



'Parents put themselves last too often'

Parent carers, cancer awareness and screening – March 2016

1. Introduction

1.1 What Amaze does

Amaze is Brighton and Hove 'one stop shop' for parent carers of children with disabilities and additional needs, providing a variety of information, advice and support covering education, health, social care, leisure, finances/benefits, and training/workshops. Since 1997 Amaze engages parent carers at all level of services provision for their child or young person, for themselves and for the whole family. The aim is to increase parent carers' resilience and confidence which in turn have a direct effect on the lives of their children and the children themselves. As from April 2014, in line with the new Children and Families Act, Amaze is supporting families, and children and young people with SEND themselves, up to the age of 25.

1.2 What PaCC does

The Parent Carers Council (PaCC), hosted by Amaze, is a city-wide engagement group with over 270 members who are parent carers who have children and young people with disabilities, complex health problems or other additional needs. PaCC also has 8 partners, some of them service providers, others community groups formed by parent carers. PaCC gives a voice to parent carers using different engagement methods as for example focus groups to gather views/opinions and presents these to service managers to influence service delivery. PaCC Parent Reps sit on many Local Authority Boards and strategic groups with the aim to improve health, social care and education services for disabled children.

1.3 Parent Carers' engagement through B&H CCG

Brighton & Hove Clinical Commissioning Group (B&H CCG), through its Engagement Gateway Contract, funds Amaze and PaCC to gather information and present concerns and suggestions on health care services which they access as carers or for their disabled children ([See Annex 1: How Amaze and PaCC engage with parent carers](#)). As a result the local CCG is provided with clear intelligence about how children and young people with a variety of disabilities and their parent carers experience local NHS services. In addition the local CCG's understanding of the needs of disabled children and their parent carers is improved, and health services are correspondingly made more responsive and are targeted to actual need. And finally parent carers feel that their views are valued and that they can influence decision making regarding local NHS services, and help effect change. PaCC and Amaze provide regular feedback and updates on the engagement work to parent carers through the termly newsletter and through social media.

2. Parent carers and cancer awareness, prevention and screening

The city of Brighton and Hove has a low cancer survival rate, with high premature mortality rates and inequalities in the city and there is also a much lower awareness of signs and symptoms in more deprived areas of the city.

Brighton & Hove Clinical Commissioning Group (B&HCCG) and Brighton & Hove City Council (B&HCC) have therefore drafted a 5 year Cancer plan with the aim to improve cancer diagnosis and consequently reduce premature mortality due to cancer, to offer best possible provision of cancer medical care for everyone living in the city and to have primary and secondary health care and voluntary sector to work together to achieve it ([See Annex 2: Health Engagement Organisations Meeting, December 2015 page 5](#)).

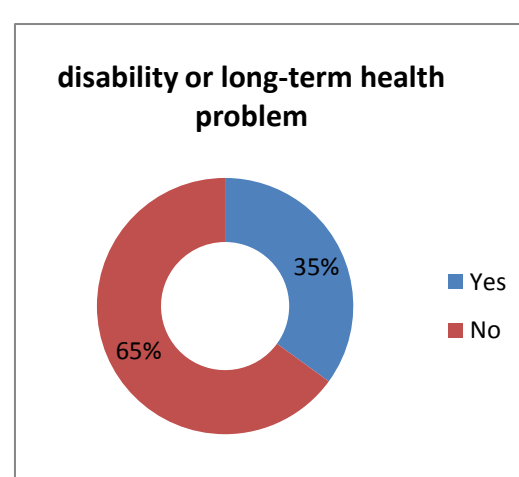
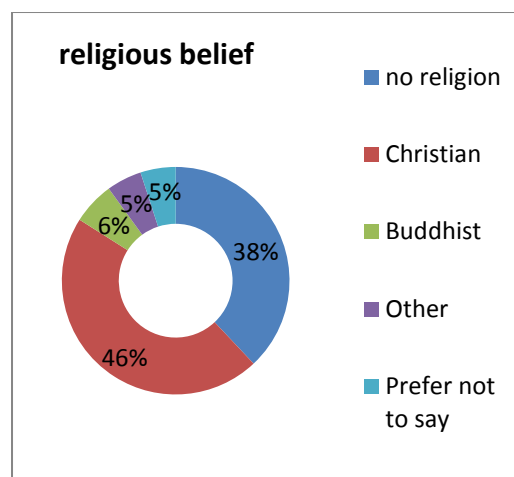
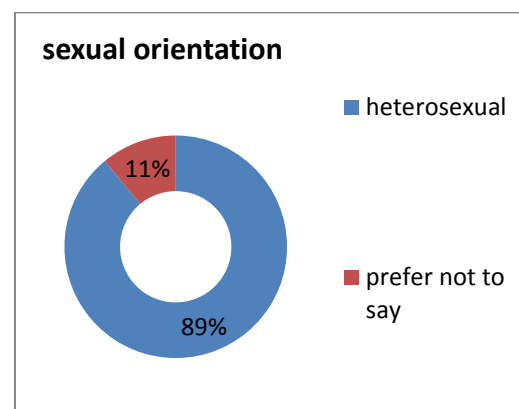
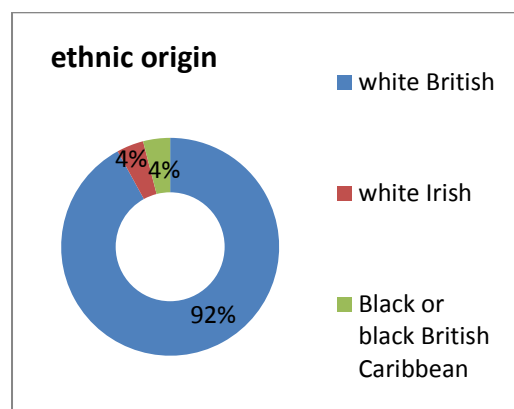
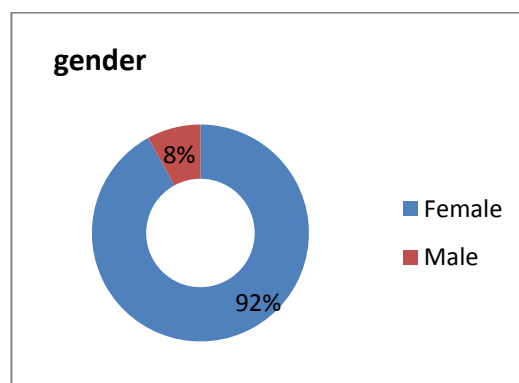
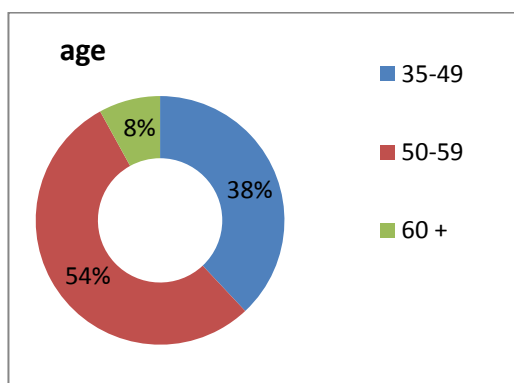
In July 2013 Amaze carried out a survey which was sent to every family in Brighton and Hove with a child registered on the Compass database. The survey focused on the impact of caring for a child with disabilities on the carer themselves. One of the findings was that 71% of respondents felt that they didn't look after themselves well enough or were in fact neglecting themselves. That increased to 85% if the parent had disabilities or additional needs themselves ([See Annex 3: Survey2013Analysis-ReportFINAL\[1\] page 5](#)). Interestingly similar issues were highlighted by a 2003 report from the Social Policy Research Unit at the University of York 'Access to Health Care for Carers: Barriers and Interventions' (www.york.ac.uk/inst/spru/pubs/pdf/access.pdf).

With this consultation we wanted to explore parent carers' awareness about cancer, cancer prevention and screening. We wanted to look into what sort of impact caring for a child has on access to cancer services, and other barriers. Finally we wanted to suggest solutions in order to maximise parent carers' response to and take up of cancer services.

3. Methodology

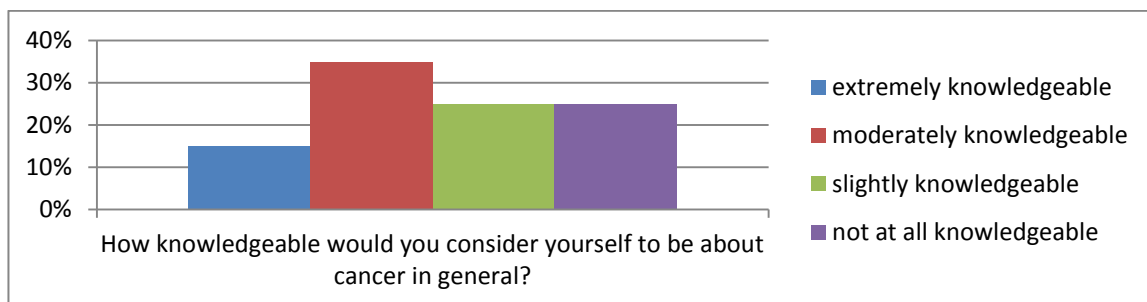
This consultation was discussed and planned with Jane Burt, Engagement Officer at Brighton Carers Centre, and the Amaze database manager who proof-read the final questions. We thought that carers faced many commonalities and so we organised a focus group in collaboration with Brighton Carers Centre. The focus group was attended by 10 carers. We also launched an online questionnaire ([See Annex 4: questionnaire](#)) which included both multiple-choice and open ended questions and it was sent to parent carers including all PaCC members and PaCC Partners and posted on our Social Media. 18 parent carers completed the online questionnaire. Responses received from the online questionnaire were collated into a summary ([See Annex 5: summary](#)) and together with notes from the focus group ([See Annex 6: Cancer focus group feedback](#)) were used to write this report. Quote from parent carers are in *blue italics* and have been recorded as written by participants.

4. Demographics



5. Findings

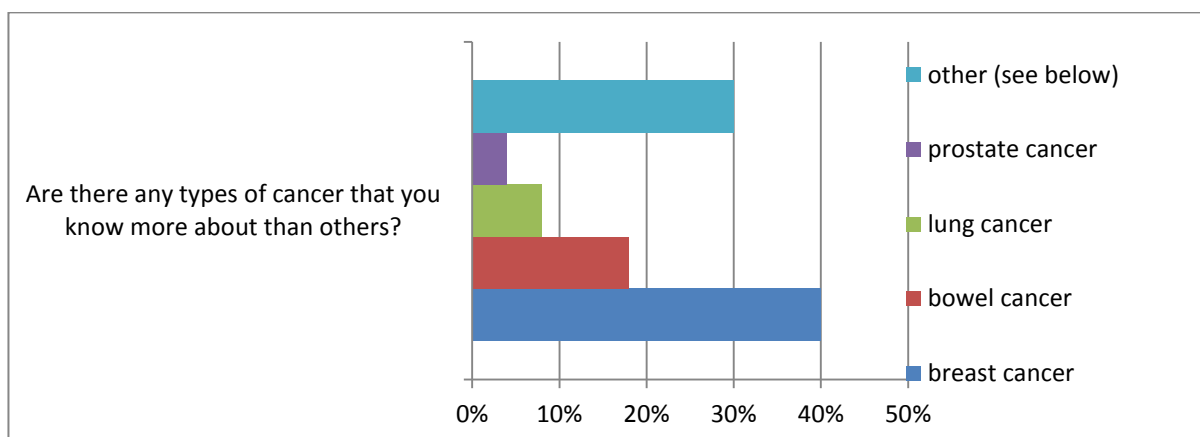
5.1 Cancer awareness



In total approx. **15% of respondents to our online questionnaire and focus group participants saw themselves as extremely knowledgeable, whilst 35% thought themselves as moderately knowledgeable about cancer.** And finally a similar percentage, 25%, saw themselves slightly knowledgeable or not at all knowledgeable. It is important to highlight that altogether **50% of parent carers who participated to our consultation reported limited or no knowledge about cancer.**

One participant to our focus group commented *'You're not thinking that it will happen to me, but when someone else is diagnosed there is then the need to want to know more'*

Some carers wanted to know if there are specific cancer preventative teams/workers in Brighton and Hove.



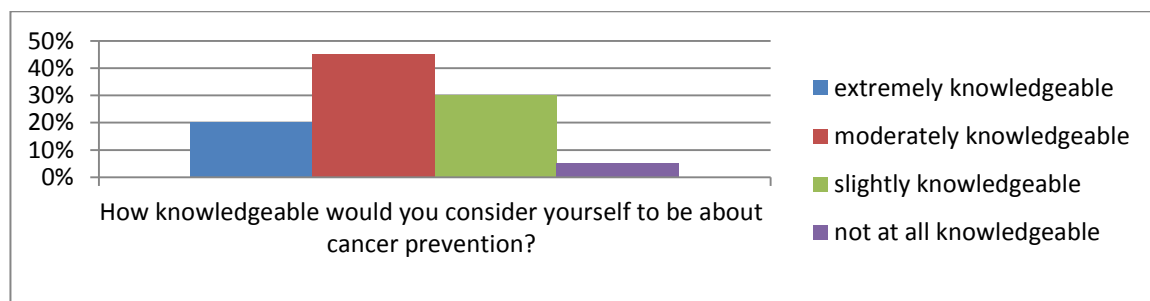
The majority of respondents, **40%, knew about breast cancer**, whilst approx. **18% were aware of bowel cancer, 8% of lung cancer and 4% of prostate cancer.** The remaining 30% mentioned childhood acute lymphoblastic leukaemia, mesothelioma, childhood cancers, leukaemia, myeloid (a type of leukaemia) and Nasopharyngeal carcinoma, skin cancer, testicular cancer, brain cancer, cervical cancer (female carer very aware due to screening), bone cancer (a carer's personal experience of looking after someone), cancer of the liver, kidney cancer and ovarian cancer (one carer had personal awareness having previously had a scare).

To note that breast cancer, probably due to its prominence on media and awareness campaign (how many people know someone who suffered/suffering or who had a breast cancer 'scare'?) is the most known cancer. Clearly the well organised awareness

campaign is having a positive impact. Apart from personal experience is also important to underline the fact that some of our parents care for someone who maybe suffers from a type of cancer *'I feel I know more than I want to know - as I have had to find out myself due to caring for someone'*

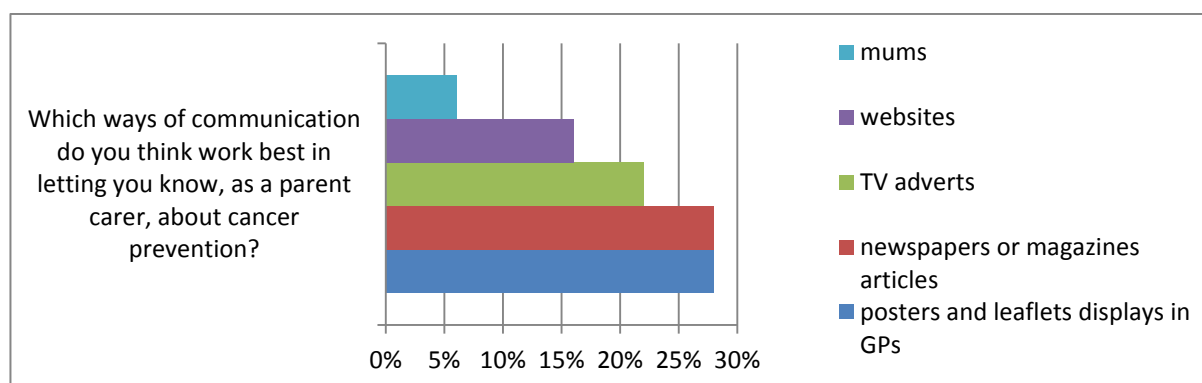
Focus group participants felt that it was important for carers to be taught about self-care when they are looking after someone. Brighton Carers Centre and Amaze were both mentioned as examples of services that advise carers on self-care in a positive way.

5.2 Cancer prevention



In relation to prevention, approx. **20% of respondents to our online questionnaire and focus group participants saw themselves as extremely knowledgeable**, whilst **45% reported to be moderately knowledgeable**, **30% slightly knowledgeable** and finally only **5% considered themselves not at all knowledgeable about cancer prevention**.

Among practices that could prevent cancer, participants to our focus group mentioned limiting alcohol intake, abstinence from smoking, following a healthy diet, a less stressful life, avoidance of strong sun during the summer or while on holidays abroad, regular exercise, careful use of chemicals and pesticides, limiting use of mobiles and the impact of pollution on people's health. Also participants were aware of cancer prevention by health checks offered by GPs and cervical screening.



An equal percentage of **respondents to our online questionnaire, 28%, thought that posters and leaflets displays in GPs and newspapers or magazines articles** were good ways to inform people about cancer prevention whilst **22% preferred TV adverts**,. A smaller percentage, 16%, thought websites would be a good way to inform about cancer prevention while 6% mentioned 'mums', probably met at school pick-ups or parent carers' groups.

Participants to our focus group thought that **trendy TV campaigns** *'with young people in helped to raise awareness with all ages'* and a *'breast cancer campaign featuring an older lady in her 70's, it was good to raise awareness with older groups'*

Bad examples in the press such as the Daily Mail, **scaremongering headlines**, often not based in any fact or truth, and the HIV 80's campaign 'Aids don't die of ignorance' were mentioned as a poor advertising campaign that really failed to get a message across to the wider public.

A respondent to our online questionnaire suggested *'We need to try and make the term "cancer" less scary. Prevention is everything'*. Perhaps a more **'positive' and engaging message** would work?

A participants mentioned **Social Media** and how effective it is in getting the message across as for example to recent *'young woman needing a bone marrow donor whose message had been shared many times across the globe'*.

In the age of **TV and 'famous people'** some carers mentioned the *'Jade Goody and Angelina Joe effect, whereby famous people talked about their own cancer survivor experiences and as a result a vast number of people then went for screening'*. Also TV programmes that 'break barriers' like 'embarrassing bodies' which give a message like 'you are not the only one'. Awareness campaigns would work on **cinemas** too as there are captive audiences in that environment.

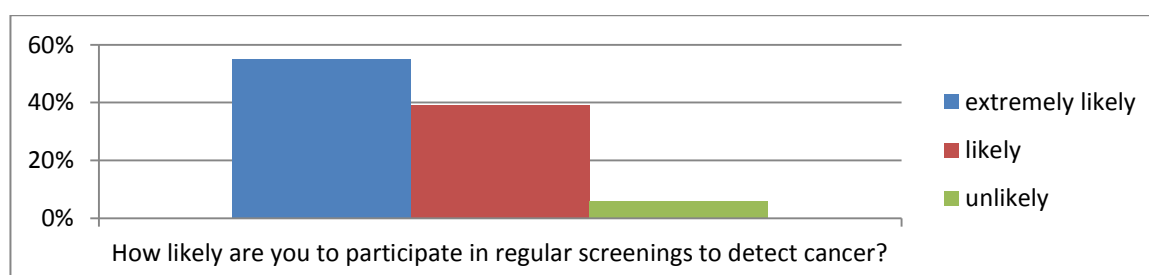
Campaigns should be run in schools and school nurses could help with awareness raising amongst young people. And **campaigns need to be innovative and be personalised** as for example *'the campaign involving the female cancer survivor who wears/creates hats to raise awareness'*

Carers frequent pharmacies on a regular basis and so they could easily access printed information there.

However some carers who participated to our focus group felt that cancer prevention it is not about campaigns about it's about a lack of resources i.e. trying to get a GP appointment can be really difficult and it is a barrier to people seeking advice.

One parent carer suggested that *'I think if we also vaccinated boys as we do girls with HPV (as they do in some other countries such as USA) it would make them immune to several cancers. Alternatively, we have to make them aware of the symptoms of those cancers and treat the cancer when they get it. To me prevention is better than cure'*.

5.3 Cancer screening



The majority of respondents to our online questionnaire, **55%**, reported to be **extremely likely to participate in regular cancer screenings**, while **39%** were **likely** and **6%**

unlikely to attend regular screening to detect cancer. In relation to this consultation it was interesting for us to look into why some parent carers would find very difficult to attend cancer screening and how to target that group.

The majority of focus group participants attended cancer screenings in the past and described the process as generally good. One carer commented that *'The bowel cancer kit in the post' initiative was a very convenient method of screening* for those people who perhaps find difficult attending screenings at clinic or GPs.

Many respondents commented that **lack of time was the biggest barrier, and so access if they had to take their child with them.** A parent explained *'Parents put themselves last too often'* and another *'Time, carers will put it on their to do list!'* Those issues were reiterated by other parent carers *'Sometimes it is difficult to book appointments at suitable times and if you have a diary full of appointments for your child, you are less likely to book appointments for yourself'* and *'Usually need to book in advance which I don't like to do in case my disabled child won't/can't go to school and I can not leave him with anyone. Also I am limited to attending only during school hours because I can't take my disabled child with me'.*

A parent from the focus group talked about her experience of finding out about cancer and struggling to carry on looking after her disabled son and also communicating what was going on with her health to him. She suggested that some **bespoke counselling** would have helped, support that took into consideration her complex situation.

A respondent noted that another barrier is the **lack of ready information** about cancer *'It is a fact of daily life for some people but people only look for information when it touches them personally. Information needs to be better communicated'.*

A parent carer observed *'I only know of screening for cervical cancer so if there are more types I don't know about them. I don't have the luxury of looking for information due to my caring responsibilities so it would be good if GPs were proactive in getting information across'.*

A respondent to our online questionnaire commented that **better information about current cancer care arrangement in the city** is needed. A participant to our focus group suggested that *'The new Cancer centre, waste of money if it does not address issues; will it be a one stop shop for patients and carers?'*

Improved support from GPs - in terms of time and knowledge - and better referral system are suggested by another respondent who explains *'GPs not given enough time for consultations. GP experience and trying to recognise symptoms. Generally incredibly poor administration in NHS in general with a general acceptance that everything takes longer than would be acceptable in other forms of service'.* A parent carer commented *'I have a good GP who takes my concerns seriously'.*

Few participants to our consultation wished a **more organised and responsive health care system, improved waiting list and not delays on treatments.** One carer gave an example of a family member who despite a quick diagnosis of tumours in the lungs and brain *'had a 6 weeks wait for chemotherapy'* A respondent to our online questionnaire commented *'Recently, a very long wait to see a gastroenterologist on the NHS so went private. Was deemed urgent but the wait was 5 months'* and another respondent noted that *'When care is across different centres communication is poor, leading to mistakes and delays. This builds up fear and mistrust in patients and their families. I would prefer to know what financial limitations the NHS inevitably puts on treatment'.*

An **improved referral system** was suggested by another respondent *'I would like to appoint 2 consultant grade posts in SEN/SLD medicine in Brighton. The NHS to recognise that statistically the occurrence of a GP treating a patient with SEN/LDS are so small that GPs cannot build up experience. So to pay for the 2 consultants stop the programme of further education training for GPs (as statistics mean it is not cost effective)'*

A parent carer argued for **better information, support and follow ups** by comparing the quality of cancer care services for children with those provided to adults: *'The care of the children's oncology unit at the Royal Alex in Brighton and Royal Marsden in Surrey are exceptional. Follow up any concerns, routine appointments, all dealt with in an understanding way and they understand how it impacts all the family not just the child concerned. Everything is done to make the child's treatment easier for them. On the other hand, the Brighton Cancer Care (adults) didn't offer anti sickness medication nor explain why the steroids given to the adult would help with their chemo'*

A focus group participant commented *'At the point of diagnosis you are still digesting the news so don't have questions ready to ask'* and another suggested *'After diagnosis professionals should allow a period of time for you to go away and then come back with questions'*

5.4 Other comments and suggestions

Overall a **better signposted system**, a **better communication system between services** *'Record sharing, why does this not happen?'* and **between services and parent carers with follows ups**.

One focus group participant suggested a **better choice for hospitals where to seek treatment** *'Can people choose which hospitals to go in order to attend those with shorter waiting list?'*

Another parent carer lamented the lack of support for carers in cancer services, who are then left to navigate and advocate on behalf of the patient, which can be exhausting alongside providing care. A participant suggested *'specialist cancer liaison workers. A liaison person could represent patients with cancer and that would be useful'*

6. Recommendations

- **Easier to access information on cancer and cancer prevention**
- **Positive and engaging awareness campaigns on TV, Social Media, schools and posters and flyers at GPs and pharmacies**
- **More information on how the cancer care system works in Brighton & Hove, including information on the new Cancer Centre (a sort of pathways into the services)**
- **GPs to facilitate parent carers attending screening by offering times more suitable to them**
- **Better referral system**
- **Improved cancer care system, which is easy to navigate**
- **Support and follow ups for parent carers who attend screenings**
- **Bespoke counselling for parent carers who are positively diagnosed with cancer**

7. Annexes

Annex 1: How Amaze and PaCC engage with parent carers

Annex 2: Health Engagement Organisations Meeting, December 2015

Annex 3: Survey2013Analysis-ReportFINAL[1]

Annex 4: questionnaire

Annex 5: summary

Annex 6: Cancer focus group feedback