



Patient Experience of Cancer Support Services in Walsall

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Healthwatch Walsall

Healthwatch Walsall (Healthwatch) is the independent consumer champion for health and social care in your local area, delivered by Engaging Communities Staffordshire. Our job is to amplify the consumer interests of those using health and social care services across the borough and give local people an opportunity to speak out about their concerns and health care priorities. We also deliver signposting to local services and give information on what is available.

Everyone who uses health and social care services has the right to expect a high standard. Healthwatch can help local services achieve these standards, by carrying out projects such as this one and producing a set of recommendations. Our role is to:

- Seek out people to discuss their local health and social care services
- Use what they say to help decision makers improve the quality of local services
- Reflect the diversity of Walsall's population, including children and young people
- Build on any example of good work that is being achieved
- Sit on the Health and Wellbeing Board and ensure progress is achieved

Background

In 2017 Healthwatch undertook a public consultation to identify what areas local people in Walsall would like Healthwatch to focus on. One of these key priorities was cancer, particularly access to and quality of support and signposting services for cancer patients, survivors, and family. Additional support services can include:

- Palliative care
- Holistic therapies
- Financial support and advice
- Wellbeing and emotional support
- Support for family members

Aims & Objectives

After being diagnosed with cancer, accessing timely treatment is important to the patient. Access and signposting to non-clinical support services is also an important part of the patient journey.

The aim of this survey was to speak to at least 100 patients and survivors to identify if they had been informed about additional support services, whether they accessed these services and how they found this experience.

Cancer support services have changed through the years and it has been important for us to talk to patients who had been diagnosed over a range of years so that we can compare how patients views and experiences vary over time.

Consultation and Engagement

We undertook this work using a survey, which was developed by our research team, based on the initial engagement that helped us identify cancer support services as a priority. The survey was undertaken throughout several locations including Walsall Manor hospital, several GP surgeries and Urgent Care Centres.

We also undertook engagement with local cancer support groups. We gave people the opportunity to complete the survey online and also through paper copies which were distributed to a number of our champion organisations and through outreach.

118 surveys were completed in total.

We visited Cancer support groups in Walsall, including:

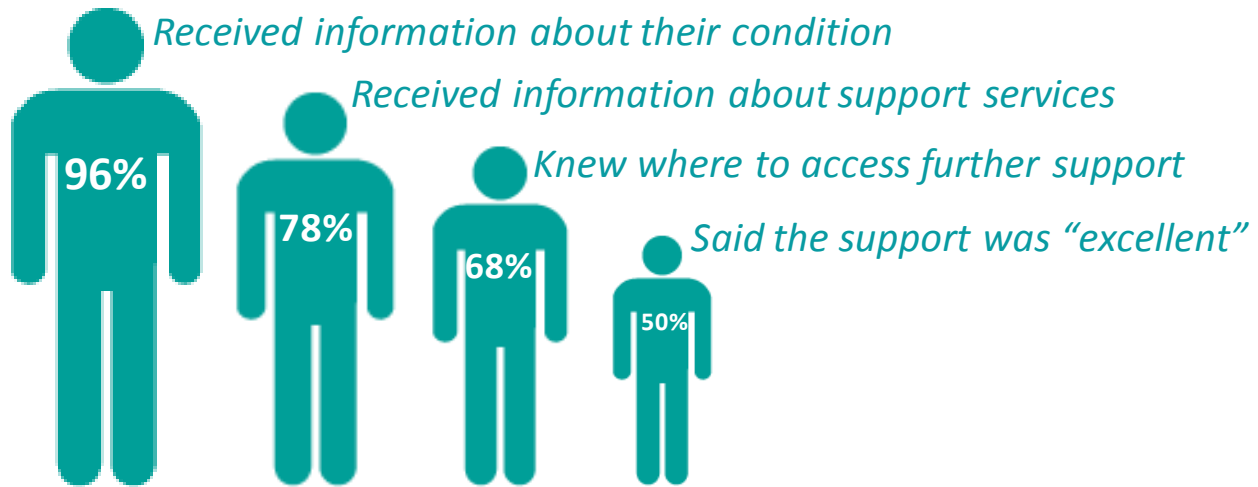
- Walsall Breast Cancer Support Group
- UGI Blues (Upper Gastro Intestinal) Support Group
- Gynaecology Support Group
- Prostate Cancer Support Group
- Urology
- Walsall PACT
- Brain Tumour Support Group
- Walsall Palliative Care Centre.

Other notable venues where we undertook engagement included:

- Walsall Manor Hospital
- Walsall Urgent Care Centre
- Pinfold Health Centre
- Anchor Meadow Health Centre.

Findings

This section of the report outlines the major findings of this project. We have collated our own desk-based research, discussions we had with survivors and patients at support groups, and the results of our survey.



Patient Experience

The patients and survivors we spoke to said that they wanted earlier diagnosis, more access to support services and better information and communication with staff.

"I was diagnosed late in relation to the stage of cancer I had."

"To make access to support easier. Everybody seems to want you to contact someone else instead of them."

"Don't leave patients in limbo. We need to be informed regarding diagnosis, treatment and aftercare."

However, those who had accessed support praised the service they received.

"Good support from diagnosis through to op, chemo & radiotherapy. Always at end of phone if I had any questions or concerns in between treatment."

"Very pleased with all the support and help I received."

While every case of diagnosis and patient journey is different, it has become evident that over the last few years the support and signposting services have positively improved in Walsall, particularly now that the Macmillan Cancer Hub is available within the Walsall Manor Hospital.

Appointments and Waiting Times

Some patients felt that there was disorganisation around appointment arrangements, appointments being cancelled and poor communication around tests and treatment.

Support and Advice

The main support services that are available for cancer patients in Walsall are the Macmillan Cancer Information and Support Hub, located in Walsall Manor Hospital, Walsall Palliative Care Centre, and from the Lead Cancer Support Nurse as well as several local support groups.

Our data highlighted that there were more negative views about support and signposting services in those patients who were diagnosed over 5 years ago than those diagnosed more recently. This is due to more information and support services being readily available in recent years.

- Patients who had been diagnosed in the last 5 years were more likely to have received information about support than those diagnosed earlier.
- 78% of patients told us that they received information about relevant support services that they could access and that they were supported and signposted where required.
- When people were offered support, the most common format was a leaflet.
- 44% of patients were given information about support by their consultant, 21% were given it by a nurse, 12% were given information by a Macmillan Nurse, 6% by a doctor and 2% by their GP.
- 68% of respondents said that they had contacted support services, while the remaining 32% had not. The most common types of support were emotional support and information about treatment options.
- Those who had not accessed support services and advice cited, difficulty with timings and availability, or the feeling that services were not relevant to them.
- 68% of respondents were happy with the support that they had received, including 50% who said it was excellent.
- 79% of patients said that they knew where to access further information and help.

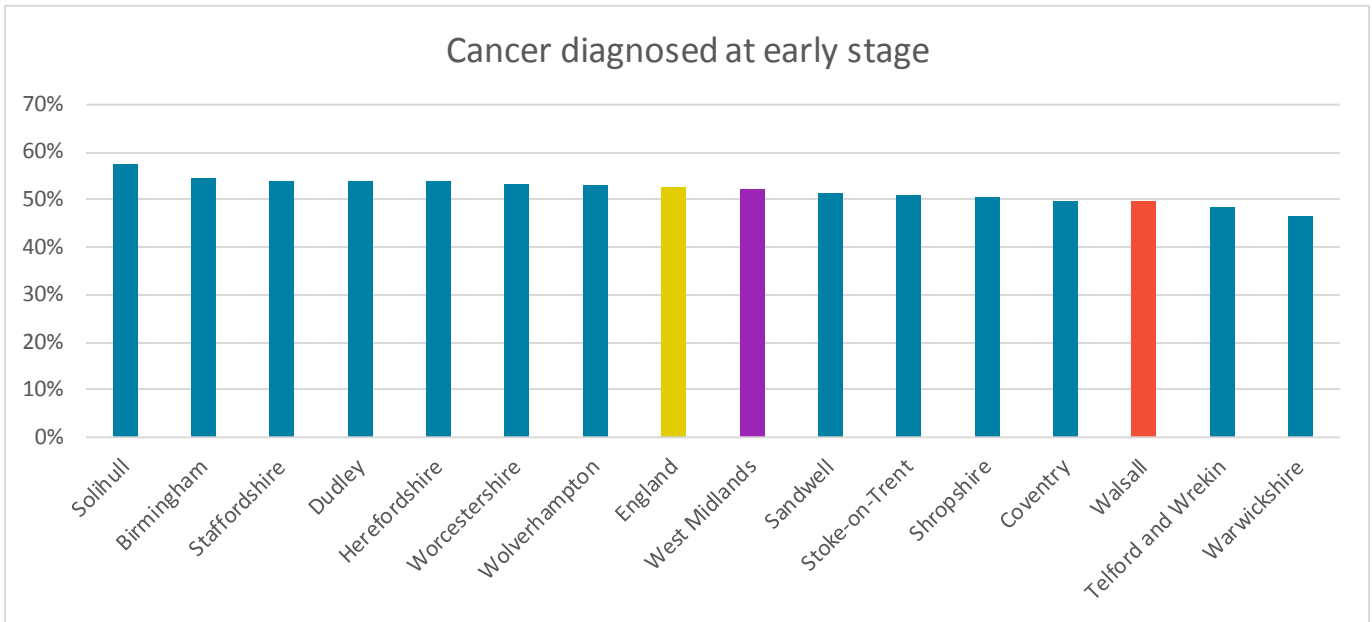
Diagnosis

- There are two pathways to diagnosis – rapid access via the GP, and A&E screening.
- Next a care plan is developed, and an information pack is given by Macmillan Cancer Support.
- 96% of the patients we spoke to said they were given information about their condition concurrently with the diagnosis.

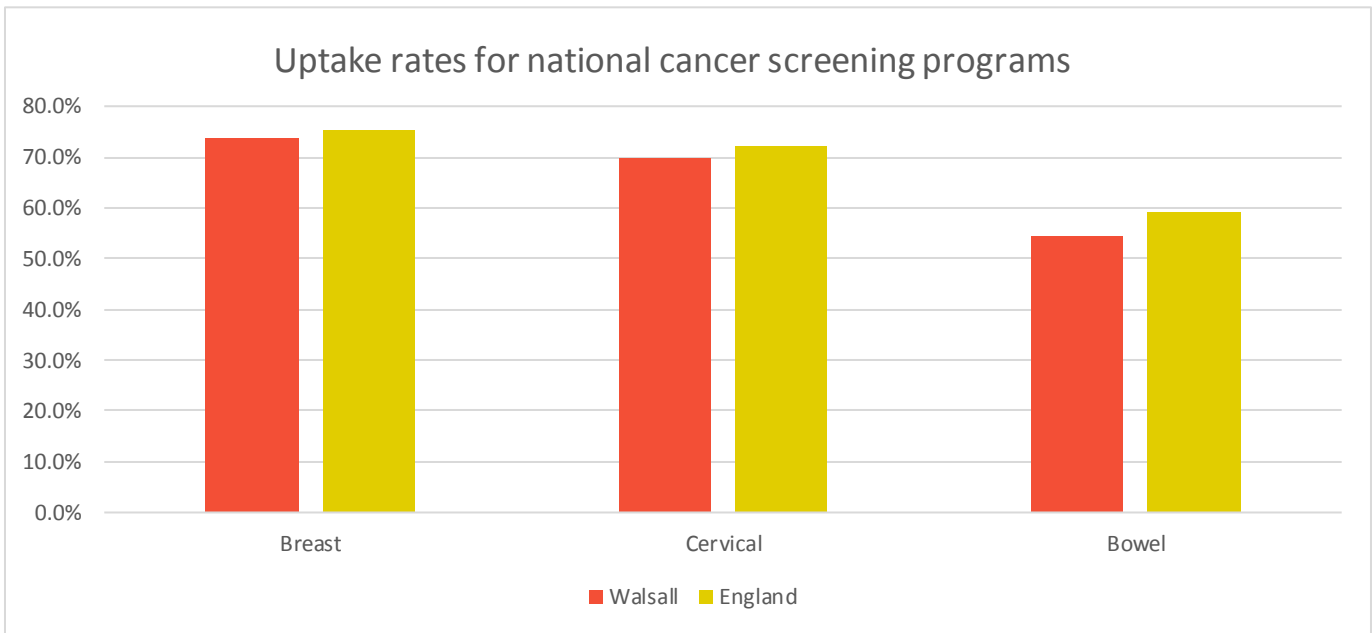
Late Diagnosis

Whilst undertaking this work and talking to patients and support organisations one of the main concerns that was highlighted was late stage of diagnosis which according to the support organisations is a borough wide issue.

- Public Health data, amongst other sources, shows that early diagnosis of cancer is lower than the national average - 47.2% in Walsall compared to 52.4% in England (2015).
- Through our meetings with support groups, it was highlighted to us that late diagnosis was of particular concern to cancer patients and survivors in Walsall.
- Survival rates are related to early diagnosis and treatment, and in Walsall the uptake of screening programs is lower than national average.
- The number of people who are presenting at primary care services due to signs and symptoms at later stage of cancer is above average. Walsall has the joint 3rd lowest proportion of new cases of cancer diagnosed at stage 1 and 2 in the West Midlands region (2016).



We understand that there are initiatives in place aimed at increasing uptake of screening programs, and we hope to see an improvement. At present, for cervical screening coverage in women aged 25-49, Walsall comes 9th amongst 14 local authorities that make up the West Midlands region, with a coverage rate of 69.7%. The average for England is 72.0%. For breast screening, Walsall again comes 9th in the region, with a coverage rate of 73.7%, lower than the average for England (75.4%). Bowel cancer screening has shown an improvement in uptake, rising from 50.1% in 2015/16 to 54.4% in 2016/17.



The complete data set collated from the survey can be found at the following website link:

<http://www.healthwatchwalsall.co.uk/our-reports/>

Conclusions

The majority of people we spoke to were happy with the support services that they received through a number of stakeholders, though not everyone was offered support. More recent service changes and improvements have resulted in people being offered more support, which should be commended. However, communication between patients and clinicians was highlighted by some people who said it needs to be more timely and reassuring to the patient. Additionally, research we have undertaken and confirmed by individual patient experiences has highlighted that Walsall has a higher rate of late diagnosis for cancer when compared to the wider West Midlands area.

Recommendations

Based on patients experiences and comments that we have received and from an analysis of the data we make the following recommendations:

- Continue to invest in effective support and signposting services such as Walsall Palliative Care Centre, Macmillan Hub and through a designated Lead Cancer Nurse. The levels of people accessing support services should be monitored and actions taken where there is poor uptake.
- A robust action plan needs developing by Walsall CCG and key stakeholders such as Walsall Healthcare NHS Trust to identify why patients are not coming forward early enough with symptoms of cancer. This should be presented to the Walsall Health and Wellbeing Board and resulting actions subsequently reported on.
- Improved communication with patients regarding updates, treatment, status and care plans to be developed and co-designed by patients and survivors and their families and carers.
- Better administration and management of appointments for treatment to reduce waiting times and cancellations. There needs to be a benchmark created of the current arrangements and an action plan created to address the issues and presented to the Social Care and Health Overview and Scrutiny who can then monitor the actions and resulting improvements in administration of appointments for treatment.

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