



Saint Francis Hospice

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INTRODUCTION

Healthwatch Barking and Dagenham is the voice of local service users. Our role is to ensure that the views of local residents are heard by decision makers, and that their opinions influence the way that services are delivered. We are independent and therefore do not have a pre-set agenda or a pre-determined interest in influencing the outcome of the results of a consultation.

When first approached by Paul Sullivan, family support services manager at the hospice, it was understood that Healthwatch involvement would be to receive and gather honest feedback from St Francis service users, their family and friends about the service they had received. However, at the start of the project, Healthwatch went along to one of St Francis' event in Barking Vicarage Fields during the 'Dying Matters' week and were surprised to see that the majority of residents we spoke to had not heard of the hospice before. This soon changed the focus of our project and research, the new focus being agreed and accepted by Paul Sullivan of St Francis Hospice.

Over the years it has been noted that the proportion of service users in any capacity from Barking and Dagenham has been much lower than the percentage of the one from Havering (data supplied by St Francis' clinical information team):

2014-15	Inpatients	Community (SCCSS)	Hospice at home	Day therapy	Total patients
Barking & Dagenham	19.7%	26.9%	22.0%	16.9%	24.5%
Brentwood	14.6%	19.4%	18.8%	14.9%	18.4%
Chelmsford		0.1%	0.2%		0.1%
Havering	54.3%	53.2%	59.0%	57.4%	52.9%
Redbridge	10.5%	0.2%		10.4%	3.9%
Southend		0.1%			
West Essex	0.3%	0.1%		0.4%	0.1%
Newham	0.6%				0.1%

2013-14	Inpatients	Community (SCCSS)	Hospice at home	Day therapy	Total patients
Barking & Dagenham	19.9%	25.7%	22.2%	15.9%	24.0%
Brentwood	15.6%	20.8%	20.2%	13.4%	18.8%
Basildon		0.1%			0.1%
Chelmsford					
Havering	50.7%	53.1%	57.6%	60.7%	52.7%
Redbridge	11.1%	0.2%		9.6%	3.6%
Southend	0.3%				0.1%
West Essex	1.2%	0.1%		0.4%	0.4%
Ealing	0.3%				0.1%
Hackney	0.3%				0.1%
Newham	0.6%				0.1%

2012-13	Inpatients	Community (SCCSS)	Hospice at home	Day therapy	Total patients
Barking & Dagenham	19.4%	26.7%	22.1%	19.2%	23.6%
Brentwood	18.0%	19.4%	16.1%	11.6%	17.0%
Basildon					
Chelmsford		0.2%	0.2%		0.1%
Havering	51.4%	53.3%	61.4%	56.3%	53.6%
Redbridge	8.9%	0.3%	0.2%	12.5%	4.7%
Southend					
West Essex	1.1%	0.1%		0.4%	0.5%
Ealing					
Hackney					
Halesworth	0.3%				0.1%
Maldon	0.3%				0.1%
Waltham Forest	0.3%				0.1%
Loughton					0.1%
Newham	0.3%				0.1%

Healthwatch Barking and Dagenham therefore tried to understand the reasons behind the seemingly low awareness and use of St Francis Hospice by Barking and Dagenham residents.

This report outlines the views of members of the public and of professionals.

Copies of this report are available by contacting Barking and Dagenham Healthwatch on 020 8596 8200 or by emailing info@healthwatchbarkinganddagenham.co.uk.

Copies are also downloadable from our website:
www.healthwatchbarkinganddagenham.co.uk.

BACKGROUND INFORMATION AND SERVICES PROVIDED

Saint Francis Hospice is situated in Broxhill Road, Havering-atte-Bower, RM4 1QH in the London borough of Havering.

“Saint Francis Hospice is an independent charity and one of the largest adult hospices in the UK. Our team of specialist consultants, doctors, nurses and a range of other health and social care professionals provide care and support to individuals with a life-limiting

illness, as well as their carers and family members, completely free of charge.

We serve the populations of Havering, Brentwood, Barking & Dagenham, Redbridge and West Essex. This year, we need to raise £7.3 million in voluntary income, so every donation from individuals and organisations is important to us. We also have a team of over 800 skilled and committed volunteers who help us keep our costs down and add huge value to the work we do.” (<https://www.sfh.org.uk/>)

Saint Francis offers the services below at home or at the hospice. Both on-site and in the community, there is access to a full range of medical expertise from trained professionals including:

- consultants
- nurses specialising in palliative care
- physiotherapists
- complementary therapists
- chaplains
- social workers
- counsellors
- Occupational therapists.

Day Therapy Service

The Day Therapy service is based within Saint Francis Hospice. It supports people at any stage of their life-limiting illness, and provides a range of specialist medical and therapeutic services.

Service users will have access to health and social care professionals such as doctors and nurses, therapies such as complementary therapy, occupational therapy, physiotherapy, family support team and chaplains. The hospice can provide clinical treatment interventions, such as blood transfusions, during your visit if it is appropriate.

The day service host a range of groups, including a six-week breathtaking course run by the physiotherapy team, a creative therapy group, a monthly social drop in and a

number of groups organised by the Family Support team, such as monthly carer drop-ins and creative writing sessions.

Take a look at some of the items service users have made during their time at the day therapy.



Complementary therapy

Complementary therapies are provided on-site in the hospice. The service provides aromatherapy, massage, reflexology and Reiki courses provided in four initial treatments. After these the staff review your progress, discuss how you're feeling about the treatments and whether or not you feel you'd benefit from continuing.

For carers, a relaxing Indian head massage is offered as part of our commitment to providing a safe, non-clinical area for people to escape the demands of illness.



Memory Tree

The solid copper, brass and aluminum leaves on the Memory Tree are engraved with the name(s) of loved one and will remain on the tree for as long as the family/friends wish. Every leaf not only creates a unique personal tribute, but they provide support for our patients and their families who may need hospice care in the future. There is a cost attached to this.



For more information on any of the services, memory tree or fundraising events, please contact Saint Francis Hospice or refer to the website

Feedback shows that service users and their families have only positive feedback.

Saint Francis is well loved by Barking and Dagenham residents who know of it. Healthwatch asked the public what their views of the hospice were on Streetlife:

- *'I've known of St Francis Hospice for about 25 years. I know of the good work they do looking after terminally ill patients and their families. It is good to have a place like that so near that can help when you need it.'*
- *'I cannot fault SFH. My dear mum spent her last few days there last summer. The staff are amazing. Very kind, caring and genuinely brilliant. My mum was in a lot of pain and I would go and fetch the nurse but they insisted that I ring the bell so that I spent as much time with my mum as possible. Not only were they there for my mum, they were there for the whole family. Both my mum and myself were given holistic therapies whilst there and I also had counseling when my mum passed away. I never had any trouble driving to or from SFH and I was going there every day, at different times of the day.'*
- *'My Dad died there. Unfortunately I lived abroad and the Gulf War was on and it took a few days to get a flight. He was gone before I got there but the nurse used to read him my letters and my whole family had nothing but praise for the hospice.'*
- *'They looked after my husband at home when he had terminal lung cancer and were brilliant with their care and advice. I knew about them before so pushed for the referral but some people do not know the referral procedure and sometimes not able to push for it.'*

St Francis Hospice is commissioned for end of life care in Barking and Dagenham by the CCG. NELFT community services also provide end of life care for B&D residents as do BHRUT. The CCG also commissions some services from Marie Curie. GPs, community nurses and social workers can refer patients to the hospice. Patients cannot self-refer at the moment. Acute trusts can also refer.

GPs currently use hard copy referral forms, the hospice is due to pilot an electronic form to assess if this makes the process of referrals easier. The hospice is engaging with various GP Practices to support this pilot.

POSSIBLE REASONS FOR THE PATTERN OF USE

AGE OF THE POPULATION

Saint Francis Hospice is situated in the London borough of Havering.

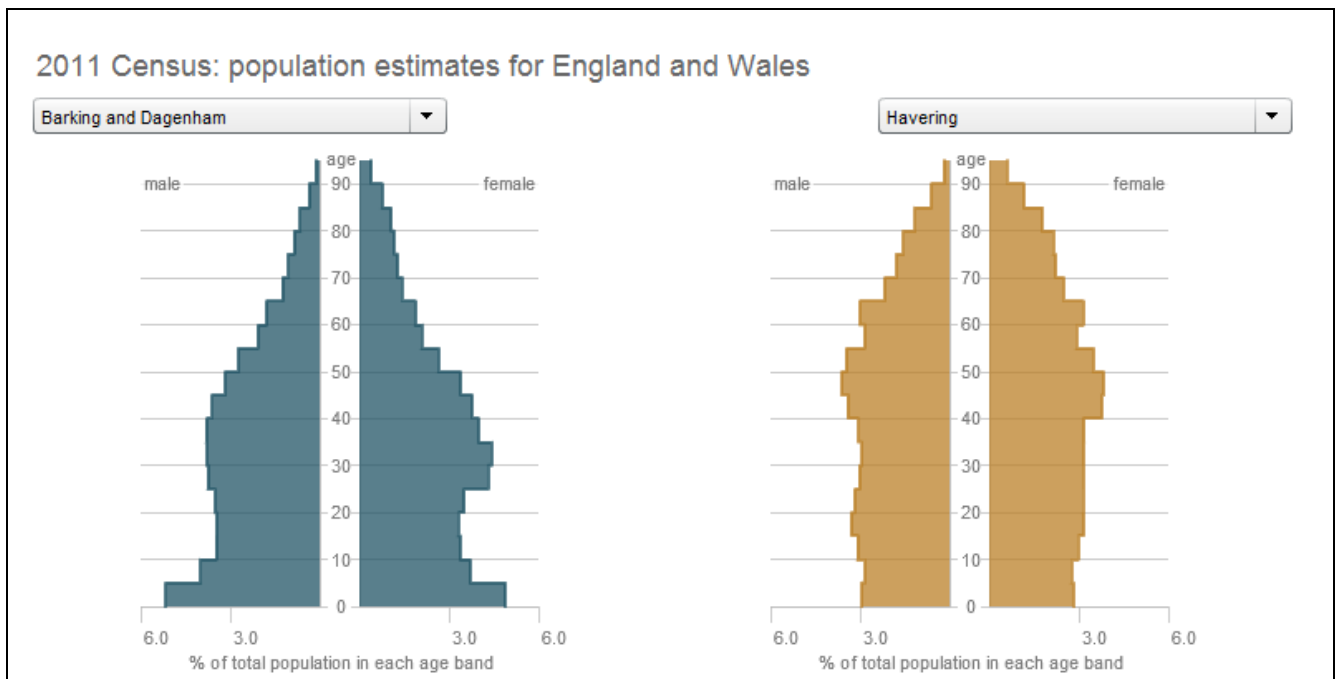
Havering has a history of high number of older residents above the age of 65:

2013	Number	Percentage of Population (%)
All persons	242,080	100.0
0-4 years	14,808	6.1
5-10 years	16,867	7.0
11-17 years	20,445	8.5
18 - 24 years	21,048	8.7
25 - 64 years	124,097	51.3
65 - 84 years	38,306	15.8
85+ years	6,509	2.7

(Source: 2013 Mid-year population estimates, Office of National Statistics)

The older population is more likely to have lived in the area for a longer period of time and be aware of the hospice as well as need its services.

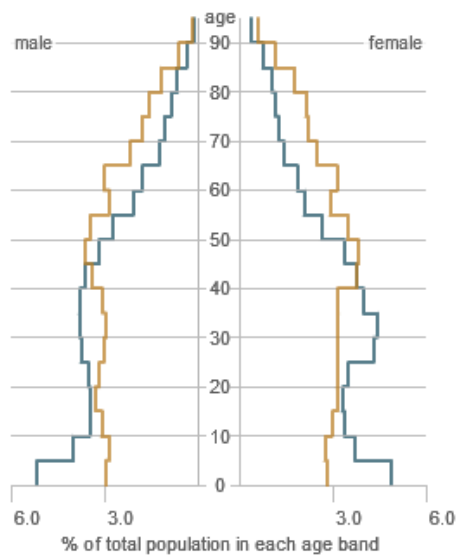
In contrast, Barking and Dagenham has a much younger population:



2011 Census: population estimates for England and Wales

Barking and Dagenham

Havering

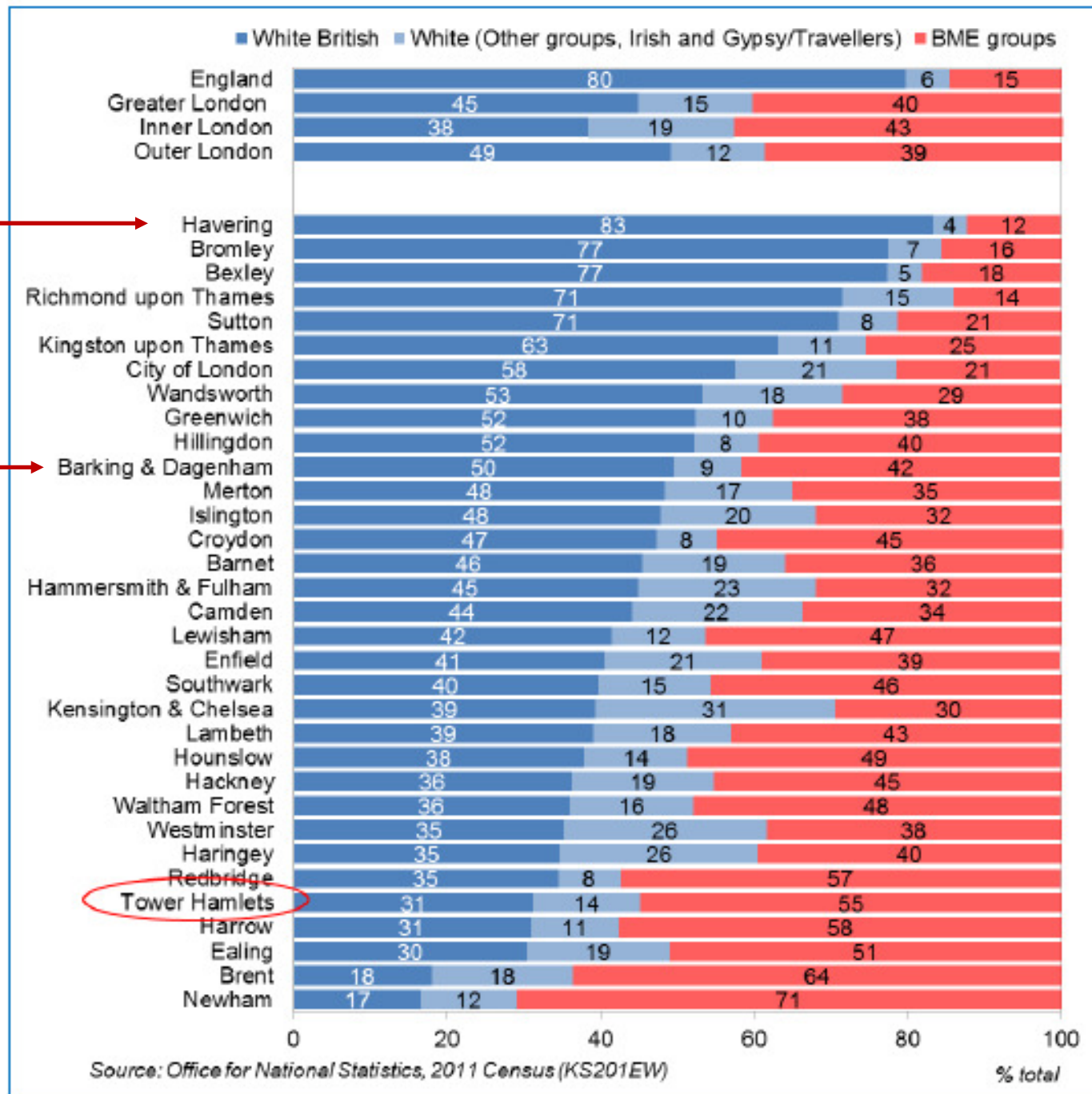


(Source: <http://www.ons.gov.uk/ons/interactive/vp2-2011-census-comparator/index.html>)

ETHNIC DIVERSITY OF THE POPULATION

The 2011 Census shows that Havering population is made up 17% of ethnic groups and 83% of White British people. In comparison, Barking and Dagenham shows that the proportion of the White British ethnic group is 49.5% indicating that 50.5% of the borough's population is of other ethnic backgrounds.

Ethnicity in London Boroughs, 2011



(Source: Tower Hamlet Research Briefing 2013)

In Havering, while the percentage of minority ethnic groups is very small compared to other London Boroughs, the borough has also seen the highest percentage increase between 2001 Census and 2011 Census as the percentage of ethnic minority population has more than doubled from 8% in 2001 to 17% in 2011.

For comparison, on the 2001 Census day, 92 out of every 100 people in Havering were “White British.” In 2011, this has reduced to 83 out of every 100 people. This represents an increase of ethnic groups (including non-British White) from 8% (2001) to 17% (2011) of the Havering Population - a 9 percentage point increase in the ten-year period.

The White British population has a very different age structure to the minority ethnic population. While a greater proportion of the White British population are in older age groups, the majority of the minority ethnic groups are in the younger age groups. For example, in Havering, most White British residents are in the 45-49 year age group, whereas most BME residents are in the 0-4 and 30-34 year age groups. In a similar way, 26.1% of the B&D population is in the 0-9 and 43.9% between 16-44. There is a need to engage with the younger generation to ensure they are aware of the services, that themselves or a loved one may need.

Saint Francis Hospice recognises the importance to engage more with the younger generation, to help to achieve this, here are some of things that St Francis already do:

- **Social media:** Facebook, Twitter and Instagram accounts which are actively used.
- **The santathon** takes place every year in Dagenham with around 500 people running, walking or strolling the 5km course. The event attracts both young and old, making it not only a successful fundraising event but raises awareness too.
- **Calendar:** A calendar was produced with support from the Barking and Dagenham Rugby club.



RELIGION

In Havering, a high percentage and the majority of the population is Christian:

	Population	Christian	Buddhist	Hindu	Jewish	Muslim	Sikh	Other Religion	No Religion	Religion not Stated
Havering	237,232	65.6%	0.3%	1.2%	0.5%	2.0%	0.8%	0.3%	22.6%	6.7%

The Christian religion is the most prevalent religion in B&D. It is worth noting that in Barking and Dagenham, not all Christians are of a traditional White English background.

	Population	Christian	Buddhist	Hindu	Jewish	Muslim	Sikh	Other Religion	No Religion	Religion not Stated
LBBD	185911	56.0%	0.5%	2.4%	0.2%	13.7%	1.6%	0.3%	18.9%	6.4%

However, there is a significant rise in the Muslim and Hindu population in the borough and some GPs we surveyed (and would be referring patients) were not sure of the religious support provided in St Francis for other religions such as Islam and Hinduism.

‘Spiritual support for those who are Muslim and Hindu.’ (a B&D GP)

CULTURE AND LANGUAGE

The GPs and community nurses who answered our survey believed that within certain communities, people prefer to look after their own or may not be aware of hospices or not sure about what they are.

‘We have a high proportion of Bangladeshi and Pakistani Muslims who may not feel comfortable using services not provided from within their own community.’

‘There is a misconception of the service.’

The end of life care facilitator for Barking and Dagenham, said that they feel ‘most Asian, African and elderly residents still think of the hospice as a ‘one way journey’.

Difficulty in reading promotional material, wanting someone with the same linguistic background to care for you, being able to make yourself understood by carers could also all be potential barriers to using the services provided by St Francis. St Francis use interpreters, however the findings do not reflect this, Healthwatch believe that this is as people are not aware of the service being available.

When we spoke to staff at the hospice they told us how Saint Francis Hospice nurses care for patients from different ethnic and cultural backgrounds.

Saint Francis staff told Healthwatch how the Specialist Community and Crisis support team always ask about religious beliefs and needs during their first assessment with the patient. Usually, it will have been documented on the referral form, but the initial telephone contact will include a discussion about the importance of their religion and their requirements. All religious or spiritual needs will be documented at the front of the patient notes and on iCare, the Hospices clinical system. If required, subsequent conversations will be held with the patient regarding spiritual and religious needs via face to face contact. Interpreters are available if there is a language barrier.

The on-call Clinical Nurse Specialists have a list of out of hours faith leaders, including Muslim, Hindu, Anglican, Greek Orthodox and Buddhist - and this is a service that's frequently used.

Hospice at Home services are provided to people in Havering, Barking and Dagenham, Brentwood and Redbridge. During every first assessment conducted, it is routine for the nurse to ask the patient and/or family about their religion, how important their faith is to them, what their beliefs are, and to explore anything additional they need to know about how it will impact on the way they care for the patient. They also observe the surroundings, for example, noticing religious portraits on the wall or the presence of religious literature next to their bed.

All of this is then fed back to the Hospice at Home team at their team meetings, as well as written in the notes. It's ensured that everyone who will come into contact with the patient is aware of their wishes.

It is recognised throughout the team that wishes and preferences will vary for each individual. For example, two patients may have the same religion, but there will be differences in their own interpretation of that religion and the importance of certain traditions; their families may have different views and there could be cultural differences, too. All of this is taken into consideration.

Saint Francis Hospice provided the following examples.

Example 1: The patient was a Female from Barking, 81years of age ,Muslim.

This patient was living in a one bed flat, with around 30 family members and friends coming and going all day. Our nurse was asked to remove her shoes but, due to health and safety regulations was unable to do this. Instead she wore shoe covers - a solution the family were happy with. The family were positioned around the patient's bed,

chanting from the Qur'an. Our nurse asked one of the family members out of the bedroom for information about the chant and what it meant. She was taught the chant, and was included in the chants going forward. In turn, she taught the rest of the Hospice at Home team about the chant, so they are now informed on its meaning and relevance.

Example 2: The patient was Female from Dagenham, 71years of age, Pakistani Muslim.

When our nurse arrived, she found the family feeding and giving fluid to the patient. The fluid was Holy Water, being delivered by a syringe. Our nurse explained to the family that there was a risk feeding the patient as she was unable to swallow properly. She conducted her mouth care using the Holy Water and sponges. As the patient was dying, our nurse was positioned at the end of the bed. One of the family members explained that that's where the spirit leaves, the Nurse moved. This was fed back to the rest of the Hospice at Home team, it's now commonplace that our team will stand elsewhere. Finally, she assisted in ensuring the patient had her head covered when a male was in the room, in line with the religious and family preferences.

Male, Chadwell Health, 60, Buddhist.

This patient didn't want any pain relief or sedation as he wanted to feel his soul leave his body. As a compromise, our nurse administered anti-inflammatory drugs and more gentle painkillers. In circumstances such as these, our Hospice at Home nurses pay particular attention to the families and friends, if they are struggling to see someone they love who has refused pain relief, in pain.

This final case study is a patient who was admitted to the inpatient unit.

Male, Muslim.

This patient clearly stated that he didn't want any pain killers as he wished to pray four times a day and needed to be pure. A compromise was agreed and he was given pain relief at certain times of the day so it had worn off by the time he came to pray. It was recognised the level of comfort he found in prayer, so it was holistically managed by our IPU nurses.

From the examples it's clear that support is provided to the service users and therefore Healthwatch recommend that these examples are showcased more through social media networks and religious organisations to help eliminate some of the stigma that the hospice is Christian based only.

Volunteering Statistics

Barking & Dagenham	Havering	London	Redbridge	Brentwood
1 x Indian 1 x Pakistani 9 x White	1 x Asian/Asian British Indian Origin 3 x Black - African 1 x Black - Caribbean 1 x Chinese 6 x Indian 1 x Pakistani 1 x Sri Lankan 169 x White	1 x Sri Lankan 4 x White	1 x Black-Caribbean 2 x Indian 1 x Mixed Race White & Black Caribbean 2 x Pakistani 19 x White 1 x Zoroastrian **	43 x White

A volunteer from an ethnic background has been volunteering for the hospice for over 5 years.

Volunteer statement provided by Rafeeda Sohail, November 2015:

"I started volunteering at the hospice in July 2015. I have wanted to contribute for some time. For the last 10 years I was working with the hospice providing a prescription service as branch pharmacist at Lloyds Pharmacy in Collier Row. During this time I developed a lovely relationship with the nurses on the ward and with Corinna Midgely and Sue Lakey. In 2012 Corinna sponsored me to take the therapeutics course which benefitted me greatly with my understanding of palliative care and prescribing. Since then I wanted to be more involved with the hospice but was unable due to time.

Last year I left Lloyds pharmacy but wanted to give something back to the community and the hospice, so I volunteered. Initially I was asked to help generally but then I was approached by finance to help them with drug budgeting which was very much part of my expertise.

Everyone has been so helpful and kind. I feel the one morning I am able to give a week is greatly appreciated. My contributions are listened to and considered.

The work I am helping with in finance is related to my field and I feel happy that I have been able to help in some way.

As to what I get out of volunteering I am just happy to contribute in some way to an organisation which helps so many families. I wish I could do more but being a working mum of 3, I am only able to give one morning at present. Very few of us have the

opportunity to help others in a way that changes lives. By contributing a little of my time I feel that that I am part of an organisation that does that.”

Saint Francis Hospice Retail has volunteers in its 15 shops from all different backgrounds, the more diverse the better! The Ilford shop has the most diverse workforce, the Manager has an area for prayer.

Healthwatch acknowledge the fact that there are a range of volunteers from different backgrounds within retail. Healthwatch recommend working with volunteer organisations, to establish ways of engaging with the younger generation and individuals from different backgrounds who may be interested in volunteering at the hospice. This way the volunteers would be able to cascade the message of what the hospice offers to their communities.

UNKNOWN SERVICE

The service or parts of it may be unknown to the residents of Barking & Dagenham. There seems to be uncertainty if B&D GPs are particularly comfortable to suggest the hospice to their patients. Many may not be very confident with advance care planning discussions and this is where the introduction of the hospice services should come in.

There is also the assumption that the Hospice is only a one way journey and only illnesses such as Cancer.

The Hospice is not only for cancer patients but patients for long term illnesses too such as neurological conditions. Some service users are admitted to the hospice but once their symptoms are stabilised are discharged back into the community. This again indicates the need to publicise Hospice care, which would assist in dispelling the myths.

DISTANCE

For B&D residents without cars, access to St Francis Hospice can be challenging as only one bus served the hospice every hour and a half and the location is quite remote. However, the end of life care facilitator for Barking and Dagenham did not feel distance was necessary an issue as St Francis nurses will travel to people's homes to provide care. Potential users may be unaware of this.

St Francis Hospice offer a volunteer driver scheme which helps, this is not be widely advertised.

GPs, acute hospitals and community nurses are referrers Saint Francis Hospice . Staff at the hospice told Healthwatch that the majority of referrals come from acute hospitals.

Healthwatch asked GPs and community nurses their opinion about the low referral percentage of service users who come from Barking & Dagenham for any of the services St Francis Hospice offer.

GPs

We sent questionnaires to 51 GP Practices in Barking and Dagenham and received answers back from 10 individual GPs. All GPs answered anonymously.

1. Are you aware of St Francis Hospice and all they offer both in the patient's home and at the hospice?

Services offered at St Francis Hospice	Number of GPs	Percentage (%)
Consultants	9	90%
Nurses specialising in palliative care	9	90%
Physiotherapy	6	60%
Complementary therapists	6	60%
Chaplains	3	30%
Social workers	4	40%
Counsellors	8	80%
Occupational therapists	4	40%
Family and carers support	8	80%
Crisis support helpline 24/7	9	90%
Not aware of St Francis Hospice	1	10%

Most GPs gave more than 1 answer.

Almost all of the GPs (90%) were aware that St Francis can provide consultants, nurses specialist in palliative care and offer crisis support over the phone 24/7. 80% are aware St Francis can provide counselling and family and carers support. 60% expressed they knew of the availability of physiotherapy and complementary therapy at St Francis.

Chaplains, social workers and occupational therapists were less known of with a below average result (30-40%)

1 GP expressed they did not know about St Francis Hospice. This may also have been the reason why other GPs did not reply.

2. Have you...

	Number of GPs	Percentage (%)
Seen adverts or leaflets	3	30%
Visited the premises (either at a professional or personal level)	3	30%
Attended a presentation on what they provide	1	10%
Other	3	30%
Not heard of St Francis	1	10%

Some GPs gave more than 1 answer.

30% have seen adverts and leaflets about St Francis, 30% have previously visited the premises and another 30% ticked 'other' with one of those expressing they knew somebody who has used the service.

Only 10% of the GPs expressed having attended a presentation about St Francis and another 1 GP said they had never heard of the hospice.

3. In the last year have you referred any patients to St Francis?

If so, roughly how many?

	Number of GPs	Percentage (%)
1-5	6	60%
6-10	2	20%
11-20	0	0%
20+	0	0%
Have not referred anyone	2	20%
TOTAL	10	100%

60% of GPs referred 1-5 of their patients to the hospice over the last year whilst 20% referred 6-10 of their patients.

20% of the GPs said they had not referred anyone.

4. If you have not referred any patient to them recently, what is the reason?

The 2 GPs who did not refer any patients to St Francis said it was because they don't have any palliative care patient at their clinic or because it had not been needed.

5. Have you ever suggested the hospice to patients who have turned down the referral?

	Number of GPs	Percentage (%)
Yes	3	30%
No	6	60%
Did not answer	1	10%
TOTAL	10	100%

3 GPs expressed having been turned down by patients when suggesting the hospice to them. However, 60% of them said that patients have never turned down a referral.

10% did not answer.

6. Do you think any of the following could prove to be barriers for some service users and/or their family?

	Number of GPs	Percentage (%)
Religion	1	10%
Culture	3	30%
Distance	2	20%
Unknown service	2	20%
Other*	3	30%

Some GPs gave more than 1 answer.

*For 'Other' reasons, GPs quoted:

- *'We have a high proportion of Bangladeshi and Pakistani Muslims who may not feel comfortable using services not provided from within their own community.'*
- *'There is a misconception of the service.'*
- *'I don't think there are any barriers.'*

The highest percentage of GPs (30%) thought that 'culture' is the biggest barrier for not using the service of St Francis Hospice for some patients, followed closely by 'distance' and 'unknown service' (20%). Only 10% of GPs believe 'religion' could prove to be a barrier.

7. In your opinion, why is there a low referral rate from Barking & Dagenham?

- *'I have no idea!'*
- *'I don't know.'*
- *'We have a good palliative care service.'*
- *'Good public transport link from and to B&D.'*
- *'I did not know that there was [a low referral rate].'*
- *'I don't know.'*
- *'There is a low level of awareness what the organisation stands for.'*
- *'Not aware of the service.'*
- *'Work overload.'*
- *'Not good communication with the hospice.'*

8. Do you have any other comments, opinions or suggestions?

- *'Support workers/advocates who are Bangladeshi, Pakistani and Indian.'*
- *'Spiritual support for those who are Muslim and Hindu.'*
- *'Outreach workers and events in mosques and temples.'*
- *'There should be more publicity and raise awareness: it would help if service users could contribute with testimonies about the good and important work the hospice does.'*
- *'Make the referral form simpler.'*

Community Nurses

The same questionnaires were also distributed to 25 Community Nurses in Barking and Dagenham and Healthwatch received answers back from 6 of them. All Community Nurses (CN) answered anonymously.

1. Are you aware of St Francis Hospice and all they offer both in the patient's home and at the hospice?

Services offered at St Francis Hospice	Number of CNs	Percentage (%)
Consultants	4	67%
Nurses specialising in palliative care	5	83%
Physiotherapy	4	67%
Complementary therapists	6	100%
Chaplains	5	83%
Social workers	4	67%
Counsellors	4	67%
Occupational therapists	4	67%
Family and carers support	6	100%
Crisis support helpline 24/7	4	67%
Not aware of St Francis Hospice	0	0%

All CNs gave more than 1 answer and there is an above average knowledge of what St Francis Hospice can provide for patients.

- All CN know St Francis can provide complementary therapy and family and carers' support.
- Most are also aware of the specialised nursing and chaplaincy.
- There is an above average number of CNs (67%) who know consultants, physiotherapists, social workers, counsellors, occupational therapists are available as well as the existence of the 24/7 crisis support helpline.

2. Have you...

	Number of CNs	Percentage (%)
Seen adverts or leaflets	3	50%
Visited the premises (either at a professional or personal level)	6	100%
Attended a presentation on what they provide	3	50%
Other*	1	17%
Not heard of St Francis	0	0%

Some CNs gave more than 1 answer.

- All CN who returned the survey to Healthwatch have visited the hospice before.
- Half of them (50%) have also either seen an advert or attended a presentation.
- *1 CN stated having received some form of training about the hospice.

3. In the last year have you referred any patients to St Francis?

If so, roughly how many?

	Number of CNs	Percentage (%)
1-5	2	33%
6-10	2	33%
11-20	2	33%
20+	0	0%
Have not referred anyone	0	0%
TOTAL	6	100%

- All CN have referred patients to St Francis Hospice in the last year.

4. If you have not referred any patient to them recently, what is the reason?

This was not answered by any of the CN as they have all referred at least 1 patient to the hospice in the last year.

5. Have you ever suggested the hospice to patients who have turned down the referral?

	Number of CNs	Percentage (%)
Yes	5	83%
No	1	17%
Did not answer	0	0%
TOTAL	6	100%

- 83% of CN have tried to refer patients to St Francis who have turned them down.
- Only 1 CN has not had a patient turning down their referral to the hospice.

6. Do you think any of the following could prove to be barriers for some service users and/or their family?

	Number of CNs	Percentage (%)
Religion	0	0%
Culture	1	17%
Distance	2	33%
Unknown service	4	67%
Other*	3	50%

Some CNs gave more than 1 answer.

- An above average of CN (67%) believes that St Francis Hospice is not known by residents of B&D and this causes them to refuse to be referred.
- ‘Distance’ away from B&D is also a possible barrier to using the service in 33% of CN’s opinion.
- Only 1 (17%) CN believe that ‘culture’ is a probable barrier.

*For ‘Other’ reasons, CNs quoted:

- *‘Fear of dying associated with place of death.’*
- *‘Patients perceiving the hospice as the final stage are often reluctant to being referred.’*
- *‘There is a stigma attached to hospices.’*

7. In your opinion, why is there a low referral rate from Barking & Dagenham?

- *‘Some patients don’t like the sound of going into an hospice as they think it is final.’*
- *‘Multicultural? Form filling exercise?’*
- *‘GPs and hospitals don’t want to fill in the forms.’*
- *‘I don’t know.’*
- *‘No idea as a CN we are made fully aware of the hospice facilities and benefits.’*
- *‘I was not aware there was a low referral.’*

8. Do you have any other comments, opinions or suggestions?

- *‘Alert GPs to make referrals and discuss end of life.’*
- *‘GPs to complete referral forms as it is mostly done by CNs.’*
- *‘Allow self-referrals.’*

Hackney has a similar demography to that of Barking and Dagenham:

The 'A Profile of Hackney, its People and Place' document (September 2014) states, 'Hackney is a relatively young borough with a quarter of its population under 20. The proportion of residents between 20-29 years has grown in the last ten years and now stands at 21%. People aged over 55 make up only 14% of the population.'

Hackney is a culturally diverse area, with significant 'Other White', Black and Turkish communities. The Charedi Jewish community is concentrated in the North East of the borough and is growing.

Polish people are the largest group who have recently come to live in Hackney from abroad followed by Spanish, Italian and French people.

Just over a third of Hackney's residents are Christian. This is a lower percentage than the London and England averages. Hackney has significantly more people of the Jewish and Muslim faith and a higher proportion of people with no religion and those who did not state a religion than London and England.'

For this reason, Healthwatch visited St Joseph's Hospice (Mare Street, Hackney, London, E8 4SA) and spoke with Beverly John, the 'Live Well Information and Support Co-ordinator for the Outreach Team' to try and understand the hospice's fairly new community outreach.

Patients can be referred to the hospice from the London boroughs of Tower Hamlets, Newham, City and Hackney. The hospice has 42 beds on 3 wards, and offers care in five main settings:

- In-patient care (end-of-life care on 2 wards),
- Respite (1 ward),
- Day hospice,
- Community-based care,
- Out-patients services.

Patients can be referred by any health and social care professionals (GPs, social workers, district nurses), family members or can also self-refer.

Over the years St Joseph's have supported many people and more recently have developed an outreach service in an effort to include those of various ethnic minorities who tend not to use their services.

Ethnic Groups Supported per Year (April 2012-March 2015)

Ethnic Groups	2012-2013	2013-2014	2014-2015
White British	261	1,486	1,769
White Irish	15	132	137
Total	276 = 52.2%	1,618 = 57.6%	1,906 = 55.9%
All Other Ethnic Groups	44	118	127
Asian (other)	19	91	76
Bangladeshi	33	159	272
Black (other)	10	57	50
Black African	25	143	167
Black Caribbean	45	274	368
Far Eastern (all)	3	10	36
Indian	29	97	112
Mixed Other	7	39	33
Pakistani	11	50	52
White (other)	21	127	183
White and Asian	1	10	11
White and Black African	2	8	4
White and Black Caribbean	3	10	14
Total	253 = 47.8%	1,193 = 42.4%	1,505 = 44.1%
Grand Total	529	2,811	3,411

Figures show that there has been an increase in the number of ethnic group patients St Joseph's Hospice has helped in 2014-2015. The Outreach Team:

- deliver presentations and workshops to community groups,
- offer drop-in one-to-one information and support assessments at local community venues,
- host information stalls at local events and organizations,
- facilitate peer support groups and self-management courses

In an effort to 'normalise' the hospice and incorporate it in the everyday life of Hackney's residents, the team also run various classes and courses (knitting, doodle club, choir, etc...) and have a cafeteria open to all in the community. They also encourage the use of their various chapels to the different faith groups in their

community and run the 'Compassionate Neighbours' scheme providing support to lonely people in the community in 30 languages.

Healthwatch also noted the leaflets produced by the hospice and their website are all very multi-ethnic with photos of both staff and patients from various backgrounds.

CONCLUSIONS AND RECOMMENDATIONS

St Francis Hospice is situated in the London Borough of Havering. However patients from the London Boroughs of Barking and Dagenham, Redbridge and the County of Essex may be referred there.

On studying the numbers referred by each for 2014-2015, it can be seen that Havering refers over 50% of all hospice patients, with the Brentwood area referring 18%, Barking and Dagenham 24% whilst Redbridge accounts for less than 4%.

Healthwatch Barking and Dagenham wanted to understand why B&D residents are underrepresented as users of St Francis Hospice (even if there are other places they can be referred to). Figures show that age, ethnic diversity, religion, culture, language, distance can prove to be potential barriers.

Only a small number of health professionals replied to our survey. However results of our questionnaires showed that GPs and community nurses are concerned about the fact that St Francis Hospice is not known by residents of B&D. They also expressed that the hospice location is seen as too far for B&D patients and their families. Finally, some said that the high proportion of Bangladeshi and Pakistani Muslims in B&D may not feel comfortable using services not provided from within their own community.

Healthwatch found that in fact St Francis Hospice recognise the importance of culture and religion of each individual patient. However there is a need to showcase this information to ensure that it help towards the stigma that the hospice is only Christian based.

Healthwatch also found that overall family and service users who had used the hospice had only positive feedback to give.

Following our research, Healthwatch Barking and Dagenham recommend:

- The CCG to consider training for GPs on palliative care pathways.
- St Francis to undertake visits to all Barking and Dagenham GPs to raise the awareness to both professionals and service users by St Francis staff. This could be done through the CCG when the GPs are all due to meet.
- St Francis Hospice should consider showcasing what they have offered and how they have personalised services to those from more diverse ethnic communities and how they are cared for both in their own homes and at the hospice.
- Marketing to be more diverse with representatives for all cultural backgrounds.

- St Francis Hospice to work with volunteering organisations to see if more volunteers can be recruited to reflect a diverse population including different age groups.

We thank Barking and Dagenham Healthwatch for their interest in Saint Francis Hospice and for taking the time to visit us and compile this report.

The report is very much in accordance with many of the issues we have identified when planning our five year strategy, so we recognise and appreciate the points raised. A summary of this strategy can be found within our 14/15 Annual Review on our website: www.sfh.org.uk/publications.

Our strategy outlines the struggles we have reaching people, specifically in the location of Barking and Dagenham. We have identified multiple initiatives to improve access across our catchment, many of which are already underway. For example we are in the process of reviewing the possibility of an outreach service, which will deliver advice, support and the planning of care for people reaching end of life at sites closer to where they live. The base would also assist us with raising awareness of the hospice services within the community. Early engagement has commenced.

Our marketing and communications team have identified a need to ensure our material reflects our local population and are taking the relevant steps to do this. We are seeking the support of a translation service so that our service information leaflets are offered in a range of languages, but it's worth noting that our website is fully translatable (this was mentioned to Healthwatch during their visit), and that we have had some of our events leaflets translated this year, for example our 'Light Up a Life' literature. The team are also very happy with Healthwatch's suggestion to promote more stories illustrating our care, and this is something they will definitely endeavour to improve upon.

We have recognised that our volunteer workforce doesn't reflect our diverse population - this is something we are exploring and seeking to improve.

We welcome Healthwatch's recommendation that CCGs should consider training on palliative care pathways. We would invite the support of Healthwatch in promoting our Education Centre which holds multiple courses that will provide GPs and other health and social care staff with the tools they need to both understand their local hospice better but to strengthen their understanding of palliative care.

<https://www.sfh.org.uk/education>

A programme of engagement with health and social care providers is commencing. We hope will result in fewer staff failing to recognise the full range of services we offer and how their patients can access them.

Once again we thank Barking and Dagenham Healthwatch for their thoughts and recommendations and look forward to updating them with our progress over the coming months.