

# **VOICES – Hospice**

## **Phyllis Tuckwell Hospice Care**



**Phyllis  
Tuckwell**  
Hospice Care

...because every  
day is precious

**Reporting period  
May 17 – Sept 17**

## **Contents**

<b>Summary</b>	<b>Pages 1 - 2</b>
<b>Section 1</b> Introduction Methods	<b>Page 3</b>
<b>Section 2</b> Response rate Completion Respondents	<b>Page 4</b>
<b>Section 3 - Findings: Inpatient care</b> Help and support available Care and Treatment Communication and involvement Food and comfort Support and communication (direct question to relatives/carers)	<b>Pages 5 - 8</b>
<b>Section 4 - Findings: Community care</b> Help and support available Care and Treatment Support and communication (direct question to relatives/carers)	<b>Pages 8 - 12</b>
<b>Section 5 - Findings: Day Hospice</b>	<b>Page 12</b>
<b>Section 6 – Findings: Circumstances surrounding death</b> Place of Death Death at PTH Support in bereavement Bereavement information	<b>Pages 13 - 15</b>
<b>Section 7 – Friends and Family</b>	<b>Page 15</b>
<b>Section 8 – Conclusions and Recommendations</b>	<b>Pages 16-17</b>
<b>Section 9 – References &amp; sources</b>	<b>Pages 17</b>
<b>Appendix one - Survey (attachment)</b>	<b>Page 18</b>

## SUMMARY

### Key findings

- ❖ The PTHC VOICES – HOSPICE Survey 2017 achieved a response rate of 49%.
- ❖ The care across the In-Patient Unit and the Community was rated as exceptional or excellent by 91% of respondents.
- ❖ For those who had discussed and expressed a preference with their relative/carer, over three quarters (78%) said they would like to die at home with 17% saying the Hospice.
- ❖ The most commonly recorded place of death was at home.
- ❖ Pain was relieved well – more so in the hospice setting than in the community/at home.
- ❖ 97% 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 49% in this year's VOICES survey.

When asked about the support the patient received with financial, spiritual and family matters the trend from previous years continued with many indicating that this was not required. The remaining reported that there was enough support available. More felt that emotional support was a need and this was reported as being 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 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 92% in the exceptional or excellent category. The high rating continued when asked if the patient was treated with dignity and respect with 95% reporting 'always'.

In the community most respondents felt that the patient saw the nurse as often as needed, with 84% saying that this was always the case. When asked specifically about support with urgent help in the evenings and at night most said that this was available with only 5% disagreeing.

The care the patient received from PTHC community team was rated very highly with 91% in the exceptional or excellent category. When respondents were asked, overall had they and their family got enough help and support, 83% agreed that this was the case.

### Support with symptoms and pain relief

Respondents reported that patients received good support with symptoms other than pain. Pain was also reported as being controlled well to varying degrees. Both were managed better than last year and to a greater degree in the in the inpatient setting (see graphs on the next page, the results from 2016 are also included).

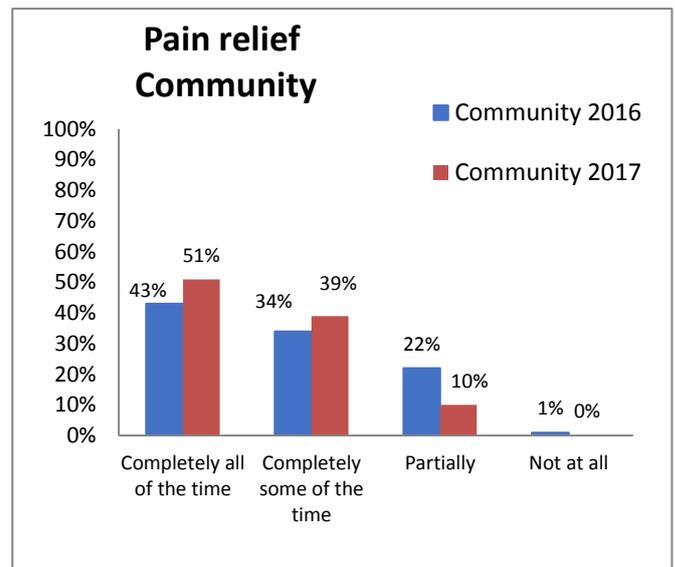
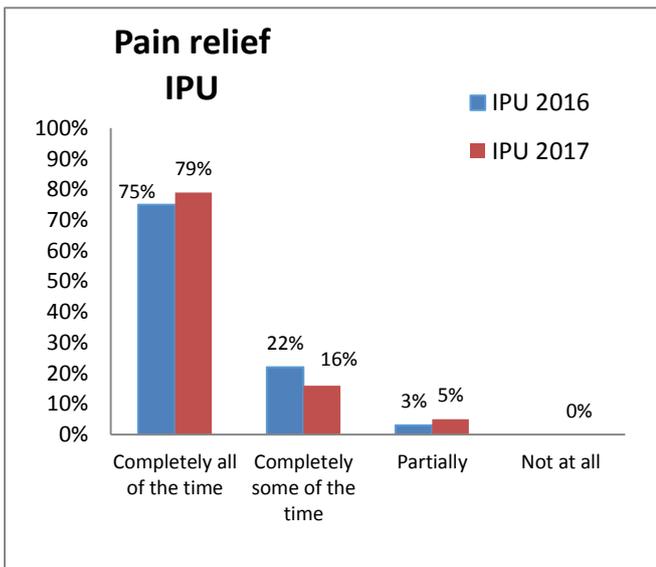


Figure 1a & 1b

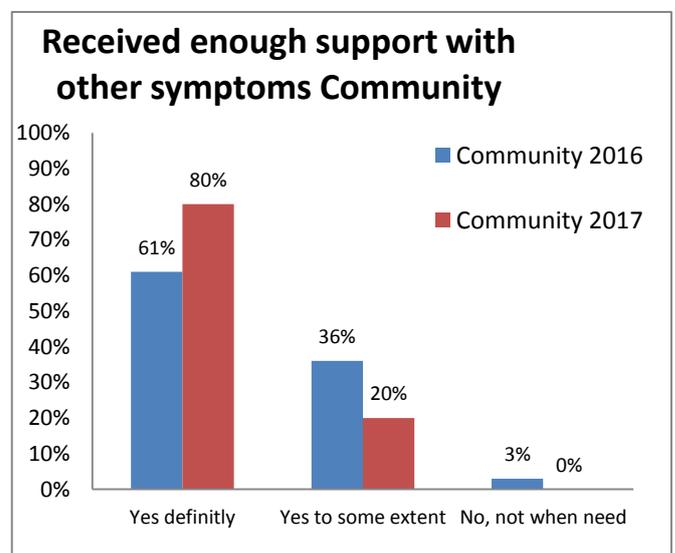
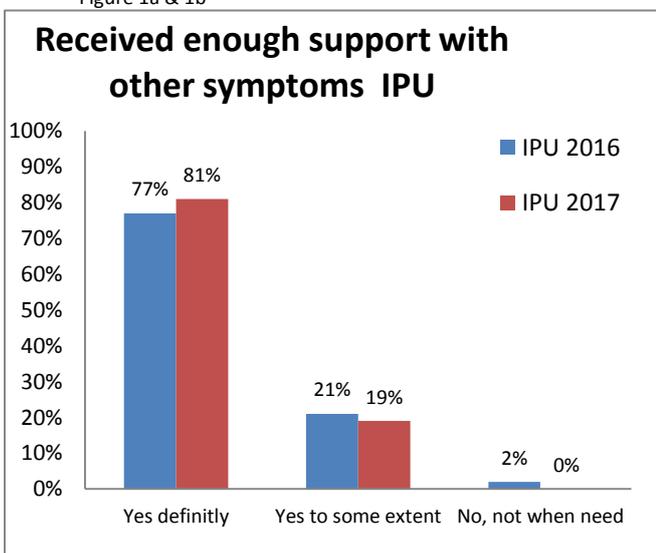


Figure 2a & 2b

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 - 78% wanted to die at home. The survey also provided information on where the patient died, 48% of patients (n=50 total sample 111) died in their home or the home of a relative and 35% (n=39) died in the Phyllis Tuckwell IPU. The proportion of people dying at home and in the Phyllis Tuckwell IPU has reversed from last year (2016, IPU = 45%, Home = 35%).

*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 (90%) of respondents thought that 'on balance' the patient had died in the right place.

Over half (56%) 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 four month period with 228 initial and 103 repeat surveys sent. The response rate was good - and better than other hospices have reported. This may be due to the time spent ensuring the survey was sent to most appropriate person. In terms of responses it was worth sending follow up surveys to those who had not initially replied. 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 bench marking.

## SECTION 1

### Introduction

This report presents the findings of the VOICES - HOSPICE survey conducted at PTHC over a four month period at the end of 2017. (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 in the community
- Day Services
- Care provided at end of life
- Bereavement care
- Demographics

The VOICES survey was conducted for the third time in 2017 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 228 bereaved relatives of patients cared for by Phyllis Tuckwell Hospice Care over a four month (eighteen weeks) period.

#### Patients

The list of deceased patients was taken from the PTHC electronic patient system. All patients known to PTHC that died in the set period were 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 will have had more than 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 392 deceased patients, known to PTHC, in the set period (380 in 2016). After examining the notes the final recipient sample (those relatives sent a survey) was 228 (220 in 2016)

Reponses rate for initial survey sent = 36%

**228 surveys were sent out,**

Reponses rate for follow up survey sent = 28%

**111 were returned = 49%**

### Completion

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

NB As the reporter had numbered the surveys they were aware of which services had been accessed by whom.

### Respondents

Patient's gender was fairly evenly split with slightly more men; however respondents were much more likely to be women.

This section gives a little information about those who took part in the survey, both those completing surveys and the person who had died. (We asked respondents a few questions about themselves and about the person who had died).

### Age, ethnicity, and gender

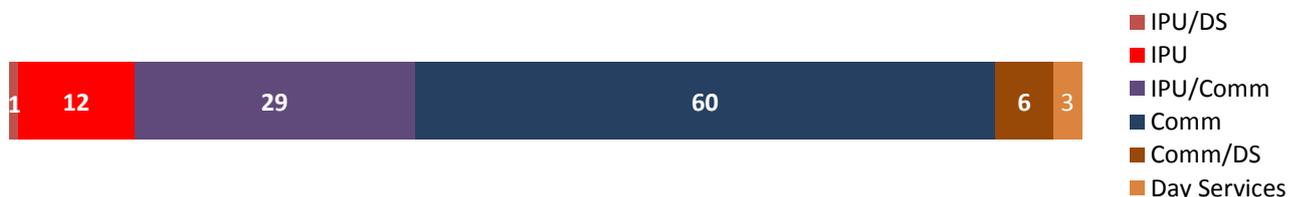
74% of respondents who returned and completed the survey were female, 26% male.

The deceased person to whom the respondents were referring in their answers was slightly more likely to be male rather than female (55% male and 45% female) and aged most commonly between the ages of 60 - 89.

One of the respondents described themselves ethnically as anything other than white British or Irish, this was true for 2 of the patients.

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

### Service areas accessed - IPU/Community/Day Services (DS)



### SECTION 3: Findings – In-Patient Unit Care

Of the total 111 respondents who completed the survey - 42 stated the patient had been an inpatient at Phyllis Tuckwell at some time before their death (56 in last year's survey). This equates to 38%.

Of the 42, 29 had also been cared for in the community and 1 had attended the Day Hospice.

The following information will refer to the information obtained from the 42 completed.

Of those who had been on the In-Patient Unit over half (57%) had stayed between 24 hrs and two weeks. Of the others, 26% had stayed 2-4 weeks, 10% up to 24 hours and 7% had stayed over four weeks.

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 82% 'strongly agreed' and 18% 'agreed' that there was enough personal and nursing care available. In terms of the privacy provided 67% 'strongly agreed' with a further 19% saying that they 'agreed', 7% neither agreed nor disagreed, 7% (n=2) disagreed. There is less satisfaction in this area than in previous years – this may be due to an increased expectation for people to be cared for in side rooms.

Respondents were asked to consider the amount of support that was available. When asked if there was enough emotional support 68% said 'Yes definitely', 17% 'yes to some extent', 10% said that 'this type of help was not needed', 8% didn't know.

For religious and spiritual support 54% said that this was not needed, 37% said 'yes definitely', 7% 'to some extent', 2% 'didn't know'.

Support dealing with financial and practical matters was reported as not needed by 78% of respondents, 15% said there was 'definitely' enough support, 2% stating 'to some extent', the remainder didn't know.

In reference to support dealing with family concerns 50% said that this type support was not required, 36% felt that the patient definitely received enough support, 12% stating 'to some extent', and 2% (n=1) saying 'No not when needed'.

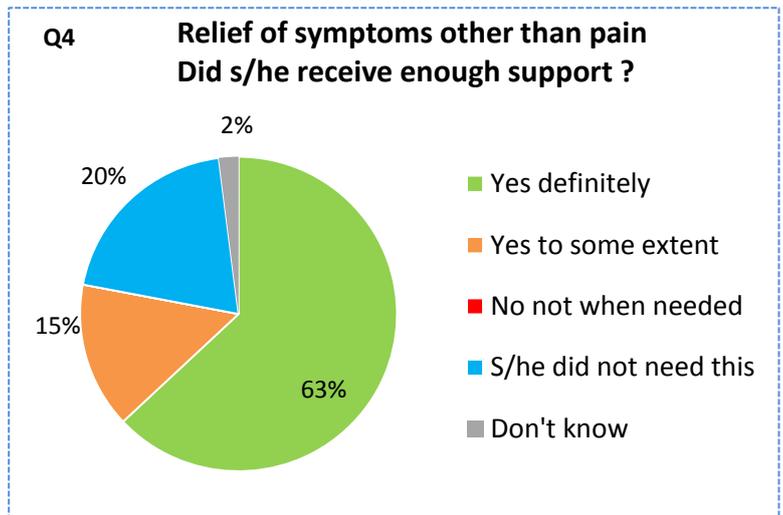
***"They were angels. My husband received the most wonderful care and devotion and we were so grateful to everyone. The cheerful volunteers, desk staff, doctors, nurses, therapists all add to the serenity and calmness of this wonderful Hospice. I can't thank them enough"***

***"Phyllis Tuckwell is a very pleasant and tranquil place to be. The staff have the utmost respect for the patients and their families. Nothing is too much trouble. We consider ourselves lucky to have such a wonderful place so close to us. Thank you!!"***

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)

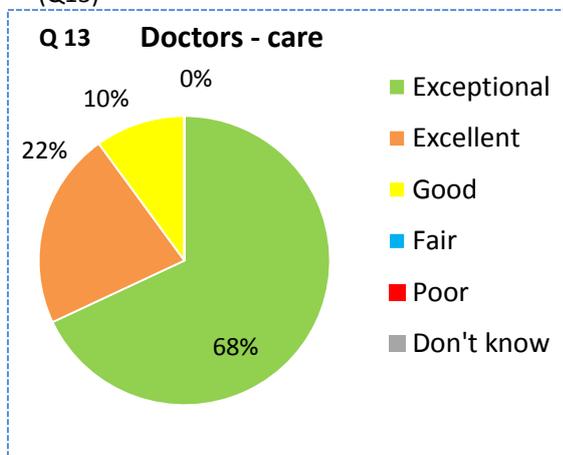


Figure 4a

Figures 6 a & b

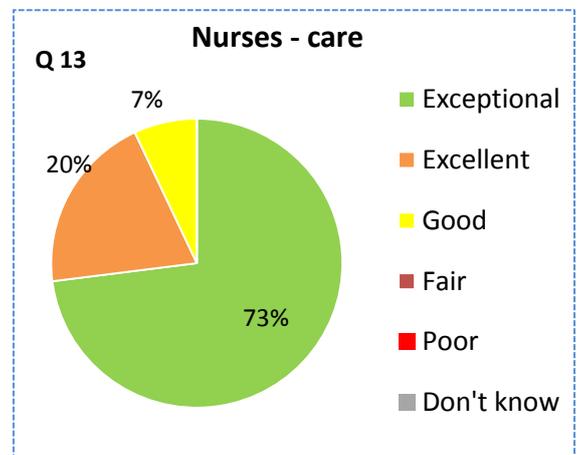


Figure 4b

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:

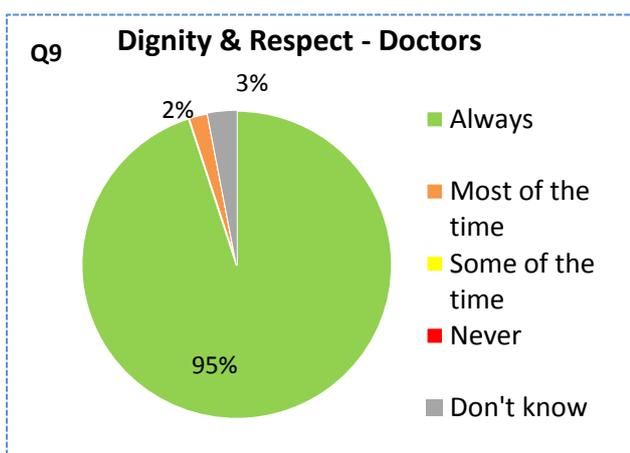


Figure 5a

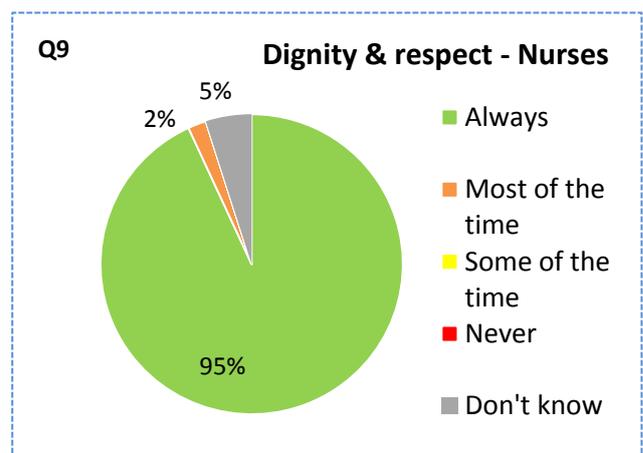


Figure 5b

*“The Doctors and Nurses were wonderful, they made my Dad's last weeks as comfortable and reassuring as they could. I am so grateful dad was in the hospice for his last weeks. The staff did not only give dad support but to the family too”*

*“The care my father received was excellent and the support and cheerfulness of ALL the staff admirable.”*

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

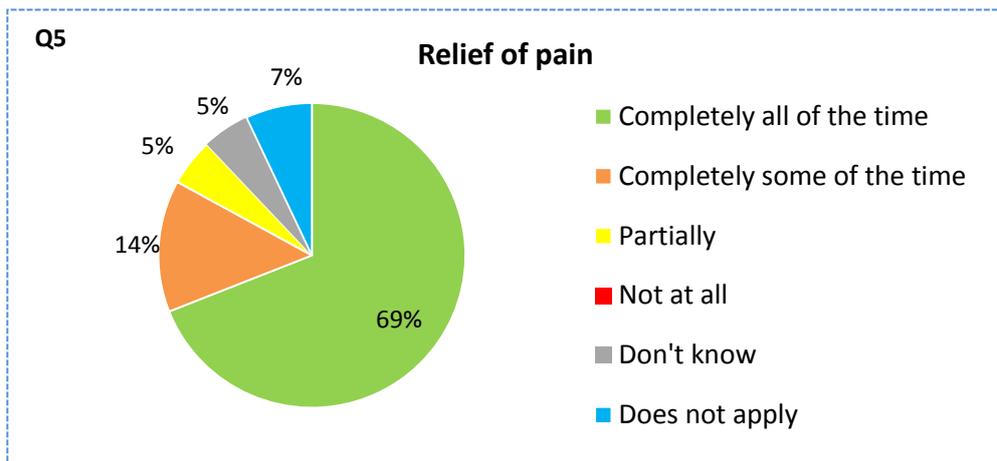


Figure 6

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” 10% didn’t know, all the remaining (90%), 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 55% saying ‘definitely’, 15% saying ‘to some extent’, 2% (n=1), said ‘no they didn’t work well together – however commented “not the fault of PTH - more FPH”. The remainder (28%) didn’t know.

***“It was lovely that the nurses and doctors spoke to dad throughout his care although he was asleep the whole time”***

Food and comfort (Q14)

61% of respondents, who rated the food given to their relative, reported it as either ‘exceptional or ‘excellent’, 35% as ‘good’ with the remainder (4% n=1) saying ‘fair’.

Environment

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

Room	Excellent 65%	Good 35%	Fair 0%	Poor 0%	Don't Know 0%
Bathroom	Excellent 53%	Good 18%	Fair 0%	Poor 0%	Don't Know 29%
Communal areas	Excellent 51%	Good 44%	Fair 2%	Poor 0%	Don't Know 3%
Coffee Lounge	Excellent 40%	Good 50%	Fair 7%	Poor 0%	Don't Know 3%
The Garden	Excellent 74%	Good 24%	Fair 2%	Poor 0%	Don't Know 0%

The survey also asked whether the patient was in a single room or a four bedded bay. 47% had stayed in a side room, 53% in a four bedded bay (20% had stayed in both).

The results are suggestive of a correlation between room satisfaction and the type of room the patient was in – i.e. More people selecting excellent if they had been in a side room. However the numbers are small and further monitoring would be required in order to draw any firm conclusions.

***“I felt that as soon as we entered the hospice we were enveloped in a giant hug by everyone there and it helped us through the next harrowing 4 days. I cannot praise all the staff at PTH highly enough for the love and care they gave to my husband and myself, allowing him to die with dignity. Thank you.”***

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 those that answered as relevant were positive with 92% saying ‘very easy’ and 8% ‘fairly easy’.

They were also asked if they and/or other family members were kept informed about the patient’s condition, 88% said ‘always’ and 12% reporting ‘usually’.

When asked about whether they themselves received enough emotional support from the hospice team there was a very positive response, with 76% saying ‘yes definitely’, 20% saying ‘yes, to some extent’ with the remainder reporting that they hadn’t need it.

When asked about staying in the IPU/relatives room overnight, 39% had stayed – they all found it useful.

***“Everyone that worked there - all nurses, doctors talked to us about everything”***

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

Of the 111 respondents who completed all or part of the survey 88 stated that the patient received care from the PTHC community team. The true figure was 95, as 7 more had also received care in the community, 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 86% of the patient sample had been supported in the community.

Of the 95, 29 had also been on the In-Patient Unit, 6 had attended the Day Hospice.

82/92 had been supported by the CNS team and 61 by HCAH (50 were supported by both). Those supported by the HCAH team alone equated to 11 and by the CNS team 32.

The remainder had received care from Doctors, Therapists and a Psychologist.

The following information will refer to the information obtained from the 88 completed surveys.

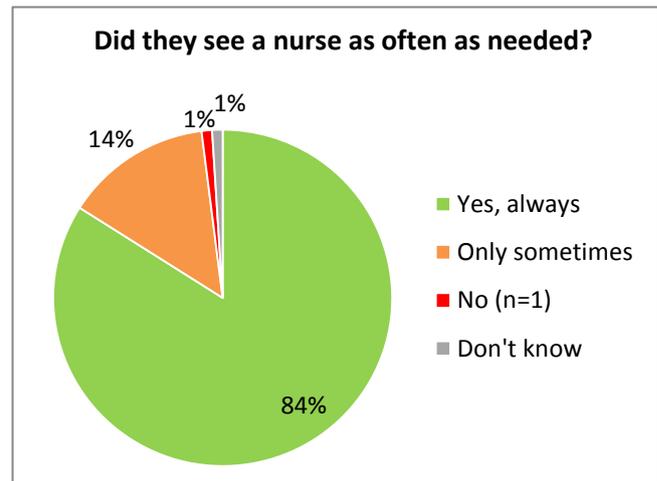
NB Percentages in the following sections are based on the questions completed. Some free text comments are included.

Help and support available (Q17)

Respondents were asked “Whilst receiving care from the PTHC Community Service, did s/he see the nurse as often as it was needed?”

The majority thought that their relative did see a nurse 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 - 60% said ‘Yes definitely’, 23% ‘yes to some extent’, 10% said that ‘this type of help was not needed’, 7% didn’t know.

***“The team travelled a long way off their ‘patch’ but always arrived upbeat and cheerful. They helped through the most difficult time in our lives. I will be eternally grateful”***

For religious and spiritual support 75% said that this was not needed, 18% agreed that there was support, 1% said ‘no not when s/he needed it’ the remaining 6% didn’t know. The results were similar when asked about support with financial matters, with 70% saying that it was not needed, 25% agreed that there was support, the remaining 5% didn’t know. When asked about support with family concerns 56% said that this type of help was not required, 21% felt that the patient definitely received enough support, 11% stated ‘yes to some extent’, 2% (n=2) said ‘no not when s/he needed it’, 10% didn’t know.

***“I had never before met such professional people with such care and attention to every need, with such love. Also the care to myself - in the way I was prepared for each stage of the illness, and the eventual death, before it occurred. Thank you all”***

When asked about receiving help with urgent problems in the evening and at night many reported that this had not been required, 36% & 38% respectively. If only looking at cases where help was needed i.e. excluding ‘not needed’ and ‘don’t know’ regarding the evening time 63% said ‘yes definitely’, 31% said ‘yes to some extent’ with only 6% (n=3) saying ‘no not when needed’. For night time 67% said ‘yes definitely’, 25% said ‘yes to some extent’ with only 8% (n=4) saying ‘no not when they needed’.

The results indicate that patients’ needs are generally being met outside of ‘regular hours’, but very slightly less so than last year, see figure 8a & 8b. Locally care provision overnight involves Phyllis Tuckwell Hospice Care at Home, out of hours community nursing and social care services.

***“I am so grateful for the community teams’ support. My dad would say the same if he were here. They were very quick to respond to calls and requests for help no matter what the time”***

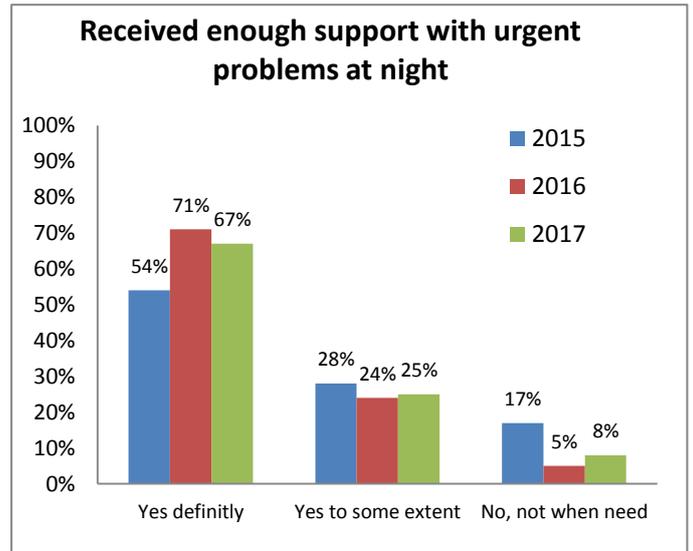
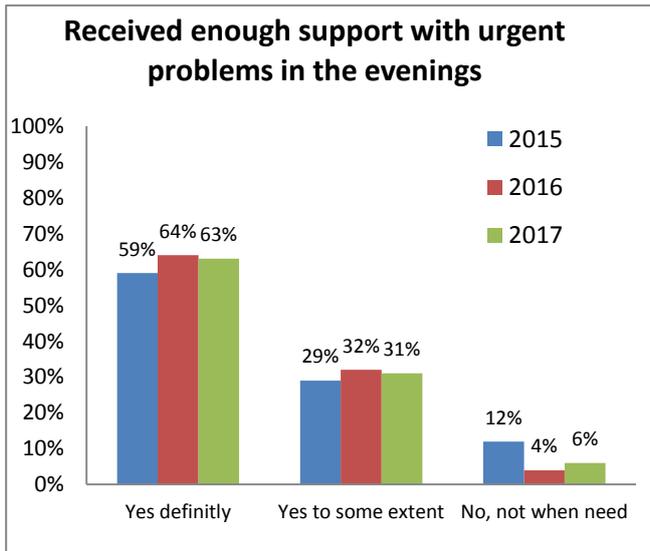


Figure 8a & 8b

**Care and Treatment (Q19)**

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

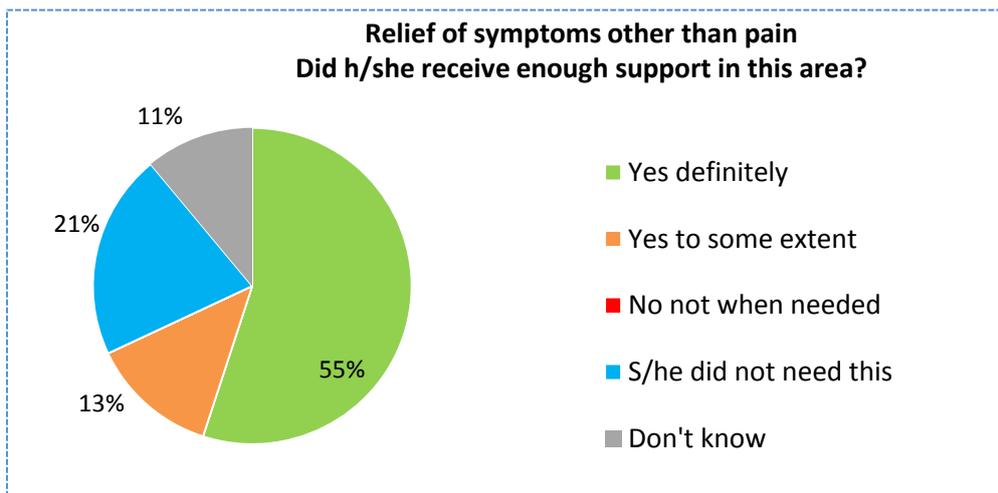


Figure 9

When relatives/carers were asked what they thought about the care the patient received (Q24) - the results were extremely good with 96% saying it was exceptional or excellent:-

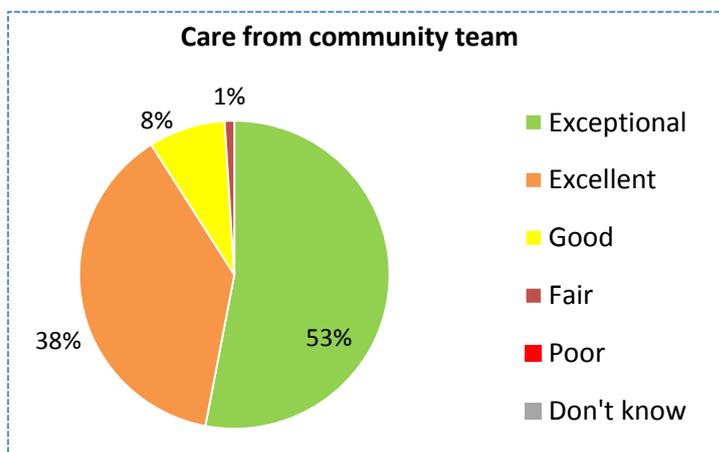


Figure 10

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

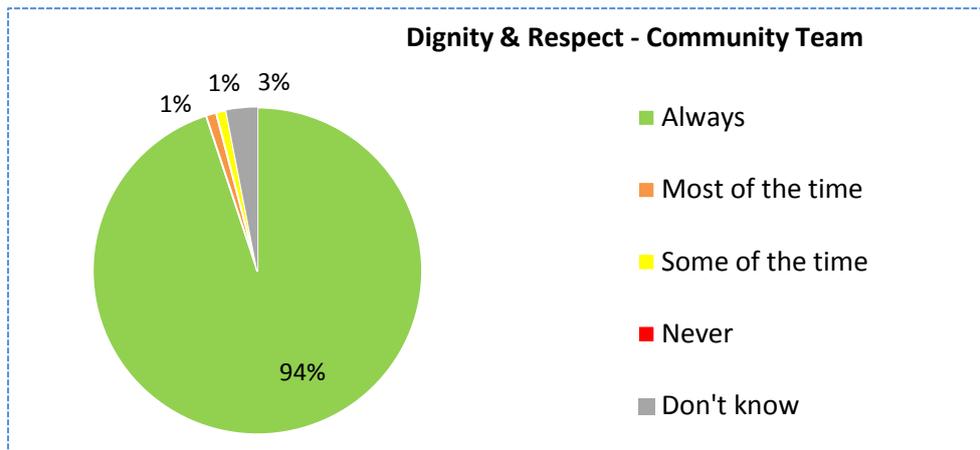


Figure 11

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

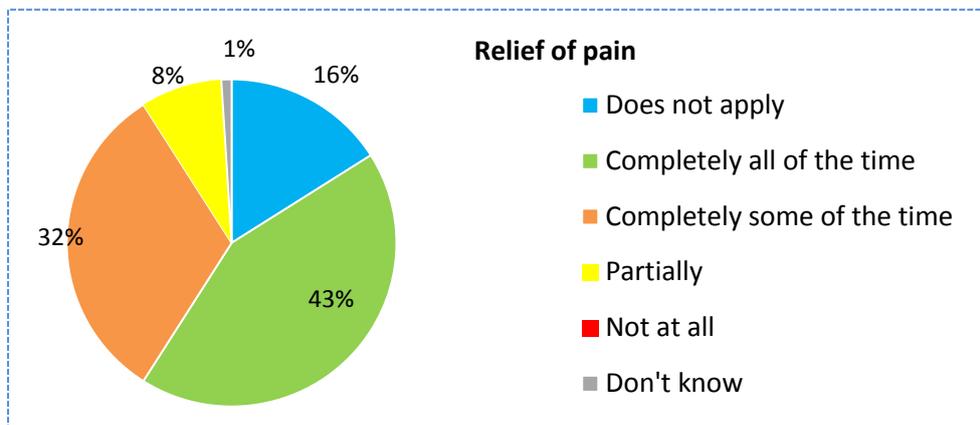


Figure 12

These results for how well pain was relieved were not quite as positive as in the In-Patient Unit, however they are significantly better than the results from the annual National Bereavement Survey – VOICES, conducted by the National Office of Statistics (NOS) 2015. The table below shows how well pain was managed in the home care setting:-  
*NB the ‘does not apply’ and ‘don’t know’ responses are discounted from the percentage responses.*

RELIEF OF PAIN	Completely all of the time	Completely some of the time	Partially	Not at all
<b>PTHC VOICES Community (2017)</b>	<b>51%</b>	<b>39%</b>	<b>10%</b>	<b>0%</b>
National VOICES Care at home (2015) (latest data available)	19%	30%	43%	8%

Figure 13, Ref 4

Support and communication (direct question to relatives/carers) (Q22, 25 & 23)

When asked if the explanations about treatment and tests were easy or difficult to understand responses were positive with 75% saying ‘very easy’ and 20% ‘Fairly easy’, the remainder said that they hadn’t had an explanation or hadn’t spoken with a nurse or doctor; however it wasn’t clear as to whether this had been their choice.

They were also asked if they were involved in decisions about her/his treatment and care as much as they had wanted to be, 97% said ‘yes, as much as I wanted to be’, 1% ‘would have liked to have been more involved’ and 2% ‘didn’t know’.

All said that staff had had time to listen and discuss things. With all saying that they had been involved in discussions regarding care and treatment.

***“All staff involved in the care of my late father were extremely professional and sympathetic at the same time. They all took care of my father very well and explained to me about everything they were doing. I can’t thank them enough for the care they gave. Thank you to all the care team involved and to the Phyllis Tuckwell.”***

***“We were very impressed with the care provided by the PT team. They were all very kind and provided answers to all our questions”***

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?” (Q24)

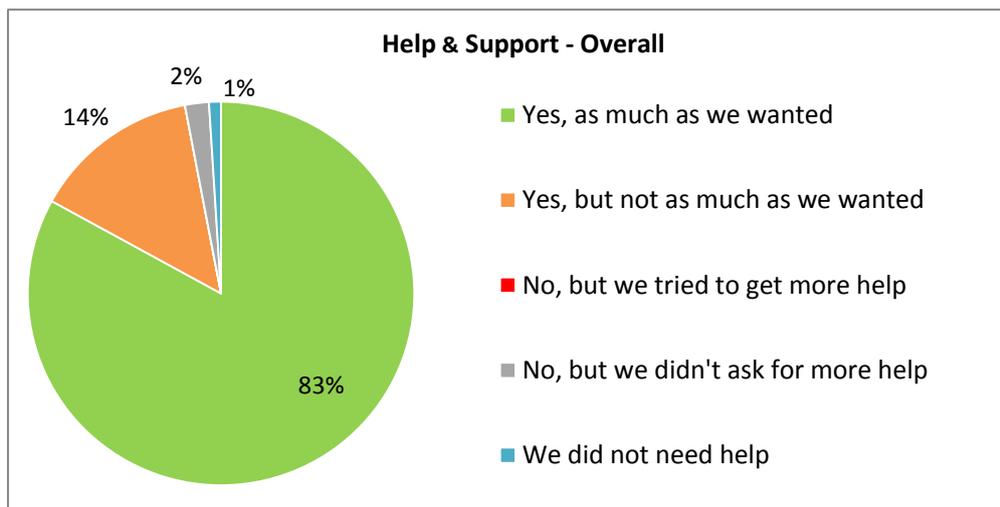


Figure 14

## SECTION 5: Findings – Day Services

Of the total 111 respondents 10 stated the patient had attended PTHC Day Services (PT Day Hospice or the Beacon Day Centre) at some time before their death. This equates to 9% of the patients involved in this survey having attended Day Services.

NB the Living Well Service had not been launched at this time.

Of these - 6 had also received care in the community, 1 in the IPU.

30% had attended more than 10 times, 10% between 6-10 times and 60% between 2-5 times.

The relatives/carers were asked whether their loved one had benefited from attending sessions day service sessions. 80% (n=8) said ‘Yes’, 1 person said that they didn’t know, the other did not answer the question.

## 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 details the place of death.

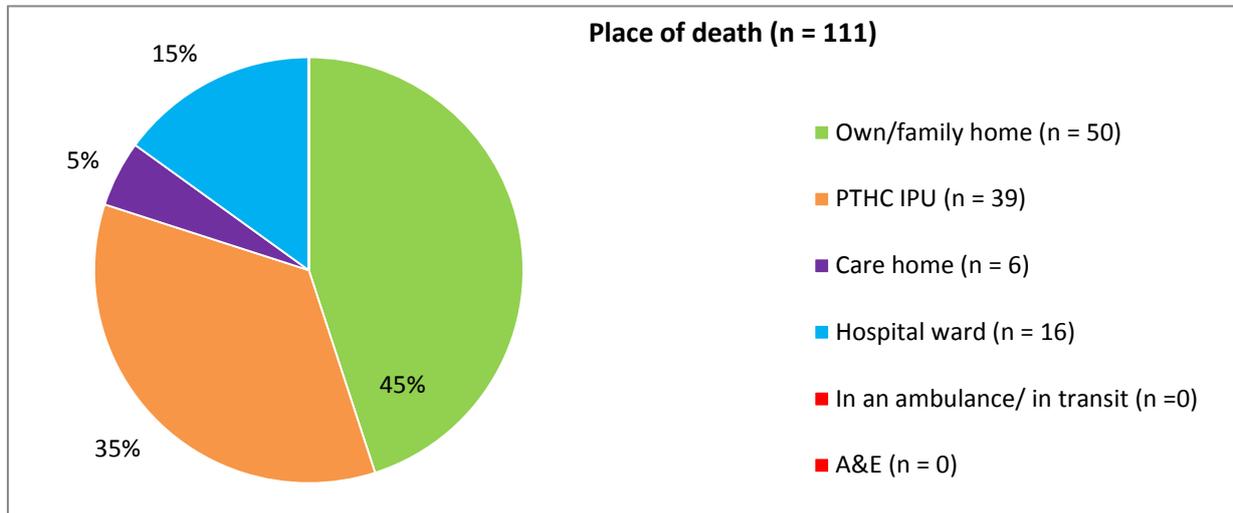


Figure 15

The picture has reversed from last year - with 45% of patients dying in their own home or the home of a relative (33% in 2016), and 35% dying in PTHC IPU (45% in 2016).

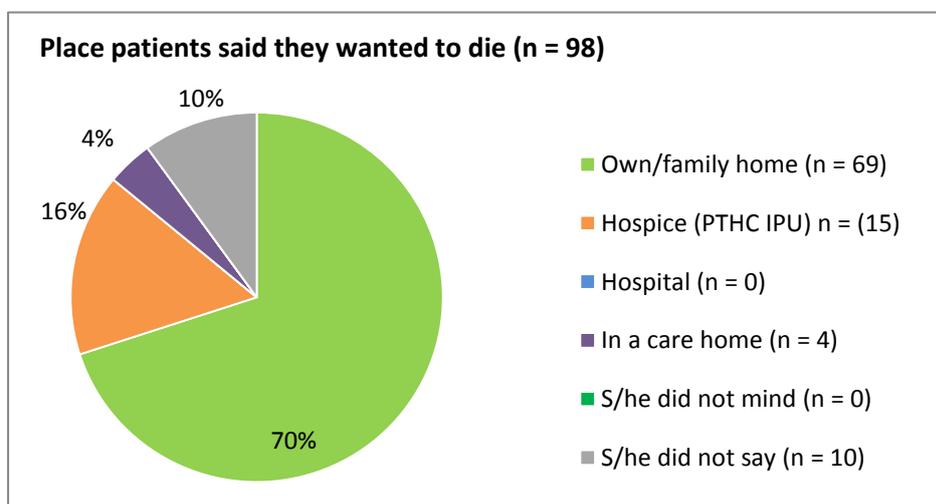
Of the total 111 respondents 104 completed all or part of this section.

The following information will refer to the information obtained from the 104 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 – 78% stated the patient had wanted to die at home with only just over a quarter (17%) saying in PTHC IPU, 5% said in a care home.

More people wanted to die at home, which is consistent with national survey data <sup>ref 2</sup>, more people had stated that they wanted to die at home than in previous PTHC VOICES surveys.



Graph also show numbers of responses  
Figure 16

More patients had expressed a preference about their place of death than last year – with only (10% n=10) having not said. This may indicate that advance care planning discussions are more common place.

More people wanted to die at home than last year and more people did. However 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 figures are similar to last year.

However it is not uncommon for patients to change their mind about dying at home in the later stages of life <sup>ref 1</sup>, 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 87% answered ‘yes’, 7% were ‘not sure’ and only 6% said ‘no’.
- “On balance do you think s/he died in the right place?” In which 90% answered ‘yes’, 4% were ‘not sure’ and 6% said ‘no’.

In the 6 cases that respondents said they didn’t think their relative had died in the right place, 3 had died in hospital, 2 at home and 1 on the PTHC IPU. Five had wanted to die at home, the other hadn’t specified. The two incidences where patients had died at home (as was their preference) but the relative/ carer had answered that they felt it wasn’t the right place reported the death as ‘difficult’ and had felt unsupported.

***“Given the choice my husband would have preferred to die at home, but due to circumstance this would not have been feasible so he was "happy" to go to PTHC IPU. He did NOT want to die in hospital”***

***“My mother died at home, without your support this would never have been able to happen, so thank you for enabling my mother to have the death she wanted”***

***“Whilst his preferred place of care was the Hospice - he died at FPH. He was known on the ward and we did have a private room. I did enquire about PT IPU but he was not stable enough to move. I did appreciate the nurse calling the hospice over the weekend for some advice to get him more comfortable”***

***“I feel so grateful that this service is available to patients and families. My mum wanted to be at home and I wanted to look after her. Without the backup of the community team it would have been very difficult even with our own very good GP. I know it made mum's last days feel more comfortable and peaceful - it certainly supported me and my brother. Thank you to all the team”***

### **Death on the Phyllis Tuckwell In-Patient Unit**

As stated previously 35% of patients died on the In-Patient unit. The relatives/carers were asked if they’ve received enough support at the time of the death. All said yes.

## Support in bereavement

Of the total 111 respondents 105 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 (59%) said they hadn't but this had been their choice. 27% had spoken to someone and 14% 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 (43%), followed by a nurse (18%), others included bereavement service volunteer (4%), doctor (7%) and complementary therapist (3%).

***"My counsellor has been absolutely brilliant. I really don't know what I would have done without her help"***

### Bereavement information

PTHC offer bereavement support to all bereaved relatives and friends. This comes in a number of forms, including leaflets and booklets. This section asked all respondents whether they received information of this kind.

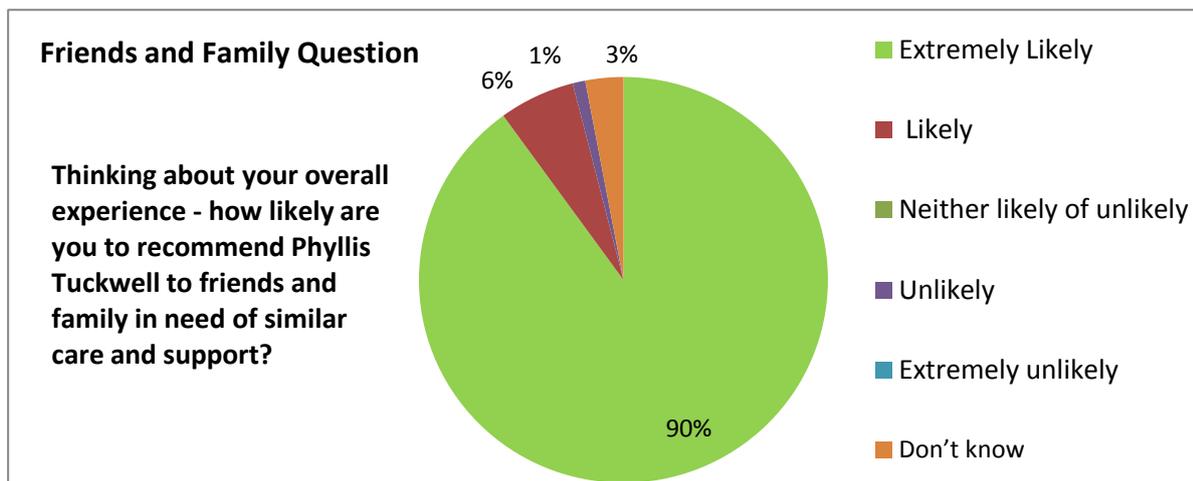
Firstly they were asked about a leaflet giving information about what to do after a patient's death. This is given to relatives/carers by the inpatient staff if the patient has died on the IPU and the community team nurses (usually HCAH) if the patient has died at home. Most of respondents (85%) said that they 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 referral window completed after death (\*there is an option to not receive bereavement support information). Again, most said that they had received this (95%), of these 84% 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 111 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 228 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 change in the services patients are accessing – with, proportionally, less patients receiving care in the IPU.

### IPU

The carers/NOK (next of kin) of the patients that had received care in the IPU, rated the communication, pain control and symptom management their loved one received highly – the results improving further on last year. This was also true of the support they received themselves.

The overall care was rated extremely highly with the majority of respondents rating it as exceptional.

The food was not rated as highly as last year however the majority rated it as exceptional or excellent.

Some areas of the environment (communal areas & coffee shop) and were not rated as highly as last year. There was also less satisfaction when asked about privacy; this may be due to the ward layout – in particular the bays containing 4 beds.

Areas for potential improvement are mainly connected to the structure/layout of the building itself and therefore limited. Any future refurbishment should consider the replacement of bays with single rooms with ensuite facilities. Staff will be reminded to ensure that they take measures to ensure that patient/carer/family privacy is maintained.

The catering department and ward manager have recently reviewed food choices and its delivery with the aim of being more responsive to patients changing needs/requirements.

### Community

The carers/NOK of the patients, that had received care in the community, rated the care very highly with the vast majority saying 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 showed a marked improvement from last year, this was also true of pain relief.

In terms of support in the evenings and at night the results remained much the same as last year. This is not unexpected due to the PTHC planned expansion in workforce being hindered by recruitment difficulties (a national trend) and the withdrawal of Marie Curie night services from the local area. Despite these challenges the majority of respondents agreed that there was support in the evenings and at night time. Locally care provision overnight involves Phyllis Tuckwell Hospice Care at Home, out of hours community nursing and social care services.

Very few respondents expressed concern about access, responsiveness or care – where this was the case the issue/event was recorded, investigated and discussed with team leads. Any learning was shared with the wider team and action plans put into place to avoid, where possible, similar incidents happening again. In total 3 respondents were contacted to discuss

their concerns and then updated as to PTHC actions and learning. All were very satisfied with the response and appreciated the follow up communication.

All comments are recorded and discussed 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 people with a terminal illness, and those closest to them, so that they live their life to the full and their ending is peaceful' (mission statement). The results of this survey i.e. care across the In-Patient unit and the Community being rated as exceptional or excellent by 91% of respondents is a testament to the hard work and commitment shown by all the PTHC staff and volunteers.

### **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. The demographic questions will be removed from the 2018 survey as this data (patient) is already collected by PTHC.

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 after a break of 2 years it is likely that the NOS National VOICES survey will be recommissioned for 2018 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 2016 report
4. NOS VOICES report 2015  
<https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/healthcaresystem/bulletins/nationalsurveyofbereavedpeoplevoices/england2015>

## **APPENDIX ONE**



VOICES A4 booklet  
2017 Final.docx