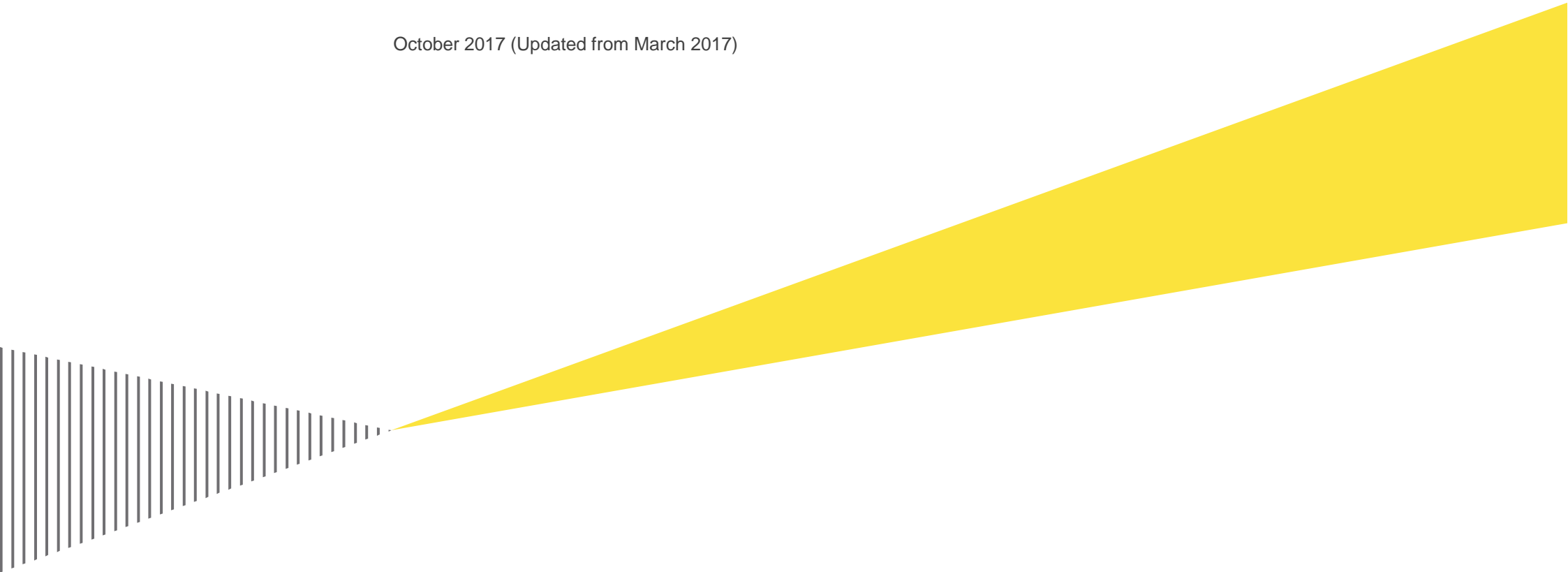


Society's return on investment (SROI) in older people's cancer advocacy services

October 2017 (Updated from March 2017)



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Executive summary

- ▶ We were commissioned by Macmillan Cancer Support, working with their delivery partner OPAAL, to evidence the benefits advocacy services for older people with cancer.
- ▶ We have utilised an approach called Society's Return on Investment (SROI), which we previously applied to a set of other services commissioned by Macmillan. This approach considers the cost and benefits of the service for the service user, the health and care system (including Macmillan and OPAAL), and for society more broadly. This is set in the context of a counterfactual which considers the social costs of cancer in the absence of the advocacy service.
- ▶ Our work involved an in depth review of three case stories, written by three service users together with their advocates, which had been selected by Macmillan and OPAAL.
- ▶ The costs associated with cancer and the benefits associated with the advocacy service have been categorised by bearer of the cost / benefit, as well as the type of cost / benefit, including:
 - ▶ Financial – the direct cost to the health care system of cancer treatment, indirect cash losses to service users as a result of their diagnosis, indirect cash benefits to the service users as a result of advocacy
 - ▶ Economic – improved employment and reduced time off work for family members
 - ▶ Social/experiential – enhanced care, outcomes, wellbeing and experience
- ▶ The results from the three case stories have been extended to the wider population of 898 cases, which represents a 12 month period from October 2015 and September 2016, on the basis of the number of support hours provided.
- ▶ We found that the SROI of the advocacy service as a whole is 6.7x – in other words £6.7 is generated for every £1 spent. Across the 898 cases this equated to a £6.31m net financial, economic, and social benefit.

Selecting three complex case studies

- ▶ As part of previous work undertaken by OPAAL and Macmillan to understand the impact of the advocacy service, OPAAL conducted interviews with a number of their service users. From this, 13 qualitative case stories were written up to provide narrative around the recorded data.
- ▶ The 13 stories were chosen on the basis that they represented the typical users of the advocacy service, and generated a real insight from older people with cancer using the service.
- ▶ For our work, Macmillan and OPAAL further refined the selection of case studies to three, two which represent the common issues emerging from service users and one which represented a more complex case.
- ▶ As such, they collectively represent the mix of cases in the database. Open coding analysis, explained later within this report, was applied to focus in on the specific costs and benefits in the case studies so that they could be used to exemplify the social return on investing into the advocacy service.

1.

Background and context

Background and context

Cancer services are better than ever before. Thanks to the hard work of NHS staff and everyone involved in cancer services in England, we are diagnosing more patients before their cancer has spread and providing more effective treatments delivered by expert teams. The experience reported by patients is increasingly positive and we know more about how to support people in living well after a diagnosis of cancer.

Yet there is no room for complacency. The outcomes are still not as positive as in some countries and, importantly, the needs of cancer patients are changing. Nearly two thirds of cancer diagnoses occur in the over 65s and one third in people aged 75 and over. By 2020 there will be nearly two million people aged 65 and over alive following a diagnosis of cancer. Therefore we need to critically assess our cancer services to ensure that they are meeting the needs of older people – the very people most likely to need them.

It is important to stress that the needs of all older people are not the same. Type of cancer, socio-economic status, gender and ethnicity all play a role in shaping people's needs and outcomes. Equally the needs of active older people in otherwise good health will be very different from those of people living with frailty and other health conditions.

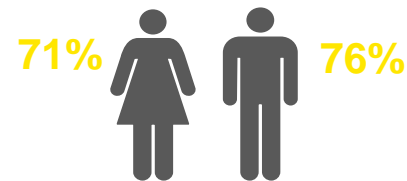
In terms of prevention, older people appear less likely to practice some of the behaviours which would increase the risk of cancer. However, older people may also have the legacy of issues such as smoking or excess alcohol consumption, which may increase their risk. They are also more likely to be overweight or obese and less physically active. We need to support older people in reducing their risk of developing cancer and taking action to be fit for more aggressive (but more effective) cancer treatments by changing their lifestyle; it's never too late for lifestyle change – but the earlier it starts, the better.

Late diagnosis appears to be a major problem in older people. They are more likely to be diagnosed following an emergency admission, diminishing their chances of long term survival. They also experience poorer survival after diagnosis with a cancer that has already spread. Encouraging earlier diagnosis in older people should be a major priority.

Older patients are also less likely to receive active cancer treatment, be it surgery, radiotherapy or cancer drugs. In some cases, there will be good reasons for this. Frailty and other issues can reduce a person's ability to withstand treatment and can result in an unacceptable impact on quality of life. However age alone should never be a barrier to treatment. We must do more to help clinicians assess a person's suitability for treatment.



Older people are **more** likely to...



75-84 year olds who are overweight or obese

Older people are **less** likely to...

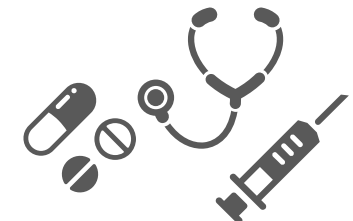


Older people diagnosed with advanced cancer have worse survival rates than younger people with advanced cancer

56%



Inpatient and day case admissions for cancer in 2012/13 were for people aged 65+



Older people are less likely to receive surgery, radiotherapy or chemotherapy treatment than young people

Background and context (cont'd)

Overall, older people report a positive experience of cancer treatment and care and NHS services should be congratulated on their continued efforts to improve patient experience. In particular, they are more likely to have confidence in doctors and nurses and feel that they were treated with dignity and respect. Patient experience surveys do nonetheless also identify areas for improvement. In particular, older people are less likely to have access to a clinical nurse specialist or report being given information on side effects of treatment.

For older people with cancer who are near the end of their life, there are substantial variations in the length of time they spend in hospital, suggesting that some areas of the country are better than others in supporting people in the community. There is substantial scope to improve both the quality and efficiency of care in this respect.

Older people are less likely to have opportunities to participate in cancer research, meaning that opportunities to develop the evidence base on how best to treat older people are missed. As an organisation with a duty to promote research and tackle inequality, the NHS should play its part in changing this.

What is advocacy?

Background and context

In 2011 Macmillan Cancer Support began working with OPAAL, the Older People's Advocacy Alliance to develop and deliver a peer advocacy project to older people affected by cancer (OPABC). The aim of this service was to address inequalities in cancer care faced by too many older people and provide advocacy support to enable active engagement in people's treatment and care.

OPAAL is the only national membership organisation promoting and developing independent advocacy services for people over fifty in England and Wales. Our member organisations provide statutory and non-statutory advocacy services to people over 50. OPAAL develops and leads a range of national advocacy projects.

The cancer advocacy project, funded by Macmillan Cancer Support and the BIG Lottery began in April 2012 with a pilot service in five areas across England. In April 2014 with a further 3 years funding from Macmillan and the Big Lottery we successfully expanded our service and currently work with 11 organisations in England and 1 in Wales. OPAAL are currently seeking funding to expand the service further including into Scotland.

By November 2016 OPAAL had trained 219 peer advocates who provided 1688 cases of independent advocacy support, 1406 were patients and 282 were carers. For the purpose of this report, the analysis of our work is based on 898 cases from October 2015 to September 2016.

What is independent advocacy?

Advocacy is a process rooted in the foundations of individual empowerment. Advocacy services recognise that interdependence is a key attribute in achieving a sense of self and alliance. Advocacy therefore aims to secure 'diverse solutions for diverse needs' by applying the tenets of self-definition, equality and assistance for all people, in their time of need, in ways that they choose. In short advocacy is about 'voice, choice and control' advocates aim to restore people's voice supporting them to make choices about their lives in ways which equip them to regain a degree of control over their situations. It is the ultimate person centred service. Advocates work in places and at times suited to the individuals they support and are independent of other services, a quality highly valued by the people they support.

What is peer advocacy?

Peer advocacy refers to one to one support provided by advocates with a similar disability or shared experience to a person using services.

In our work highly trained and professionally supported volunteers, all of whom have themselves experienced cancer, support their peers with issues they identify as causing concern and distress. These issues are wide ranging and include but is not limited to support with shared decision making around treatment, emotional support, issues around family relationships, finances, transport, accommodation and planning for the end of life.

Our advocates have highly developed skills and knowledge, which coupled with the shared experience, brings a high degree of empathetic compassionate understanding to the relationship. It is this empathy, if you like the 'been there, worn the T shirt, felt that' experience that is crucial to the speedy development of the trusting relationship that is at the heart of this service.

When cancer enters a persons life they are forced to engage with the meta system (the multiple systems – all with different sets of rules and cultures) which has the effect of pulling the person to pieces, the unique nature of peer advocacy intervention has the effect of re-integrating it all, effectively re instituting the individuals personhood.

Scope of our work

Social Return on Investment

Society's Return on Investment (SROI) is a way of capturing and measuring the full range of costs and benefits – financial, economic and personal – of an intervention or programme, across all sectors and stakeholders.

We have formulated a standard approach to calculating SROI which can form the basis of consistent business cases at the system and organisational level. SROI has the potential to be an essential enabler to transforming health and social care.

Scope of our work

EY has been commissioned to support Macmillan through the development of an approach and SROI model which will allow Macmillan to better understand the value created by the patient advocacy service, not solely for its users, but also for its advocates, the health service and the wider society.

Our work aims to analyse the effectiveness of the service and assess whether there is a need for more investment. The analysis will further be able to be used as an evidence base for the fundraising and design of future services.

Our analysis is significantly underlined by the extensive amount of work previously undertaken by Macmillan and OPAAL, which is discussed in section 2 of this report. Our work focuses on three key 'complex'¹ case studies selected by Macmillan and OPAAL to provide a detailed insight into how the advocacy service works in practice. The findings from these case studies have been extended across the whole cohort of people included in the service and divided categorised into four themes.

Our findings by Theme

Our findings have been grouped into the following four themes:

- ▶ **Voice:** I'm involved in my own care, I'm the expert on me, what matters most to me, no decision about me without me
- ▶ **Choice:** I get the right support for me, I have choice, I have access to the most appropriate support for me, support that is responsive to my needs
- ▶ **Control:** I know where, when and who I can get help from, I feel in control, I can maintain my independence, I can manage on my own, I feel like I can face cancer, I can cope
- ▶ **Advocacy:** The advocacy service invests in me

1. OPAAL defines a complex case as one where there are three or more issues present.

2.

Case studies

Introduction to case studies

Our analysis is underpinned by work undertaken by Macmillan and OPAAL, including a series of interviews with a number of their service users to gain a detailed insight into how the advocacy service works in practice. From this, 13 qualitative case studies were written up to provide narrative to augment information recorded on OPAAL’s database.

Our work focused on three of these case studies: Joan, Diane and Albert.

Macmillan and OPAAL selected these stories to represent the entire cohort of complex cases in OPAAL’s database. Joan and Diane’s case studies, although different, have been determined to collectively represent the “average” complex case, meaning that the challenges raised within their stories are considered to be common challenges faced by older people living with cancer. Similarly, the support activities in response to the challenges mentioned within these stories were common activities provided by the service across the wider cohort. Albert’s case was identified as an outlier, his needs and his story are representative of older people with cancer with more complex needs, e.g. those considered marginalised or vulnerable.

The issues that Joan and Diane enable us to also apply the SROI findings to demonstrate the impact of the service in addressing the common challenges faced by older people living with cancer. Similarly, Albert’s needs allows for looking at the impact in addressing significant inequalities.

For all three cases we have looked at the negative impact of their cancer, the costs of running the advocacy service on an individual basis, and the benefits arising from advocacy support. The costs and benefits have been broken down into financial, economic and social, classifications as well as by bearer, for example the individual, the advocate or the NHS.

The social return on investment for Joan, Diane, and Albert have been calculated by comparing the cost of providing them with the service, against the benefits realised. The SROI findings have further been extended to the wider cohort of service users for the year from October 2015 to September 2016 in order to assess the return on investment for a whole year of running the service. We have extended the results on the basis of number of support hours within the year.

This section looks at the three case studies in greater detail, providing the background to the stories, the challenges they presented upon entering the patient advocacy service, and how the service supported their needs.

By nature, these cases are complex and unique, therefore any extension based on a small number of cases presents its challenges. As such, these extensions should be viewed as indicative. Macmillan will continue to develop further case studies in order to strengthen the evidence base and refine the view of SROI that advocacy services produce.



Overview of results from selected case studies:

| 1 Joan | 2 Diane | 3 Albert |
|---|--|--|
| Costs associated with cancer – without advocacy £96,282 | Costs associated with cancer – without advocacy £132,589 | Costs associated with cancer – without advocacy £163,679 |
| Benefits with advocacy support £18,534 | Benefits with advocacy support £106,768 | Benefits with advocacy support £43,592 |
| Social Return on Investment £8.30 per £1 invested | Social Return on Investment £6.20 per £1 invested | Social Return on Investment £7.60 per £1 invested |

Note: figures are on a per person per annum basis

Case study: Joan

Joan's story

Joan was 78 years old when she was diagnosed with Non-Hodgkin's Lymphoma. She had previously been treated for breast cancer. She was referred to the advocacy service when she was due to be discharged from hospital. Participating in the advocacy service highlighted Joan's significant challenges in terms of isolation, depression and anxiety and poor overall health.

Joan used the advocacy service for a total of 54 days, benefitting from 19 hours of support, and 9 activities including home visits, accompaniment to hospital appointments, engaging with social care on her behalf, and independent research of information by the advocate.

Cost and benefit assumptions

The most significant challenges associated with Joan's cancer and the benefits she derived from having access to the advocacy service have been identified within her story by the open coding analysis.

These challenges included delayed hospital discharge, social exclusion, depression, financial worries, loss of overall good health, lack of access to the right support, and challenges with transport. In addition to this we have valued the cost of loss of work days for a relative of Joan, which would have been a cost had she needed support from a relative in place of the advocacy service. The cost of treating Joan's cancer, Lymphoma, has also been accounted for.

Joan accrued a number of benefits as a result of accessing the advocacy service, these included gaining more control in her life, receiving support similar to that of a family member, reduced financial anxiety, support with information (both verbal and written), improved clinical communication, improved overall health and assistance with transport. The benefits identified also stretch to the wider society, for example avoided lost work days for Joan's relative, reduced missed hospital appointments, reduced delayed hospital discharge, employment generated from the existence of the service, and volunteer satisfaction.

The values attributed to the identified challenges and benefits have largely been sourced from the Social Value Bank 2016 and the Manchester New Economy Model. A full list of sources can be found in the Appendix.

Social Return On Investment for Joan



The overall SROI for Joan's case was £16,310 (or 8.3x).

The resultant costs of Joan's cancer to society totalled £96,282 in terms of value. The majority of this was in terms of financial and personal costs to Joan herself. The remaining costs include the financial cost to the NHS of cancer treatment. Joan's share of operational costs of the patient advocacy service was £2,224, representative of her support hours during her 54 days of using the service.

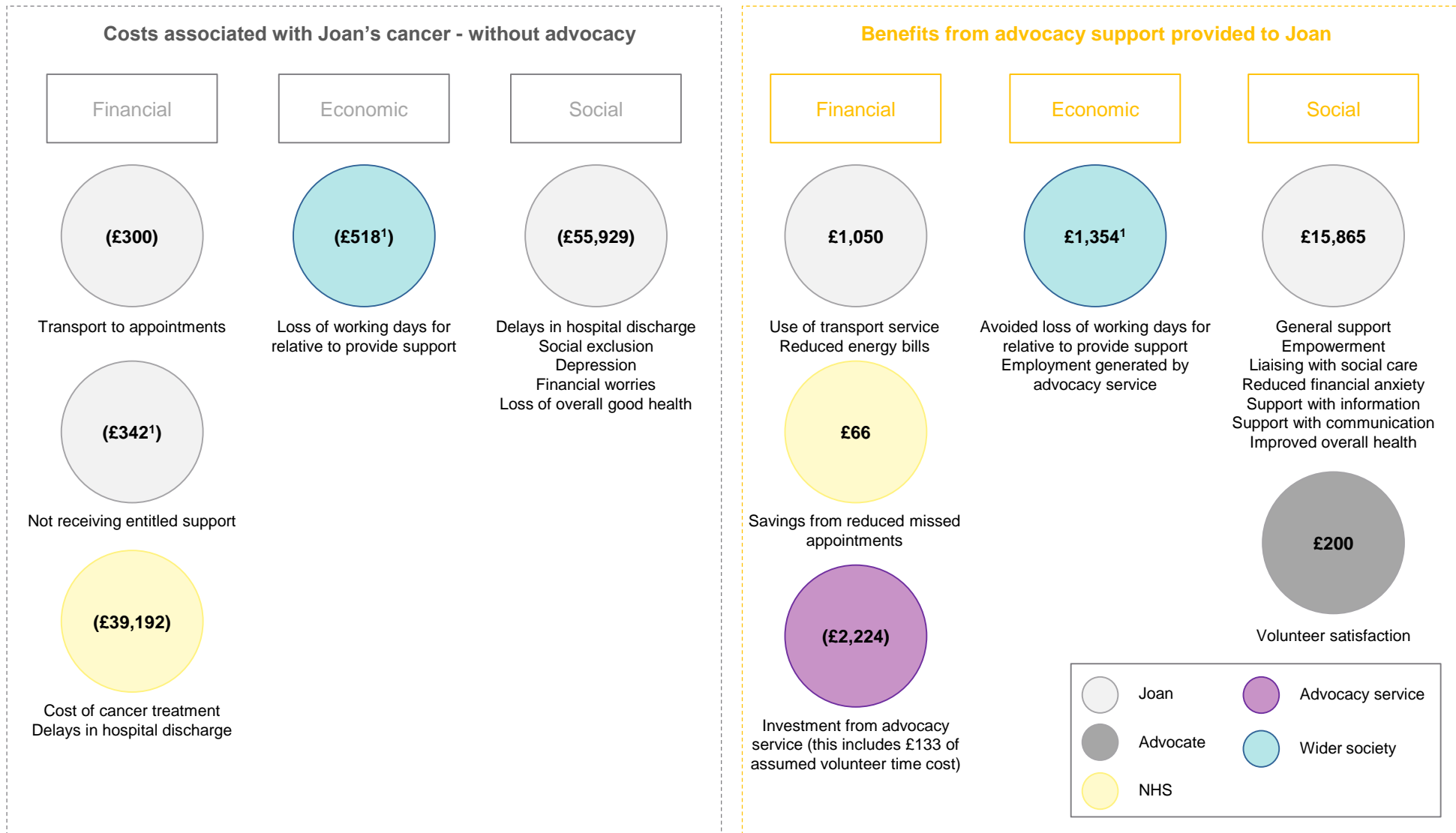
The benefits derived from the service were very large in comparison with the running costs. Almost £20,000 of value was restored, largely to Joan, but also to the advocate in terms of the satisfaction felt from donating their time to a good cause.

Benefits accrued from the service were also extended to NHS system, with savings made in terms of reducing the number of missed appointments and reducing delays in hospital discharge.

| Bearer | Costs associated with Joan's cancer - without advocacy | Costs associated with Joan's cancer - with advocacy | Overall saving as a result of the patient advocacy service |
|--------------|--|---|--|
| Person | (£56,572) | (£39,657) | £16,915 |
| NHS | (£39,192) | (£39,126) | £66 |
| Advocate | - | £200 | £200 |
| Family | (£518) | - | £518 |
| Society | - | £835 | £835 |
| Total | (£96,282) | (£77,748) | £18,534 |

Note: figures are on a per person per annum basis

Joan's findings



1. If not for the advocacy service, these costs would have also been incurred

Case study: Diane

Diane's story

Diane was 64 when she was introduced to the patient advocacy service following being diagnosed with skin cancer. Diane had, at the time of writing, been in the service for almost two years and has benefited from support from four advocates. On entering the service, Diane was faced with a number of significant challenges such as financial worries, anxiety, depression, transporting issues and loss of overall good health.

Within a one year period (September 2015 - October 2016) Diane benefited from 138 hours of support, and 107 activities including general and emotional support, home visits, arranging services and independently researching information for her.

Cost and benefit assumptions

Diane's most significant challenges associated with her cancer diagnosis were brought to light by the open coding analysis which was applied to her case story. These results showed that Diane upon entering the patient advocacy service, was distressed, anxious and showing signs of depression, all contributing to a poor emotional wellbeing. In addition to this she demonstrated signs of poor overall physical health. Other challenges exposed include isolation and social exclusion, loss of self esteem and loss of agency and control of life. We have further included the potential costs of mental health care which we would assume Diane to have sought had it not been for the support of the advocacy service. The cost of treating Diane's skin cancer has also been accounted for.

Receiving advocacy support brought a number of benefits to Diane, including relief from distress and anxiety, and increased self esteem. The results from the coding analysis emphasised a significant feeling of regained control and independence in her life as a result of having access to networks informed by the advocacy service. We have also modelled the benefit of having support and companionship similar to that of a family member, and the value of having access to services such as home visiting and counselling. The benefits identified also stretch to the NHS and the wider economy, for example reducing the need for mental health care provision, the employment generated from the existence of the service, and volunteer satisfaction.

The values attributed to the identified challenges and benefits have largely been sourced from the Social Value Bank 2016 and the Manchester New Economy Model. A full list of sources can be found in the Appendix.

Social Return On Investment for Diane



The overall SROI for Diane's case was £89,635 (or 6.2x).

The resultant costs of Diane's cancer totalled £132,589 in terms of value lost to society. The majority of this was in terms of financial and personal costs to Diane herself. The remaining costs include the financial cost to the NHS of cancer treatment. Diane's share of operational costs of the patient advocacy service was £17,133, representative of her support hours during one year of her using the service.

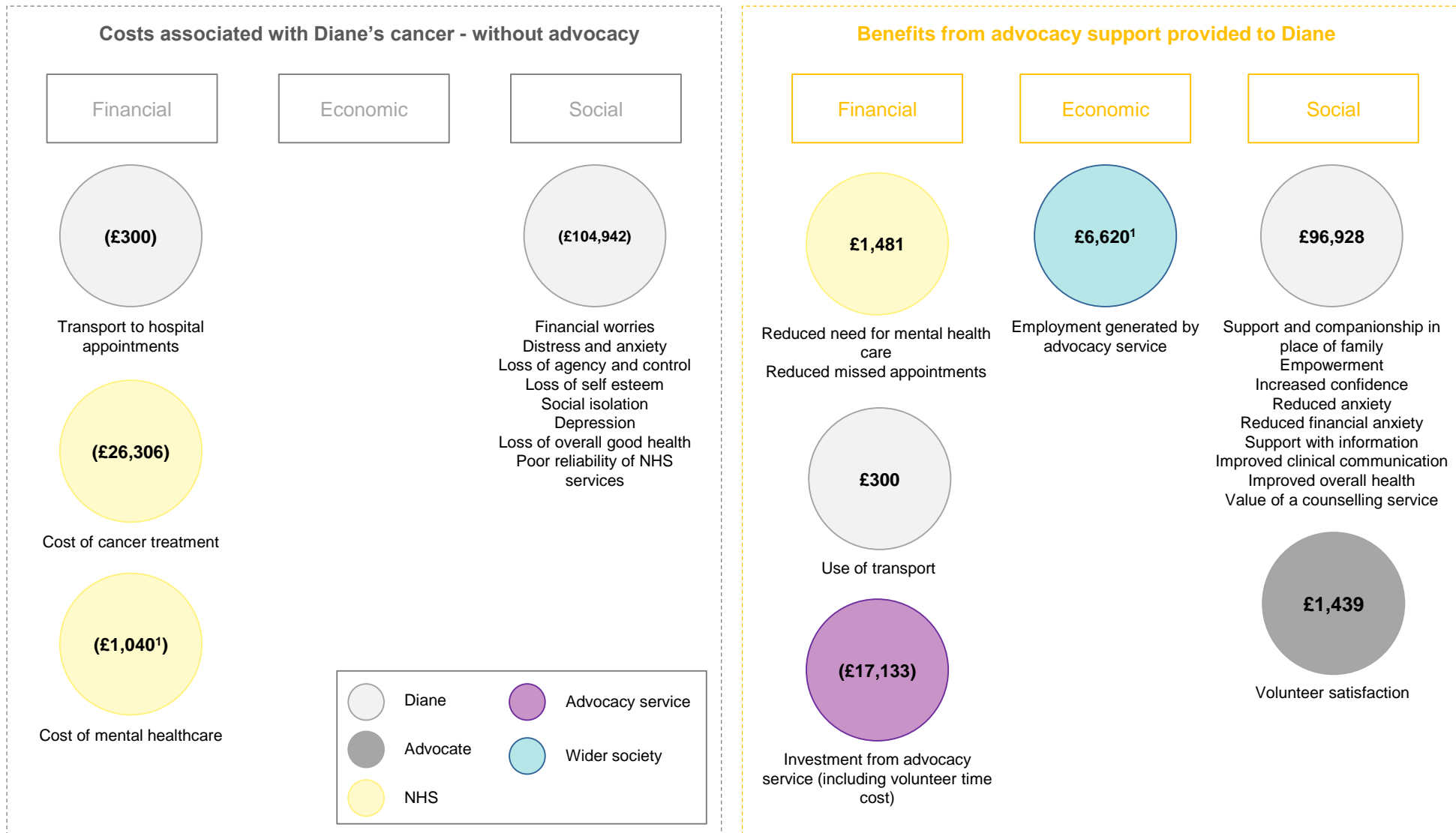
The benefits derived from the service were over six times greater than the respective operational costs. Approximately £97,000 of value was restored to Diane.

Benefits accrued from the service were also extended to NHS system, with savings made in terms of reducing the number of missed appointments and reducing the need for mental health care provision. In addition, we have modelled the benefit of satisfaction achieved by the advocate of donating their time.

| Bearer | Costs associated with Diane's cancer - without advocacy | Costs associated with Diane's cancer - with advocacy | Overall saving as a result of the patient advocacy service |
|--------------|---|--|--|
| Person | (£105,242) | (£8,014) | £97,228 |
| NHS | (£27,346) | (£25,865) | £1,481 |
| Advocate | - | £1,439 | £1,439 |
| Family | - | - | - |
| Society | - | £6,620 | £6,620 |
| Total | (£132,589) | (£25,821) | £106,768 |

Note: figures are on a per person per annum basis

Diane's findings



1. If not for the advocacy service, these costs would have also been incurred

Case study: Albert

Albert's story

Albert was 65 when he began using the advocacy service, after being diagnosed with pancreatic cancer. At the time of writing, he had been in the service for 19 months and has interacted with two advocates. Participating in the advocacy service highlight Albert's significant challenges in terms of uncertainty, anger, feeling let down by the system, isolation, depression and anxiety.

Within a one year period (September 2015 - October 2016) Albert benefited from 53 hours of support, and 35 activities including home visits, accompaniment to meetings with health professionals, and arranging services for him.

Cost and benefit assumptions

Albert's story presented a more unique case of complex needs. Albert has a learning difficulties and Asperger Syndrome, as well as having suffered from bad childhood experiences, the effects of which were all exacerbated by his cancer diagnosis. We have been careful to model the costs directly associated with his cancer and not to inadvertently inflate the benefits derived, whilst still considering the significant inequalities he faced in order to present a fair reflection of the SROI.

Albert's challenges included distress and anxiety, signs of depression and loss of overall good health. In addition to this he lacked self esteem, felt isolated from society and felt he had significantly lost his independence and control within his life. Other challenges uncovered included financial worries and limited access to transport. We have further included the potential costs of mental health care which we would assume Albert to require had it not been for the support of the advocacy service. The cost of treating Albert's cancer has also been accounted for.

The patient advocacy service provided a vast array of benefits to Albert, including relief from anxiety and financial worries, increased self esteem and a significant regain of control within his life. Albert's advocates provided significant support with accessing and understanding information, both verbally and written, which further assisted with improving clinical communication between Albert and health professionals. His story also emphasised benefits including improved overall health and improved access to transport. We have also modelled the benefit of having support and companionship similar to that of a family member, and the value of having access to services such as home visiting and counselling.

The benefits identified also stretch to the NHS and the wider economy, for example reducing the need for mental health care provision, the employment generated from the existence of the service, and volunteer satisfaction.

The values attributed to the identified challenges and benefits have largely been sourced from the Social Value Bank 2016 and the Manchester New Economy Model. A full list of sources can be found in the Appendix.

Social Return On Investment for Albert



The overall SROI for Albert's case was £37,865 (or 7.6x).

The costs associated with Albert's cancer totalled £163,769 in terms of value. The majority of this was in terms of financial and personal costs to Albert. The remaining costs include the financial cost to the NHS of treating Albert's cancer, as well as the hypothetical cost of mental health care provision which Albert would have needed had he not received advocacy support.

Albert's share of operational costs of the patient advocacy service was £5,726, representative of his support hours during one year of him using the service.

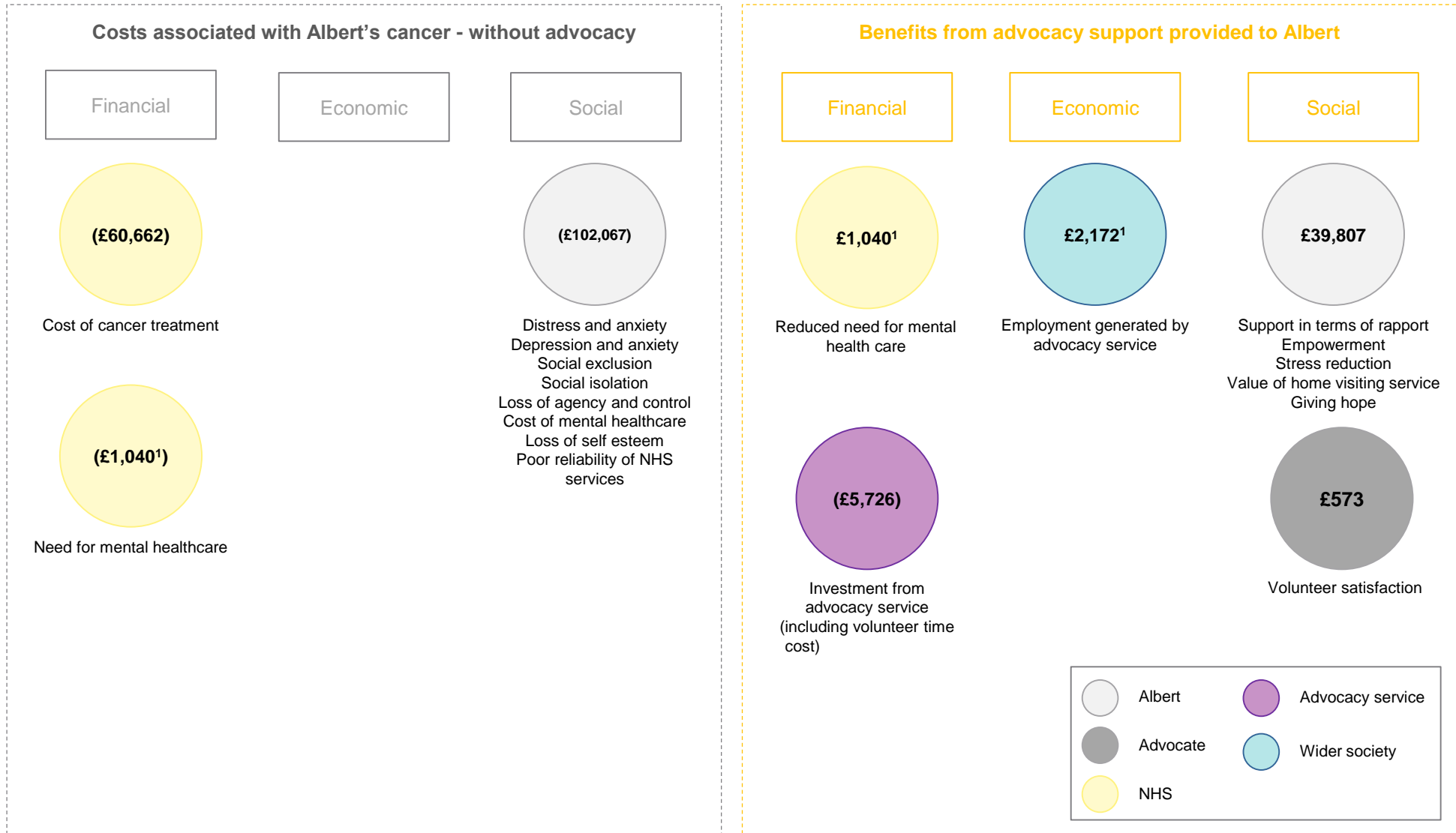
The benefits derived from the service were almost eight times greater than the respective operational costs. Approximately £40,000 of value was restored to Albert, with an additional £4,000 of benefits accruing to the NHS through the reduced need for mental health care, to the wider society through employment generated by the advocacy service, and to the advocate through satisfaction of donating their time to helping someone.

These benefits focus on the success of the advocacy service in addressing issues created by the cancer. Albert's story does suggest wider benefits related to his other pre-existing conditions, but these have not been included in our calculations as they are outside the scope of this review.

| Bearer | Costs associated with Albert's cancer - without advocacy | Costs associated with Albert's cancer - with advocacy | Overall saving as a result of the patient advocacy service |
|--------------|--|---|--|
| Person | (£102,067) | (£62,261) | £39,807 |
| NHS | (£61,702) | (£60,662) | £1,040 |
| Advocate | - | £573 | £573 |
| Family | - | - | - |
| Society | - | £2,172 | £2,172 |
| Total | (£163,769) | (£120,178) | £43,592 |

Note: figures are on a per person per annum basis

Albert's findings



1. If not for the advocacy service, these costs would have also been incurred

3.

Findings by theme

Voice: I'm involved in my own care, I'm the expert on me, what matters most to me, no decision about me without me

Context

- ▶ Older people overly trust in doctors and clinical judgement.
- ▶ Clinicians don't have the support (tools, practice, policy) or the evidence to make decisions confidently.
- ▶ Older people feel unable to ask questions, limited sometimes to "medical" only issues where the doctor knows best. This increases the chances of later staging and accessibility to all treatments post 65.
- ▶ Reality shows that older people feel unable to ask questions, don't want to be a burden, and lack the confidence to speak up about health problems. This subsequently has a negative impact on the quality of discussion and ability to participate in shared decisions about care.
- ▶ There is further concern that older people feel the NHS is age bias, with problematic relationships with doctors in terms of not being treated with dignity and respect.

Specific issues identified in all the stories

- ▶ Provision of written and verbal information, being able to make sense of this Clinical communication, understanding information and being able to ask questions about care.
- ▶ Involvement in decisions about care, feeling involved in decisions about care.
- ▶ Trust in the doctor and a relationship of understanding, enabling medical information to be captured correctly.
- ▶ Decisions and wishes at end of life and within the carer dynamic (as well as presumptions about capacity in the outlier case study given learning disability).

Findings

- ▶ Our findings showed that the advocacy service generated an estimated £18,107 across the three cases, per year, in value with respect to giving Joan, Albert, and Diane the opportunity to be more involved with their own care, including power of their own decision-making.
- ▶ The support provided by advocates with regards to retrieving, understanding, and interpreting information, produced a social value of £4,324 per year. The exponential benefit of this support has been modelled as an estimated £7,061 per year, assuming that the support led to improved clinical communication and greater access to the social care system.
- ▶ In gaining a greater voice about their own care and the benefits derived from this as per the case study narratives, we have further estimated secondary benefits such as reductions in delayed hospital discharge, and reductions in the number of missed appointments. Together this has been estimated at a saving to the NHS of £2,198 per year.

- ▶ A further component of the benefits derived from the advocacy service, is the potentially reduced need for mental health services. Much of the case study narratives referred to feelings of anxiety and depression, to which the advocacy service helped to reduce and stem through the provision of support and listening to the service users. Therefore it could be assumed that without the advocacy service in place, the service users would have sought help from mental health services, costing the NHS on average £2,080 per year.
- ▶ Overall, the advocacy service improved the overall reliability of care received by Joan, Albert and Diane. This improvement has been modelled at £2,444 per year.

Support with information



£4,324 per year

Improved clinical communication



£4,128 per year

Reduced delayed hospital discharge



£1,691 per year

Support with accessing the social care system



£2,933 per year

Reduced number of missed appointments



£507 per year

Reduced need for mental health services



£2,080 per year

Improved reliability of care



£2,444 per year

Note: All figures are based on the findings from Joan, Diane, and Albert case stories

Voice: Joan, Albert, Diane

| Costs resulting from lack of voice | Support from advocacy | Overall improvement |
|--|--|---|
| <p>Joan was struggling to find information relevant to her support and care. Lack of information, being misinformed as a result of mis-interpreting or not understanding information can lead to the wrong decisions being made for the individual, or them to feel as if decisions about their care is beyond their control. The social cost to Joan of failing to access the right support criteria was estimated at £342. An additional economic cost would arise if a relative of Joan had to take days off work in order to care for her. This has been modelled as the cost of 9 work days (9 days x 8 hours x £7.20 national minimum wage).</p> | <p>Volunteers from the advocacy service are able to help older people with cancer access and better understand information. Joan's advocate was able to help her with both verbal and written information, as well as explaining the options relating to her care and support available to her. This allowed Joan to feel involved with her care and make decisions for herself.</p> | <p>Support with information and communication has been valued using the Social Value Bank's entry for the ability to obtain advice, which is comparable to being a better informed patient, which has a full year value of £3,391 for someone of Joan's age*. The impact of this benefit has been reduced proportionately to the time Joan was using the service (54 days). There is also an associated economic benefit in terms of avoided loss of work days, which Joan's stepson would have had to bear if not for the service. This has been calculated as the cost for the loss of 9 work days for a relative. (9 days x 8 hours x £7.20 (NMW)).</p> |
| <p>For Diane, the fact that she struggles with reading and is registered as deaf, meant that receiving and understanding information and communicating her needs to health services was very difficult. This led her to feel distressed and anxious, a social cost valued at £4,522 per annum for someone of her age (Manchester New Economy Model). In addition to this, it led to loss of agency and control for Diane as she was unable to advocate for herself effectively. This bears an experiential cost of £15,734 per annum for someone of her age (Social Value Bank 2016).</p> | <p>Diane's advocate read and explained letters to her, made phonecalls on her behalf, set up and attended meetings with health services in order to clarify Diane's needs and prioritise them. They also helped her to employ a new care worker and made sure that all the required paperwork was completed appropriately.</p> | <p>The experiential benefit of improved written and verbal communication for Diane has been attributed the full year value of £3,931. This support further resulted in improved communication between Diane and health professionals which encouraged Diane to make informed decisions about her care. Improved clinical communication has also been valued at £3,931 per annum for someone of Diane's age. There is a further experiential benefit to Diane of liaising with social services to get a new care worker, as a result of the support by her advocate. The value of this is estimated at £489 (New Economy Model; full year value £2,444 reduced for singular instance).</p> |
| <p>Diane also has a serious issue with her designated care worker. Unable to feel she could voice her concerns to anyone, this left her feeling incredibly anxious and distressed, resulting in a social cost of £4,522 per annum (as above).</p> | <p>In addition to the above, the secondary effects of being better informed and feeling heard about important matters significantly reduces the distress and anxiety which can be associated to feeling helpless. In both cases it was identified that the above supported provided to Joan and Diane resulted in reduced stress and anxiety, and improved control within their lives.</p> | <p>The impact of the secondary effects of this (i.e. regained control, reduced distress and anxiety) have been captured in Themes 2 & 3.</p> |

Choice: I get the right support for me, I have choice, I have access to the most appropriate support for me, support that is responsive to my needs

Context

- ▶ Older people are more likely to experience multiple long-term conditions, more likely to live alone and more likely to live below poverty line.
- ▶ They are the biggest losers of changes to social care and eligibility criteria changing, more likely to be widowed, in need of practical support as well as psychosocial and medical.
- ▶ The biggest manifestation of inappropriate care is the delays in older people getting out of hospital – usually because medical care is not set up to provide support to other needs, and inappropriate provision with little integration or care coordination between primary, social care and community.

Specific issues identified in all the stories

- ▶ Eligibility to the right support (social care provision, transport, practical support, tailored support from third sector).
- ▶ Management of multiple morbidity.
- ▶ Numerous health appointments.
- ▶ Housing needs.
- ▶ Family support structures and support groups.
- ▶ Emotional health.

Findings

- ▶ Through this greater choice, the service users have benefitted from getting the right support for them and their needs, including support with accessing transport, seeking financial help and therefore reducing their financial anxiety and improving their emotion wellbeing. Together, these benefits have collectively been estimated at approximately £80,000 per year for Joan, Albert, and Diane's cases.
- ▶ As a result of the above, the secondary benefits that have been modelled within our analysis is the improvement to overall physical health. For the three selected case studies this generates an estimated value of £4,643 per year.
- ▶ An additional benefit incorporated into our analysis as a result of the greater choice given to the service users of the advocacy service is the reduced need for family to be out of work in order to directly support the individual. In place of a family member the service user is able to rely on the advocate, saving an estimated £518 per year (collectively for Joan, Albert and Diane).

Support with access to transport



£450 per year

Support with eligibility for reduced fuel costs



£900 per year

Reduced financial anxiety



£10,211 per year

Improved emotional wellbeing



£68,922 per year

Improved overall physical health



£4,643 per year

Reduced need for family to be out of work



£518 per year

Note: All figures are based on the findings from Joan, Diane, and Albert case stories

Choice: Joan, Albert, Diane

| Costs resulting from lack of choice | Support from advocacy | Overall improvement |
|---|--|---|
| <p>As a result of her diagnosis and feeling in the dark of options available to her, Joan was suffering with depression. This has a social cost of £39,302 per annum (Social Value Bank 2016) for someone of her age. In addition, living on her own in a rural village with no close relatives nearby, returning home from her hospital stay would have left her to feel very isolated. Isolation and loneliness has an assumed social cost of £6,004 per annum (Social Value Bank 2016).</p> | <p>We conceptualise the benefit provided as helping Joan come out of her depression by enabling her to take control back within her life. Joan's advocate provided general support which aided in an overall improvement in her health, and also helped her to access suitable transport to her appointments. In addition, they researched available groups and activities in her village for her to participate in, from which Joan was interested in the Widows Group. Through this research Joan also became aware of the local Age UK Befriending Scheme and was keen to have a befriender. Her advocate contacted them and they agreed to arrange for someone to visit Joan. Giving Joan access to these support networks allowed her to understand the options and choices available to her, and for her to make them for herself.</p> | <p>The provision of general support has been modelled at £807 per annum for a case similar to Joan's. This is based on the New Economy Model's value for the annual cost of day services for the elderly (£2,460), apportioned for the time Joan spent within the service. The improvement to her overall health provided a saving of £606 (Social Value Bank 2016 full year figure £20,186, reduced to account for time spent within the service and the fact her health could not be restored fully). The support from extended networks provides an overall saving of £7,036 per annum for someone of Joan's age (Social Value Bank 2016).</p> |
| <p>Albert felt very let down by the NHS system, in particular during a time when his GP was not available to see him, despite saying they could. He felt he wasn't receiving the right support and uninformed of his choices. The cost of feeling let down by the NHS in this instance has been valued at £1,920. This is equivalent to the financial value of a hospital appointment, used to represent the lost experiential value to the individual from having not had that appointment.</p> | <p>Albert's advocates regularly visited him and frequently checked the reliability of services he was using. Examples include contacting Albert's nurse to check when they will next visit him, contacting the electricity company to check whether they needed a meter reading, and notifying his housing association of a problem within his building.</p> | <p>The support and the rapport Albert built up with his advocates enabled him to seek the right support for various aspects in his life. We have modelled this support to be aligned to the Social Value Bank's description of the ability to rely on family, £7,306 per annum. We have reduced this value by 50% to account for the fact that Albert's contact with his advocates would have been less frequent in comparison to an someone's family member.</p> |
| <p>As a result of her diagnosis and subsequent cancer experience, Diane suffered from mood swings and severe low morale. The New Economy Model values the cost of individual counselling sessions at £52. Anxiety would be treated by CBT in medical practice (as well as pharmacologically). Based on the assumption of 20 sessions, the cost of mental health care to the NHS in a case like Diane's would be £1,040. She also indicated that she wasn't able to get a wheelchair to help her mobility. This would have affected Diane's agency, mood and independence. It also triggered financial anxiety for Diane. This presents a cost of £8,879 per annum for a person of her age. She also lives alone with no close relatives nearby. This made her feel alone which contributed to her signs of depression. The cost of isolation and feeling depressed would pose further additional costs of £1,850 and £39,302 per annum respectively for someone of Diane's age.</p> | <p>The support provided by Diane's advocate, including the relaying of information, emotional support (particularly through traumatic experiences), and frequent home visits, would have reduced the need for Diane to seek support elsewhere. This support is comparable to that of a counselling service, and has been assumed to restore the full potential cost of mental health care. The advocate was able to introduce Diane to the Macmillan grant scheme, enabling her to purchase a wheelchair. As a result, Diane's financial anxiety relating to this situation was eliminated by the support provided by her advocate.</p> | <p>We view the support provided by Diane's advocate, notably helping her understand the choices available to her in getting the right support, as standing in place of support of family members, in particular since she noted that her advocate became the most important person in her cancer survivorship experience. This had been valued at £7,036 per annum, the Social Value Bank's value for the ability to rely on family. Diane's advocate was able to arrange additional visits and attend meetings with Adult Services and other local authority officers to provide support around the issues which caused her low mood. In addition they spent time with her to prioritise her issues and deal with them in a systematic way. We conceptualise the benefit provided as helping Diane relieve her depression, restoring the full social cost.</p> |

Control: I know where, when and who I can get help from, I feel in control, I can maintain my independence, I can manage on my own, I feel like I can face cancer, I can cope

Context

- ▶ Older people are more likely to experience widowhood or death.
- ▶ It is more difficult for them to maintain social support networks, and have family who live far away.
- ▶ Isolation and depression is an increasingly significant issue for older people, with limited access to emotional and psychological services.
- ▶ Services outside of the NHS are severely under-utilised by older people, with little connectivity to social support.
- ▶ Lack of warm homes can be a leading cause of death in 65+.

Specific issues identified in all the stories

- ▶ Social isolation— physical and emotional isolation which can lead to significant breakdown in mental health.
- ▶ Rural living and lack of networks of social support.
- ▶ Practical aspects such as bathing, making food, shopping, cleaning all either temporarily or permanently hindered.
- ▶ Lack of money or worries about money.
- ▶ Lack of confidence and hope for the future.
- ▶ Being able to stay at home, out of hospital.
- ▶ Fuel bills can be a challenge for older people.

Findings

- ▶ The benefits we have measured include feeling empowered and greater control of life, as well as companionship and support in place of family. These benefits, collectively for Joan, Albert and Diane have been modelled at £52,225 per year.
- ▶ Similar to how a counselling service provides the user to feel greater control within their life, we have estimated the benefit of this as £2,080 in value per year (for all three cases combined) as the advocacy service provides similar support.

Feeling empowered and greater control of life



£33,828 per year

Companionship and support in place of family



£18,397 per year

Providing a service similar to counselling



£2,080 per year

Note: All figures are based on the findings from Joan, Diane, and Albert case stories

Control: Joan, Albert, Diane

| Costs resulting from lack of control | Support from advocacy | Support from advocacy |
|---|---|---|
| <p>At the point of advocacy referral, Joan was in hospital waiting for a care package so that she could be discharged and return home, but this had been delayed due to social care receiving incorrect information about Joan's living arrangements. When Joan returned home from hospital, she was physically very unwell, in a distressed state, and unable to even make herself a hot drink or shower.</p> <p>Joan was further worried about her financial situation. Due to the incorrect information held by social care she wasn't receiving the financial support she was entitled to. She was also worried about her fuel bills, given that she was having to keep the house warm all the time.</p> <p>With a blood test looming prior to her next session of chemotherapy, Joan was also anxious about how she would get to the hospital due to both physical and financial challenges.</p> | <p>The help provided by Joan's advocate meant that she was able to reduce a further delay of discharge from the hospital, saving both money to the NHS and leisure time for Joan.</p> <p>Joan's advocate also contacted Social Services and requested an assessment urgently. They agreed to provide support to shower and have someone come in at lunchtime to make sure she was eating. This, in addition to the general support provided, reduced Joan's distress and financial anxieties.</p> <p>Joan's advocate contacted patient transport and arranged for her to be picked up and taken to the hospital for her blood test and treatment.</p> | <p>Assuming the service saved Joan 4 days of which she would have stayed in hospital, and at a cost of £250 per day, this equates to a saving of £691 to the NHS. This would also have an experiential saving to Joan personally, as she would have gained 4 days of theoretical leisure time back. This has been modelled as 4 days x 24 hours x £7.20 minimum wage = £691. The support from Social Services is estimated to have provided her with £2,444 in value (New Economy Model) over the course of a year. The specific support provided by Social Services for the period in which Joan was in the patient advocacy service restored £299 in overall good health value. This support either replaced activities that she could have done for herself had she been in better health, or they prevented her health from declining further as she was receiving adequate nutrition.</p> <p>In addition, the support provided by Joan's advocate is estimated to have restored some of her independence. This has been valued using the Social Value Bank's definition of feeling in control of life, valued at £2,328 per year for someone of Joan's age (full year value; £15,734).</p> <p>Joan's awareness of her eligibility for reduced energy tariffs saved her an estimated £900 a year in energy bills. This is Npower's average saving per customer household affected by cancer. Joan's anxiety regarding her financial situation was reduced by £1,332 (two months' relief of the full cost of financial anxiety).</p> |
| <p>Albert's diagnosis made him feel very uncertain and confused. He became increasingly frustrated and short-tempered with people, defensive of his personal space, and demonstrated a lot of anger.</p> <p>Albert was visited by a nurse most weeks but she often failed to turn up when he expected. This left him feeling very stressed, frustrated and rejected.</p> | <p>Albert notes that his advocates went out of their way to make his life as easy as possible, taking a considerable amount of pressure off him. In addition, his advocates significantly empowered him to regain control within his life. One advocate assisted him in planning a tractor-driving holiday, a real passion of Albert's. This help gave Albert hope that he will achieve things he has always wanted to do, in spite of his cancer diagnosis.</p> | <p>The support provided by Albert's advocates, their understanding, pleasant manner and relaxed attitude was particularly helpful for him, particularly at times when he was stressed. This support has been estimated to reduce the levels of distress (valued at £4,522) per annum, as well as the benefit of liaising with Social Services, valued at £2,444 per annum.</p> <p>The additional value of feeling empowered and giving hope to Albert has been at £15,734 and £12,549 per annum respectively, as per the Social Value Bank (2016).</p> |
| <p>Albert's Asperger Syndrome exacerbated this, feeling continually tested, and missed out on a number of opportunities. For Albert, his cancer diagnosis has only cemented these thoughts and feelings.</p> <p>Following her diagnosis Diane became housebound and in need of a wheelchair. One weekend Diane's vehicle was stolen and damaged, affecting her ability to travel independently.</p> <p>Diane also needed oxygen bottles as part of her care package. She was also only able to eat pureed food, and needed someone with her to ensure she didn't struggle. After the infrequent delivery of oxygen bottles, Diane lost faith in the reliability of NHS services. This resulted in a severe loss of confidence.</p> | <p>As well as providing emotional support, Albert's advocates conducted home visits, helped with administrative issues with regards to electric and housing associations.</p> <p>Diane's advocate was able to organise a wheelchair to improve her mobility. This further enabled her to go on trips with her church congregation, as well as go on a caravan break. We have estimated this benefit as having restored Diane's independence, fully eliminating the social cost.</p> <p>Diane's advocate also supported her at meetings with Adult Services and other local authority officers to ensure she was receiving the required support. They also visited her fortnightly. As a result of this support, Diane was able to partially restore her overall health.</p> | <p>The value of support received by Diane has been estimated at £4,037 (20% of the full year value), given that Diane's health status would not be fully restored. The advocate's ongoing presence and encouragement helped reassure Diane and build back up her confidence in the system, which has been valued at £12,549 per annum.</p> <p>The general value of companionship has been estimated to reduce the social cost of isolation by £15,734 per annum.</p> |

4.

Overall Return on Investment (SROI)

The advocacy service invests in me

The costs and benefits of the advocacy service accruing to Joan, Diane, and Albert have been extended to the rest of the complex case cohort – a total of 898 cases as per OPAAL’s records from October 2015 to September 2016. We have extended these results on the basis of number of support hours provided to the cohort, a total of 6,818 ours. This produces an overall SROI of 6.7x for the service for one year.

Findings by theme

When looking at the results by theme, the largest benefit can be attributed to choice, providing an estimated benefit of £3.5m across the cohort. Examples of these benefits accruing to the individuals include the improvement to overall health, transport, increased confidence and relief from distress and anxiety. Wider benefits include avoided loss of work days for relatives, which, if not for the advocacy programme, would result in an economic loss of £691 per case.

The advocacy service also proved to allow its users to regain control within their lives, providing an estimated £2.3m in financial and social benefits per annum across the cohort. This included reducing financial anxiety, providing value equivalent to that of a counselling service, and providing support and companionship, collectively enabling the individual to feel more empowered, and confident in their ability to maintain their independence.

The advocacy service also provides its users with a voice of their own, producing an estimated benefit of £790k across the cohort. Although a smaller benefit in value, these results made up the majority of the wider benefits of the advocacy service, with value added in terms of reducing missed hospital appointments, reduced need for mental healthcare, and reduced delayed hospital discharge.

| | Costs associated with cancer - w without advocacy | Benefits provided by advocacy support | Cost of advocacy service provision | Overall SROI |
|---------------------------|---|---------------------------------------|------------------------------------|-------------------------------------|
| Joan | (£96,282) | £18,534 | (£2,224) | £8.30 per £1 invested |
| Diane | (£132,589) | £106,768 | (£17,133) | £6.20 per £1 invested |
| Albert | (£163,769) | £43,592 | (£5,726) | £7.60 per £1 invested |
| Total (3 cases) | (£392,640) | £168,894 | (£25,083) | £7.40 per £1 invested (avg.) |
| Cohort (898 cases) | (£17,204,502) | £7,400,519 | (£1,099,074) | £6.70 per £1 invested |

On balance:

Across 898 users we estimated benefits worth £6.7 for every £1.0 invested

Financial benefits of advocacy, e.g.

- Savings to the NHS
- Financial support to service users

Economic benefits of advocacy e.g.

- Less missed work for families
- Employment by advocacy service

Experiential/social benefits of advocacy e.g.

- Relief from physical and emotional health issues
- Increased agency and independence
- Sense of community of companionship – reduced isolation and loneliness
- Reduced anxiety
- Better access to information
- Better health outcomes

Costs of advocacy

- Service costs
- Donated time of volunteers



(Not drawn to scale)



Conclusions

Health leaders are becoming increasingly aware that systems are challenging to navigate for patients and that these challenges potentially diminish quality of care, damage patient experience, and produce a cost burden to the system in terms of delays and waste.

The data and case studies collated by Macmillan and OPAAL provide tangible evidence that system navigation is extremely difficult for older people with complex needs in particular.

These case studies highlight that cancer services are typically designed and provided in a clinically focused way, in isolation from the patient's social, emotional and wider health needs, and it is often those who have the most complex needs, beyond just cancer, who do not feel adequately supported by these services.

A diagnosis of cancer can have an overwhelming emotional impact, and this coupled with the isolation that cancer often creates means that there is a huge burden for patients in terms of their emotional wellbeing as well as their physical health.

The evidence shows that these needs and challenges become much easier to manage with the support of an advocate, and in particular where that advocate has the flexibility and freedom to be responsive to the very singular needs of a particular individual.

The case studies also bring out the value of independent yet well trained peer advocates in particular, who understand the impact of a cancer diagnosis on the individual through their similar, personal experiences and are equipped with the right skills and knowledge to help them navigate the system and access the support they require. This extends well beyond what would be conventionally thought of as the health system to accessing, for example, financial relief and opportunities for social interaction and participation.

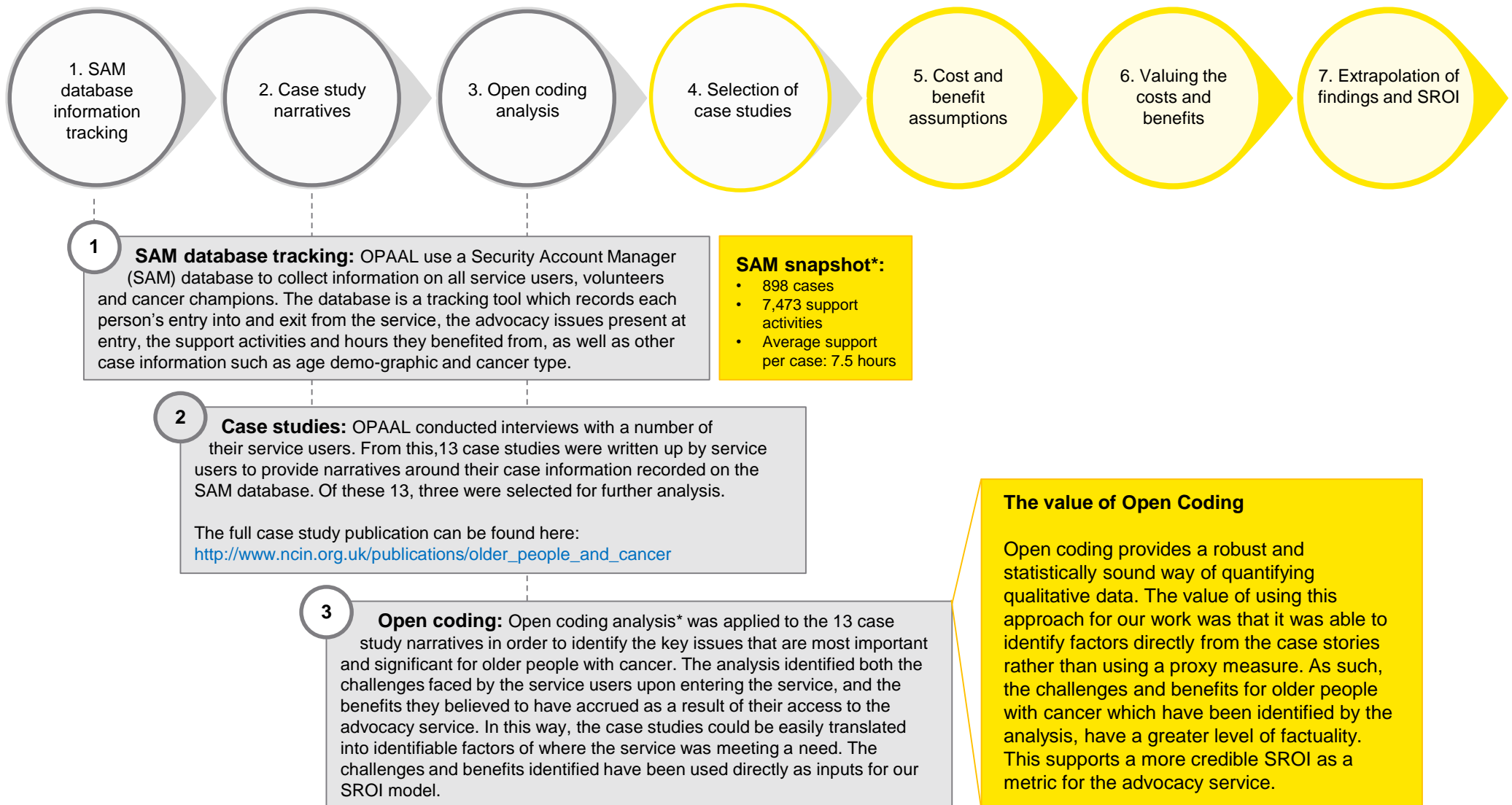
The financial cost of advocacy is small compared to the overall cost of cancer treatment – especially where delivered through volunteers – and hugely increases the value to the patient, as well as releasing some efficiencies for the health system itself, such as reducing delayed transfers of care, which at least partially offsets these costs.

Our analysis shows that the meeting of these non-clinical needs is greatly valued by patients, with a return in terms of financial, economic and social benefits of £6.70 for every one pound spent. This is achieved through the advocacy returning patients voice, choice and ultimately control.

Appendix A: Methodology

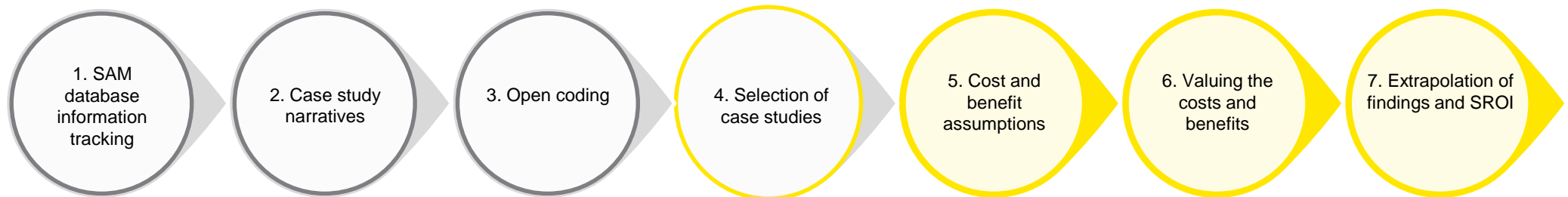
Methodology

We have applied a 7-step methodology to assess the SROI of the advocacy service. The preliminary steps, outlined in grey, are those which were undertaken by Macmillan and OPAAL prior to our engagement. These steps have provided the foundation for, and further enabled, our analysis.



* For the purpose of our work, all figures are based SAM database records from October 2015 and September 2016.

Methodology cont'd



4

Selection of case studies: Out of the 13 case study narratives, three were selected by Macmillan and OPAAL for deeper analysis on the basis that together they cover all needs of a complex case. Two case studies, which for the purpose of this report are referred to as Joan and Diane in the interest of data protection, have been considered as representative of an average complex case, with the third case, Albert (again falsified for the purpose of our work) selected to show the outrebound of uniqueness and complexity. These narratives not only yielded data about what had happened for older people affected by cancer who had been supported by OPAAL; but yielded rich data on the negative things that might have happened in the absence of the support.

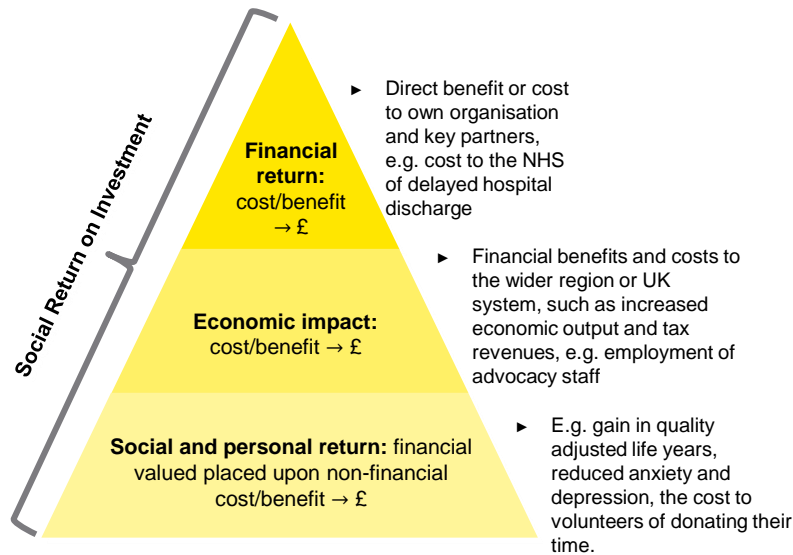
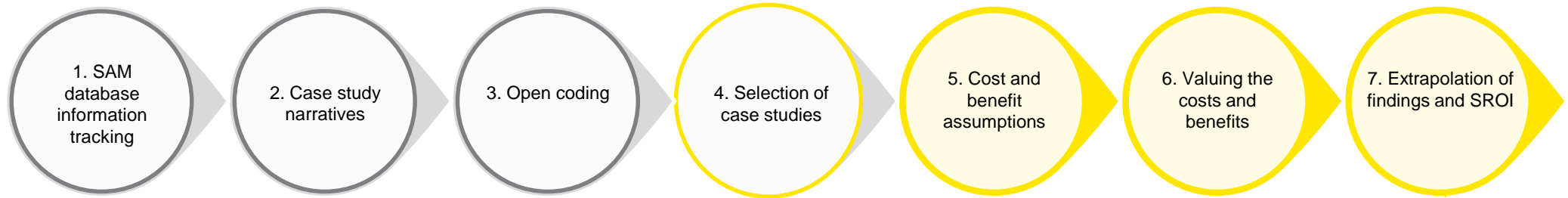
What is a complex case?

Currently OPAAL are defining a 'complex' case as one with three or more issues. This definition draws on academic research, advocacy casework in action and a recent training pack commissioned by OPAAL from Dorset Advocacy (2016) on complex cases.

5

Cost and benefit assumptions: we have worked closely with Macmillan and OPAAL to determine the challenges faced by the three individuals and the corresponding support provided to them via the advocacy service, using the open coding analysis as the basis for this.

Methodology cont'd



This method of calculating SROI is similar to that used by EY to support Macmillan's strategy on their strategy for 'A Cancer Open London'.

6 Valuing the costs and benefits: the costs and benefits have been defined into financial, economic and personal, as demonstrated on the diagram opposite. They can further be attributed to a bearer. The values for the costs and benefits have largely been informed by the Social Value Bank and Manchester New Economy model and further been adjusted to account for factors specific to the individual, such as the time they spent within the service. They have also been adjusted for assumptions we have made through interpretation of the case study narratives, for example, whether they would have received the full value of a specific benefit, or if not, at what percentage.

7 Extension of findings: The costs and benefits of the advocacy service accruing to the three individuals have been extended across the whole cohort of patients included in the SAM database from October 2015 to September 2016 (898 cases), resulting in an overall SROI metric for the service. The extension and categorisation of findings are discussed in greater detail in Section 5.

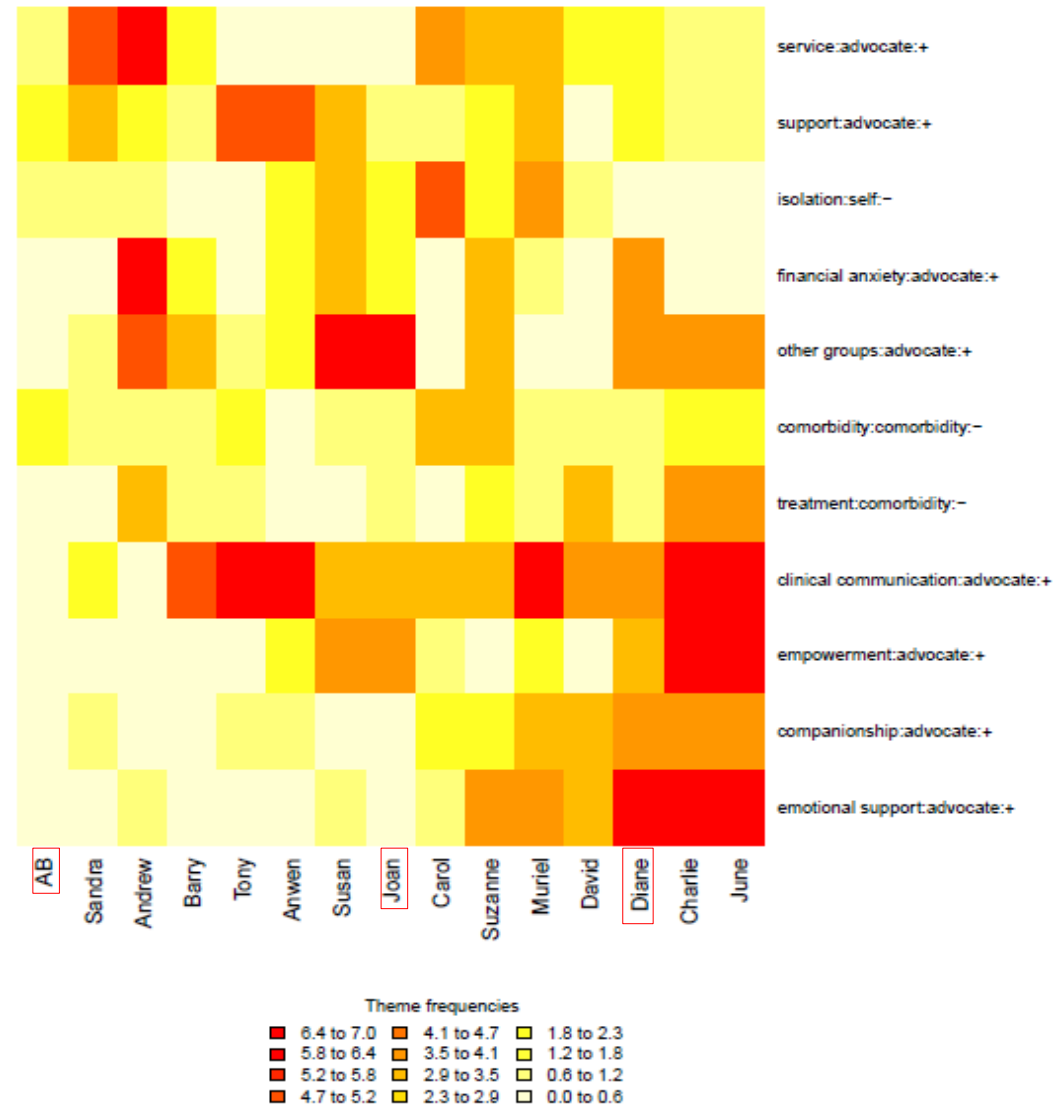
What is Open Coding?

Background and context

- ▶ Open coding has recently become a widely used concept in social science and psychometrics, and is a way of harvesting meaning from bodies of qualitative data, such as patient stories.
- ▶ Coding identifies and compares the themes present in each individual story, enabling a richer understanding of people's experiences.
- ▶ The open coding approach is not only capable of breaking down barriers between the different sources of experience (GP, hospital, community and so on); it is also capable of assigning possible causes to visible effects. This makes it possible to look at the costs of both doing certain things, as well as not doing them.
- ▶ Macmillan, along with their members in User-led Taskforces, worked with Patient Powered Medicine to develop an open coding framework capable of "coding" the content of the case stories.

The heat map opposite has been produced by Patient Powered Medicine to demonstrate the common themes found between the 13 case study narratives. The map shows 11 common themes identified through the open coding analysis. Clinical communication, emotional support and empowerment in particular are significant common themes across the case studies, as they show the highest frequencies, i.e. the number of times they have been mentioned.

The three selected case studies, upon which our work is based, are outlined in red. As shown by the heat map, they collectively cover the whole range of themes across the group.



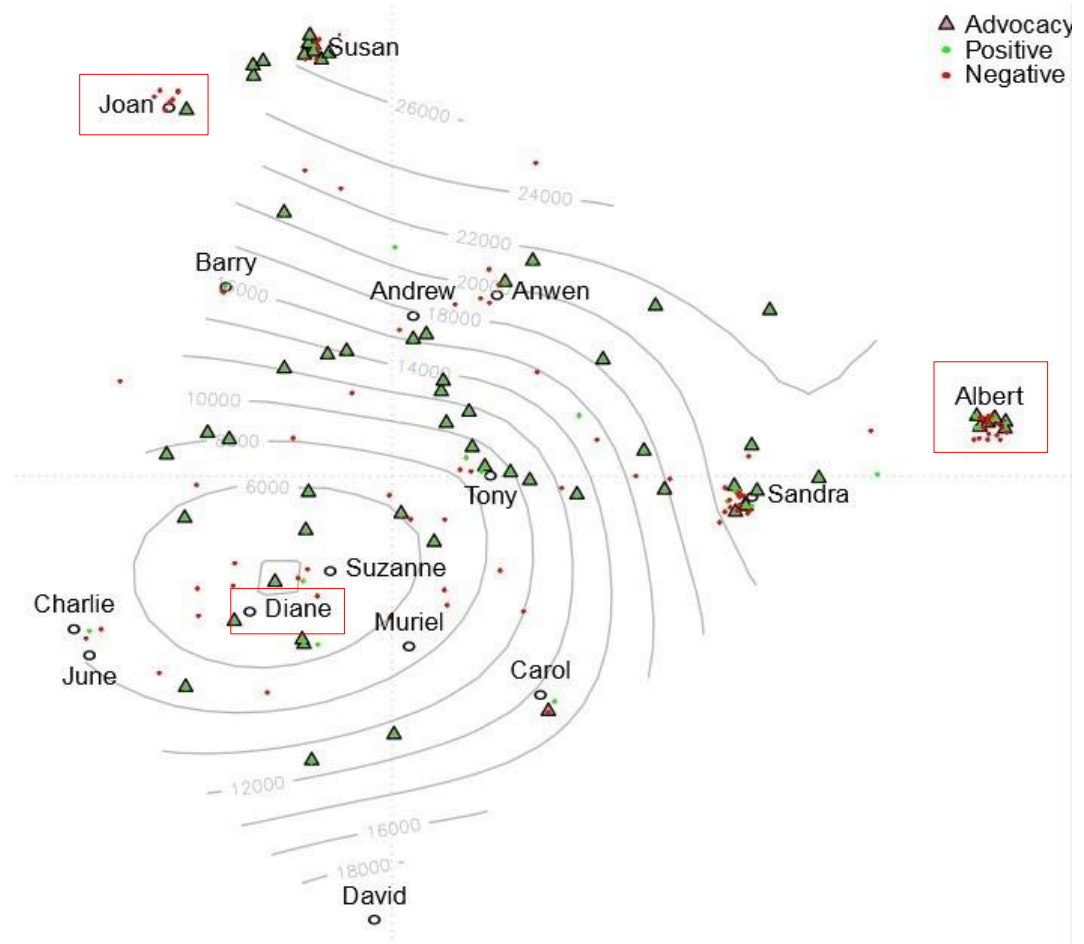
Source: Patient Powered Medicine

Open coding cont'd

The gradient map opposite, also produced by Patient Powered Medicine, is an alternative way to display the challenges of cancer, and the support from advocacy as described in the case studies.

The map shows the dispersion of individuals in terms of the challenges facing them post cancer diagnosis (shown by the red dots) and how they were supported by the advocacy service (shown by the green triangles and green dots). The closer the green triangles are placed to the individual, the more directly supported they were by an offering of the advocacy service.

Our three case studies are again outlined in red and are dispersed widely across the gradient map. As such, they capture the whole range of common themes between the 13 individuals.



Working example

Below is a working demonstration of how we have used the case study narratives and the findings from the open coding analysis in our model. The themes found have been used as model inputs for the costs associated with cancer and the benefits of the advocacy service. The example below is extracted from case study 1, Joan.

Negative impact of cancer

“Because she was having to keep the house warm all the time, Joan was worried about the fuel bills.”

Extract from Joan's case study narrative

| Theme | Frequency (F) | Weighting (W) | F x W |
|---|---------------|---------------|----------|
| challenge of a rural location lacking in strong family ties | 1 | 3 | 3 |
| challenge of a second different cancer episode comorbidity | 1 | 3 | 3 |
| challenge of depression comorbidity | 2 | 3 | 6 |
| challenge of emotional distress | 1 | 3 | 3 |
| challenge of falling through support criteria | 1 | 3 | 3 |
| challenge of financial worries | 1 | 3 | 3 |
| challenge of hospital discharge | 1 | 3 | 3 |
| challenge of inability to prepare food | 1 | 3 | 3 |
| challenge of inability to wash | 1 | 3 | 3 |
| challenge of lack of energy | 1 | 2 | 2 |
| challenge of multiple treatments and tests | 1 | 2 | 2 |
| challenge of social isolation | 2 | 3 | 6 |
| challenge of transport from rural location | 1 | 2 | 2 |
| challenge of waiting for hospital discharge | 1 | 1 | 1 |

Joan's challenges identified by open coding

Person 1 costs

1.1 Cost on a yearly basis

1.1.1 Costs associated with cancer

| |
|--|
| Cost of cancer treatment - Lymphoma initial |
| Delays in hospital discharge |
| Experiential cost of delay in hospital discharge |
| Social exclusion |
| Social cost of depression |
| Financial worries |
| Loss of good overall health |
| Falling through support criteria |
| Transport from rural location |
| Loss of work days for relative |
| Noted not valued |
| Total cost of cancer |

| Type | Bearer | Cost p.a. |
|-----------|--------|------------------|
| Financial | NHS | (57,881) |
| Financial | NHS | (1,750) |
| Social | Person | (1,210) |
| Social | Person | (6,004) |
| Social | Person | (19,651) |
| Social | Person | (8,879) |
| Social | Person | (20,186) |
| Financial | Person | (342) |
| Financial | Person | (300) |
| Economic | Family | (518) |
| n/a | n/a | - |
| | | (116,721) |

* Figure sourced from Social Value Bank 2016

Excerpt from our cost modelling – assignment of indicative costs against identified challenges

Benefits of advocacy

“I told her that some energy companies would provide special tariffs for people undergoing cancer treatment.”

Extract from Joan's case study narrative

| Theme | Frequency (F) | Weighting (W) | F x W |
|--|---------------|---------------|----------|
| advocacy support in terms of empowerment | 3 | 3 | 9 |
| advocacy support in terms of general support | 1 | 2 | 2 |
| advocacy support in terms of liaison with social services | 1 | 3 | 3 |
| advocacy support in terms of planning for the future | 1 | 2 | 2 |
| advocacy support in terms of verbal information | 1 | 3 | 3 |
| advocacy support leads to outcomes in terms of ability to prepare food | 1 | 3 | 3 |
| advocacy support leads to outcomes in terms of ability to wash | 1 | 3 | 3 |
| advocacy support leads to outcomes in terms of empowerment | 1 | 3 | 3 |
| advocacy support leads to outcomes in terms of reduced financial anxiety | 1 | 3 | 3 |
| advocacy support leads to outcomes in terms of reduced heating bills | 1 | 2 | 2 |
| advocacy support leads to outcomes in terms of transport | 1 | 2 | 2 |
| advocacy support of correcting information on medical files | 1 | 3 | 3 |
| advocacy support with accessing support networks outside the NHS system | 6 | 2 | 12 |
| advocacy support with clinical communication | 3 | 2 | 6 |
| advocacy support with financial worries | 1 | 2 | 2 |
| advocacy support with transport | 1 | 3 | 3 |
| advocacy support with verbal information | 2 | 3 | 6 |
| advocacy support with written information | 1 | 3 | 3 |

Advocacy support received by Joan, identified by open coding

Person 1 benefits

2.1 Benefits on a yearly basis

2.1.1 Benefits of advocacy

| |
|--|
| Empowerment / feeling of control in life |
| Support and companionship in piece of family |
| Support in terms of liaison with social services |
| Reduced energy bills |
| Reduced financial anxiety |
| Support with verbal information |
| Support with written information |
| Improved clinical communication |
| Good overall health |
| Transport |
| Experiential benefit of timely discharge |
| Experiential benefit of timely discharge |
| Total benefits of advocacy |

| Type | Bearer | Benefit p.a. |
|-----------|--------|---------------|
| Social | Person | 2,360 |
| Social | Person | 7,036 |
| Social | Person | 2,444 |
| Financial | Person | 900 |
| Social | Person | 1,332 |
| Social | Person | 197 |
| Social | Person | 197 |
| Social | Person | 197 |
| Social | Person | 606 |
| Financial | Person | 150 |
| Social | Person | 691 |
| | | 16,108 |

Excerpt from our benefit modelling – assigned of indicative values of benefits against identified support

Note: This example looks at financial worries as a cost associated with cancer, and relief from financial anxiety as a benefit of the advocacy service. This cost and benefit falls under the theme of "control" - define

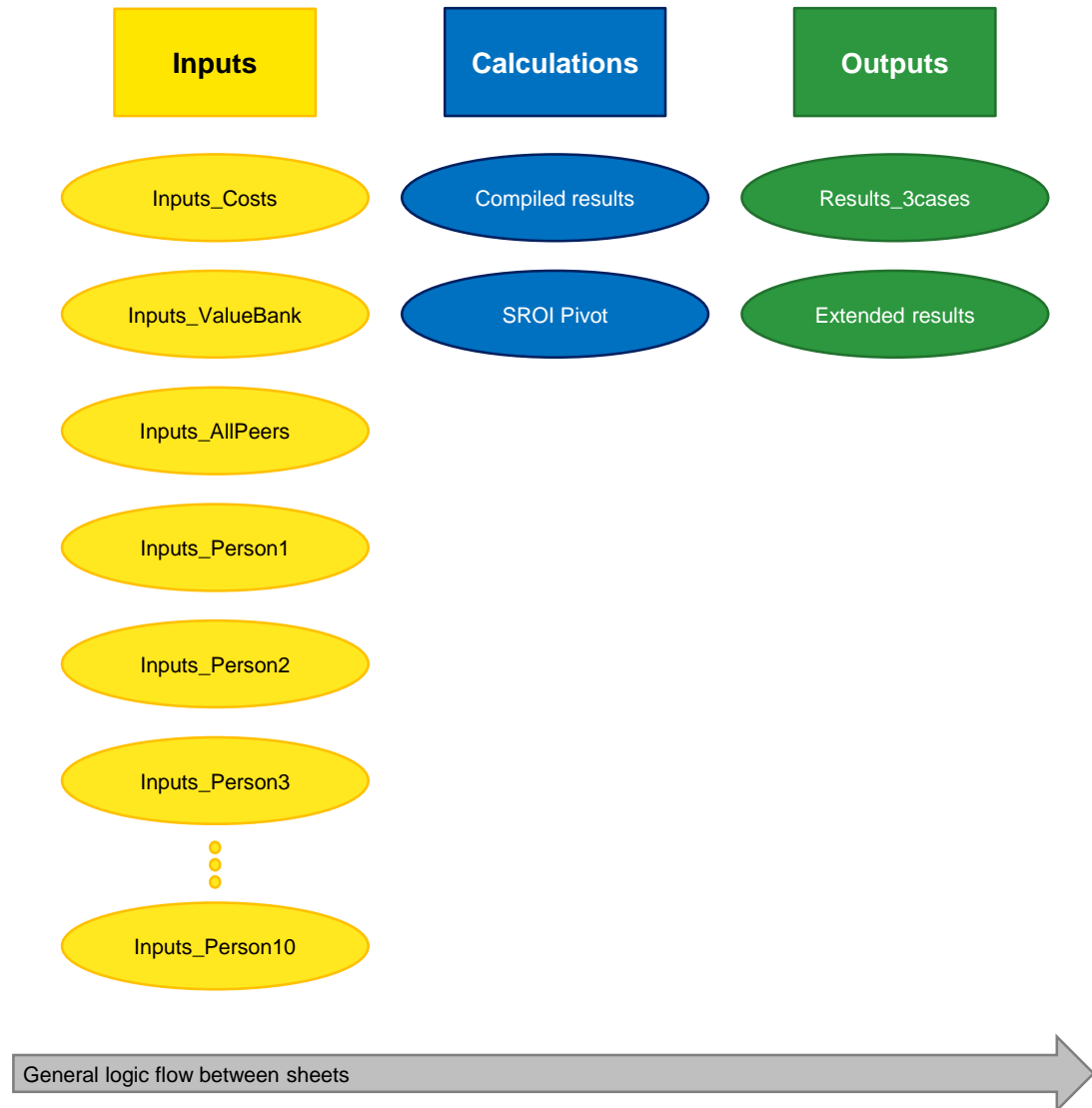
Modelling and interpreting

Model structure

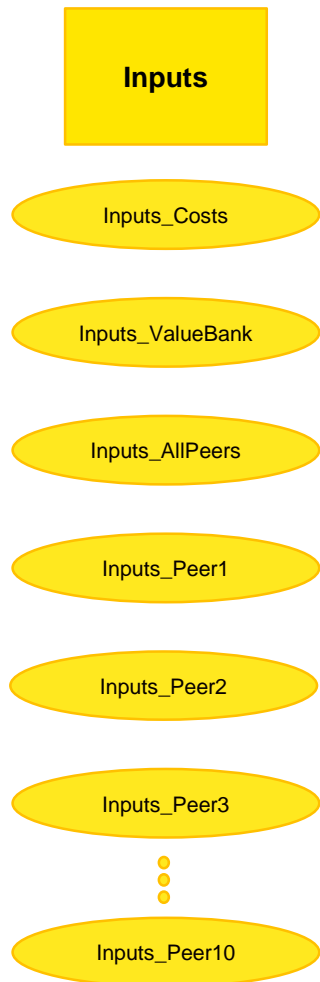
The diagram opposite describes the structure of our model. The purpose of the model is to take the costs associated with cancer, the running costs of the advocacy service, and the benefits derived from the advocacy service, for all three individuals, and apply those costs and benefits to the remainder of the complex case cohort to obtain an SROI for the whole service for one year.

The sections of the model are as follows:

- ▶ **Inputs:** the inputs for the model have been derived largely from three sources: OPAAL financial information, Open Coding analysis, and publicly available data.
 - ▶ *Cost of cancer:* costs associated with cancer per person have been determined using the case story narratives and open coding analysis. The per person / organisation per year costs associated with cancer - including social, economic and financial - have largely been sourced from the Social Value Bank 2016 and the New Economy Model.
 - ▶ *Cost of advocacy service:* per person per year cost of running the advocacy service has been calculated using the figures from OPAAL's three year budget and adjusted for the proportion of time for which the individual has used the service.
 - ▶ *Benefits of advocacy service:* benefits associated with the advocacy service have been determined using the case story narratives and open coding analysis. The per person / organisation per year benefits associated with the advocacy service - including social, economic and financial - have largely been sourced from the Social Value Bank 2016 and the New Economy Model.
- ▶ **Calculations:** the cost and benefit results for up to ten individuals have been consolidated so that they can be easily manipulated to derive SROI calculations for a defined population.
- ▶ **Outputs:** Summary of SROI results for three methods and extended results on a benefit per support hour basis.



Modelling and interpreting: inputs



Inputs_Costs

- ▶ The costs input tab consists of a breakdown of OPAAL's three-year budget for the advocacy service. The budget is broken down into direct revenue costs, central costs, one-off costs¹, and regional partner costs. These costs have been averaged to obtain figures indicative of an annual cost for running the advocacy service. This cost has further been divided by 898 cases² to determine the amount it costs to support one case.
- ▶ The cost per case figure feeds into the Inputs_Peer1-10 tabs in order to calculate the cost of advocacy service per peer per year. The variable costs, i.e. direct revenue costs, and regional partner costs have been adjusted proportionately to the number of support hours received by the peer.

Inputs_ValueBank

- ▶ The Value Bank tab contains the cost and benefit values which feed into the Peer1-10 tabs to calculate the costs associated with cancer and the benefits of the advocacy service.
- ▶ The Value Bank is made up of two sections. The first lists the costs associated with cancer as per the challenges identified from the open coding analysis, e.g. depression, with their attributed values. These values have largely been sourced from the Social Value Bank and the Manchester New Economy Model. Although not mentioned in the case study narratives, we have included the financial cost of cancer treatment within this section, which varies with the each cancer type. The second section follows the same format but lists the benefits derived from the advocacy service, as identified by the open coding analysis, e.g. reduced anxiety. A full list of sources can be found in the Appendix.
- ▶ A number of challenges and/or benefits found by the open coding analysis have not been attributed a value and these have been noted at the end of the worksheet. We view these costs/benefits to have been captured in other identified challenges or benefits and as such they have been excluded to avoid double counting the value.

Inputs_AllPeers

- ▶ The All Peers input tab details information about the peer being analysed - including name, age, location, cancer type, case opening date and case closing date - all sourced from the SAM database. The tab also includes support information such as the number of advocates the peer was supported by, the activities provided, and the number of associated support hours.

Inputs_Peer1-10

- ▶ The model consists of 10 peer input tabs. The first three tabs are reflective of the three case studies (Joan, Albert and Diane). The remaining seven tabs are blank templates which follow an identical format as the first three, and therefore allow for additional case studies to be valued as required.
- ▶ Each peer input tab is set out with a leading summary section detailing peer information e.g. name, age, etc. Beneath this sits the calculations of costs and benefits, firstly the costs associated with cancer and of providing the advocacy service on an annual basis, and secondly, the benefits of the advocacy service on an annual basis.
- ▶ The model is set up so that costs and benefits can be categorised into financial, economic and social, and further able to be assigned to a bearer (i.e. peer, NHS, advocate), allowing users to see what type of costs and benefits are accrued by whom.

Modelling and interpreting: calculations and outputs

Calculations

Compiled results

SROI Pivot Table

Compiled results

- ▶ The compiled results tab simply amalgamates all the information from the Peers 1 -10 input tabs into one place, in order to facilitate the SROI calculation. The results feed into the SROI Pivot Table tab.

SROI Pivot Table

- ▶ The Pivot Table tab allows for the results of the cases to be looked at in a number of ways by cutting the data as desired. For example, it is possible to look at an overall summary of the costs and benefits by theme, by type (e.g. financial) and to which party they accrue to.

Outputs

Results_3 cases

Extended results

Results_3 cases

- ▶ Output tab containing the SROI findings from Joan's, Albert's and Diane's cases.

Extended results

- ▶ Output tab containing the SROI findings extended from Joan's, Albert's and Diane's cases to the remainder of the complex case cohort for one year, on a support by hour basis.

**Appendix B:
SROI model
See separate excel file**

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