



Project Report

Macmillan Cancer Information Network
September 2015 – September 2017
East Sussex

Report compiled by:

Greta Anderson
Macmillan Information Network Coordinator

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Executive summary

This project report covers the two-year period (September 2015 to the end of August 2017) of the Macmillan Cancer Information Network Project. The aim of the project has been to create a network of cancer information hosts across East Sussex in support of all those affected by cancer. Working with partners in both acute and primary health care as well as the voluntary sector and community services.

The report looks at the progress made over the two years and how well the process of establishing hosts, with a variety of partners and locations, has worked. The report looks at the results of the engagement undertaken, how the first established sites have progressed and what we have learnt from them. Also, covered here are recommendations for the future of the information network.

This report illustrates that although a great deal has been achieved over the two years, it is clear that this project has only come to the edge of what needs to be done, in terms of building a network of information and support that is people centred, accessible and equitable.

This end of project report does reference and include findings and statistics from an earlier report which covered the work undertaken in the first 12 months of the Macmillan information network.

The main partners in this project have been Macmillan Cancer Support, East Sussex Community Voice (ESCV) and East Sussex Healthcare NHS Trust.

Background

Prior to the creation of the network information project in September 2015, East Sussex did not have a dedicated cancer information centre, therefore those affected by cancer did not have one place to go where they could access professionals and resources that could provide them with trusted information and support.

Cancer Patient Experience Survey statistics from (2010 – 2011) support the view that people in East Sussex were not getting good access to cancer information, with some answers on information coming into the bottom 20% on performance. ¹

As part of a mapping and scoping exercise, Macmillan Cancer Support led a “Making Links” workshop in Uckfield in September 2012, the workshop participants flagged up several key issues. The workshop was attended by 55 people, including 15 patients and representatives from Health and Public services as well as a range of voluntary sector organisations. ²

Important conclusions were reached about the lack provision of three types of information service. They were identified as:

- Information that can be accessed very locally – for example on High streets

- Information available at GP practices
- One to one support – supported access to information ³

Geographically, rural villages and coastal towns were identified as places where access was poor. For example: Crowborough, Heathfield, Broad Oak / Hurst Green as well as Bexhill, Hastings, and Eastbourne were mentioned. ⁴

It was concluded that certain groups were particularly at risk of being unable to access information, because of the lack of specialist provision and dedicated providers. These groups were: ⁵

- Children and Young People
- Hard to reach groups (Homeless, BME communities)
- Carers

It was also determined that there was a lack of awareness amongst information and sign posting providers of just what services and support were available. It was sometimes complex or random, meaning that their ability to sign post effectively was hindered. ⁶

They also recognised the gap in information provided about transport and advocacy. ⁷

It should also be acknowledged that gaps in access due to poor internet connectivity, lack of capacity and or willingness to access information via websites and other online platforms were also identified as a barrier to accessing information. ⁸

The workshop participants identified potential opportunities to fill the gaps. The key focus being to build on existing structures and organisations, rather than to aim to create a new structure or stand-alone information service. The participants suggested that the best approach would be to create a network of information Champions and Hosts, through partnerships and utilising existing information services and tools. ⁹

September 2015 saw the introduction of a new role – that of the Macmillan Information Network coordinator. The role, delivered by East Sussex Community Voice, was created to carry out the previously identified objective of developing a diverse network of cancer information and support across East Sussex. The Macmillan information network project began in September 2015, initially scoping and mapping to update the knowledge previously gathered around the provision of cancer information and support, which in turn quickly moved on to creating partnerships and establishing host sites.

The Macmillan Horizon Centre opened in Brighton in November 2016. The centre provides a wide range of specialist information and access to quality resources, advice and counselling and complementary therapies. ¹⁰ The vision has always been that the centre plays an important part in continuing to develop and improve support and information across East Sussex.

Project aims and objectives

The aim of the information network project is to give people affected by cancer in East Sussex greater access to information about cancer and support services. Creating easy access to reliable and trusted information for individuals and communities will result in all those affected by, or living with and beyond cancer, being well informed, empowering them to make good decisions about their care and supporting them to live healthy and active lives.

The Macmillan partnership agreement stated that the expected outcomes for the project were:

- At least twenty level 1 (self-access) information sites in place (1 per 25,000 people)
- Three level 2 (supported access) information sites in place (1 per 175,000 people)
- Two Level 3 (specialist support) information sites in place (1 per 250,000 people)
- A structured training and development plan in place for information hosts and volunteers
- At the end of the project a volunteer structure to be in place providing on-going support and co-ordination for the network of Macmillan information sites and volunteers

By the end of September 2016, the intended outcomes for the first 12 months had been achieved, these were:

- Agreed strategic vision with a network of potential partners either in place or being developed
- A funding plan worked out for the 2nd year of the project

By the end of the first year the necessary actions required to ensure that access to cancer information became more equitably had been identified. These were:

- Project work should specifically target information provision to places where people go to access health professionals
- Understanding where people, visit, work and shop
- Look to partner organisations that work with difficult to reach groups

The following strategy was developed: setting out the direction and scope of the information network.

The cancer information network will be:

- People centred – patient experience, the public and communities will be listened to and feedback used to provide information services in the places they have recommended
- Established with a good level of awareness, by those effected by cancer, as to how and where to access information
- Innovative – taking the view that the information provision is adapted to the needs of the people and communities it is providing the service to

- Collaborative - built on effective partnership working resulting in a good level of signposting and advocacy
- Accessible and equitable - focusing on making information available to the hard to reach
- Sustainable and long term - Sufficient built in sustainable capacity within the network to maintain it beyond the end 2017

Demographic Information

Population

The population is growing, and the number of older people is rising. The current population of East Sussex is 545,400. Wealden is the largest district/ borough (151,290 people) and Hastings is the smallest (90,889) ¹¹

By 2021 there will be 12,423 more people living in East Sussex (+2.3%), with most growth at ages 65+ .¹² Within the county, Bexhill and Seaford and parts of Eastbourne and the surrounding areas have the oldest age profiles. ¹³

Homes and jobs

East Sussex has 250,330 dwellings. Social housing consists of 9,670 Local Authority and 16,960 Private Registered Provider in 2016 ¹⁴

Home ownership stood at 69.2% in 2011, highest in St. Marks, Bexhill at 91.3%, lowest in Central St. Leonards, Hastings at 26.7% ¹⁵

74.2% of working age population (age 16-64) in employment 2015/16 (up from 73.9% in 2015), England 74.3%, South East 77.6%¹⁶

NHS Trusts and CCG'S

East Sussex Healthcare NHS Trust provides acute hospital and community services throughout East Sussex.

East Sussex is covered by three Clinical Commissioning Groups (CCGs): High Weald, Lewes and Havens (HWLH); Hastings and Rother (H&R) and Eastbourne, Hailsham and Seaford (EHS)

East Sussex Better Together (ESBT) and Connecting for You (C4Y) are the local health and social care transformation programmes, which will develop a fully integrated health and social care system.

ESBT has been a 150-week programme to transform health and social care service. It has been a collaboration between East Sussex County Council, Eastbourne, Hailsham and Seaford and Hastings & Rother CCGs to develop a fully integrated health and social care system.¹⁷

By 2018 the aim is to be moving forward with:

“A coherent and co-ordinated system which maintains and improves health and wellbeing and links people with a care and support need or increased risk of health inequalities to community interventions and support”¹⁸

Connecting 4 You is the HWLH’s project to develop a fully integrated health and social care system.

“Connecting 4 You (C4Y) is a new transformation programme that is being created in partnership by High Weald Lewes Havens Clinical Commissioning Group and East Sussex County Council. This programme is being developed to address the specific population needs, geographical challenges, arrangement of services and patient flows of the High Weald Lewes Havens area.”¹⁹

Health and Cancer

The cancer incidence rate in East Sussex is around 572.7 per 100,000 1. There are 15,751 patients on GP cancer registers²⁰

When it comes to Screening for cervical, breast and bowel cancer Hastings and St Leonards and Eastbourne localities have the lowest percentage uptake of screening and significantly lower values than East Sussex. Seaford has the highest uptake of breast and bowel cancer screening and joint highest uptake of cervical cancer screening for women aged 25-49 years. Lewes and Havens has the joint highest uptake of cervical cancer screening for women aged 25-49 years and of breast cancer screening.²¹

It is recognised that the demand for cancer services is increasing every year as people survive cancer or live longer with cancer.²²

There are 5,464 patients on dementia registers and modelled estimates suggest that GPs have identified just over half (54%) of the people with dementia in East Sussex.²³ By 2020 there will be a 10.5% rise in people living with dementia and those living with a limiting long-term illness is set to be up by 9.1%²⁴

At the time of the last census (2011) 11% of people in East Sussex provided an hour or more of unpaid care per week, and a third of them (33%) provided 20 or more hours unpaid care per week.²⁵

Wellbeing and Resilience in East Sussex – Annual report of the director of Public Health, gives some useful self-assessed quality of health information by ward.

Wards with higher than average proportion of residents who are in very good / good health (vs. 69% overall) - It should be noted that these are predominantly in Wealden or rural Rother and therefore in the least deprived areas. ²⁶

| | |
|-----------------------------------|-------------------------|
| Danehill/Fletching/Nutley (86%) | Battle Town (80%) |
| Ticehurst and Etchingham (82%) | Salehurst (84%) |
| Chiddingly and East Hoathly (85%) | Crowborough North (78%) |
| Frant/Withyham (81%) | Darwell (82%) |
| Mayfield (84%) | |

Wards with higher than average proportion of residents who are in bad / very bad health. High concentration of wards in coastal areas. (vs. 7% overall) ²⁷

| | |
|---------------------------|------------------------|
| Hailsham East (18%) | Silverhill (14%) |
| Barcombe and Hamsey (14%) | Hollington (17%) |
| Central St Leonards (17%) | West St Leonards (14%) |
| Newhaven Valley (14%) | Sidley (16%) |
| Hampden Park (17%) | Sovereign (11%) |

Indices of deprivation.

Hastings has the most areas of high deprivation and Lewes and Wealden have the least. In East Sussex 13% of people live in income deprivation. 17% of children and 13% of older people are income-deprived. ²⁸

This section has set out some key statistics that are important factors during the planning and development of the information network. They are useful as they support much of what we know from the early scoping exercises and from the engagement work carried during this project.

These statistics add to what we already know and help to build a useful picture of the county. Rural areas and coastal areas both have barriers when it comes to accessing information. Although predominantly wealthier, rural areas, and places like Rotherfield although asset rich can still be health poor, they can have very poor transport links and very little in infrastructure. ²⁹

Coastal areas have growing populations of older people and Hastings has the highest levels of deprivation in East Sussex. Hastings and Rye are also the furthest points away from the Macmillan Horizon Centre with no easy access to services across the county border in Kent

Project Activity Analysis

Engagement

Everyone who gets cancer is different. And the care and support they will need to live with a cancer diagnosis in a way that makes sense for their own life, particularly after treatment has finished, will be different.

NHS - achieving world class cancer outcomes: taking the strategy forward 2016

Methods

There have been 3 main methods used in engagement. These are:

- Surveys - both targeted at groups, for example carers, and some open to anyone with a view about cancer information. The surveys have been carried out in hospitals, on the street and at public events and forums. There have also been several surveys sent out via social media as well as general requests for people to comment via online platforms. There have been 102 completed surveys used in these findings.
- Focus groups – there have been 67 people engaged through targeted focus groups. These have been used to look at much narrower subjects and predominantly used to talk to current cancer patients undergoing treatment, to gain their views on: the most accessible ways information, and the most useful types of information
- Engagement activities – Much of the engagement undertaken during this project has been face to face, meeting cancer patients, carers, clinicians, and information and signposting professionals, in a range of diverse environments. This face to face engagement has taken place at public events and meetings, at networking events and forums. From October 2015 to September 2017 the project has engaged (face to face) with more than 350 people.

There have been a defined set of questions used to form the basis of most of the engagement activity.

These have been:

- What information is most needed or most useful?
- Where are the best places to access information?
- How would you like to access the information?
- When? At what point in the cancer journey?

The project from the start has maintained the people centred focus that has been the ethos of the project began with events such as “Making Links” in 2012. Listening to the views of

those affected by cancer and capturing their feedback has provided a wealth of evidence and insight that has very much informed the desired direction in which the project has travelled and the aim of placing information services in the places recommended and the ways in which cancer patients and health professionals have suggested are best has sat at the centre of the project.

However, to achieve this has proved much more difficult. Matching patient recommendations with the opportunities on the ground has highlighted some real challenges. The lack of an information and support infrastructure in many places, particularly rural areas and the difficulty of finding willing partners to work with means that it hasn't always been possible to achieve the desired outcomes in the time allowed for the project.

Engagement outcomes

The level of engagement has been high throughout the 2 years of the project and paints a positive picture, especially for people undergoing treatment.

“information from the breast cancer nurses at first diagnosis was excellent and they also gave information on reconstruction as I had to have a mastectomy and I was worried about the long term”
Cancer patient – Focus group 2017

It is possible to identify several themes that have emerged strongly from engagement activity that should be considered significant. These are outlined as follows:

Information in Primary Care

In a survey of 80 people carried out in August 2016, we asked, looking back on their experience of accessing information, where they felt would be the best places for people to pick up information. On “self-accessed information” 88% of respondents said that they felt GP practices would be the best place closely followed by pharmacies. Again on “supported access” (where someone is on hand to help) 72% said G.P practices. Day centres, community centres and gyms were felt to be the least appropriate places for both types of information.

However, there have been concerns picked up across all the engagement activity was that some G. P's lack knowledge and skills in information and signposting. There has been a very strong concern voiced that G. P's did not have time or were not as supportive as they could that have been in terms of giving them information.

“even after several visits to get a diagnosis – I still didn't feel my doctor had time to search out helpful information for me”
Cancer patient – Healthwatch Red Bus tour 2016

Information in Acute Settings

Prior to the beginning of this project the National Cancer Patient Experience Surveys 2010 and 2011 had shown that there was an issue with patient's receiving information whilst in acute settings - with some answers on information coming into the bottom 20% on performance. There has certainly been a marked improvement in these scores and is indicative of the cultural change in acute care in terms of greater importance being given to patient information.



This certainly seems to be supported by the results from the projects engagement. In terms of the results from face conversations, survey results and focus groups people overall have indicated that during treatment, in acute settings the information they received from their cancer nurse specialist was very good.

Feedback on the Macmillan information area at the Conquest hospital has been very positive from those able to access it. Comments have shown it to be a good resource containing relevant and trusted information and had been accessed by cancer patients and carers. There has also been positive feedback from nursing staff at the Conquest who have noted that it is well used.

In 2016 the statistics for the 3 CCG's in East Sussex showed that in terms of information given to patients about support groups and getting financial help, although lower than the national average, had improved. It should be noted that the least improvement seems to be around information on getting financial support.

"I didn't get any information about financial help until about a year after diagnosis and after my operation and I got this from Care for the Carers not from a nurse or doctor"
Cancer patient – Care for the carers forum 2017

Understanding information

There has been some evidence gathered that Information is not always easy to understand. And can be more difficult for patients with learning difficulties and whose first language isn't English

"the service I had whilst undergoing cancer treatment was fantastic and I had no barriers when it came to accessing information. The only question I would raise is the patient's capacity to understand/digest the information they are getting whilst they are undergoing treatment"
Cancer patient – online focus group 2017

Cancer patients at a focus group in Hastings expressed a need to have to continued support in accessing information – information wasn't always needed at once and some patients indicated that they need to be reminded that information was available and certain stages of their treatment.

There was also very strong anecdotal evidence and personal experience given from the focus group that there was not enough information, in all settings, to help those with complex needs such as cancer and dementia and cancer and special needs and autism.

Getting access to information

Engagement has also shown that both patients and non-patients would like information to be local and regularly updated.

A survey of patients and health professionals in August 2016 found two of the major issues for people, that prevented them from getting information, were distance and lack of transport. Transport is a major issue equally for people living in rural locations and those in or near coastal towns. They report that this influences their ability to attend hospital appointments, support groups and to receive the same support they perceive that those living in larger towns with better transport links have access too.

Internet and access to websites also comes across strongly as a problem for many people. Comments about a lack of ability to use IT, and little or no access to the internet are prevalent across the engagement.

“What prevents me to get good information is lack of internet access, poor search features or incomplete / out of date information”

Survey response - 2016

Case studies

Set out here are a series of case studies of a selection of the information sites. They have been chosen because they illustrate the complex and diverse nature of the partners and sites that the project has been working with.

1. Rotherfield St Martin – Rotherfield

Rotherfield is a rural village in Wealden and the Parish itself is the largest in area in East Sussex. The nearest main towns are Crowborough (3 miles) and Tunbridge Wells (7 miles). The Parish population is around 3,500 of which approaching one third are over the age of 65. Rotherfield is a very rural area with exceptionally poor transport links.



Rotherfield St Martin is a Church - in -community project providing on-going social support, care and wellbeing for older people. Their aim to ensure that older people in the community are active and fully supported to live the lives they want to live. RSM have a membership of 250, 140 volunteers and a board of 6 trustees. They have substantial links with other voluntary groups and statutory bodies.

RSM is well positioned as a community centre and geographically to host a Macmillan information stand the aim was that this information would be of benefit to existing service users as well as the wider community. The RSM centre run a full programme of events and activities each week, they also host a therapy room offering a range of therapies in support of the local GP surgery, a volunteer transport scheme and support those living with dementia and their carers with reminiscence sessions.

RSM have a Macmillan info point situated in the entrance way of the Memorial Institute in the centre of the village. Feedback back was gathered in September after the information point had been in site for 6 months.

Rachael Wood – the CEO of RSM reported that the information point has been well received in the community centre. They estimate that currently over ten leaflets are being taken away by visitors to the centre and that usage is on a weekly basis. By far the information most in demand has been the Macmillan cookbook and materials aimed at carers for example “helping a loved one through cancer”. RSM have been using the be.Macmillan website to re order information leaflets and booklets

RSM have, yet, have not had any requests for information that they haven’t been able to fulfil.

RSM have been promoting the information point through their own networks, via newsletters and social media. However, they do feel that they could benefit from more help and support on an ongoing basis in raising awareness of the information site.

RSM is continuing to develop a good relationship with the GP surgery in the village and it is hoped that this will lead greater awareness and use of the information.

RSM is a growing and expanding charity, with plans for a purpose-built centre in the future. This would provide the opportunity to work further with the charity, possibly expanding the amount of information available and offering Macmillan training to RSM volunteers to enable to support users to access information and support.

2. Age Concern (ACE) - Eastbourne

Eastbourne has been previously identified as one of the areas where there was a need to build greater access to information and support for people affected by cancer. This is borne out by the high demand experienced by the Macmillan mobile information service who reported a high number of interactions (around 80) in 2016 when they visited Eastbourne town centre.

The Macmillan Information hub located at Age Concern – Eastbourne is one room consisting on an InfoPoint and wall mounted leaflet racks, there is a desk, with space for a laptop. The room is always accessible while the centre is open.

The purpose of the information hub is to provide access to information for people who regularly visit Age Concern. ACE currently sees in the region of 800 - 950 people visit their centre each week and support in the region of 300 people in the community. The aim of the service is not only to reach those effected by cancer within these numbers but to also expand on this and reach more people in the wider community. Due to the central position in the town (near to shops, parking and the train station) and its high profile in the local area the information hub is equally easily accessible to all people affected by cancer in the Eastbourne area.

People accessing the hub can get information on a range of Age Concern Eastbourne activities and services including activities at the Venton Centre, welfare rights services, information and advice, befriending, home from hospital and help at home.

The information hub has supported and widely advertised with print materials, it has been promoted in Age Concern shops, via social member, and at activities and events.

The Survivors Club is a cancer support group that meets monthly at Age Concern Eastbourne. The group is looking to increase its membership and plans to advertise the group through the information hub. The cancer support group is very much in favour of the information hub and wish to be able to contribute by being able to suggest what information is included in the hub.

The management team at ACE have reported that the information hub has been well received by service users and anecdotal evidence suggests both regular and non-centre users have been accessing the information. Age concern considers their level of use to be around about 20 leaflets or booklets per month, and they are very confident that they have been

able to meet nearly all the information requests received. Age Concern report that information on signs and symptoms is most in demand.

Jo Wood – Macmillan Information network volunteer, carried out a site visit to the centre in August 2017 and found the information hub to be well stocked and the information supplied was comprehensive in its range. Jo did report that some of the information was very specialist, but this may reflect the centre responding to individual's information requests. Jo also commented the information hub promoted well other local support and advice services.

It is apparent that the information hub still has potential to reach many more people. It has been agreed that a volunteer information support role will be piloted at the centre, initially every Friday from 10.30 – 2.30. It is hoped that a volunteer can be found from the existing pool of age concern volunteers to take up the role.

Plans for the future include working with the Pevensey Day unit at the Eastbourne District General Hospital to signpost patients and their families to the information hub and advertise the hub in its regular newsletter. It is hoped that the relationship between the hospital cancer services and Age Concern Eastbourne can be developed further in the future.

3. Hailsham Foodbank – Hailsham

Hailsham foodbank is part of the nationwide network of foodbanks supported by the Trussell Trust. They are there to provide three days emergency food and support for local people who are referred to them in crisis. During 2016 the Hailsham foodbank issued 980 emergency food supplies.

The foodbank is situated in a good location in the centre of the town. The site is small, so wall mounted leaflet racks were used rather than an InfoPoint. Unlike some of the other sites that make up the network, that carry the widest range of information and support leaflets, the information leaflets in the wall mounted racks were very much deliberately targeted at financial support, emotional wellbeing and keeping healthy, reflecting the information needs of the service users.

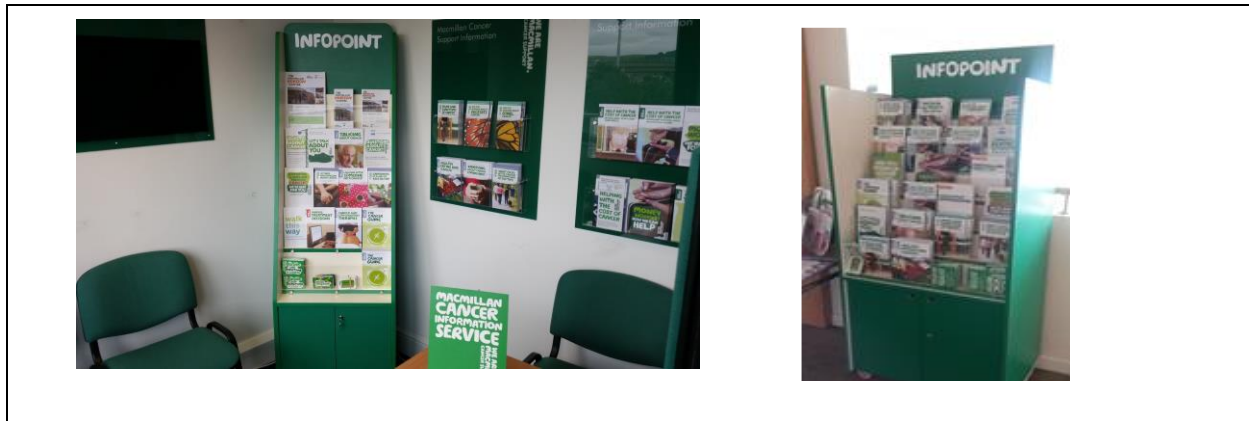
Counter top leaflet holders have also been used to promote Macmillan support line cards.

It was always anticipated that use here would be relatively low, and partner feedback from the centre has reported that less than 10 leaflets and booklets are taken away each month, but because the information is very focused then it must be considered to be successful in getting to those people who are in most need of it.

Also, there is potential here for the service to be expanded and greater access given to the wider community. The aim is that when the foodbank moves to larger premises in a more prominent position on the high street then the amount and scope of the Macmillan information can be increased and be accessed by the wider community.

In the most recent partner feedback survey, Julie Coates – Hailsham foodbank manager commented “visually it is great and a good range of information, just limited access to it now, for foodbank users only, whereas in or new space it can be accessed by everybody and therefore advertised more.”

A full list and description of all current and pending sites will appear after these case studies.



| Location | Contact Name and Address | Details of service |
|------------|-----------------------------------|--|
| Eastbourne | | |
| | Seaside Medical Practice | Macmillan information point situated in the centre's information area which is on the ground floor next to the main reception area. |
| | Park Practice | Park Practice has a series of wall mounted leaflet racks on the wall. Doctors and other health professionals at the practice hold a few plastic wallets containing a credit size card containing Macmillan contact information. All consulting rooms have a number of the Macmillan wallets. |
| | Esperance Private Hospital | The Esperance hospital has a row of wall mounted leaflet racks and noticeboards. |
| | Age Concern - Eastbourne | Age Concern - Eastbourne have a small information and support centre that offers wide ranging information and support. |

| Hastings and St Leonards | | |
|--------------------------|--|---|
| | Hastings Library Future site * | Hastings library have agreed to having a Macmillan information point when the new library opens in Spring 2018 |
| | Isabel Blackman Centre | The Isabel Blackman Centre has one wall mounted leaflet rack and a small number of free standing leaflet holders. |
| | The Bridge Community Centre | The bridge has an InfoPoint situated in the front entrance of the centre. |
| | Sedlescombe Road North Medical Practice | Wall mounted leaflets racks situated in the entrance hall. |
| | Age UK East Sussex and Care for the Carers - Information Centre | The information centre has a wall mounted leaflet rack and is looked after by an AGE UK volunteer. |

| Hailsham | | |
|----------|--------------------------|---|
| | Hailsham Foodbank | Hailsham foodbank has one wall mounted leaflet rack and a small collection of leaflets. |

| Newhaven | | |
|----------|---|--|
| | Newhaven Library | Newhaven Library has an InfoPoint situated at the front of the building. |
| | Sussex Community Development Association | SCDA has a Macmillan information and support area in its information and advice centre at The Hub. |

| Lewes | | |
|-------|--------------------------------|--|
| | Lewes Prison Library | The prison library has an InfoPoint in the health area of the library. |
| | Phoenix Day care centre | The Phoenix day care centre has one wall mounted leaflet rack and a small number of free standing leaflet holders. |

| | | |
|--------------------|---------------------------------|---|
| Uckfield | | |
| | The Meads Medical centre | The Meads Medical practice has a Macmillan info point situated in the main entrance. |
| Bexhill | | |
| | Charter Centre | The Charter Centre (day care centre) has one wall mounted leaflet rack in their entrance way. |
| Rotherfield | | |
| | Rotherfield St Martin | Rotherfield St Martin has an info point situated in the entrance hall of the community centre |
| Hospitals | | |
| | Conquest | Macmillan Information area - outpatients Oncology |
| | Eastbourne DGH | Two info points (one pending) Located in Pevensey Day Unit and Outpatients |
| | Bexhill Community Hospital | Wall mounted leaflet racks located in outpatients - area B |

| | | |
|----------------------|--|--|
| Pending Sites | | |
| Hastings | Hastings 1066 Community Hub (Bus) At the moment the 1066 Community Hub parks in areas of the Ore Valley every Friday and is available to the local residents to visit and get access to information on local service providers / events /groups etc. | 1 wall mounted leaflet rack - in community bus |
| | Ore community Centre 455 Old London Rd, Hastings TN35 5BH | Current working with the centre to find a space for wall mounted leaflet racks in the centre |
| | Carisbrooke Surgery Falaise Road, Hastings, East Sussex, TN34 1EU | Currently waiting to hear from Practice Manager to confirm a wall mounted leaflet rack. |

Challenges

Engaging Potential Partners

The aim of the project was to target partners shown to be in the best position to reach communities, with the greatest need, indicated by the evidence. The early consultation and engagement quickly brought forward several partners who showed a willingness to become part of the information network.

However, communication has been a significant challenge - working across the county with such many disparate organisations and partners of varying sizes and with very different areas of work and focus has been time consuming and sometimes difficult.

Warming up potential partners from the point of initial interest and then getting organisations to move forward quickly within this time limited project has been a time-consuming process. It has often taken months of meetings and communication to move from initial agreement to the setting up of an information site.

Potential partners sometimes lacked an understanding about what Macmillan Cancer Information and Support could offer. Most partner organisations have heavy workloads and full agendas. It was crucial therefore to build in time to be able to work with organisations to identify the positive outcomes that would be gained for them by having a Macmillan cancer information point or hub.

This has almost certainly meant that the potential to set up more sites have been missed and that in future set up times should be acknowledged and built into a project timeline.

Internal Processes

There is no doubt that the process of applying for funding, the paperwork involved, putting agreements in place and the long lead up time experienced by partners in receiving their InfoPoint, furniture and equipment has been a huge challenge to navigate for all parties. And the difficulties that faced by partners during this process has led to several not seeing it through to the end.

We were however able to make changes to the process, like having generic partnership agreements in place, that overcame some of the initial problems. And the willingness of the Macmillan management team to help make the process of acquiring the funding easier was of great help.

Projects Achievements

The achievements of this project have been to establish 19, and a further 2 pending, information areas across East Sussex. These sites will give greater access to many more

people, accessing information in hospitals, G.P surgeries, community centres, day care centres and libraries.

The work has built on previous partnerships and created new, long lasting working relationships with a diverse range of partners and organisations.

The project has accomplished some real achievements in raising awareness of and finding solutions to the barriers experienced by those affected by cancer in accessing information.

A planned programme of events and activities has resulted in good public engagement. We have been able to offer advice and information signposting to cancer patients, health professionals and many more people affected by cancer.

There has been a successful pilot completed of the Information Network volunteer role which has indicated that a volunteer to support the host sites would work well and is very much favoured by the host organisations, who through the partner feedback process have voiced their support for extending the role to offer supported access, helping people at sites to navigate the information available.

The insight and evidence and the patient voice gathered during the project has been extremely useful to inform further work and opportunities for Macmillan Cancer Support, East Sussex Community Voice, Healthwatch and other partner organisations.

Learning and Development

Working with such a varied number of partners has led to a greater understanding of information and signing posting structures and organisations across east Sussex. What has also been gained from this is a better understanding of the challenges and problems facing information providers in the future and experience that can be put to good use in helping to find solutions to those issues.

There has been a great deal of learning and knowledge gained around the working practices, structures, and work carried out by health and cancer services, in both acute and primary care.

This project has also enabled a lot of experience to be gained in how to engage with cancer patients in a worthwhile and insightful way. This has certainly lead to new skills being gained and a greater understanding of how evidence and insight can be used to change and improve cancer services.

Risks

Ongoing support

By far the biggest risk to the network as it stands will be the lack of ongoing support and information sharing which would come from a coordinator role. There is a risk that information hubs and InfoPoint, that have been put in place over the two years of this project, will become underused and the information they contain out of date and not as relevant to the communities in which they are sited and aimed at.

Signposting

The risk is that managers and staff in partner organisations will be less aware of the information and support available for cancer patients and their families and therefore less likely to signpost for example to services like the Macmillan welfare and benefits service or the Horizon centre.

Patient experience

The information network is built upon a strategy developed to ensure that patient experience is at its centre. The risk of losing the public input that has developed from this project is of a concern. At the time of writing there are still very few opportunities for cancer patients and their families to be listened to and for their experiences to be used in a positive way to influence and improve services. It should be considered a retrograde step if patients lose further opportunities to be listened to in a time of substantial change in health services.

Development

A continued link between Macmillan and the host partners in the network is needed to enable the network to continue to grow and to develop in a way that keeps pace with the moves towards more integrated health and care services and importantly with emerging partnerships being built between information and signposting organisations (being developed by new roles such as the Locality Link Workers) working across East Sussex.

In July, the independent Cancer Taskforce published their strategy setting out how we in England could achieve the very best cancer outcomes by 2020. It was universally welcomed and backed by the health Arms-Length Bodies, the Government and the wider health community.

The strategy is comprehensive in showing how we can achieve:

- fewer people getting preventable cancers;*
- more people surviving for longer after a diagnosis, with 57% of patients surviving ten years or more;*
- more people having a positive experience of care and support*

Achieving World-Class Cancer Outcomes: Taking the strategy forward

Recommendations for future work

Working towards achieving planned outcomes

As stated in the executive summary the Macmillan Information Network has achieved much, but we cannot consider that enough has yet been done to have significantly addressed the problems faced by people needing information and support, or that enough sites have been created to say that barriers have been overcome and access has become more equitable. This project has started to put in place the building blocks to enable further work to happen and has created strong relationships to carry forward.

It would be recommended that a way to allow the network to continue to grow and develop beyond this two-year project be identified.

We know that where we do have InfoPoints and hubs and they have had time to become established and communities have become aware of them, then partner organisations are reporting good levels of use.

The option to scale down the scope of the network and to focus resources in the areas which have the most need and the least favourable outcomes for cancer patients, is very much supported by the findings in this report. Limiting the scope of the work to the areas in most need, would lead to a more effective and efficient project model and help to overcome the challenges that arise from working across a whole county as highlighted previously in this document.

Primary Care

G.P practices, alongside existing information services and signposting organisations, are for many a starting point if they want to find out about local services and access information. We have found that G.P practices are a focal point for many people we have spoken to when it comes to accessing trusted information. Surveys showed that people want to be able to turn to their G.P surgery to get the information they need.

It is recommended that there should be a continued focus on working with GP's and practice managers, building upon the work started by the information network. This has the potential to generate constructive relationships with G. P's, practices managers and Patient Participation Groups, which could open up opportunities to continue work in raising awareness of signs and symptoms and screening programmes.

Our engagement work has shown that patient choice is a concern for cancer patients and their carers. Many patients we spoke to said they needed more information to feel they were in control of their cancer journey. Here then is also the opportunity to work with practices to improve health literacy, meaning that more people can be supported to understand,

appraise and use information to make treatment choices and decisions, as well as more widely helping patients to be more informed about their health and therefore live well with and beyond cancer.

Lastly, continuing to work with G.P practices will mean that Macmillan can be part of the movement to upskill staff in GP's practices, enable them to be better equipped, more informed and skilled in information and signposting for cancer patients and their families and carers.

Rural Communities

There is a strongly identified need to continue to work towards finding solutions for those who find distance and lack of transport an issue to accessing help and support. Work should continue to identify potential partners, with creative ideas, who are working in or positioned in rural communities supporting communities to access online content.

There remains a need to continue to find ways to:

- To raise awareness of online cancer information
- To improve access for those with poor internet access
- To support those with a lack of willingness to access information online

A recommended way forward would be to establish a volunteer role of digital information and support volunteer, delivering information support in rural communities, working in partnership with local charities, information providers and rural G.P

Information volunteers

As highlighted in the risks there is a need to continue to offer support to the current sites in the network to allow them to carry on providing good quality, trusted information.

This could come from an information support volunteer role that would work with the information hubs and larger sites. The volunteer role would:

- Visit sites, carry out stock takes and provide support with ordering replacement information
- Run information sessions on a regular basis helping people navigate cancer information
- Run stands at community events

There is also a strong case for developing a volunteer champion role in G.P practices, patient participation groups and with hospital volunteers. These roles would promote the key messages around cancer information and support and play a part, along with surgery staff and clinicians, to help improve information services. These volunteers would be in a good position to raise awareness of information sites and be advocates for the service.

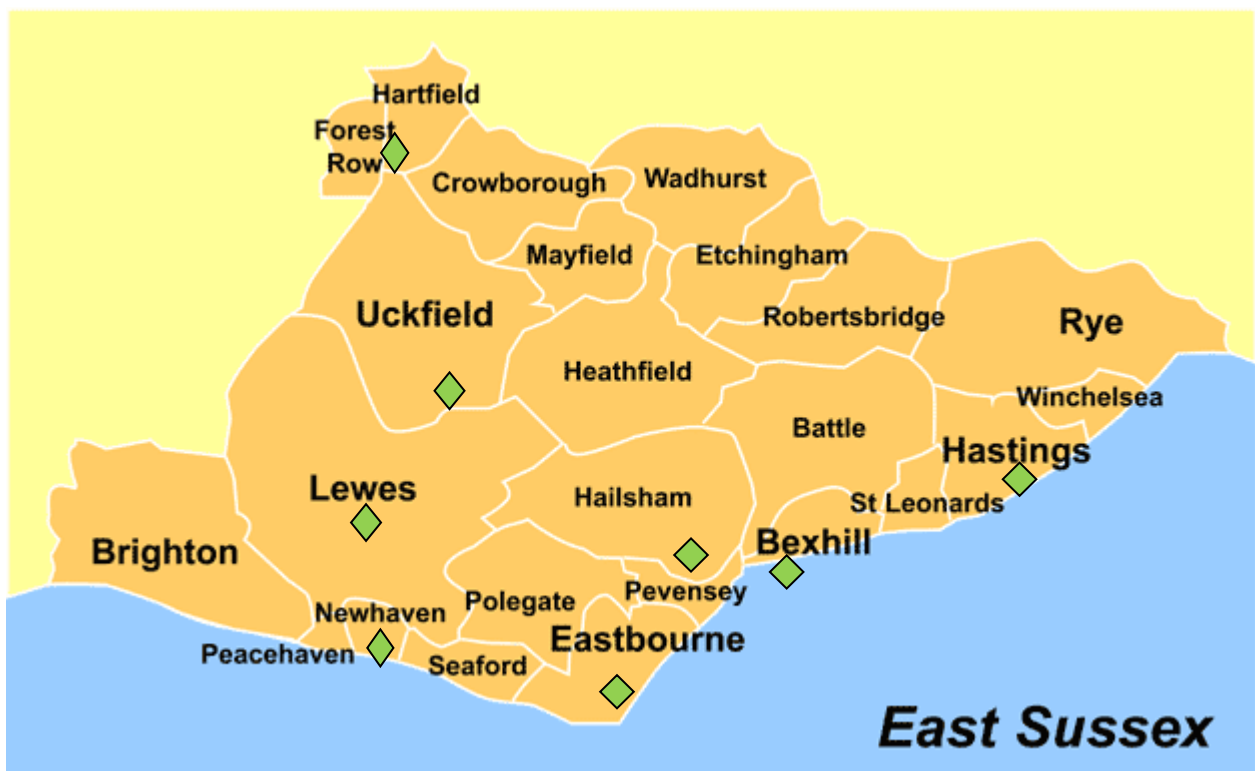
Raising awareness.

There is a need to do more work in raising awareness of the current sites and to encourage advocacy of the information network amongst partners and other information providers.

It should also be an objective of future work to create strong communication links and advocacy between sites and the Horizon Centre (Brighton) as well as other information and support centres in nearby counties. Continuing to build upon the network of Macmillan information sites (both self-access and supported access) will strengthen the reach of the Macmillan Horizon centre, helping to raise awareness and access to the services they provide.

Maps

Location of current and upcoming sites



Citations

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