

The Prince of Wales Hospice Engagement

December 2022 and January 2023

Contents

Executive summary.....	3
Introduction	4
Methods.....	5
Findings	6
Recommendations.....	13
Appendices.....	18

If you need this report in another format, please contact Healthwatch Wakefield.

Information in this document can be copied or reproduced but please credit Healthwatch Wakefield.

Healthwatch Wakefield is a registered charity and company limited by guarantee registered in England and Wales. Registered charity number 1166797 and Registered company number 09907848.

Executive summary

Between August 2022 and December 2022 Healthwatch Wakefield carried out engagement work for The Prince of Wales Hospice, in order to inform their service planning and delivery.

The aim was to increase the number of people in the early stages of a life limiting illness, and their families and carers, who access services and support from The Prince of Wales Hospice.

Thirty six people completed an online survey. Following up people who had left their contact details on the survey led to six one-to-one telephone interviews taking place, these were written up as brief case studies.

Main findings from the survey and interviews:

- 91 per cent of respondents had heard of The Prince of Wales Hospice, however, there were many areas of support that people weren't aware of, particularly outreach, support for families and carers, Lymphoedema clinic, and complementary therapy. Most people were aware of in-patient and bereavement services.
- There are a range of reasons why people haven't been to the hospice and a range of things that may make it difficult for them to access support. The main ones being that they don't need support at the moment, they haven't been referred, or it is difficult to get to.
- A large proportion of people mentioned that open days and more information about services on offer would encourage them to go and have a look around the Hospice.
- Respondents were interested in a wide range of support, in particular support for family and friends, advice on nutrition and exercise, exercise sessions, and advice on planning for the future.
- Most people prefer to access support and information relating to their illness in person or online. Telephone and written or email information were less popular.
- There were a range of responses as to what people might find helpful or might have found helpful in the past. Knowing what is available early on, increased options for people to visit the Hospice, for example, through open days, reducing negative perceptions and also more promotion and information about the support available featured in several responses.
- Social media, leaflets, promotion through newsletters, and more information given out by other professionals, such as GPs, were thought to be the best ways to promote the Hospice.
- Those that had visited the Hospice, as a patient or, for example, attended an open day, were full of praise for the atmosphere, physical environment and support that they had received.

Introduction

Healthwatch Wakefield is your local health and social care champion. From Overton to Knottingley and everywhere in between, we find out what communities want from health and social care services, provide people with information and advice about local services, and we make sure NHS leaders and other decision-makers hear your voice and use your feedback to improve care.

The Prince of Wales Hospice, in Pontefract, provides palliative care and support for patients with life limiting illnesses and their families. The Hospice are keen to engage with more people who are at the early stage of their diagnosis, particularly people with a life limiting illness who have a life expectancy of over a year. This is in order for the hospice to make sure that the services that they offer, and the way that these services are promoted, is as appropriate and supportive as possible. They also requested some staff training around project planning, outcomes and evaluation, in order to be able to best show the impact and value of the work that they do.

Between August 2022 and January 2023, Healthwatch Wakefield worked with The Prince of Wales Hospice to help them to access the views of people who may have used their services, or know someone who has; but also, to get the views of others in the community who may not have had any contact with the hospice.

The overall aims of the work were:

1. To increase the number of people in the early stages of a life limiting illness, and their families and carers, who access services and support from The Prince of Wales Hospice.
2. To increase the in-house ability at The Prince of Wales Hospice to be able to demonstrate the impact of the work they do.

The planned objectives and activities were:

- Gain insight into the wants, needs and barriers to support, of a minimum of 20 people, or their families and carers, at the early stages of a life limiting illness by December 2022.
 - Produce a survey and promote as widely as possible.
- Provide face to face training in basic research skills and project planning to a minimum of 10 staff members at The Prince of Wales Hospice by February 2023.
 - Provide a written reference guide for staff to keep and refer to.

Methods

Survey and Interviews

A survey ran between the beginning of August 2022 to the end of November 2022. The survey was promoted through websites and social media of both Healthwatch Wakefield and The Prince of Wales Hospice. Paper surveys and posters were also printed and posted to local venues, including, but not exclusively:

- Local GP's surgeries
- Pinderfields and Pontefract Hospitals
- Castleford Heritage Centre
- St Mary's Pontefract
- Kellingley Club
- The Chesney Centre
- Normanton Town Council
- Featherstone Town Council
- Castleford Tigers Ground
- Local libraries

Thirty six surveys were completed. One of the survey questions asked if people would be willing to be contacted to discuss their experience in more detail. Eight people agreed and were contacted by telephone or email at a later date. This resulted in six one to one interviews taking place over the telephone.

Training

Eleven members of staff from The Prince of Wales Hospice attended a three hour 'Introduction to Research and Data Collection' training session on Wednesday 25 January 2023. The training was run by Suzy Jubb and Michelle Poucher from Healthwatch Wakefield.

Findings

Feedback from Surveys

Full demographic information can be found in Appendix One.

A total of 36 people completed the survey, these ranged from ten people with a life-limiting illness, ten friends or family members, nine carers, and seven who described themselves as 'other'. There were also a range of responses as to how the person's life limiting illness affects their life at the moment. Fifteen people said the illness currently affected their life 'very little' or 'not at all'. However, 18 people told us that their or the patient's life limiting illness was currently affecting their life 'quite a lot' or 'very much'.

When asked if they had heard of The Prince of Wales Hospice, 31 people said that they had and only three people had not. Two people had attended The Prince of Wales Hospice as a patient, a further 11 people had visited as a friend or family member and six people had been to attend an event. The remaining 13 respondents had never been to the Hospice and four people skipped this question.

A range of responses were given as to why people had not attended the Hospice, with not needing care or support at the moment being the most frequent response:

6. If no, why not? Tick as many as apply

Answer Choices	Response Percent	Response Total
1 I haven't heard of The Prince of Wales Hospice	11.76%	2
2 I, or the patient, haven't been referred	17.65%	3
3 I don't want or need, or the patient doesn't want or need, help or support at the moment	35.29%	6
4 They don't offer the type of support that I would want	5.88%	1
5 It's difficult for me to get there	11.76%	2
6 I don't like the idea of going to a Hospice	5.88%	1
7 Other, please specify:	23.53%	4

An open-ended question then asked whether there was anything that might encourage them, or the patient, to go and have a look around. Seven people said that open days would encourage them to go, or already had done in the past.

“It’s worth having a look, I was very reserved about going to look around but was completely amazed at what I found”

More knowledge about what they offer was mentioned and another person said that transport would help them to get there. One person said that they would be more likely to visit the Hospice if dementia day care services were offered.

A list of support that The Hospice offers was given, and people were asked which they were aware of. In-patient care and bereavement support were the services that were most known. Around half of respondents were not aware of outreach, support for families and carers, lymphoedema clinic or complementary therapies:

The Prince of Wales Hospice offers the following support for people and their families. Please tell us which you already knew about

Answer choices	I knew about this	I didn’t know about this
In-patient care	27	6
Outreach, social groups in locations away from the Hospice	11	18
Support for families, practical and emotional support	18	15
Support for carers, practical and emotional support	15	17
Lymphoedema clinic	16	16
Complementary therapy, for example, massage and aromatherapy	16	17
Bereavement support	24	9

The survey asked whether there was anything that made it difficult for people to access help or support from The Prince of Wales Hospice. The most frequent response, given by eight people, was that it is difficult to get there. Three said that they prefer support to be in person, two people said that not being sure what support they offer is a barrier and one person mentioned that family commitments made it difficult for them. One person mentioned that they had contacted the Hospice, and nobody got back to them, and another said they weren’t sure how much support was available:

“I have received support from the hospice in the past but was made to feel as though I could only access it for a short while and not an ongoing thing”

The preferred way to access support and information was either online, 18 people, or in person, 17 people. A further 10 people said they would prefer telephone and seven people said they would prefer it to be in writing, either through the post or email.

Respondents were asked to think about what support may have been useful to them or the patient, when they were at the early stages of their life limiting illness diagnosis. The range of responses is shown below:

Would you, or the patient, find any of the following useful? If you, they, are not at the early stages, please could you think back to things you may have found useful when you were.

Answer choices	Yes	No	Not sure
Face to face social groups	10	4	9
Online social groups	9	5	7
Advice on planning for the future, for example, wills, power of attorney	13	5	4
Advice on nutrition or exercise	17	3	2
Exercise sessions	14	4	4
Support for friends and family members	21	2	1

The final, open question, asked about anything else that might be helpful to someone at the early stages of a life limiting illness. There were sixteen response to this question. A theme that emerged was that it would have been beneficial to know what the hospice offered earlier on:

“That we could have used the hospice services earlier and that we didn’t know, feel we should, could access services. Could have helped pain management and quality of life”.

“Need to remove the negative perception of ‘hospice’ care to get people through the door earlier to access the wider services. Maybe link up with GP’s to have a Prince of Wales Hospice counsellor call a few days after a terminal diagnosis as in our experience no support has been available from any other agencies”.

“Early contact from hospital. My relatives non-local hospital seem reluctant to mention hospice care despite a very poor prognosis for what is a terminal illness, but don't seem to offer any similar help themselves”.

"I think a tour of the hospice showing the work it does to help the community with life limiting illnesses rather than people thinking it is just for end of life care. Help to access other local support groups, benefits etc and a support group for carers."

Several people also mentioned that face to face support and someone to talk to would be helpful:

"Support face to face is very important to a patient as they feel more cared about".

"[my husband] is coping much better than me and it would be nice to be able to talk to other patients partners".

Three people mentioned details about their illness and situation and felt that the hospice didn't have expertise in the area they needed. Another point was that even when for example, clear of cancer, there are often other illnesses and effects, often as a result of treatment, that people would like support with.

"My condition is rare so there are limited people that can deal with my illness".

"My acquaintance had a drug dependency as well as a life limiting illness and some members of staff were not sufficiently equipped to deal with this... in a non-judgemental way."

Further responses were:

- Day care for dementia sufferers to provide respite for carers
- Recommendations for affordable travel insurance
- Information on options available regarding treatment
- Advice centre
- Wheelchair loan

Case Studies

Eight people left their contact details on the survey, and this resulted in six one to one interviews being carried out over the telephone. These interviews have been written up as individual case studies which are presented below.

Case Study 1:

D's husband had a terminal cancer diagnosis in March and the Macmillan nurses told them about the hospice quite soon after. She and her husband had never been to a hospice before. It wasn't somewhere that they had thought about going to as she saw hospices as 'somewhere you go to die'. When her husband was very ill, he went into the hospice for over a week so that they could sort out his medication. When he was there, they saw what an amazing place it was.

"We thought at first that it was a place you went to die, we didn't realise you could just go in for treatment, sorting his medication out and to be able to talk about things. It was really good because there were other things you could do, activities and therapy. They are there for you 24/7 if you want to ask anything."

She couldn't be more complimentary about the hospice and how it has helped them as a family. She talked about not knowing that things such as alternative therapies are available for family members as well as the patient.

"They're really helpful for the family, you can ask them anything. It's a wonderful place, it's peace of mind".

Case Study 2:

Lady in her seventies who recently attended an open day at The Prince of Wales Hospice, that's the only time she has been. She knows about the hospice as it is her nearest one and she tries to support it. She heard about the open day through an outreach worker from the hospice attending a local afternoon tea to talk about it. She felt that it was a good idea to attend and see what it was like as 'you never know when you might need it'. Having visited the hospice, she was extremely positive about it:

"The open day was a really good way to get people in. I looked at a room, it was everything that anyone could want."

After attending the open day, as she is a carer, she was offered aromatherapy, before the open day she didn't realise the range of support that the hospice offers:

I think the main thing is the care, it shows. Hospitals are not the places they used to be because they're short staffed. Anyone needing that service wouldn't be able to find anywhere better [than The Prince of Wales Hospice]."

She felt that promotion through Facebook and online would be best, she didn't feel that posters would work as well as people often don't notice them.

Case Study 3:

C a Team Leader for a Care Coordinators team. Part of the role of the Care Coordinators is to put personalised care plans in place for example, people who are living with dementia. She told me that the Care Coordinators often have conversations with people, whilst the person still has mental capacity to make their own decisions, about whether they have thought about the future. Hospice care is something that may come up in this conversation if the person asks about end of life care.

Some of C's team visited the Hospice for the open day, C is keen to go and visit herself and also to encourage new members of staff to do so. It was useful to get that personal experience of the hospice.

Case Study 4:

Female in her seventies, she knows about the hospice through family who have worked there, through receiving support herself, and more recently through a volunteer role.

Many years ago, she accessed day care and told me that just being there 'helped enormously.'

She is now a volunteer for the outreach programme and told me how much people appreciate the outreach sessions. It's a chance for people to talk to each other and offer support.

"I think it [the outreach] works wonders, everybody that goes say how they look forward to being there".

She also talked about the stigma of the hospice:

"I do think that people think I'm not going in there because that's where you go to die, but actually, there's more laughter in the hospice than there are tears".

She suggested that GP's could play a part in promoting what is on offer and inform people what is available. Also, articles in the local newspaper could help to promote it to local people.

Case Study 5:

Female in her seventies, a carer for her husband who was diagnosed with dementia in 2020. Her husband's diagnosis was over the phone, and she feels that after this they were really just 'left to get on with it'. Her husband now attends dementia day care once a week at Wakefield Hospice as this is the nearest one for them. She found out about it through recommendation from someone in a similar situation.

"When someone mentions a Hospice, you think it's not a good sign... it's a last resort... but it's marvellous, it's the only break I get all week".

Suggestions for promoting things that are happening at The Prince of Wales Hospice are dropping leaflets at local places such as cafes and community groups.

"Leaflets are a good idea, I've had ones that I've filed and then gone back to later, it feels like a recommendation if you see it in a place, you're familiar with."

She also receives a magazine from Carers Wakefield and District who she is registered with, and this would be a good place to advertise. She also talked about the possibility of providing transport to help people to be able to get to The Prince of Wales Hospice.

Case Study 6:

A lady in her sixties who has a long-term diagnosis of pancreatic cancer. She has never attended The Prince of Wales Hospice as a patient but has visited other people there a couple of times. She feels that it would be useful for hospices to think about is how a person's life can change due to treatments and surgery. Also having to stop working at a young age and the psychological and financial repercussions of this.

"Surgery can be so major that it totally changes your whole body, living with the after effects of this can be hard and some psychological support would be helpful".

She feels that they need to get the message out that it's not just about cancer and it's not just about caring for people in the last weeks of their lives. More of an offer around adapting and coping with a new way of life would be helpful.

"I had to stop working and I lost my identity for a while, hospices could help people who are struggling in this way".

We also talked about 'expert patients' and how it can be helpful to bring people together to support each other. This could be done remotely, for example through a Facebook group.

She felt that social media and also newsletters from other organisations such as Healthwatch are good ways to promote services. Open days and events are good things to do but they need to think about when these are, they should offer evenings and weekends

too as some people are working. She felt that hospices should be working with other community groups and organisations as well as other healthcare providers to promote their services.

People need help when they're looking after someone at the end of life, the support is needed for family members as well as the patient. Offering respite care for a couple of weeks would be something really helpful for families. Hospices can also be really good at helping people to get on the correct treatment pathway, not everyone will know about this.

Training

A training session with Hospice staff took place on Wednesday 25 January 2023 and was delivered by Suzy Jubb and Michelle Poucher from Healthwatch Wakefield.

Topics covered in the training were:

- The importance of collecting and evaluating data
- What is currently being collected, what would you like to collect?
- Barriers and challenges
- Ways to collect data
- Tools to do the job

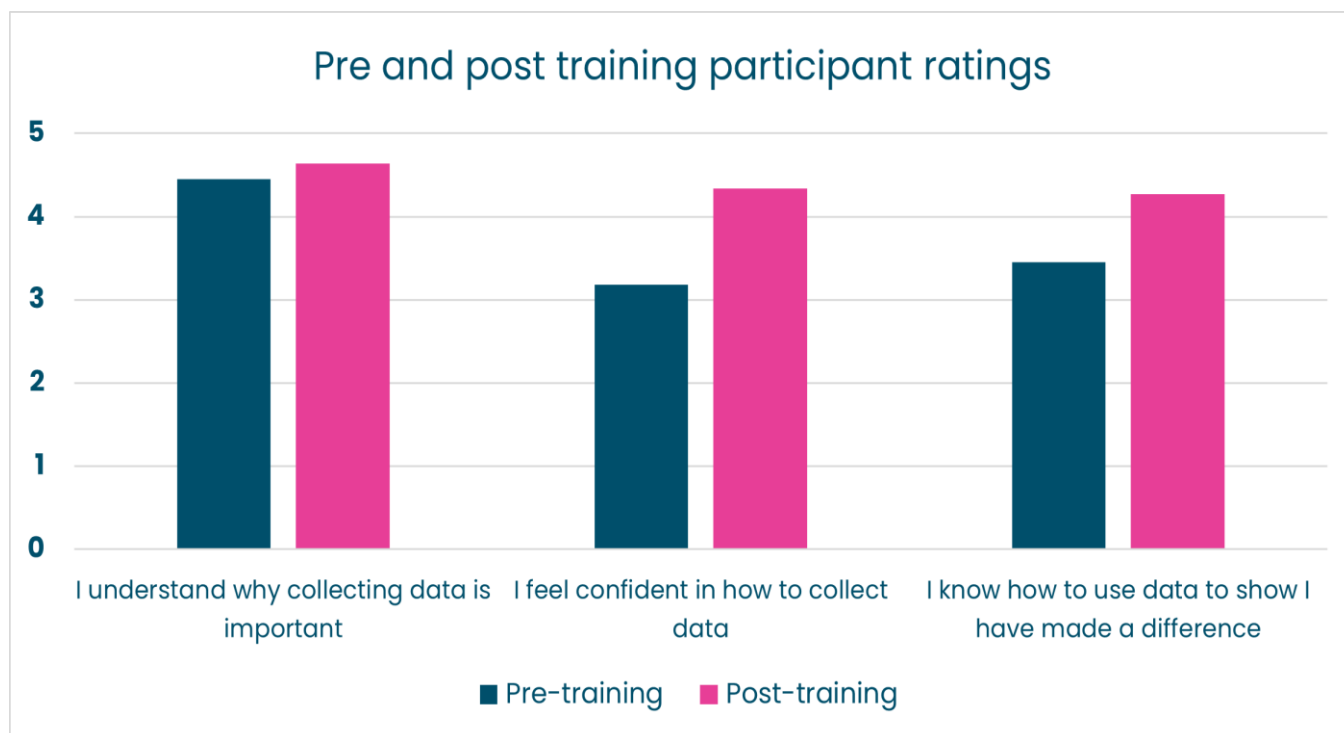
Participants completed an evaluation form both pre and post training. The findings from the evaluation forms are discussed below.



Participants had increased knowledge and confidence in collecting and using data

Participants were asked about their understanding of the importance of collecting data, their confidence in collecting it and their knowledge about using that data to show that they have made a difference. There was a positive increase in all three of these areas following the training session, see Chart One.

Chart One



The aims and objectives of the training session were met

All participants either 'strongly agreed' or 'agreed' that the aims and objectives of the training were clearly stated and that the information was relevant and useful.

Eight out of 11 participants 'strongly agreed' that the handouts were helpful, a further two participants 'agreed' and the remaining person was 'neutral'.

When asked if the overall experience of the workshop was positive, seven out of 11 people 'strongly agreed' and the remaining four people 'agreed'.

The training was useful and will positively affect how the participants do their day to day job

Participants were asked what they found most useful about the training. All 11 participants responded, and these responses were categorised into three themes, please note some people gave more than one response.



The first theme was how useful the session around outputs, outcomes and impact was, particularly relating to work they are currently doing at the Hospice:

“It helped us to understand what we have documented, outputs, and what we don’t do so well, outcomes and impact, and why we need to do this.”

The second theme was that the handouts and activities were most useful and helped them to work through real and relevant examples:

“Having one tool for us to use – streamlining.”

“Being interactive and directly applied to real life situations.”

The third theme around what was most helpful was practical tips on collecting data:

“Not to overthink what data we need to collect. Simplify it.”

When asked what they might do differently in their day to day job following the training, all participants identified at least one thing. A range of answers were given:

“Look closer at the start of project, take more time initially.”

“A more structured approach to project management with a common language.”

“Ask more questions... on what data is going to be collected and why.”

“Think about possible things I may need to collect data on and the best, easiest way of collecting that data.”

“Be aware of patient feedback and how we could collect this better.”



“The training session was fantastic, really well received by those who attended.”

Joanne Schofield
Director of Clinical Services
The Prince of Wales Hospice

Recommendations

1. Hold regular open days. Consider the possibility of providing transport and also holding them at a variety of times including evenings and weekends. Promote widely, including through social media, leaflets and through other local organisations.
2. Consider offering exercise sessions, sessions offering advice on nutrition and exercise, and also sessions offering advice on planning for the future along with face to face and online social groups.
3. Work with local groups and organisations to make sure that their staff and volunteers have the knowledge and resources, for example, leaflets, online details, to be able to promote The Prince of Wales Hospice.
4. Consider ways to further promote the variety of support on offer, particularly around support for friends and family members. This is something that most people were interested in, but many weren't aware was available.
5. Consider seeking user feedback on current marketing and promotion of activities including website, social media and leaflets, to ensure that the variety of support on offer is clear.
6. Continue the planning, started at the training, to audit the data that is currently collected and to plan and prioritise future data and evaluation work across the organisation.
7. Consider standardising the use of the Healthwatch Wakefield Project Initiation and Project Planning documents, or similar, across the organisation.

At the time of publication, The Prince of Wales Hospice have already started to take the recommendations on board in order to improve their offer.

"I have processed the report and have used the findings to help us develop the Wellbeing community programme."

Wellbeing Team staff member, The Prince of Wales Hospice

We look forward to hearing more about their work moving forward and wish them every success.




Appendix

Appendix one

Demographics

Thirty-six people completed the survey. Here is the breakdown of demographic information collected.



13. What is your age?

Answer Choices			Response Percent	Response Total
2	25 - 49		21.43%	6
3	50 - 64		39.29%	11
4	65 - 79		39.29%	11





14. What is your gender identity?

Answer Choices			Response Percent	Response Total
1	Woman		81.48%	22
2	Man		18.52%	5
















15. Is your gender identity the same as the sex you were assigned at birth?

Answer Choices			Response Percent	Response Total
1	Yes		96.30%	26
2	No		0.00%	0
3	Prefer not to say		3.70%	1

16. Is your marital status

Answer Choices			Response Percent	Response Total
1	Single		7.41%	2
4	Married		85.19%	23
5	Separated		3.70%	1
6	Divorced		3.70%	1

17. Aside from your, the patient's, illness, do you consider yourself, the patient, to have a disability or long term condition? If yes, which of the following? Tick as many as apply

Answer Choices			Response Percent	Response Total
1	Physical or mobility impairment		38.10%	8
2	Asthma, COPD or respiratory condition		9.52%	2
3	Blindness or visual impairment		4.76%	1
4	Cancer		38.10%	8
5	Cardiovascular condition		14.29%	3
6	Chronic kidney disease		9.52%	2
7	Deafness or hearing impairment		4.76%	1
8	Dementia		9.52%	2
9	Diabetes		4.76%	1
11	Hypertension, or high blood pressure		23.81%	5
13	Mental health condition		9.52%	2
14	Musculoskeletal condition		9.52%	2
15	Sensory impairment		4.76%	1
16	Prefer not to say		9.52%	2
17	Other, please specify:		28.57%	6

Other, please specify:
Mobility problem at the moment/Awaiting a hip replacement
Xerostomia, Eating limitations
Drug dependency
None other than terminal cancer diagnosis
Dry eyes cataracts left ear deficit plus other issues

18. What is the first part of your postcode?

Answer Choices	Response Percent	Response Total
Open-Ended Question	100.00%	22

WF7 x 2
WF9
WF2
WF9
LS8
WF x 2
LS25
PL x 2
WF10 x 4
DN6
DN14
WF8 x 5



healthwatch
Wakefield

Healthwatch Wakefield
The Plex
15 Margret street
Wakefield
WF1 2DQ

www.healthwatchwakefield.co.uk

telephone: 01924 787379

mobile: If you are Deaf, you can text us on 07885 913396

email: enquiries@healthwatchwakefield.co.uk

twitter: @healthywakey

Facebook: [Facebook.com/HealthwatchWakefield](https://www.facebook.com/HealthwatchWakefield)