



Healthwatch Peterborough Local Non-clinical Cancer Services Report 2014



Background

Healthwatch Peterborough Cancer Services Review Group, with membership including current and previous cancer service users, has been evaluating access to local non-clinical services since 2012.

The group felt that the emotional response caused by receiving a diagnosis of cancer such as fear, anger, resentment and disbelief was not given adequate recognition compared with the extensive medical care available for cancer patients from the local acute hospital.

For a carer, to try to help alleviate these feelings was an extremely daunting task, which is why an increasing number of organisations around the country were being set up to help cancer patients and their carers cope with the trying times that inevitably follow diagnosis.

Evaluations focused primarily on the locally based Robert Horrell Macmillan Centre (RHMC) based on the Peterborough City Hospital site, specifically whether this was being utilised sufficiently to provide the type of emotional, practical and social support that other centres provided.

Healthwatch Peterborough made a number of requests for information to Peterborough and Stamford Hospitals NHS Foundation Trust (PSHFT/the Trust) to establish use, ownership and utilisation of the centre. Further, an Enter and View visit was carried out to the RHMC to assess the environment.

Whilst initial findings showed limited use of the RHMC, including a number of rooms unused, over the last two years, activity and usage has increased. However, the site remains dated and the environment was comparable to a care home. Healthwatch Peterborough recognised a lack of services provided, but needed to establish exactly what do local patients and carers need and want.



Robert Horrell Macmillan Centre (RHMC)

The RHMC opened in 1991 and was commissioned to provide a day therapy service for cancer patients and patients with a life limiting illness. There was no provision for a service for carers; the patient attendance was specified as day therapy so there was no provision for a 'drop-in' service or for patients that only required specific elements of the service.

As the service evolved, day therapies were offered to patients having active treatment with potentially a good outcome, as well as to those that had secondary diseases.

Services are delivered in two models, traditional day therapy and 'Moving Forward' courses. A Lymphoedema service is also run from the centre and 2 clinics are offered daily. There are also a number of specialist nurses and community Macmillan nurses who are based within the centre, but are not part of the day therapy service.

Healthwatch Peterborough compared delivery of service at RHMC to what was being offered to patients in the Region.



Norwich

The Norwich Big C Cancer Support & Information Centre is open to cancer patients, their carers, family and friends. It is advertised as somewhere to sit and reflect, away from the hospital and the clinical environment.

Based in the grounds of the Norfolk & Norwich University Hospital the Centre offers a variety of cancer related information, a wide range of practical and emotional support; as well as somewhere to relax with a cup of tea and the opportunity to talk to the trained Centre staff if needed.

Visitors to the Centre do not have to be attending hospital, the Centre exists to support anyone affected by cancer in the Norfolk & Waveney area. Patients can call in at any time and do not need an appointment to speak with them about any concerns or problems. The Centre has a fully stocked Library of cancer information with leaflets and books to browse or borrow and access to computers.

Cambridge

Maggie's, situated on the Addenbrookes Hospital site offers practical, emotional and social support to people with cancer and their families and friends. Help is offered to anyone with any type of cancer and patients can talk to and get advice from a range of professional people.

The Centre is staffed by Cancer Support Specialists, Benefits Advisors, Nutritionists and Psychologists and provides support in managing stress, relaxation techniques, eating a healthy balanced diet as well as management of particular treatment-related food challenges. Attendee's are guided to the information they need before, during and after treatment and can learn about exercise groups including yoga and tai chi, creative writing as a way to explore thoughts, ideas and emotions and information about money and benefits.

These Centres have been developed because they recognized that patients need emotional, social and pastoral care alongside their treatment for the disease and have adapted the support they offer to reflect this new reality.

Local Context

Cancer is one of the leading causes of death in the UK, with one in three people being diagnosed at some point in their lives. In the Peterborough population, cancer is the second commonest cause of death. It has also been shown that premature deaths from cancers are one of the factors contributing to the lower life expectancy in the Peterborough area when compared to the UK average.

Forecasts suggest further increases in the number of cases. The Eastern Educational Research Association population scenario gives 923 new cancer cases per year in the 2017-2021 periods and the Office of National Statistics population projection gives an average of 868 new cases per year for the same time period.

Next Steps

Having researched the background information, Healthwatch Peterborough looked to establish evidence that:

- Cancer patients their carers and families were not being given the same support services as others in the CCG area regionally
- The RHMC offered a limited service to patients and was not being run as an active cancer centre
- PSHFT had focused efforts on clinical excellence and not on the need for emotional and social support alongside their treatment for the disease

Patient experience is at the forefront of the NHS agenda, and providing patients with the best possible experience while using their services, is a key priority of the Trust.

In recognition of this, and the remit of Healthwatch Peterborough to establish the patient voice, it was agreed that Healthwatch Peterborough provide further evidence of the full scope of support services users would like to see.

Pilot survey

Together with the Cancer Service Review Group and Macmillan project worker, a survey was devised, revised and then piloted with the Peterborough Breast Cancer Support Group.

Once finalised, the questionnaire was used to survey the opinions of patients attending the Trust's Oncology Clinics. The survey took place over a number of weeks and on different days in order to capture a range of patients, family members and carers. Almost all surveys were carried out on a one-to-one basis, for the most accurate reliable result.

Survey Results

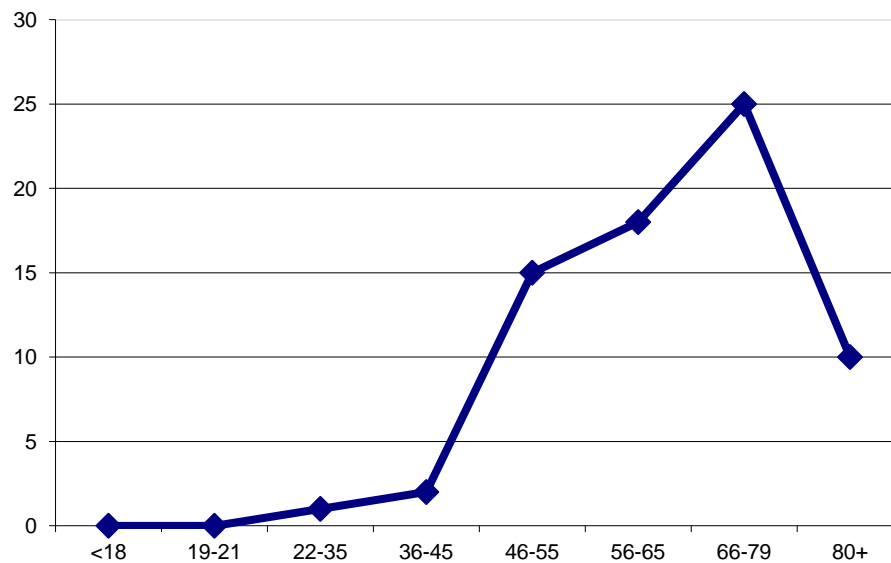
One hundred people's opinions were surveyed, the majority in clinic, 71 were patients and 29 were carers or/and family members.

68% of patients were female and 32% were male. It should be noted that some cancers affecting men are not seen in Oncology Clinics.

Reflecting the national picture, the majority of carers were female 78% and 22% were male.

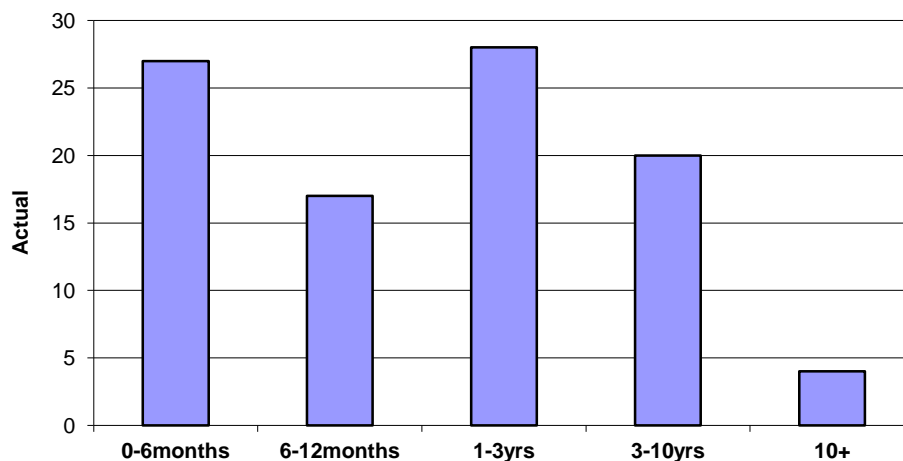
The largest age groups affected by cancer were in the 66 - 79 age range followed by 56 - 65 and 46 - 55 years (reflecting the national picture of an increase in cancer rates in older age groups).

Patients Age



Nearly all those surveyed had received a cancer diagnosis within the last three years, the majority within the last 12 months.

How long ago was cancer diagnosed?

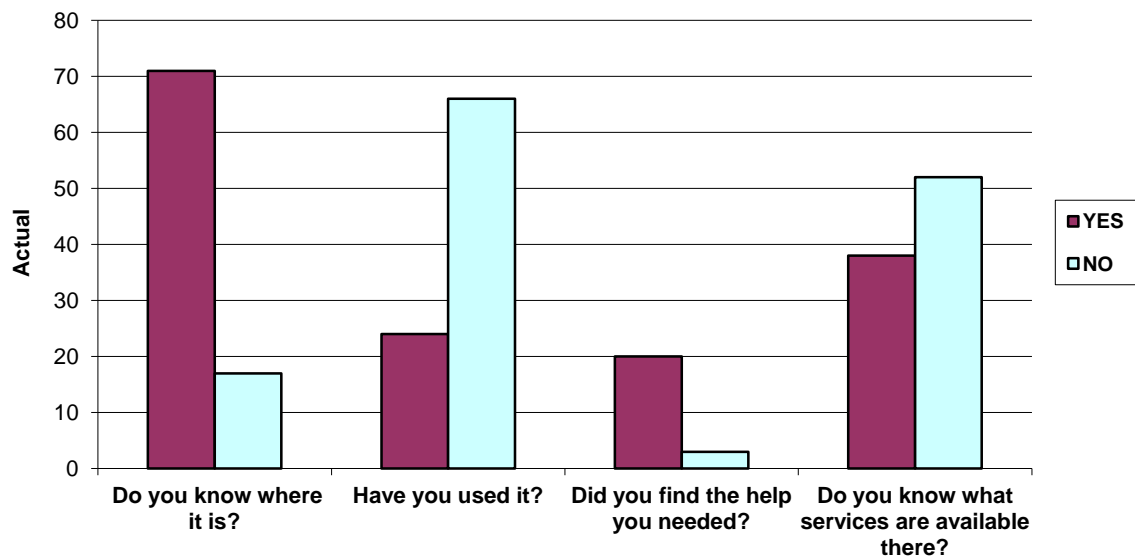


Situated within the Oncology Clinic, is the Hospitals Cancer Information and Advice Centre. Healthwatch Peterborough established the scope of awareness among those surveyed.

The survey found that nearly all respondents knew where the Advice and Information Centre was and 21 people said they had used it and found it helpful and that the Macmillan information leaflets were brilliant.

However, the majority of patients and carers had not used the Information and Advice Centre and were unaware what services were available to them.

PCH Cancer Information Centre



The survey asked what advice, information or services would they like to see from a defined list based on what was offered at other dedicated Cancer Centres.

The majority need identified for both patients and carers was after treatment and survivorship, information for patients, families and carers and diet and lifestyle.

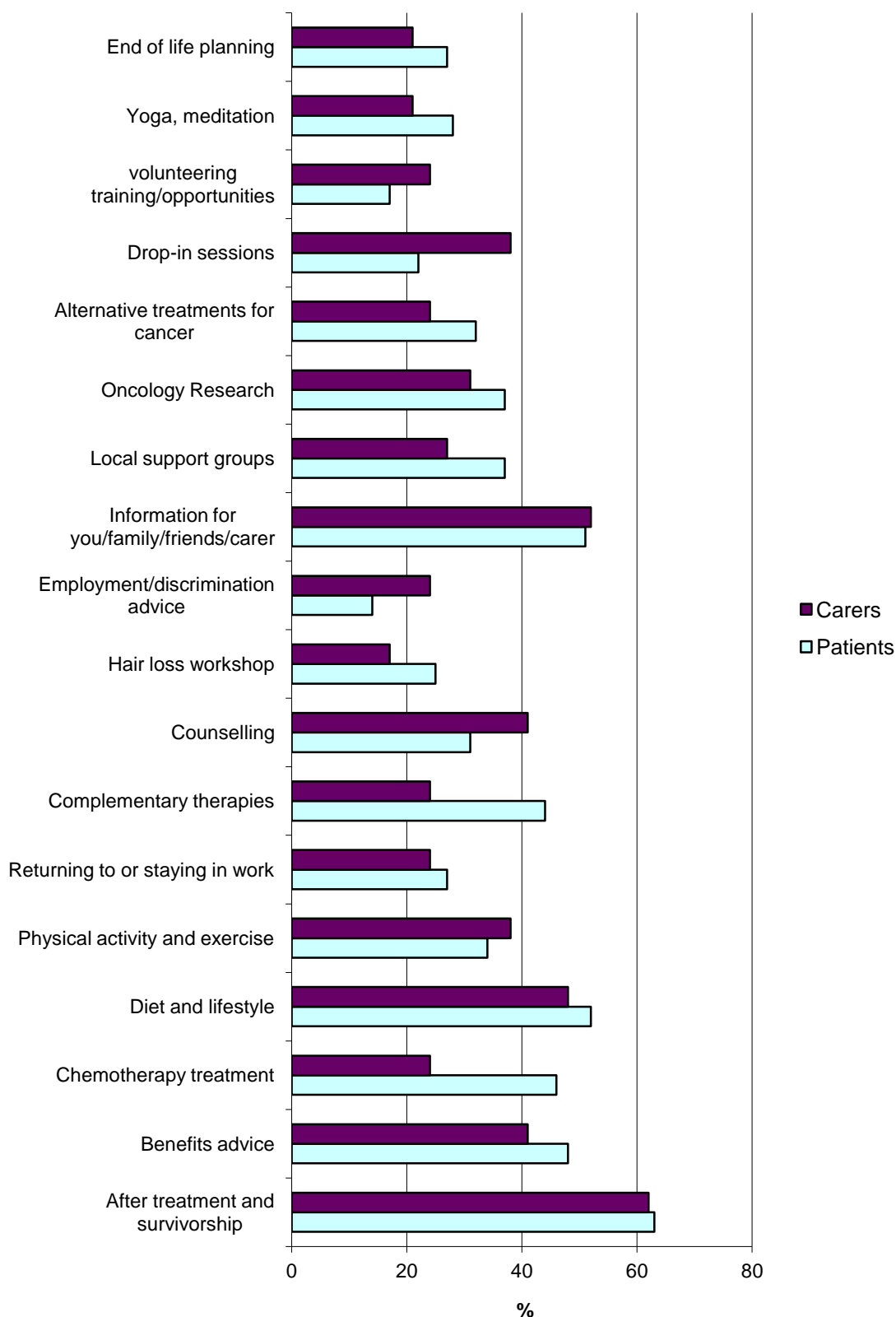
Patients specifically wanted chemotherapy treatment information and access to complimentary therapies.

Families/carers particularly cited drop-in sessions and counselling.

In addition to those listed, respondents suggested additional services/provisions including herbal teas and fruit in waiting area, massage, Reiki, homeopathy.



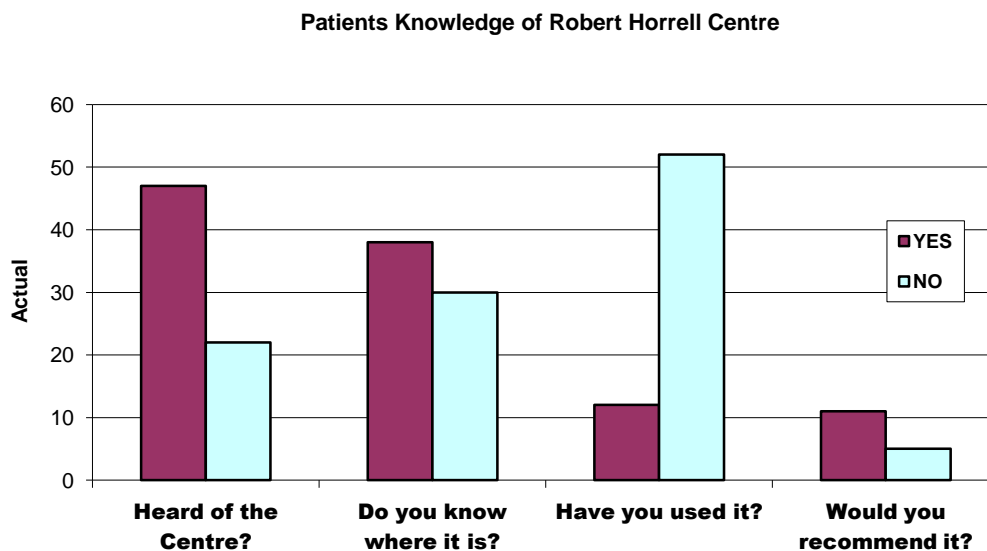
Services that patients/carers would like to see



Patient awareness of the RHMC

The Trust's website did not list the RHMC amongst its core services and information about its existence was only found under lymphodema and palliative care provision. Yet artwork was being loaned and fundraising taking place for the building. The Trust stated in a press release that 'the centre provides support for people with cancer and other life limiting conditions'.

To establish awareness of RHMC among cancer patients, the survey asked patients and carers: **had they heard about the RHMC, did they know where it was, had they ever used it and if so would they recommend the Centre to others.**



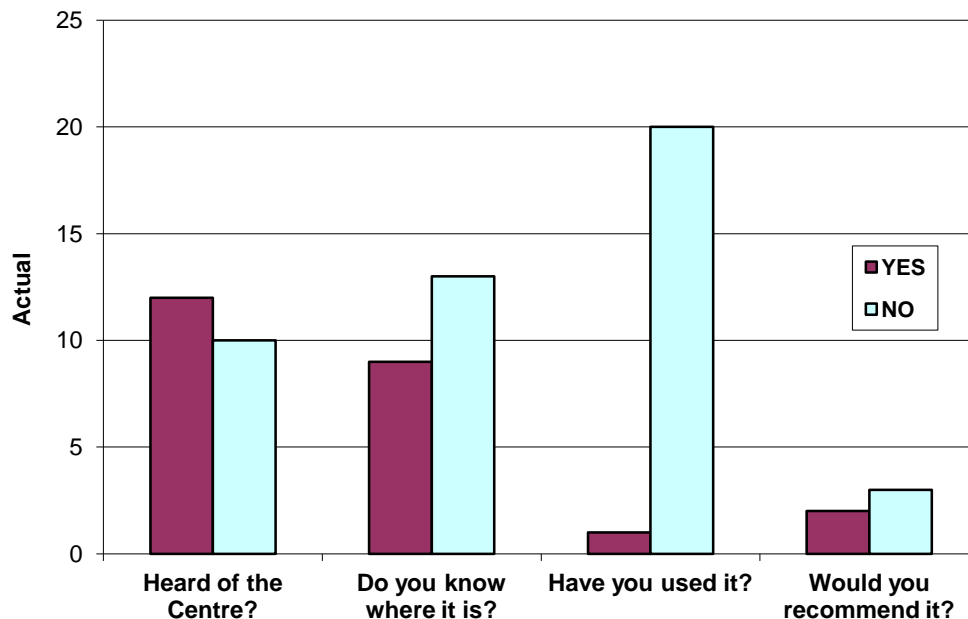
66% of patients had heard of the Centre and 53% knew where it was but only 17% of patients had used it to attend the Survivorship course, Lymphodema clinic, Moving Forward course or Stoma care meetings and only 15% would recommend it to others.

The 5 people who did not recommend it said they had:

- *'Tried to visit it and was rejected by them by letter.'*
- *'Felt uncomfortable at the centre, this could have been the wrong time for me'.*
- *'Tried to help - Volunteer - and to meet nurses and get involved to help me deal with end of life, unfortunately I was not required'.*
- *'Failed attempt to contact the service'.*
- *'The patient spoke to a lady there that's all'.*

Of Carers and family members, 41% had heard of the Centre, 31% knew where it was, 3% had used it and 6% would recommend it.

Family/Carer Knowledge of Robert Horrell Macmillan Centre (RHMC)



Finally the survey asked: **Have you ever accessed any other Cancer Support Centre?** 4 patients said they had. These were Maggie's at Addenbrookes, St Barnabas Hospice Grantham, internet cancer forums and learnt from other people's experiences.

NICE guidance

The National Institute for Health and Care Excellence (NICE) clinical guidance on supportive and palliative care advises those who develop and deliver cancer services to make sure that patients, and their families and carers are well informed, cared for and supported.

Their key recommendations are:

- People affected by cancer should be involved in developing cancer services.
- There should be good communication and people affected by cancer should be involved in decision-making.
- Information should be available free of charge.
- People affected by cancer should be offered a range of physical, emotional, spiritual and social support.
- There should be services to help people living with the after-effects of cancer manage these for themselves.
- People with advanced cancer should have access to a range of services to improve their quality of life.
- There should be support for people dying from cancer.
- The needs of family and other carers of people with cancer should be met.
- There should be a trained workforce to provide services.

Overview

There can be little doubt that a cancer diagnosis will affect hundreds of people in Peterborough year on year. While clinical care and survival rates for cancer patients have significantly improved, attention to their health and social care needs have lagged behind.

For patients this means understanding more about the psychological, emotional and physical affects of cancer, learning how to support their immune system, an ability to practice self-help and stress management techniques.

Provision of access to drop-in type sessions can facilitate access to sharing with others, in similar circumstances, (which has been shown to have better outcomes in terms of experience, confidence and knowledge to manage their health and better use and awareness of health service resources). Experience is personal and how patients, their families or carers feel about their experience of using health services will influence their perception of local providers.



Update (June 2014)

We are delighted that in PSHFT confirmed a project proposal for a wellbeing centre, hoping to once again utilise the RHMC, being discussed with Macmillan.

Joanne Clapton, General Manager, Cancer & Diagnostics Clinical Directorate PSHFT said:

The Trust is currently working in partnership with Macmillan Cancer Support to create a Wellbeing Centre for patients and their families who are affected by cancer.

We hope this centre will be located in the Robert Horrell building on the Peterborough City Hospital site and will look at innovative ways of providing ongoing supportive care for cancer patients.

We will use the Healthwatch Peterborough patient survey results as part of our research to understand what the patients want from such a centre.

Healthwatch Peterborough shared interim survey findings with Macmillan and the Trust, so that the project is developed to give consideration of the meaningful patient needs established from our findings. As a key stakeholder in the project, Healthwatch Peterborough is delighted to support this initiative for the benefit of local people.

Conclusion

The findings primarily show a lack of awareness of the RHMC, continued under utilisation of the site and need for modernisation. The response from those who could not access/engage with the Centre is particular concerning.

The survey demonstrates a great need for locally delivered non-clinical and holistic provisions as well as information and advice, not typically provided as part of the clinical patient pathway.

In Peterborough, there is a lack of provision and access to support, which can be seen successfully benefiting patients in other locations. This inequality/gap in services needs to be addressed.

The full scope, as discovered in this report, of the needs of those living with, or caring for someone with cancer in the Peterborough area, have to be recognised.

Recommendations/Actions

The report will be shared with Macmillan and the Trust to contribute further evidence to show the need for a better provision of local non-clinical services.

The findings will also be shared with the Cambridgeshire and Peterborough Clinical Commissioning Group, and Peterborough Local Commissioning Group.

Healthwatch Peterborough will work with services users to establish meaningful and patient-centred recommendations based on the report findings and their experiences of services.

Acknowledgement

Healthwatch Peterborough would like to thank:

All the patients and carers who took the time and effort to complete the survey and provide honest and valuable feedback.

Peterborough and Stamford Hospitals NHS Foundation Trust, who provided access and information to facilitate the project over a two year period.

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