was relieved were not quite as positive as in the In-Patient Unit,

Support and communication (direct question to relatives/carers) (Q 21, 22, 25 & 23)

When asked if the explanations about treatment and tests were easy or difficult to understand responses were positive with 76% saying 'very easy' and 19% 'fairly easy', one respondent said explanations were difficult to understand, the remainder (n=2) said that they hadn't had an explanation or hadn't spoken with a nurse or doctor.

They were also asked if they were involved in decisions about her/his treatment and care as much as they had wanted to be, 94% said 'yes, as much as I wanted to be', 3% 'would have liked to have been more involved' and 3% 'didn't know'.

The majority, 96%, said that staff had had time to listen and discuss things. One respondent answered 'no' the remainder didn't know.

Finally relatives/carers were asked - "Overall, when caring for him/her, do you think you and your family got as much help and support from the PTHC Community team as you needed?" (Q21)

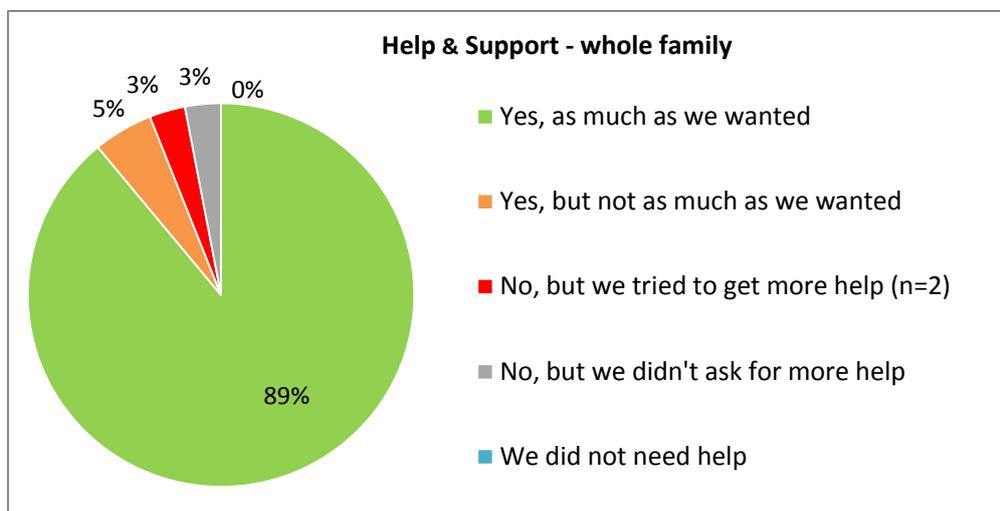


Figure 14

"The PTHC community nurse was outstanding, she was the glue in the communication and advice between family-GP-care home-patient."

"The team were amazing. They treated both my mum and myself with the upmost respect and were a godsend. If it wasn't for the team we would not have been able to fulfil my mum's wishes to die at home. Thank you"

SECTION 5: Findings – Living Well

Of the total 84 respondents 24 stated the patient had accessed Living Well Services (Farnham site Day Hospice and Group work and Outpatients on both sites) at some time before their death, this equates to 29% of the patients involved in this survey. None had accessed Living well in isolation; 10 had also received care in the community, 3 on the IPU, 11 had accessed all three services.

Of the 24, 13 had attended the Farnham Day Hospice. 18 had attended either outpatients (mainly counselling and therapies) or a group (including exercise, creative therapies and horticultural groups).

Relatives/carers were asked whether their loved one had benefited from attending sessions/appointments, all but one (who didn't know) reported that they had.

The respondent themselves were asked if they themselves had felt supported by the Living Well Team, all said yes.

SECTION 6: Circumstances surrounding his/her death

This chapter presents responses in a section of the survey concerned with seeking views about a range of aspects concerning the patient's death. All respondents are asked to complete it.

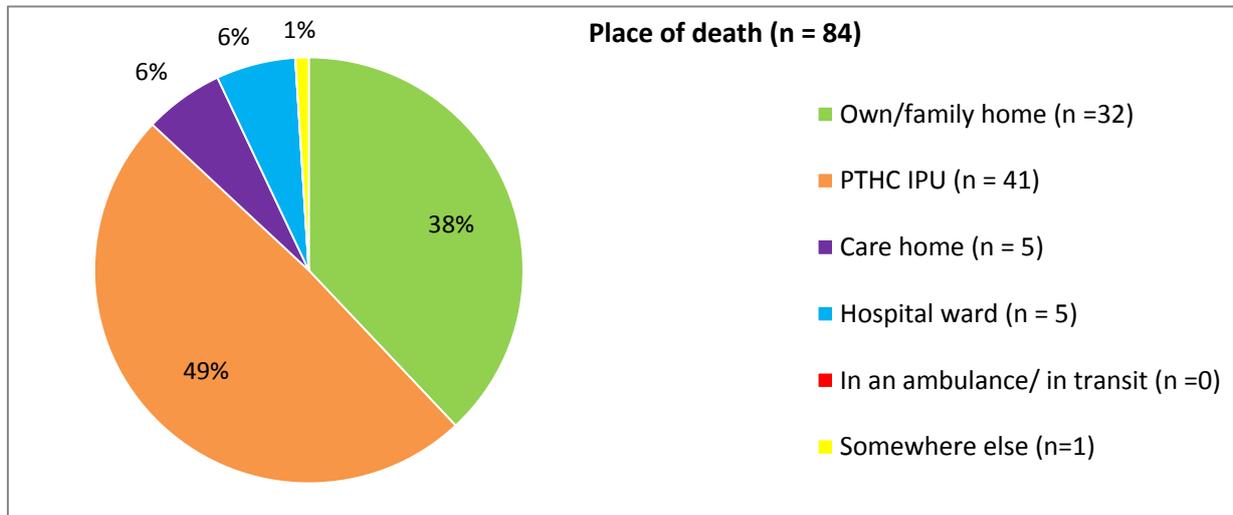


Figure 15

The picture has reversed from last year - with 38% of patients dying in their own home (45% in 2017), and 49% dying in PTHC IPU (35% in 2017).

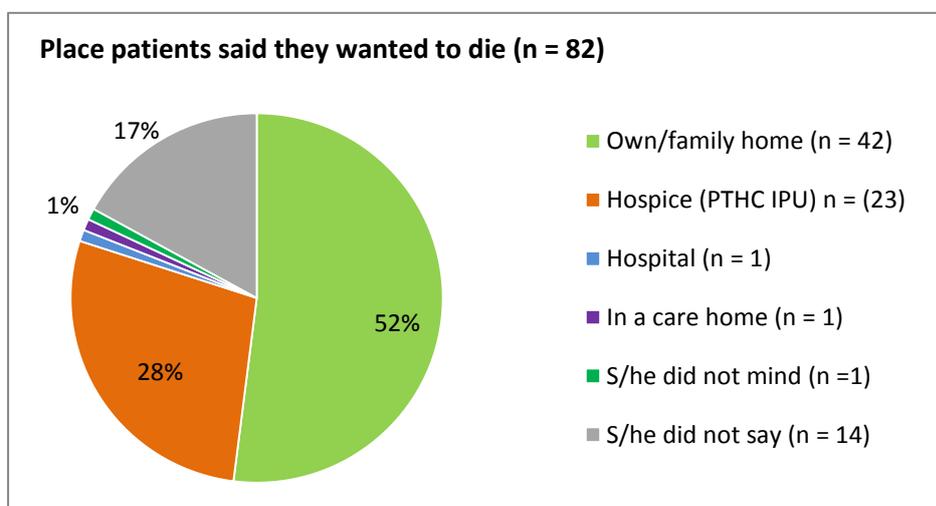
It is worth noting that most people consider the care home in which they live as their home. If this is premise is applied then the figure for people dying 'at home' increases to 44%.

Of the total 84 respondents 83 completed all or part of this section.

The following information will refer to the information obtained from the 83 completed.

NB Percentages in the following sections are based on the questions completed. Some free text comments are included.

Respondents were asked where the patient said they wanted to die. If only using the answers where the patient stated a choice – 63% stated the patient had wanted to die at home with 35% saying the PTHC IPU, one person said in a 'care home', another said in 'hospital'.



Graph also show numbers of responses
Figure 16

More people wanted to die at home, which is consistent with national survey data ^{ref 2}, although slightly less people had stated that they wanted to die at home than in last year's PTHC VOICES survey.

When comparing the percentage results between the two questions regarding where patients wanted to die and where they actually died (figures 15 & 16) it is evident that less patients died at home than had wanted – the percentage is slightly improved from last year.

However it is not uncommon for patients to change their mind about dying at home in the later stages of life ^{ref 1}, this may be supported by the responses of the following two questions:

- “Do you think s/he had enough choice about where s/he died?” In which 84% answered ‘yes’, 9% were ‘not sure’ and only 7% said ‘no’.
- “On balance do you think s/he died in the right place?” In which 88% answered ‘yes’, 8% were ‘not sure’ and 4% (n=3) said ‘no’.

“Without the Phyllis Tuckwell 'Angels' mum wouldn't have been able to stay at home, so I can't begin to thank you all enough. There are times in our lives that we may need help, as mum did. The help mum and I needed was very different however it was always unconditional and I thank you for that.”

“It was the very best possible outcome given the circumstances. I was thrilled he could die at home, in dignity and with as much peace as possible, surrounding by love.”

“Before his dementia became worse towards the end he always made it clear he wanted to die at home. And with the support of PTHC, the GP and the Community Matron I was able to fulfil his wishes.”

“I feel she would have liked to die at home. But as she was away in hospital, then Phyllis Tuckwell, and finally the care home for 5 months - that was her home. Moving her wasn't an option. She died with her family around her, which was priceless.”

“We had planned for her to die at home, but the escalation in the pain and the constant changes to drug dosage made this hard. Phyllis Tuckwell were very fast to make the change and find a place in the Hospice.”

Death on the Phyllis Tuckwell In-Patient Unit

As stated previously 49% of patients died on the In-Patient Unit. The relatives/carers were asked if they received enough support at the time of the death. All said ‘yes’.

Support in bereavement

Of the total 84 respondents all completed all or part of this section.

Respondents were asked if they had talked to anyone at Phyllis Tuckwell Hospice Care about their feelings surrounding the illness and death. The majority (60%) said they hadn't - but this had been their choice. 25% had spoken to someone and 11% said they would have liked to.

NB All the respondents that said they 'would have liked to' (talk to someone) had been sent details of the bereavement services offered by PTHC and how to get in touch.

Of those that had spoken with someone from PTHC - most reported to have spoken to a bereavement counsellor followed by a nurse.

"The leaflet explaining what was likely to happen as he got nearer death which I found helpful"

Bereavement information

PTHC offer bereavement support to all bereaved relatives and friends. The information about this support is provided in a number leaflets and booklets. This section asked all respondents whether they received information of this kind.

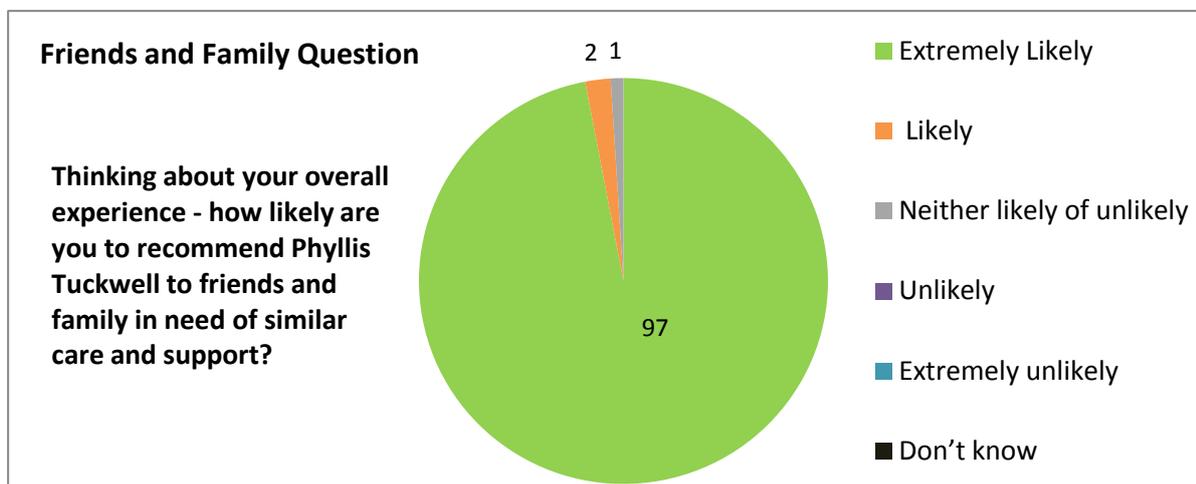
Firstly they were asked about a leaflet giving information about what to do after a patient's death. This is given to relatives/carers by the In-Patient Unit staff if the patient has died on the IPU and the community team nurses (usually Hospice Care at Home) if the patient has died at home. Most of respondents had received the leaflet. Of these, all but one, found it helpful.

Secondly they were asked if they had received a booklet called 'Breaking through the clouds'. This is sent to the relatives/carer listed on the bereavement data base generated from the bereavement referrals completed after death (*there is an option to not receive bereavement support information). Again, most said that they had received this and all found it helpful.

SECTION 7: Friends and family

The Friends and Family Test is feedback tool commonly used in the NHS. It asks people if they would recommend the services they have used and offers a range of responses.

The responses were extremely positive.



SECTION 8: Conclusions and recommendations

Conclusion

NB This is based on the data from returned surveys and may not be truly reflective of all patients and their families that had assessed PTHC services in the months leading up to their death.

In general, the feedback received from the 84 surveys reflects a high level of regard for the work of Phyllis Tuckwell Hospice Care, with the majority of carers very satisfied with the support provided to them and their loved one.

The 181 surveys sent indicate that the number of patients accessing PTHC services (fitting the criteria) is similar to last year. The data from the responses shows some differences in the services patients are accessing – the most accessed service is Care at Home, as it was last year, however more patients received care in the IPU than in 2017.

IPU

The carers/NOK (next of kin) of the patients that had received care in the IPU, rated the symptom management their loved one received highly – the results improving further on last year. However pain, specifically, was controlled less well than last year.

More respondents felt that emotional, spiritual and support with family concerns was a need with the majority strongly agreeing that the patient had received this.

In terms of nursing care and help with personal care there was a slight drop in those ‘strongly agreeing’ – with a shift to ‘agreeing’.

Communication with the patient’s GP and other services outside of the Hospice was rated highly, an increase from last year.

The overall care was rated extremely highly with the majority of respondents rating it as exceptional. All reported the patient was treated with dignity and respect.

The food was scored highly with the many rating it as exceptional or excellent.

The environment (bed space, bathrooms, communal areas, coffee shop and the gardens) improved its rating across all areas.

Care at Home

The carers/NOK of the patients, that had received care in the community, rated the care very highly, improving further from last year. The vast majority said that they had seen the team as often as was needed. They reported feeling involved in decisions and felt well supported. When asked about support in the relief of symptoms the patient received, the results were not as good as last year, see figure 1b & 2b.

In terms of support in the evenings and at night the results remained much the same as last year. There was some movement across the responses with more people definitely agreeing there was support available but also an increase in those saying there was not enough.

Living Well

The Living Well service is a new service so comparison data with last year is not available. It is encouraging that 29% of the sample (84) had accessed the Living Well services, many attending varied sessions and appointments at different times of need or support. This demonstrates the flexibility of the service and how it is helping patients manage the impact of their illness whilst still living at home.

In terms of the survey itself, one person said that they felt the survey had arrived too soon after their loved one's death (12 weeks) and was a little lengthy, but after leaving for several weeks felt able to complete. In total 7 respondents had indicated that they wanted to discuss their comments further. 6 were able to be contacted, all of these were just offering to provide further information if needed, all were very complimentary about the care they and their relative had received.

All comments are recorded and action plans, if required, drafted and discussed with the service Manager. This report containing all comments is presented at both the Clinical Governance and the Senior Clinical Team meetings (both have representation from all clinical services/areas).

Final note

Phyllis Tuckwell Hospice Care aims: - 'To care compassionately for adults living with an advanced or terminal illness, and those closest to them, so that they have the best possible quality of life and the patients' final days are peaceful' (mission statement). The results of this survey i.e. care across the In-Patient Unit and the Care at Home being rated as exceptional or excellent by 98% of respondents is a testament to the hard work and commitment shown by all the PTHC staff and volunteers. Feedback from this VOICES Survey will help us to continue improving our services supporting our vision of providing easy access to compassionate supportive and end of life care for patients and families in a place of their choice.

Recommendations for continued use of the VOICES survey

VOICES - HOSPICE is now established as an ongoing data collection method at PTHC. The planned cycle of a four monthly data collection period annually is providing quality feedback whilst remaining manageable in terms of resources. It is therefore recommended that the VOICES HOSPICE Survey continues on the same basis.

Any new methods or emerging tools for measuring quality is developed they will be discussed and considered by both the Clinical Audit and Research Group and the Senior Clinical Team.

NB this year only covered 3 1/2 months due to a change in the patient record system.

NB it is hoped that the National Office of Statistics (NOS) National VOICES survey will be recommissioned for 2019 which will allow future comparison of data.

SECTION 9

References and sources

1. Source: Gomes et al. Heterogeneity and changes in preferences for dying at home: a systematic review, BMC Palliative Care 2013, 12(1):7)
2. Source: National audit office report on end of life care 2008
<https://www.nao.org.uk/report/end-of-life-care/>
3. PTHC VOICES 2017 report
4. NOS VOICES report 2015
<https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/healthcaresystem/bulletins/nationalsurveyofbereavedpeoplevoices/england2015>

APPENDIX 1 – VOICES Survey

Please click on the image below - this can then be viewed or printed separately.



VOICES A4 booklet
2018 Final.pdf