

# **The Cancer, Older People and Advocacy (COPA) programme**

## **Mid-term evaluation report**

**TwoCan Associates**

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## **Acknowledgements**

We would like to thank the advocacy staff who kindly agreed to be interviewed for this evaluation. The people we interviewed are listed in Appendix 1. We would also like to thank the staff at OPAAL for their help in shaping the questions, and setting up the interviews.

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# Executive Summary

## Background

The Cancer, Older People and Advocacy (COPA) Programme is expanding the delivery of peer advocacy support to older people affected by cancer (OPABC) in twelve locations in England and one in Wales. The Programme started in May 2014 and will run to March 2017 with funding from the Big Lottery and Macmillan Cancer Support. The aims are to embed and augment good practice, and to establish independent advocacy as an accepted part of the cancer pathway for older people.

Eight organisations were selected for inclusion at this stage of the evaluation to maximise the learning within the resources available. They were: Age Connects Cardiff, Dorset Macmillan Advocacy (delivered jointly by Dorset Advocacy and Help & Care Bournemouth), Sefton Pensioners Advocacy Centre, Knowsley Pensioners Advocacy Information Service, Oxfordshire Advocacy, Independent Community Advocacy Network North and Sandwell Advocacy. The COPA programme is led by OPAAL, the national umbrella group for older people's advocacy organisations around the UK, who provide national project management and oversight.

This report summarises the findings from the interim evaluation, which was carried out 18 months into the three-year project. The aims were to draw out lessons for future roll-out and to reflect on the learning to date in terms of its implications for the second half of the programme.

## Methods

The evaluation involved carrying out telephone interviews with project managers, paid advocates and volunteer co-ordinators from across the selected project partners. The experiences of volunteers were captured via face-to-face interviews conducted by OPAAL. Monitoring data was obtained from the project database.

## Findings

### Lessons learnt about referrals

#### *Obtaining referrals*

Over the past 18 months, all of the project partners have had difficulties in obtaining a sufficient number of appropriate referrals. In particular, there seem to be significant challenges in obtaining referrals from health professionals. Two partners (Dorset Macmillan Advocacy and Sandwell Advocacy) had experienced some success in this area.

In Dorset, this had been working well for some time and the team felt the service was working as they originally intended i.e. providing advocacy support to OPABC during cancer treatment. By way of contrast, other partners were mostly receiving referrals from within their own organisations or externally from other voluntary sector and social care organisations. They reported a sense that these referrals were often inappropriate as the clients were not always in genuine need of advocacy support. The evaluation therefore explored the factors contributing to these differences and the lessons learnt in terms of how best to encourage health professionals to refer their patients.

### ***The need for referrals from health professionals***

Reflecting on whether referrals from health professionals are necessary, most interviewees concluded that this is important, because this is the most effective way to reach OPABC at the time they are receiving treatment. Many concluded that providing advocacy support at this stage is vital because:

- There is currently an unmet need amongst OPABC
- No other cancer services are providing this kind of support – so it's a niche for the COPA service
- Providing advocacy support at this relatively early stage may help to prevent crises at later stages
- Once they are aware of the service, OPABC may self-refer at later stages of the journey if they want further help

Clinical nurse specialists appear to be the best target for engagement because as advocates for patients themselves, they are more in tune with the aims of the cancer advocacy service. GPs have been the hardest group to engage.

### ***'Telling' versus 'selling'***

The strategy that many of the project partners appear to have adopted in order to obtain referrals from health professionals and others, is to publicise the service through leaflets, talks and stalls at local events. This is all about 'telling' people about the service i.e. giving information. This approach has not worked well to date. This is probably for two reasons, firstly advocacy is not well-understood. Secondly, information alone is not enough to change people's behaviour.

The alternative to 'telling' is 'selling', a process of engagement. This involves finding out the needs of the person you're trying to 'sell' the service to and then explaining how the service will meet those needs. This involves answering the important motivational question 'What's in it for me?' for health professionals. It is this approach that has underpinned the success in Dorset and Sandwell.

### ***Establishing working relationships with health professionals***

A key factor in motivating health professionals to refer to the advocacy service is ensuring that the service has credibility and can be trusted. This requires building relationships with individuals, giving them the information they need to be able to judge the quality of the service and establishing working partnerships around the client. The people who seem most effective at building these relationships are peer champions – people who understand the value of the service and have a health professional background.

### ***Which clients are most appropriate and how are they referred***

Many project partners questioned whether all their referrals from voluntary organisations and social care are appropriate, given that many do not seem to require the type of support provided by an advocacy partnership. These clients either need one-off support, or want practical support e.g. help with shopping. Others are at the point of crisis, near to end-of-life or represent complex cases, which may not always be possible to hand over to volunteers. In this scenario, the service seems to be plugging whatever gap exists locally, meeting any and every need. This does not give cancer advocacy a clear identity or purpose. This

makes it more difficult for potential referrers to know when to refer to this service, as opposed to one of the many other types of cancer service that already exist.

By way of contrast, the referrals coming in from health professionals do seem to be people in genuine need of an advocate. In Dorset, the paid advocates have worked with local CNSs to define the needs of people to refer to the service as 'the OPABC who are struggling' for whatever reason, i.e. the people who are vulnerable. This definition works well because:

- This is a group of patients that CNSs are able to easily identify and for whom they already have concerns.
- It avoids defining patients by a specific need and putting them in 'boxes' – e.g. a person with a housing problem, or a financial problem – this means people with multiple and varying needs will be referred to the advocacy service.
- It includes patients at all stages of the cancer journey.

### ***Encouraging self-referrals***

Some OPABC may want advocacy support but may not be referred by health professionals for a number of reasons. Firstly, a patient may appear to be supported by family members, friends or partners, but in reality may be experiencing conflict and need independent advice. Secondly the OPABC may not feel they need advocacy support until post-treatment, when they are no longer in contact with health professionals. In these situations, self-referral may be the only option.

To date there have been few self-referrals. Leaflets do not appear to be effective. In the same way as for health professionals, a form of 'selling' rather than 'telling' involving peer champions may prove to have more of an impact.

### ***How cancer advocacy is distinct from other cancer services***

The messages about cancer advocacy that have been communicated to date may have been confusing. They claim that advocacy does a 'little bit of everything' in terms of the kind of support offered, whilst not actually duplicating what other cancer services do. To people on the outside these messages can be easily misunderstood to mean that advocacy is about 'care co-ordination' or 'signposting'.

Based on the findings, advocacy seems to meeting a very different set of patient needs which include:

- Time – providing support over period of time to help OPABC take in information, consider options and make informed decisions
- Being empowered to make decisions rather than being 'told what to do'
- A person to speak to – rather than more leaflets
- Support at home – rather than having to go to an organisation
- Independent support from someone who has no connection to other services, who can speak up for the client with no conflict of interest

Explaining the way in which cancer advocacy meets this different level of need may be helpful in clarifying how this service is unique.

## Lessons learnt about volunteer recruitment and retention

The project partners have had varying experiences in terms of being able to recruit to the peer advocate role. Some have found it easy and some have found it very challenging.

There was unanimous agreement that the peer advocate role is very demanding and therefore only attractive to a selective group of people. It requires finding older people who have experience of cancer, who are in the right space and time in their personal lives to make a commitment, and who also possess the range of high-level skills necessary for advocacy.

In spite of these challenges, many services were surprised to find they had no difficulty in recruiting the target number of volunteers, who have proven to be of very high-calibre. They linked their success to being able to recruit from an existing pool of volunteers and having a good reputation locally. One of the project partners who had particular difficulty in recruiting volunteers, had limited experience of providing advocacy services before the COPA project.

A major challenge has been that with a limited number of appropriate referrals, it has not always been possible to match advocates to partners very quickly. It has been important to find ways to keep volunteers engaged through ongoing training and support.

In terms of supporting the volunteers in their role, different partner organisations adopt different approaches. In some cases, the paid advocate is responsible for supervision on the basis that they have most experience of casework. In others, a volunteer co-ordinator takes on this role, although they highlighted the importance of taking a course in advocacy supervision to equip them with the relevant skills.

The volunteers also need emotional support and consideration of their welfare given the nature of their role. For example, they may need extra support if their advocacy partner has a terminal diagnosis and then dies. This kind of support is typically provided by the volunteer co-ordinators on an ad hoc basis.

## Lessons learnt about the impact of the service

### ***Impact on clients***

670 OPABC used the advocacy service between May 2014 and October 2015. The majority were aged 55+ (79%) and women (53%). Amongst the clients whose ethnicity had been identified (n=494), 90% were white British, 4% were white (other). Clients from other ethnic groups each contributed to less than 1% of the total.

This evaluation did not involve talking directly with clients. However, a number of staff described how they had witnessed the added-value of *peer* volunteer advocates and their significance to clients. Talking to peers seems to notably enhance the quality of the advocacy relationship.

Similarly, a number of paid advocates identified several challenges for OPABC when they are first diagnosed and undergoing treatment for cancer, which the staff believe underpins the need for COPA at this stage of the cancer journey. The challenges include navigating the health service, managing the emotional impact of a cancer diagnosis, dealing with many different professionals, and not being able to access or make sense of information, especially on the internet.

### ***Impact on volunteers***

A total of 245 advocates were recruited across all project partners between May 2014 and October 2015. The majority were aged 55-84 (54%). Of those identified, most were women (57%), while 35% were men. Among those whose ethnic identity had been identified (n=179), 91% were white British.

In-depth, one-hour, face-to-face interviews with 28 volunteer advocates showed that the majority found the role had met with their expectations. They felt they had developed new skills and increased in confidence, through being well-trained and supported. All wanted to continue in their role except where a change in their personal circumstances made it difficult. They benefited greatly from feeling useful to others and knowing that their work was valued. The main challenge they felt needed addressing was increasing the number of referrals.

## **Lessons learnt about staff management**

### ***Training and support for staff***

The staff reported that the training they had received nationally had been very useful. Some wanted further training in end-of-life care, and had arranged this locally, using the project's local training budget. Some felt well-supported in their role, but others felt they could do with more emotional support to deal with the challenges. They felt project managers might need to be allocated more time to be able to do this more effectively.

### ***Shared learning for project staff***

A number of different approaches have been put in place to support shared learning across the partners. The most beneficial of these seem to be the project managers' quarterly meetings, which the managers feel enable them to share information and learn from each other. Similarly, the mentoring system worked very well, whereby each of the new project partners had a mentor (one of the advocacy organisations that had taken part in the pilot). Many of the interviewees commented on how much they valued and had benefited from the advice and support from their mentoring organisation.

However, some questioned the value of the other shared learning initiatives. A major barrier to their effectiveness is lack of time. Many staff feel they are under-resourced solely in terms of local service delivery, but have also been required to participate in multiple and varied activities at a national level (blog posts, filming and numerous strands of the evaluation). The staff are frequently already working overtime to try to meet targets and objectives, so the extra demands of these activities feel burdensome, rather than supportive. This has meant the other initiatives have met with limited success to date.

### ***Working with Macmillan***

The project partners have had varying experiences in working with Macmillan staff in their local area. Some have been very positive, for example, where Macmillan staff and volunteers have provided introductions to the local cancer community. However, some report that although the advocacy project is funded by Macmillan nationally, local Macmillan staff do not seem to know about the service and not all of them have been supportive. Furthermore, there does not seem to be a mechanism for joining up local Macmillan-funded services to promote cross-referrals, share publicity etc. The culture seems to be competitive rather than collaborative.



### ***Working with OPAAL***

A number of the interviewees reported that they felt well-supported by OPAAL, particularly in overcoming challenges in meeting the project targets. Some felt the package of materials that were made available at the beginning of the project, e.g. the training materials and leaflets, were not appropriate for their organisation. However, they have amended and adapted these to suit their own purposes. They suggested that in future, project partners be offered a template or choice of materials that are more clearly labelled 'for adaptation'.

## **Lessons learnt about project management**

### ***Setting up the service***

The majority of project partners have not found it difficult to set up the service because they have been able to draw on their experience as established advocacy service providers and have employed their learning from setting up other new projects.

### ***Monitoring the service***

Many of the interviewees commented on the limitations of the current online project database, SAM. In particular, they reported that the system is often slow, the process of data entry cumbersome and the reporting system not closely linked with priorities for project monitoring. However, they were grateful that this feedback had already been taken on board, and hoped that the new revised version (in development at the time of the interviews) would be much improved.

Some also questioned whether the numerical targets for referrals were appropriate and suggested they might need to be altered to reflect what happens in practice. Others expressed concern that simple numerical targets did not accurately reflect the amount of effort and work going into the project. As a new service, there are no benchmarks for what success looks like and this may benefit from further reflection.

### ***Resourcing the service***

Many staff reported feeling under-resourced and simply not having 'enough hours in the week' to fulfil all of their responsibilities. This was true for advocates, managers and admin support. This has become more of an issue with all of the time that has been invested in publicising the service with the aim of obtaining greater numbers of referrals. Many reported that they were working more hours than were funded by project.

## **Conclusions & Recommendations**

The main conclusion from the findings of this evaluation is that the model of service is being developed in different ways across the project partners. These differences seem to have arisen partly because of the different kinds of referral routes into the service at each locality, which has meant that the clients present with different kinds of needs. This in turn has implications for client load and the capacity of volunteers to support OPABC.

This variation in how the service is functioning in different areas has implications at a strategic level in terms of describing cancer advocacy to future funders and at a managerial level in terms of how best to staff and structure the service. It also has implications at an operational level in terms of where to prioritise efforts during the remainder of the project in order to increase the number of referrals.

Before any further work is carried out, we recommend that a period of reflection and shared learning takes place to develop a consensus on the optimum service model for cancer advocacy. This will be essential to do first, as this thinking will influence the shape and direction of all future developments.

# Introduction & Background

## 1. Introduction

### About this report

- 1.1 This report summarises the findings from the mid-term evaluation of the Cancer, Older People and Advocacy (COPA) programme. The programme aims to develop peer advocacy services for older people affected by cancer at numerous sites across England and Wales. The evaluation was carried out 18 months into the three-year national project.
- 1.2 There were two main aims to this stage of the evaluation:
  - (a) To draw out any lessons learnt about establishing the advocacy service for older people affected by cancer (OPABC). These will be relevant to any future sites.
  - (b) To reflect on the lessons learnt during the first half of the project and consider whether these have implications for the next 18 months.
- 1.3 This report was written by Kristina Staley from TwoCan Associates, who were commissioned by OPAAL to undertake an independent evaluation of the COPA programme. TwoCan carry out research projects and evaluations, develop policy and guidance, and provide training and support. They help organisations to develop client-centred services and to develop meaningful partnerships that will genuinely make a difference to practice. For further information, please see [www.twocanassociates.co.uk](http://www.twocanassociates.co.uk)

### Terms used

- 1.4 In this report we use the following terms to refer to the individuals involved in the running and delivery of the service.

**Advocate** – a paid member of staff who provides advocacy support to OPABC

**Client** – a person receiving advocacy support via this service

**OPABC** – older person/ people affected by cancer, including patients and carers

**Project manager** – member of staff involved in managing staff and service delivery

**Project partner** – one of the organisations who are a partner in the COPA programme and are currently delivering the advocacy service

**Volunteer/ peer advocate** – a volunteer who provides advocacy support to OPABC and who is an older person and has some experience of cancer themselves

**Volunteer co-ordinator** – a paid member of staff who recruits and supports volunteers

## **2. Background to the COPA programme**

- 2.1 The Cancer, Older People and Advocacy (COPA) Programme is upscaling the delivery of peer advocacy support to OPABC, a service which was successfully piloted during 2012 - 2013. Between May 2014 and March 2017, funding from the Big Lottery and Macmillan Cancer Support is extending the delivery of the service to eleven locations in England and one in Wales. The aims are to embed and augment the good practice developed through the pilot project, and to establish independent advocacy as an accepted part of the cancer pathway for older people.
- 2.2 The COPA advocacy services recruit and train peer volunteers, people who have experience of cancer as a patient or carer, to become independent advocates. The volunteer advocates provide advocacy on a one-to-one basis to people over fifty at any stage of their cancer journey. A professional staff team, including a paid advocate and volunteer co-ordinator, supports and supervises the volunteers. Each service is supported and guided by a Local Cancer Champions Board (LCCB), made up of professionals, patients and carers who have some knowledge and understanding of cancer and an interest in older people's services. Nationally the programme is supported by three boards, The National Cancer Champions Board a Health Professionals Board and the National COPA Management Board.

### **Project partners**

- 2.3 There are thirteen partner organisations delivering the cancer advocacy service as part of the COPA Programme. This includes organisations who took part in the pilot, some of whom are being evaluated by other independent evaluators. Some organisations began in May 2014. Others had a later start date and at the time of this evaluation were still in the setting up stage. The following organisations were therefore selected for inclusion in this evaluation project to maximise the learning within the resources available:
  - Age Connects Cardiff
  - Dorset Macmillan Advocacy – delivered jointly by Dorset Advocacy and Help & Care Bournemouth
  - Sefton Pensioners Advocacy Centre
  - Knowsley Pensioners Advocacy Information Service
  - Oxfordshire Advocacy
  - Independent Community Advocacy Network North
  - Sandwell Advocacy
- 2.4 The COPA programme is led by OPAAL, the national umbrella group for older people's advocacy organisations around the UK ([www.opaal.org.uk](http://www.opaal.org.uk)). They provide national project management and oversight.

### **Main activities to date**

- 2.5 The main activities undertaken by the project partners to date have included:
  - Recruiting staff to develop and run the service including a volunteer co-ordinator, paid advocate and project manager

- Recruiting and training OPABC to become volunteer peer advocates
- Providing support to trained and practicing volunteer peer advocates
- Networking extensively and publicising the service to obtain referrals
- Setting up referral processes
- Matching advocates to partners and providing advocacy support via the paid advocate and volunteers
- Setting up Local Cancer Champions Advisory Boards to advise on project implementation locally and to feed into national development
- Recruiting a suitable local health professional to sit on the National Health Professionals' Board
- Contributing to national publicity e.g. via blogs and advocacy stories
- Contributing and supporting the involvement of clients in films
- Taking part in the evaluation and shared learning activities
- Contributed to research led by the University of Manchester.
- Developed new tools to support their work including, a new set of national Advocacy Standards for COPA.
- Extensively reviewed SAM (the project database) leading to a new system being developed and implemented.

### **Main challenges to date**

2.6 The main challenges to date have been (a) obtaining a sufficient number of appropriate referrals and (b) recruiting and retaining volunteers. Section 4 on the lessons learnt about setting up the service therefore relate to these two topics.

### **3. Methods used in this evaluation**

#### **Monitoring data**

- 3.1 The COPA programme began on 1 May 2014. All project partners have been collecting monitoring data on a project-wide database since this date. This data was collated and analysed at the end of October 2015. It is summarised in Sections 6 and 7 of this report, while the complete dataset is available in Appendix 2.

#### **Qualitative interviews with staff – lessons learned to date**

- 3.2 With the aim of capturing the lessons learned to date, semi-structured telephone interviews were held with 12 staff from the eight project partners included in the evaluation. These staff included project managers, advocates (paid) and volunteer co-ordinators. No staff were interviewed from OPAAL. The interviews were held in October and November 2015. A list of the interviewees can be found in Appendix 1.
- 3.3 The interview questions were agreed with staff from OPAAL. Each interview lasted 45-60 minutes. With the interviewee's permission, the discussion was recorded and later transcribed by the interviewer. The transcripts were analysed to identify key themes and the main points for the interim report. All recordings and transcripts were deleted at the end of the project.
- 3.4 A draft report was sent to all of the interviewees so they could check they were happy with the interpretation of their quotes. Their suggestions for amendments and corrections were included in a second draft. This was sent to OPAAL staff for review and subsequently to all the project managers from all 13 project partner organisations for discussion at one of their management meetings. The same draft was sent to all paid advocates and volunteer co-ordinators and discussed at their annual shared learning event. The reflections and conclusions from all staff were used to write the conclusions and to develop recommendations for action in the second half of the project.

#### **Interviews with volunteer advocates**

- 3.5 OPAAL also conducted a series of in-depth, one hour, face-to-face interviews with volunteer advocates. Twenty-eight volunteer advocates took part in an interview with the OPAAL chief executive. Thirteen were peer advocates working with project partners who have been part of the COPA programme since the original pilot. The other 15 interviewees were volunteering with project partners who became service providers on 1 May 2014. The interviews were carried out between June and September 2015. The complete dataset can be found in Appendix 3 and a summary of the results in the main report.

#### **Mini-projects**

- 3.6 Each project partner is undertaking a mini-project as part of the evaluation to reflect on a specific aspect of their work and draw out the lessons for others. Many are developing new ways of engaging health professionals. Others are focusing on a particular client group e.g. people with learning difficulties, or on assessing impact. At the time of writing this report, none of the mini-projects were ready to report their findings. These will be included in the final evaluation report.

# Lessons learnt about setting up the service

## 4. Obtaining referrals

### Overview

- 4.1 Over the past 18 months, all of the project partners included in this evaluation have had difficulties in obtaining a sufficient number of appropriate referrals to their cancer advocacy service. This was also the experience of the organisations involved in the pilot project. In particular, there seem to be significant challenges in obtaining referrals from health professionals.
- 4.2 At the time of the evaluation interviews, two partners (Dorset Macmillan Advocacy and Sandwell Advocacy) had recently experienced a surge in referrals from health professionals. In Dorset, this has been working well for some time and the team now feel the service is working as they originally intended (See Box A). By way of contrast, the other partners were mostly receiving referrals from within their own organisations or externally from other voluntary sector and social care organisations. They reported a sense that these referrals were often inappropriate as the clients were not always in genuine need of advocacy support. In the remainder of this section, we explore the factors that appear to contribute to these differences and the lessons learnt in terms of how best to encourage health professionals to refer their patients.
- 4.3 We discuss the lessons learnt in relation to the following topics:
- Are referrals from health professionals necessary?
  - Which health professionals are a priority to target and why?
  - ‘Telling’ or ‘selling’? Information or engagement?
  - Which OPABC should be referred to the advocacy service?
  - Establishing credibility and trust, building relationships – what works?
  - How is cancer advocacy distinct from other cancer services?
  - Encouraging self-referrals – what works?

## **Box A: The experience of the paid advocate at Dorset Macmillan Advocacy – a successful approach to obtaining referrals from clinical nurse specialists**

### **Where did you start?**

I first did some research on the role of CNSs. I found their job description and looked at the details to see how our advocacy service could support them to do their job. I was looking to see where our goals were aligned and where there might be cross-overs in what we do.

### **How did you find the CNSs in your area?**

I found the nurses by searching the internet and finding their names and contact details. I emailed them and if they didn't respond, I tried someone else or I called and got them on the phone and arranged to meet them one-to-one. Sometimes they said 'There are three of us – come and meet us all'. And I did whatever suited them best. Once I had met with a few, I could say I had met so-and-so last month etc. and that probably helped.

### **What did you say to them when you met them?**

After introducing myself and the service, I started talking *about them*, saying things like 'I've had a look at your job description and I can't believe one person is expected to do all that' and steered the conversation towards how we might be able to *help them* to support their patients. I asked about their experiences and who were the patients they were worried about. They told me that they were most worried about the people who either phone a lot when they feel unable to meet all those requests for help – or they worry about the people who never phone, because they don't know what's going on for those patients.

I help the CNSs understand who it is they need to refer by talking about time. What we've got, that they haven't got, is time. So if they see that someone is struggling and they'd like to give them more time but aren't able to, that's often the point to refer the patient to us.

As well as giving them a brief explanation of how the service works, I make sure to emphasise how we ensure the quality of what we do, explaining how the volunteers are screened, trained to professional standards and supervised on an ongoing basis.

Most often the goals of the CNS and the patient are aligned but we make it clear that we are independent advocates supporting the patient to have his or her voice heard. Our experience so far is that CNSs appreciate that and already act according to the patient's wishes, offering information so that individuals can make the decision that suits them best. Where extra support is needed, it's usually around an extra pair of ears, extra time to process information or around access to new services.

### **How do you work with the nurses after a referral?**

Once they've made a referral, I make sure to keep a dialogue going with them, so they don't feel excluded. This is obviously dependent on the patient consenting to this communication, but so far all of our clients have had good relationships with their CNSs and are keen for us to be able to communicate on their behalf, usually to clarify details or to help build a better narrative around their cancer journey.

It's important to respect the fact that health professionals have a sense of ownership



around their patients – they have a duty of care towards them. So they don't want to refer to a service that excludes them.

Maintaining communication helps us and the CNSs feel that we are all working alongside the patient. We talk about what's happening, appointments etc and what the person's needs are. Everyone gains from that. From the CNS' point of view, there's no sense of handing over the patient to someone else – the advocate can support the nurse to support the patient, whilst remaining focused on the patient's needs and wishes.

With the patient I saw today, I phoned the nurse before going with him to hospital and asked if there was anything she thought I should be aware of or wanted to find out. She also wanted me to email her to say how things went. So she feels she's still got ownership - control and responsibility for that patient. The nurses are generally very holistic and caring.

## Are referrals from health professionals necessary?

- 4.4 A number of the current advocacy services are based within a voluntary organisation with a wider remit e.g. Age UK. This means they receive many internal referrals, which they report as working well. Others have secured referrals through other local voluntary sector organisations.

We have a hospital discharge service that visits people on discharge, and performs simple tasks like getting the shopping, meal prepping etc. If that person has got a cancer diagnosis they are referred to us - which has worked really well. **Advocate**

The bulk of our referrals come through other charities because we had good links with the voluntary sector which made it easier to explain the service... we either reinforced relationships we already had or built better relationships with people only had loose contact before. Referral rates have been good but I would prefer it to be higher.

**Project manager**

- 4.5 Given the long-term challenges there have been around obtaining referrals via the health service, one of the issues discussed with interviewees was whether it would be worth considering developing another strategy, avoiding the need to engage health professionals altogether. Some interviewees thought that focusing on the voluntary and social care sectors might help to achieve the target number of referrals. However, others questioned whether this would deliver appropriate clients (see also 4.18).

The people who need advocacy might not have the energy or confidence to go to another service or another voluntary organisation. Those are the people who need our service most – we might miss those people if we ignore the health sector. **Advocate**

- 4.6 There were two further reasons interviewees thought that it important to continue to aim for referrals from health professionals. The first was some people's views of the purpose and unique selling point of the service – supporting OPABC in making treatment decisions. A number of interviewees highlighted the unmet need for this kind of support.

We need to keep going into the hospitals because that's where we're needed... we're the one service that people with cancer don't already have... OPABC should have advocates to go to meetings with them, so that when they walk away from the appointment, they've got notes and know what they are doing and are clear about their treatment. There must be so many wasted appointments with older people who find it difficult to remember, not necessarily because they've got dementia, but because people get in a muddle because they often aren't given clear information. Hospitals need this service to make sure the communication from their very-pushed professional staff is effective. The advocate makes it effective. **Project manager**

Often people are not able to take the information in during a hospital appointment. They can't get beyond the cancer word – their emotional response is overwhelming. Cancer advocacy can help them understand their diagnosis and their prognosis so they can make better decisions about their future – without being blinded by the word cancer. **Advocate**

I had a client who had a hearing impairment and the hospital was ringing to say the date of her appointment had changed, and then sending letters where the language used was completely inaccessible – it talked about DNA which we later worked out was ‘do not attend’ – she can’t read anyway. She needed support from an advocate to understand what the hospital was saying. **Advocate**

- 4.7 The second reason for targeting health professionals was to try to get referrals at an earlier stage of the cancer journey. Some advocates believed that if their clients had received support earlier on, these patients might have avoided developing serious mental health problems at a later stage. This would be a better experience for everyone involved.

Ideally we’d be working with OPABC at the point of diagnosis and providing a supportive relationship to enable them to self-advocate long enough and effectively enough to have effective symptom control. We would introduce them to other support networks so as to enrich their lives and improve their quality of life throughout their cancer journey. **Advocate**

- 4.8 As a result of receiving referrals from other agencies, some advocates found that their clients were being referred after having reached crisis point, when the OPABC required intensive and urgent care:

Some referrals come quite late and many of our clients have mental health problems, even though they didn’t have a history of mental illness before their cancer diagnosis. People are sometimes traumatised by their diagnosis and treatment. The psychosocial needs of these people are not being met, so they become increasingly isolated, lose confidence and become institutionalised in their own home. The idea of building up an empowering advocacy relationship at that point has gone out the window. We’re down to safeguarding and crisis management, often with people at the end of life. Then we’re just making sure the person is not at risk and not dying alone. **Advocate**

### **Which health professionals are a priority to target and why?**

- 4.9 Some interviewees felt there had not been sufficient clarity at the beginning of the project about which health professionals to target for referrals and why. Based on their collective experience to date, many concluded that the main target should be the clinical nurse specialists (CNSs), because as advocates for patients themselves, CNSs are most in tune with the aims of the cancer advocacy service. CNSs are also in contact with OPABC at the point of diagnosis, and in carrying out holistic needs assessments are more likely to be in a position to identify people in need of advocacy than either hospital consultants or GPs.

We did our own prioritising. We already knew it was difficult for GPs, but at the shared learning event, I took home the fact to prioritise nurses more. So since January this year we’ve prioritised nurses. Nurses are now our major referrer – although we’re not getting enough referrals, 50% of our referrals come from CNSs. **Advocate**

- 4.10 A number of project partners have made the decision to stop targeting GPs because they are such a difficult group to engage and because there have been so few referrals from GPs to date.

We've given up on GPs. We can't break the culture. The amount of time and effort it would take to generate referrals would not be a good use of our time. **Advocate**

### **'Telling' or 'selling'? Information or engagement?**

- 4.11 The strategy that many of the project partners appear to have adopted in order to obtain referrals is to publicise the service through leaflets, talks and stalls at local events. This is all about 'telling' people about the service i.e. giving information. This approach has not worked well to date. This is probably for two reasons, firstly advocacy is not well-understood. Secondly, information alone is not enough to change behaviour.

- 4.12 As one of the interviewees concluded, because advocacy is a misunderstood term for many people, simply raising awareness of a new advocacy service doesn't help people know whether they would want to use it, or for health professionals to know whether they would want to refer their patients.

If we were setting up a new nail bar for example, then leafleting everybody would probably work. People would know what we were doing and whether they needed us. They'd give us a go to see whether we're any good. But with advocacy, this kind of publicity just isn't enough. **Advocate**

- 4.13 Recognising this problem, some partners have started work on rewriting their leaflets trying to give a clearer explanation of what the service does, providing illustrations of how advocacy has already helped OPABC. Some interviewees report that it is sometimes easier to explain what advocacy *doesn't* do. However, given the nature of advocacy, this may be hindering rather than helping, creating greater confusion. The messages seem to become '*We help people with their finances, but we're not a benefits service. We provide emotional support, but we're not a support group. We go with people to their hospital appointments, but we're not a befriending service. We support people in crisis, but we don't provide urgent care. We help people understand their treatment options, but we're not an information service*'. These kinds of messages may make it difficult for health professionals to know which patients to refer (see 4.18-19) and to understand precisely how the advocacy service is distinct from other cancer services (see 4.31- 32). We discuss alternative approaches that may bring greater clarity below (see 4.21-23 and 4.34).

- 4.14 In some partner organisations, the failure of information-giving has been assumed to be the result of health professionals 'forgetting' what they've heard or losing the leaflet amongst 'piles of papers'. It is then assumed that what's needed is to repeat the information '*We need to flood all the GP practices with leaflets again – we need to keep reminding them*'. Based on the observations to date, it is not clear that this repeat approach will be any more successful than the first, and that a different strategy may be required.

4.15 The second problem is that simply giving health professionals information is not enough to change their practice. Making referrals requires them to change their behaviour, which also means giving them the motivation to want to change and removing any psychological or practical barriers to doing something different. By way of analogy, it is often not enough to tell people about the benefits of ‘five-a-day’ to make them change their diet. The limitations of simply ‘telling’ people may explain the experience of many advocacy staff, who report having given talks that have been enthusiastically received by health professionals, but then haven’t had any further contact.

A GP said after I had given a talk ‘You must be inundated!’ Every single health professional I’ve spoken to can think of a patient who would benefit – but then they don’t give us any referrals! **Advocate**

4.16 The alternative to ‘telling’ is ‘selling’, a process of engagement. This involves finding out the needs of the person you’re trying to ‘sell’ the service to and then explaining how the service will meet those needs. From the point of view of the health professional thinking about whether to make referral it’s answering the important motivational question ‘What’s in it for me?’ It is this approach that has underpinned the success in Dorset and Sandwell, as the paid advocates from those services describe (See also Box A):

I approach the CNSs individually, making sure I’m sensitive to their needs and have a clear understanding of their role. I explain how I can help them. It a basic sales technique – I’m asking ‘What do you need?’ so I can sell them a solution to their problems – rather than saying ‘I’ve got this. I want to convince you it’s really good’.

**Advocate (Dorset)**

I’ve worked with Macmillan teams and CNS teams in a previous role so I’m well aware of the issues they face, what they have to do and what they are finding difficult and I know how we can help them to achieve what they need to do. As well as explaining advocacy and handing out referral pads, I talk about this in my presentations to groups of nurses. I also meet regularly with nurses individually and talk about the pressures on them and their holistic and well-being approach. I know that to just sit and listen to someone is a luxury nurses can’t do, but that’s where we can make a positive contribution. **Advocate (Sandwell)**

4.17 A number of the mini-projects (see 3.6) are looking to develop a similar engagement strategy to obtain referrals from other health professionals including District Nurses and a CNS specialising in care for people with learning difficulties. At the time of the evaluation interviews, this work was ongoing.

### **Which OPABC should be referred to the advocacy service?**

4.18 The majority of the project partners are receiving referrals and are able to help those individuals, but question whether these clients are the most appropriate, given that many do not require the support that’s characteristic of an advocacy partnership. These clients fall into the category of either needing one-off support, or wanting practical support e.g. help with shopping. It seems that sometimes whoever has

referred the client has not understood what an advocate does. This can also mean that the client has mismatched expectations.

We're getting a lot of clients at the end of life almost at crisis point, or people early on who want someone to talk to because they are frightened at the diagnosis – but not really people with advocacy issues. Our lines can get blurred – we go to medical appointments and sit while they have chemo and can make enquiries while we're there about meds, so that's advocacy, but mostly it's about sitting for a few hours and getting to know them. Then there's an expectation we can do shopping and provide transport – we have to be clear we don't offer that and give them the contacts instead. **Advocate**

- 4.19 Some project partners had begun to think there might not be a need to support clients with treatment decisions given that so few of their current clients had requested this kind of support. They thought there were greater needs at other stages. However, this experience might reflect the source of the referral rather than an absence of need (see 4.4 - 5).
- 4.20 It can also feel like the advocacy service is 'joining up the dots', meeting the various needs of OPABC who are not sure where else to go or don't have access to the service they need in their local area. The service then seems to be plugging whatever gap exists locally, meeting any and every need. This does not give it a clear identity or purpose. This again makes it more difficult for potential referrers to know when to refer to the advocacy service as opposed to any other type of cancer support.

With the internal referrals or referrals from the voluntary sector, the staff don't understand what advocacy is, so yes the client they refer has cancer, but all that person really wants is the telephone numbers of 2 or 3 gardeners. **Project manager**

- 4.21 By way of contrast, the referrals coming in from health professionals at Dorset Macmillan Advocacy do seem to be people in genuine need of an advocate. The paid advocates there have worked with the CNSs to define the needs of people to refer to the service as 'the OPABC who are struggling' for whatever reason, i.e. the people who are vulnerable:

Most CNSs come across patients where they feel uncomfortable at the end of the appointment, because they feel like that person is struggling, which leaves the nurses with a worry about what they can do to provide extra support, because they have limited capacity. Now the CNSs have got the advocacy service to turn to and feel confident that something more will be done for that patient. **Advocate**

- 4.22 This definition of 'the people who are struggling' works well because:
- This is a group of patients that CNSs are able to easily identify and for whom they already have concerns.
  - It avoids defining patients by a specific need and putting them in 'boxes' – e.g. a person with a housing problem, or a financial problem (see 4.32) – this means people with multiple and varying needs will be referred to the advocacy service.

- It includes patients at all stages of the cancer journey.

4.23 To date the OPABC who have been referred by CNSs based on these criteria include:

- People with a mental health problem
- People with learning difficulties
- People with communication problems – a hearing or visual impairment
- A woman whose husband was unsupportive who was feeling very alone
- A patient whose carer was speaking on their behalf
- People who don't respond to letters or phone calls from the hospital

4.24 The triggers for a referral are therefore varied and depend on the individual's circumstances. It's whatever makes the CNS feel concerned about that patient and may be a symptom of a wider problem:

If someone is struggling to work out how to get to their radiography appointments, that's symptomatic of problems in other areas and when go to see them, we can work out where else they are struggling and then help. **Advocate**

4.25 The current level of demand in Dorset and Sandwell is raising issues about the capacity of the service, which may become more challenging if they were to start receiving referrals from all the CNSs in the local area. At the time of the interviews, they were receiving 2-3 referrals a week. Further thought will need to be given as to how to respond, particularly given the current climate in the NHS and social care services.

With the continuing reform of health there may be an avalanche in terms of need – it's not getting any better and many more vulnerable people may fall through the net. We've seen safeguarding issues go through roof and I don't see that changing. We need to be sure we can deliver on what we promise or the health professionals will stop referring - nor can we start creating long waiting lists. **Advocate**

### **Establishing credibility and trust, building relationships – what works?**

4.26 The other key factor in motivating health professionals to refer to the advocacy service is ensuring that the service has credibility and can be trusted. This requires building relationships with individuals, giving them the information they need to be able to judge the quality of the service and establishing working partnerships around the client.

Why would a health professional want to recommend a service they've never heard of, that's not got a track record, why would they send their patients to us? I wouldn't use a garage for my car that had never had a customer. It's a huge expectation they will refer, we need to more astute about that. **Volunteer co-ordinator**

4.27 One of the biggest challenges the advocacy staff are facing is making any in-road into the health service, when they get no response to emails, leafleting and calls.

The strategy that appears to be in use is to try to access the cancer service leads locally and to try to set up a talk to a group of professionals. In Dorset, this approach has been complemented by emailing individual nurses on the ground and asking to see them on a one-to-one basis (see Box A). This provides a means of developing relationships with individuals and having a more informal discussion about the service. Thus far this approach has met with more success – perhaps because again it's a process of engagement rather than information-giving.

- 4.28 It also seems important to work with 'peer champions' of the service. In the same way that peer advocates have power in a relationship with partners that's different to relationships with paid advocates, other health professionals have the power to influence their peers. It is of note that in both areas where the advocacy service is getting referrals from health professionals, the paid advocate either has a health professional background themselves, or had an existing relationship with the CNSs.

It's about building connections and personal relationships. **Advocate**

- 4.29 Other project staff who didn't have these connections at the beginning have found other ways and means of creating them, employing the same principle:

I happen to have a mate who's very senior in the local strategic partnership networks – she told me about a cancer commissioning event last week and she emailed her colleagues so I was able to attend. I wouldn't have got in there if I didn't have a friend who was very powerful in that network – that was a really important lesson. **Advocate**

If you haven't personal or professional connections with the health service yourself you can make use of other people's. We got a meeting with the chair of the CCG – because someone on our local champion's board who's an advocate with us, sits on a patient partnership forum and nobbled this guy at another meeting. It was the advocate's initiative that got us that meeting. **Advocate**

We have good relationship with the lead cancer nurse locally. Our Macmillan service development manager helped with that. She's an ex-nurse herself and they're very chummy. The lead nurse organises meetings of smaller groups on the wards once a month, where the nurses get together and invite someone from outside to hear about something that might improve their practice. It's worked well to take one of our volunteers along. She's a retired nurse with 48 years in nursing and she's used the advocacy service herself. It's been very powerful having her come along and talk to people – she has a unique perspective - more powerful than a film or a manager or paid advocate speaking. **Advocate**

I had a meeting with district nurse because she was a friend. That's the only way I could do it. It was done very informally over a cup of coffee. There was no pressure, It was in her own time, she couldn't have possibly done it during work time. Shae said 'It sounds fabulous, come and speak to all the other nurses'. **Advocate**

- 4.30 The feedback from health professionals in the pilot project included concerns about whether the volunteer advocates would act professionally, maintaining boundaries and avoiding giving advice about treatment based on their own limited experience. These issues have emerged again in the current programme, based on feedback



from referring CNSs and from one of the mini-research projects. What helps the health professionals feel they can trust the service is to know that the volunteers are screened and selected, that they receive extensive training and continuous supervision. It is not clear whether all the partner organisations include this information in their presentations to health professionals.

- 4.31 In Dorset, the working relationships with CNSs have evolved over time. It has developed into a partnership around the client. This gives the nurses confidence in the advocacy service, and brings important benefits to the advocates.

By working in partnership with the CNSs, I'm not taking patients away from them. They have a strong sense of responsibility and naturally feel reluctant to hand their patients over to an unknown service. If we work together, the nurses feel included and more confident in what we're doing. There's a dialogue, openness and transparency - which feels like a joined-up piece of work supporting the individual. It's really useful for me because often the OPABC doesn't have all the information about their diagnosis or their choices. With the partner's permission, you can have those conversations with the nurse and get access to more information than you might have got otherwise. After I've seen a client, I can also update the nurse on anything the individual wishes me to pass on – so then she feels reassured that her patient is being well-supported. **Advocate**

### **How is cancer advocacy distinct from other cancer services?**

- 4.32 As described above (see 4.13), the messages about advocacy to date may have been confusing, as it seems do a 'little bit of everything' whilst not actually duplicating what other cancer services do. To people on the outside these messages can be easily misunderstood to mean that advocacy is about 'care co-ordination' or 'signposting'.
- 4.33 The current culture surrounding cancer services is to define patients' needs in relation to specific problems and to develop services that meet a single need, for example recognition that OPABC have financial difficulties results in the development of a welfare benefits service. It is very hard to switch people out of this mind-set. As soon as advocacy is described as addressing any of the well-known problems, people want to place advocacy into one of the existing service siloes. This is another barrier to understanding advocacy, for referrers as well as for the providers of other cancer services, who might feel threatened by this new service.
- 4.34 Based on the findings from the pilot and this mid-term evaluation, advocacy seems to be meeting a very different set of patient needs which include:
- Time – providing support over period of time to help OPABC take in information, consider options and make informed decisions
  - Being empowered to make decisions rather than being 'told what to do'
  - A person to speak to – rather than more leaflets
  - Support at home – rather than having to go to an organisation

- Independent support from someone who has no connection to other services, who can speak up for the client without any conflict of interest

4.35 Our sense is that communication with potential referrers and other services has so far focused on finding ways to get them to understand what advocacy is and how it is different from what they might be doing. This might be difficult for people to hear, because they think about patient needs in a very different way. On this basis, it might be more effective to develop a ‘need to know’ approach. What is it that other stakeholders need to know to make this work? This may be different to what advocacy practitioners think they ought to understand. Furthermore, it seems that people only really ‘get’ advocacy, once they have experienced it (see 4.40), because its subtleties can be hard to describe. A deeper understanding of advocacy may therefore come at a later stage, once people have seen it in action and experienced or seen its benefits— whether that’s a health professional or a patient.

### Encouraging self-referrals – what works?

4.36 Another potential route for referrals is via clients referring themselves to the service. If health professionals were referring every patient they deemed to be in need of advocacy, it might be argued that encouraging self-referrals may be less important. However, there are at least two situations when health professionals may not be in a position to identify a person in need. Firstly, a patient may appear to be supported by family members, friends or partners, but in reality may be experiencing conflict. For example in the pilot project, one of the clients who self-referred required an advocate to help her make the decision to refuse treatment, when the consultant, nurse and her daughter all seemed to be putting pressure on her to go ahead. With a supportive daughter accompanying her mother to all her appointments, the health professional may not have recognised there was any cause for concern. One of the paid advocates described a similar example:

One of our trained volunteers asked for an advocate when she became unwell again. She understood how it would make a difference and avoided hugely risky surgery as a result. During the appointment to discuss her treatment, the consultant was offering the gold standard of lung surgery and briefly mentioned ablation. The advocate stopped the discussion and asked the client ‘What do you want? What is this ablation?’ The client later reported that up until then she felt she was being bullied into accepting the gold standard but because she had the advocate with her, she was able to stand her corner and assess her own health and chose to go for the ablation. She was an articulate, well-educated person but advocacy made all the difference to her, though she might not have been someone we thought was in need. **Advocate**

4.37 The second situation where an OPABC may need advocacy support is post-treatment, when patients often report feeling abandoned by the health service and are still needing to deal with the long-term effects of their treatment. At this stage in the cancer journey, there will be no health professional in contact with the patient to detect whether people are struggling. In situations like this, self-referral is the only option.

4.38 However, the experience to date of many of the current advocacy services is that they get limited numbers of self-referrals. Again, this might be explained by a strategy based on informing people about advocacy, rather than approaches based on engaging them. For example, a number of the project staff described ‘flooding the pharmacies, libraries, GP waiting rooms etc with leaflets, but not having a single referral where the client stated ‘I picked up your leaflet...’ One interviewee concluded:

Leaflets don’t work. The sort of person who picks up a leaflet and then phones and says ‘This is for me’ is the sort of person who doesn’t need advocacy. **Advocate**

4.39 Others have concluded that the leaflet is only as useful as the person handing it over. Given the fact that health professionals and staff in other voluntary sector and social care organisations don’t always have a good understanding of advocacy, they may not be doing this very effectively:

We had clinical support person, a triage person, employed at the Macmillan cancer centre who said she would introduce the service, but then told us that the patients she approached weren’t interested. We don’t know if the language she was using was overly complicated and if she was using the word advocacy which may have put people off. But if I’m able to meet the potential client myself, then 9 times out of 10, I will be able to encourage them to use the service if there is a need for it. **Advocate**

4.40 Again, some of the project partners have decided to respond to this issue by rewriting the leaflet using concrete examples of how advocacy has helped previous clients. It is not clear whether this is the information that patients ‘need to know’ (4.34) to understand if the service is for them. It may be valuable to work with a group of patients to review a prototype and discuss with them what information would be most useful.

4.41 All the same issues that were discussed in relation to health professionals will also apply here. Firstly, simply giving people information may not be enough for them to understand whether the service is what they want and need. Patients will have the same preconceptions about what services do and may find it hard to hear how advocacy is different:

Even a well-written leaflet might not do the job. An OPABC might be uncertain about a volunteer coming into their lives, unless a trusted health professional or social worker has made the referral. I find that with the clients that have been referred to me, even after a gateway call and a call from me, they still don’t understand what I do, until I’ve gone to meet them and have spoken to them. I have to work through that each time, then you see the light go on, ‘Oh so you’re not from Macmillan, you’re not from social services, you’re here to listen to me’. **Advocate**

4.42 Similarly, passing information via ‘peer champions’ may be an important way to get the information heard. For example, having a volunteer advocate in the waiting room, talking to people on a one-to-one basis and handing out leaflets might prove very effective. Publishing clients’ stories in local press and through radio might also engage patients in a different way. Finding strategies to support ‘word of mouth’ referrals might be more effective than finding different ways to present the written information.

## 5. Volunteer recruitment and retention

### Overview

- 5.1 The project partners have had varying experiences in terms of being able to recruit to the peer advocate role. Some have found it easy and some have found it very challenging. In this section, we discuss the factors that might have contributed to these differences.
- 5.2 Some organisations have also faced occasional challenges in retaining volunteers. With a limited number of appropriate referrals, they have not always been able to match advocates to partners very quickly. However, they have gained considerable experience in training and supporting the volunteers, providing important lessons for any future service development.
- 5.3 In the remainder of this section, we discuss the lessons learnt about recruitment and retention of volunteers under the following headings:
  - Factors influencing the recruitment of peer advocates
  - Training and induction
  - Ongoing supervision and support

### Factors influencing the recruitment of peer advocates

- 5.4 There was unanimous agreement amongst all the interviewees that the peer advocate role is a demanding role and is therefore only attractive to a selective group of people. It requires finding older people who have experience of cancer, who are in the right place emotionally and in their personal lives to make a commitment, and who also possess the range of high-level skills necessary for advocacy.

We're looking for quite rare individuals, who although they have had personal experience of cancer, are able to compartmentalise their experience enough to offer support for others. Advocacy also requires a lot of high-level communication and support skills – it's like looking for needle in a haystack! **Project manager**

I've had over 20 people make enquiries, but then don't follow through. They may still be having the emotional side effects and lack confidence. They may want to do it to give something back, but making that first step after cancer is huge. **Volunteer co-ordinator**

We're looking for very special people. **Volunteer co-ordinator**

- 5.5 In spite of these challenges, many of the services were pleasantly surprised to find they had no difficulty in recruiting the target number of volunteers who have proven to be of very high-calibre. A number linked their success to being able to recruit from an existing pool of volunteers and having a good reputation locally.

We had a good bank of volunteers already, and we're well embedded in the local community in terms of volunteering. We have a good structure for supporting them and a good reputation, so we've hardly had to do any proactive recruitment.

**Project manager**

- 5.6 A variety of outlets have been used successfully for recruitment including local newspapers and parish magazines, the partner organisation's own website and newsletters, Macmillan's Cancer Voices website, social media, local radio shows and volunteer bureaus. Some organisations have advertised in areas bordering the region they cover so as to boost the numbers. The majority of people who come forward seem to understand what will be expected of them:

When we advertise for volunteers in the local press we always get enquiries. When we interview people they seem to have self-selected very well – we rarely have to decline somebody or send them somewhere else. They get it – because they've had cancer and have been in that position, so they understand the need. They say they would have loved to have had someone doing the same for them. **Volunteer co-ordinator**

- 5.7 However, there are a minority of candidates who are either not suited for the role or later decide it's not the right role for them. It appears to take some time for people to make this decision.

If they're not the right people, you get a feel when you first meet them. You've got to be mindful that you're putting that person with very vulnerable people, so you have a duty of care to make sure they're up to the job and if you have any doubts, you've got to talk about it and offer another volunteering opportunity. We look for people who have a caring nature, have a reasonable knowledge base, are patient and flexible, and willing to commit to completing the training. **Volunteer co-ordinator**

Some volunteers can find the role quite difficult, if they've gone through a cancer journey themselves – once they see the reality of working with cancer clients, it may remind them of their mortality – it's not always comfortable. It's not something that everyone wants to see. **Advocate**

You have to be very straight with people from day one and explain the demands of role – so as not to invest a lot of time and resource in someone, only for them to realise it's too difficult later down the line. **Volunteer co-ordinator**

With our most successful recruits, they've often said 'I saw this opportunity ages ago, looked at it and then put it on back burner'. Then they see the advert again and then decide, so they've been thinking about it for a while. Other people who respond to a newspaper ad and phone immediately, later reflect and don't want to do it. They react too quickly without giving it enough thought. **Volunteer co-ordinator**

- 5.8 One of the project partners has had particularly difficulty in recruiting volunteers. It is of note that this organisation had limited experience of providing advocacy services before the COPA project. Their experienced advocate left before the COPA Programme began and therefore they lacked in-house expertise. Nor could they recruit from an existing pool of volunteers, or rely on their existing reputation in their community. They also employed their usual processes for volunteer recruitment which weren't successful in this case. They are now adopting a strategy which is more targeted at older people:

We have taken some of the information that other advocacy organisations are using for recruitment and using that to take a smarter approach – for example talking on radio

shows aimed at an older audience rather than generic programmes, and talking to local organisations that are older-people led, rather than being about general volunteering. I'm talking to cancer support groups and the older people's forum, being more focused on recruiting a very particular type of volunteer. **Project manager**

- 5.9 All partners have faced the perennial problem of not being able to co-ordinate the intake of volunteers with the rate of referrals, especially given the limited number of appropriate referrals and the time delay between recruiting a volunteer and them being trained and ready to go out alone.

### **Training and initiation**

- 5.10 Many of the project partners already had training and support in place for their existing advocates. As planned, they made use of their local training and the package provided by OPAAL (see 10.7) to develop a programme tailored to the cancer advocacy role.
- 5.11 After completing their training, volunteers first shadow paid advocates or may be accompanied by a paid advocate on their first few visits. This process takes time because advocates need to be matched to a suitable partner, and also need to develop their skills and experience over time, starting with more straightforward cases to build up their confidence. There have been more delays in this process than usual, because the services haven't been receiving many clients in genuine need of advocacy (see 4.18) and the clients that have been referred have often had complex needs and have therefore not been suitable for newly trained volunteers.

As the paid advocate I take on the complex cases, for example people with chronic substance misuse problems, that maybe not for the volunteers to deal with. **Advocate**

I've not passed on some clients to volunteers because if the person is near the end of life, they simply haven't got time to set up that relationship... Also some cases are too emotive. But now the volunteers are getting more experience, they probably could take on more challenging clients – in the early days that would have been too much. I wouldn't want to scare them off, they're wonderful volunteers. You need to tread carefully to give them the experience and then when they're confident and more skilled, you can say 'Here's a tricky case would you consider taking it on?' **Advocate**

- 5.12 Some volunteer co-ordinators reported that the induction process has taken several months for some of their volunteers, but this was also because the volunteers had been unavailable for some of that time. This time-lag has not always been a concern for the people who have been recruited. It suits some individuals to go at a slower pace. However, some have expressed frustration at not being able to get going sooner. During quiet periods, partner organisations have offered volunteers other advocacy opportunities to keep them motivated and engaged.

Many of our volunteer advocates are recently retired and want to find the right life balance in their new situation. They want to see how much time they can give – and usually end up giving more than they ever set out to, because they want to, and it's come naturally. This work has to go at their pace – and not impact on other aspects of their lives. **Volunteer co-ordinator**

## Ongoing supervision and support

- 5.13 All of the interviewees highlighted the importance of the organisation practically demonstrating that it values its volunteers and providing supervision and support on an ongoing basis.

It's essential that volunteers feel valued and recognised for what they're doing and feel integrated into the organisation and part of a team. They need ongoing opportunities for development, and they've got to have buy in to what they're doing and believe in what the organisation is doing. **Volunteer co-ordinator**

- 5.14 Supervision is required to enable individuals to develop their skills and confidence and to manage the challenges thrown up by different cases. The level of supervision required will therefore depend on the individual's needs and their particular case load. Therefore, staff tend to offer this support on an ad hoc basis, but with more intensive oversight at the beginning.

Some volunteers have had clients that want to muddle boundaries, asking them to do things out of their remit. The volunteers need to learn how to manage this on the job, so they're clear about boundaries and know how to refuse in a friendly way not harsh way. **Advocate**

I have a volunteer who had cancer, who previously only had cleaning jobs. She was low in confidence but has got so much potential. She's needing a lot of support through her first partnership, but I'm sure she will grow in confidence and will be a fantastic asset, which might lead to a career change for her – but then I have someone else who doesn't want any support at all, so it's very varied. **Advocate**

We provide monthly one-to-one supervision at the start which goes to three monthly meetings after three months. We have a close relationship with all the volunteers and encourage them to be honest. So if any problems arise in the interim, they can arrange to come and see me and not have to wait for supervision. **Volunteer co-ordinator**

- 5.15 Different partner organisations organise supervision in different ways. In some cases, the paid advocate is responsible for supervision on the basis that they have most experience of casework. In others, a volunteer co-ordinator takes on this role, although they highlighted the importance of taking a course in advocacy supervision to equip them with the relevant skills.
- 5.16 The volunteers themselves also need emotional support and consideration of their welfare given the nature of their role. For example, they may need extra support if their advocacy partner has a terminal diagnosis and then dies. This kind of support is typically provided by the volunteer co-ordinators:

I meet each volunteer every six months, where the agenda is all about them – not the service and not their casework. It helps keep my relationship with them going and puts the focus on their needs. We generally keep an eye on what's going on for them personally, to find out where they are at before they take on a new partnership, so we can check they are still able to manage. **Volunteer co-ordinator**

I'm there for them. My role is their welfare. They may witness and experience very challenging things - if that client dies, we may have to pick up pieces because they will have developed relationship with that person and it may take them back to when they lost a parent, sister or brother. They're aware that if they need me, they can just come and speak to me. **Volunteer co-ordinator**

If clients have died during matches it can feel very odd, because the advocate will feel close to their partner, but then the family take over and the advocate can be forgotten about or on the periphery. So we offer debrief meetings and training days around loss and bereavement, where we include a section on working with a partner with a terminal diagnosis. **Volunteer co-ordinator**

Support is crucial. I asked some of my existing advocates to come to a training session for an informal chat with new advocates, and what they talked about as keeping them going, was the support on offer – knowing they could contact staff any time they needed. **Volunteer co-ordinator**

- 5.17 Given that all the partner organisations have considerable experience in supporting and managing volunteers as evidenced by the above, none has experienced a serious problem with retaining volunteers. Some volunteers have left realising that the role is not for them and others have been forced to resign either because of their own ill-health or the need to care for a family member who has become unwell.



# Impact of the service

## 6. Impact of the service on clients

### Overview

- 6.1 This evaluation has not involved any direct work with clients, so does not include accounts of their experience, but does include an analysis of the monitoring data (See Appendix 2).
- 6.2 This section also includes a brief discussion of the project staff's views of the benefits for clients and their experience of the need for a service that supports OPABC during treatment.

### Who has used the service?

- 6.3 Between May 2014 and October 2015, 670 OPABC had used the advocacy service, when including data from all project partners. The majority of the clients were aged 55+ (79%) and women (53%), while 37% were men (amongst those who provided these details). Amongst the clients whose ethnicity had been identified (n=494), 90% were white British, 4% were white (other). Clients from other ethnic groups each contributed to less than 1% of the total. (See Appendix 2)
- 6.4 One of the goals of the COPA programme has been to equip cancer advocates with the skills and capacity to support OPABC from LGBT communities. The staff report feeling well-trained in this area (see 8.1), but not all project partners have had many referrals from these groups.

### Perceived benefits for clients

- 6.5 A number of staff described how they had witnessed the added-value of *peer* volunteer advocates and their significance to clients. Talking to peers seems to notably enhance the quality of the advocacy relationship, when all is working well.

When I take a peer advocate out, someone who's has been through the experience, you see the reaction on the partner's face when the peer opens up a little bit, or the client realises the peer advocate has been through what they are going through. I've seen that on several occasions – the power of that added dimension. **Advocate**

With peer advocacy OPABC are supported by people who truly understand where they are. That helps during the initial introductions and down the line it helps to build a rapport – there are big positives. **Volunteer co-ordinator**

### The need for advocacy support during treatment

- 6.6 A number of paid advocates identified several challenges for OPABC when they are first diagnosed and undergoing treatment for cancer, which the advocacy staff believe underpins the need for an advocacy service. These include the following:

- Most people with cancer in later life have never been ill before, so have no idea how to navigate the health and social care systems. They have lived independently and never claimed benefits or asked for help. They are then expected to do this, to master a completely new domain, when they have no previous experience and are feeling frightened and very ill.
- The word 'cancer' creates an emotional reaction that makes it difficult for people to take in information during appointments. An advocate can take notes and absorb the details because they are not emotionally connected with the information.
- There are a wide range of professionals that patients will receive services from in hospital and at home, and it can become impossible to keep track. As one advocate described in a recent hospital visit with a client, 'Today there were five health professionals in the room at one point. We saw different people on reception, different nurses and different transport guys throughout the day. I was the only constant for the patient.'
- OPABC may not be computer literate, and while there is a wealth of information online about treatment options and prognosis, they may need help with finding and accessing that information *from home*. If they are frail and ill, they won't be able to get out to other support services.

## 7. The volunteers' experience of peer advocacy

- 7.1 A total of 245 advocates had been recruited across all project partners between May 2014 and October 2015. The majority were aged 55-84 (54%). Most were women (57%), while 35% were men. Among those whose ethnic identity had been identified (n=179), 91% were white British. The remainder came from a range of ethnicities, with 0-2% in each group. (see Appendix 2)
- 7.2 A series of in-depth, one hour, face-to-face interviews with 28 volunteer advocates showed that the majority found the role had met with their expectations (See Appendix 3). More than half felt they had improved their people skills, their social and communication skills and their team-working skills through their advocacy work. About a third reported having improved their management and organisational skills. As a result of receiving high quality training, more than 80% said they felt more confident in their knowledge of cancer and felt better able to support OPABC. All but one of the interviewees wanted to continue in an advocacy role. This one person felt obliged to stop because of other caring responsibilities. All the volunteers particularly valued the high quality training and support they received from advocacy staff and found it very rewarding to know they were helping their partners. The main challenge they felt needed addressing was increasing the number of referrals.
- 7.3 In summing up their overall volunteering experience to date peer advocates made the following comments:

It helped me feel useful and increase confidence. Been a godsend to feel useful again.

Very gratifying when people acknowledge help and support they've been given, one clients' son said 'Thank you very much. I don't know if Dad would have come through this without you.'

## Lessons learnt about staff management

### 8. Training and support for staff

#### Training

8.1 When asked about training many of the staff commented that the national LGBT training had been very good, even for the people who had had similar training in the past, as they still learnt something new.

8.2 When asked whether they had other training needs, some identified that they needed more training on supporting people at the end of life. They had already arranged to receive this training from local organisations, both for themselves and their volunteers, making use of their local training budgets.

We're getting training from a local cancer charity on how to manage emotive cases, how to manage when you're in somebody's home and they're in floods of tears because their partner died a week ago. I'm not a counsellor, so I need some advice to draw on, so I know what to say and not to say. **Advocate**

More training around end of life is being planned, we've invited someone from the local hospice to help with that - how to communicate, where to start and how to have a difficult conversation that people might not want to have... **Advocate**

8.3 Some explained how much of what they had learnt had come from experience on the job, which is an essential and normal part of developing any new service.

It's been a learning curve in terms of the new situations we've been encountering, but we're building our knowledge base and creating a landscape which we can now navigate. Every case is different every person is an individual – but some themes do start to emerge. We feel more informed now for example about the packages available when people come out of hospital. **Advocate**

I've learnt a huge amount over last 12 months and have got far more knowledge and understanding of the project than did at the beginning. So I'm more confident in talking to people. I can answer people's questions. We now know what's working and what people are coming to us with, and what we're doing for them. So I know what we can realistically offer and what to say to potential volunteers. It's been a huge learning curve, but a really positive one. **Volunteer co-ordinator**

#### Support

8.4 Some staff reported that they felt well-supported in their role, but others felt they could do with more emotional support to deal with the challenges. They felt project managers might need to be allocated more time for this.

Management hours are thin on ground. I very much feel that I am left to get on with it. I've had to deal with some really difficult emotional cases. I've done advocacy for a long time and I've got broad shoulders, but some days they are not as broad as I'd like them to be. It is difficult dealing with people who are extremely upset or absolutely bereft. I

have to deal with that and not take it home... and I'm feeling unsupported when I have to deal with that. **Advocate**

## 9. Shared learning across the project partners

### Overview

9.1 There are a number of initiatives that have been put in place to support shared learning across project partners. These include:

- Mentoring
- Project managers' meetings
- Annual meetings of paid advocates and volunteer co-ordinators
- An online forum
- Mini-projects

These will be discussed in turn in the remainder of this section.

9.2 The main barrier to these initiatives working effectively is lack of time (see 13.1). All staff are working part-time for only two or three days a week, so taking time out for shared learning activities can feel like taking time away from clients in need. As the staff are conscientious, dedicated and passionate about advocacy, supporting clients always comes first. They are frequently already working overtime to try to meet targets and objectives, so the extra demands these activities make on their time can feel burdensome, rather than supportive.

Ten years ago, when we were all working full time, we had space to analyse and reflect, which was part of the service development and our career development and training. Without that you're on a rudderless boat. So I'm 100% behind it. But we're so stuck for time... if it's a choice between an event or going to a client assessment – there's no contest. **Advocate**

Evaluation and planning need to be resourced outside of our existing hours – otherwise we're just paying lip service. **Advocate**

### Mentoring

9.3 Each of the new project partners was given a mentor – one of the advocacy organisations that had taken part in the pilot. This has worked very well. Many of the interviewees commented on how much they valued and had benefited from the advice and support from their mentor.

It worked well. I got on well with the people I've worked with from the mentoring organisation. It's been good feeling like no question is a stupid question. I've been able to ask anything, and they have responded. **Project manager**

### Project managers' meetings

9.4 Many of the project managers also reported that they found their quarterly meetings very useful. It has provided a means to share information about what each of the partners have been doing and to set up informal networks.

We've also networked outside the meetings to help with problems. We're all helping each other out. It's nice not to be stuck in your own location. **Project manager**

- 9.5 However, others thought that the meetings could be improved by also allowing time for genuine shared learning, to go beyond reporting what has been done, to reflect on what has been learnt and what this means for the strategic direction of the project.

### **Annual meetings of paid advocates and volunteer co-ordinators**

- 9.6 There has been one meeting to date, where the consensus amongst participants was that they wouldn't want to meet any more frequently than once a year. The main concern was lack of time. A trip to London for a day's meeting for some staff, effectively takes all of their 14 hr working week. Some were uncertain as to the purpose of such meetings, believing that their support needs were being met by supervision. Others thought it would be valuable to meet and problem solve with their peers.

It would be useful to discuss problems like how to manage volunteers who overstep the boundaries, they give their mobile numbers out even though they are told not to... I'd like to talk with other people in the same role about how they deal with things.

**Advocate**

It would help to go in depth though cases and ask 'Have I dealt with this properly?' Somebody could say 'Have you thought about managing it that way?' We've all got different experiences in life and different ways of looking at things. It might be valuable to do with other advocates on the project. **Advocate**

- 9.7 Our experience as evaluators on this project and others, is that not everyone has the same understanding of 'shared learning'. Some understand it to be 'information sharing' or learning about 'case management', which may be why it seems of less importance. To make these meetings seem worthwhile it will be important that these events have a clear purpose and participants understand what they will get out of the day. Some interviewees thought that these meetings would be of more interest if they were clearly about genuine 'shared learning' – a chance to reflect on experience to date, identify unanswered questions and develop the means to address them.

I think my staff could justify attending if there was more structured learning, not just information sharing but discussion about what questions this is raising.

**Project manager**

Perhaps some reflection on which are the appropriate referrals, we probably have different ideas about that – do we have a consensus? Do we need one? How do we go about getting consensus, if we do? **Advocate**

## An online forum

- 9.8 In response to a request from project staff, an online forum was established to enable all staff to share documents, ask questions and provide advice and support to each other. This has not been well-used for the following reasons:
- Some people are unclear about the purpose, having practiced as an advocate for a long time, they don't see how the forum will help them. They source information and assistance locally.
  - Some people avoid going online and would prefer to 'pick up the phone and talk to someone' or email them directly.
  - Some found the standard free software cumbersome and not easy to use.
  - Lack of time.
  - Some people may not want to go public with what might be perceived as a 'stupid' question or something others think they should know.
- 9.9 A few people did like the forum. They suggested that the main points from the project managers' meetings be shared in this way. However, without a critical mass of people using the forum, its usefulness is limited, which is again another barrier to its uptake.

## Mini-projects

- 9.10 The mini-projects have had variable success. This is because they have seemed like an additional burden to some staff, an extra piece of work they 'have to do for the evaluators', taking time away from their core business. An important lesson for the evaluators is to find a better way to describe this work, as our intention is to support reflective practice, albeit on a small-scale, and to *enable* staff to carry out their business.
- 9.11 Some people have found these mini-projects useful. They report having been motivated and encouraged to look at one area of their work in depth.
- I've kept a dialogue going with the evaluators whilst doing a piece of work I was planning to do anyway. It's not been too demanding. It gets me going. When I have a date in the diary to speak about it, I get myself organised to do it. **Advocate**
- I've liked the focus on a small area. It's been useful ongoing learning – and motivation to keep trying other areas. **Project manager**



## 10. Partnership working with Macmillan and OPAAL

### Working with Macmillan

- 10.1 The project partners have had varying experiences in working with Macmillan staff in their local area. Some have been very positive, for example, where Macmillan staff and volunteers have provided introductions to the local cancer community:

The links with our local Macmillan have been amazing – at all levels. The regional co-ordinator gave me a list of local services, which has been useful in terms of publicity and finding volunteers. We have a Macmillan volunteer on our local Board, who has attended every meeting, and introduced me to frontline services in local hospitals as well as getting me meetings with support staff in welcome centres. A lot has stemmed from that. **Project manager**

- 10.2 However, some report that although the advocacy project is funded by Macmillan nationally, regional and local area Macmillan staff do not seem to have been informed about this new service. Not all of the staff have been supportive. Furthermore, there does not seem to be a mechanism for joining up local Macmillan-funded services to promote cross-referrals, share publicity etc. The culture seems to be competitive rather than collaborative.

Although they [Macmillan staff] have been very supportive, it seems as if this was dumped in their lap and they didn't know anything about it until we rocked up with this project... we've been trying to get our service on their website, but it still hasn't happened. **Advocate**

We've not even got referrals through Macmillan. I can't say there has been a lot of communication with them. It's not been easy to pin them down and meet up with them. **Advocate**

We thought being a Macmillan service, we'd have been introduced into local health networks – but we haven't. They have been guarded about their contacts, they've only given us other Macmillan contacts – but they are sitting outside the health system as well. **Advocate**

We're not seen as a Macmillan service. **Advocate**

- 10.3 There were varied views amongst interviewees about the value of the Macmillan brand. Some thought it would help with referrals.

The cancer charities like Macmillan are well known and trusted. We are an older people's charity not associated with cancer, so OPABC don't have that immediate thought to come to us. If our partnership with Macmillan was functioning properly it could work really well. **Advocate**

We'd like more support from Macmillan. We're a tiny charity in comparison – we'd like support in promoting our project... **Advocate**

- 10.4 Others had found working with Macmillan on publicity to be a mixed blessing, for example when developing press releases to advertise volunteering opportunities. It's easy for small organisations to be lost in the shadow of such a well-known brand.

There are many positives to being associated with a well-known brand, we are instantly recognisable to a huge number of people who may need our support or like to get involved...Alongside our work with the Macmillan communications team, we have found using our own local brand and publicity opportunities (such as parish magazines) extremely important. **Advocate**

- 10.5 Some interviewees also questioned whether the partnership with Macmillan at a national level was working well. They were aware of national policy developments e.g. work around holistic assessments, which could help to provide leverage for the introduction of cancer advocacy, but were unclear whether any work was taking place on this at a national level and who was taking responsibility for this strategic development.

### **Working with OPAAL**

- 10.6 A number of the interviewees reported that they felt well-supported by OPAAL, particularly in overcoming challenges in meeting the project targets.

They have been efficient, organised and quick with responses always hitting the right tone. It has been more difficult than expected to meet targets – and they have been very reassuring and positive about how to do things differently and better. **Project manager**

- 10.7 Some felt the package of materials that were made available at the beginning of the project, e.g. the training materials and leaflets, were not appropriate for their organisations. However, they were encouraged to amend and adapt these for their own purposes. They suggested that in future, project partners be offered a template or choice of materials that are more clearly labelled 'for adaptation'.

# Lessons learnt about project management

## 11. Setting up the service

- 11.1 The majority of project partners have not found it difficult to set up the service because they have been able to draw on their experience as established advocacy service providers and have employed their learning from setting up other new projects.

We had the general paperwork in situ already and I had the knowledge from being an advocate previously. I did bring a lot of experience to it, which has been really helpful.

**Advocate**

It's very important to spend enough time in the planning stages. We have set up another project from scratch, so we've adapted our learning from that in how to do things for COPA. You need all your systems and procedures in place before you start taking referrals, which takes about 3- 4 months. **Project manager**

- 11.2 One partner has found the process more challenging, simply because they did not have an existing advocacy service in their organisation. They have therefore had to develop completely new policy, systems and processes. The support they received from their mentoring organisation has been invaluable in this regard.

- 11.3 The other major challenge has been finding a health professional to attend the project's National Health Professional Board.

If we can't persuade health professionals to refer clients to us, how can we persuade someone to send a day a quarter in London to discuss the project? Also the people who are good tend to be busy. **Project manager**

## 12. Monitoring the service

- 12.1 Many of the interviewees commented on the limitations of the current online project database, SAM. In particular, they reported that the system is often slow, the process of data entry cumbersome and the reporting system not closely linked with priorities for project monitoring. However, they were grateful that this feedback had already been taken on board, and hoped that the new revised version (in development at the time of the interviews) would be much improved.
- 12.2 Others found a lack of time to be a problem with data entry. Although advocates record all client information on paper as they go along, there is then a second step of logging this information onto SAM. It's not always simply a matter of handing over this task to administrative assistants. Their time is also limited and already allocated to supporting meetings, and the advocates often need to interpret the client's notes.
- 12.3 Some also questioned whether the numerical targets for referrals were appropriate and suggested they might need to be altered to reflect what happens in practice.

The original targets were for volunteers to support 30 people, 10 volunteers having three clients each. But it doesn't work like that, because volunteers vary in how much time they can give and how easy it is to match them with clients. Some volunteers see a client a handful of times and the issues are resolved quickly. We can't be so prescriptive. **Advocate**

- 12.4 Others expressed concern that simple numerical targets did not accurately reflect the amount of effort and work going into the project. As a new service, there are no benchmarks for what success looks like and this may benefit from further reflection.

The ability to fulfil targets is outside of your control. It depends on the individual volunteer or on outside people to refer – so a lot depends on hoping other people will step up. **Project manager**

Even though our numbers are low, the workload is high because individual clients can take a lot of time and energy – the cases have been longer term and more intense than we were expecting. More people are being referred in to the service than we are closing – though the rate is not high, the client load is large. What does that mean for targets?

**Project manager**

## 13. Resourcing the service

- 13.1 Many staff reported feeling under-resourced and simply not having 'enough hours in the week' to fulfil all of their responsibilities. This was true for advocates, managers and admin support. This has become more of an issue with all of the time that has been invested in publicising the service with the aim of obtaining greater numbers of referrals. Many reported that they were working more hours than were funded by project.

In a 14 hr per week role, I'm trying to deal with the cases coming in, the volunteers and updating the database and blog posts, evaluation – which leaves me limited time for promoting the service. Although I do it, I would have liked more time set aside to purely do that. **Advocate**

- 13.2 For advocates, having limited time creates logistical problems, especially when supporting clients through treatment phases, because hospital appointments cannot be easily changed.

Not all volunteers are flexible enough to fit round the client. They often want to fix things in advance, but may not be available to support people when needed. It would be OK if we had full-time staff, but they often have more than one role, and are not always able to split their two days over the five day week to meet clients' needs. Sometimes we are unable to support a client on a certain date – there genuinely isn't anyone available. **Project manager**

## Conclusions & Recommendations

### 14. Conclusions & Recommendations

- 14.1 The main conclusion from this evaluation is that the cancer advocacy service model has developed in different ways across the project partners. These differences seem to have arisen partly because of the different kinds of referral routes into the service at each locality, which has meant that the clients present with different kinds of needs. This in turn has implications for client load and the capacity of volunteers to support OPABC. For example, in Dorset where the focus has been on referrals from CNSs, clients are supported through treatment stages and volunteers have been able to provide advocacy support at this level. In other localities, many of the clients have been referred through other routes, and have either presented with complex and multiple needs or are already at the end of life. This has prohibited involvement of new volunteers.
- 14.2 This variation in how the service is functioning in different areas has implications at a strategic level in terms of describing cancer advocacy to future funders and at a managerial level in terms of how best to staff and structure the service. It also has implications at an operational level in terms of where to prioritise efforts during the remainder of the project in order to increase the number of referrals.
- 14.3 The interviewees were asked what they thought were the priorities for next year and they identified the following:
- Getting more referrals and appropriate referrals – focus on CNSs
  - Gathering evidence to make the case for future funding including financial data
  - Keeping up to date with national and local cancer initiatives which can be used as levers to promote the service
  - Retaining volunteers and ensuring support for end of life cases
  - Preparing for an end to the service in case future funding is not secured
  - Developing systems and processes for quality assurance in service delivery – how can we demonstrate we are truly acting as independent advocates?
- 14.4 However before any further work is carried out, based on our observations, we recommend that a period of reflection and shared learning takes place to develop a consensus on the optimum service model for cancer advocacy. This will be essential to do first, as this thinking will influence the direction of all future developments.

## **Appendix 1 – The people who were interviewed for this evaluation**

Angela Clarkson, Sefton Pensioners' Advocacy Centre

Janet Cullingford, Independent Community Advocacy Network North

Paddy Elmore, Sandwell Advocacy

Kathleen Gillett, Dorset Macmillan Advocacy

Angela Jones, Age Connects Cardiff & The Vale

Naomi Karlake, Oxfordshire Advocacy

Valerie McGregor, Knowsley Pensioners Advocacy & Information Service

Jen Rimmer, Dorset Macmillan Advocacy

Ben Sansum, Age UK Bristol

Juanita Williams, Sandwell Advocacy

Some of the interviewees chose to remain anonymous and have not been named.

## Appendix 2: Monitoring data from the project database (SAM)

All project partners have kept records detailing the demographics of the clients and advocates and the nature of the advocacy support provided to those clients. The data from the period May 2014 to October 2015 have been analysed for this report. This includes data from all thirteen project partners, not only from the eight organisations that were included in the interviews.

### 1. Advocates

A total of 245 advocates were recruited across all the partner organisations. Their ages, gender and ethnicity are summarised in Tables 1-3.

**Table 1: Age of volunteer advocates**

Age		
	Number of advocates	% of total
25-34	1	<1%
35-44	6	2%
45-54	22	9%
55-64	38	16%
65-74	54	22%
75-84	38	16%
85 and over	11	4%
Not specified	75	31%

**Table 2: Gender of volunteer advocates**

Gender		
	Number of advocates	% of total
Female	139	57%
Male	85	35%
Undefined	21	9%

**Table 3: Ethnicity of volunteer advocates**

Ethnicity		
	No. of advocates	% of total
White British	162	66%
White (other)	4	2%
White Irish	2	1%
Black Caribbean	2	1%
Asian Indian	2	1%
Asian Pakistani	2	1%
White and Asian	1	<1%
Black (other)	1	<1%
Asian (other)	1	<1%
Any other	2	1%
<b>Not specified</b>	<b>66</b>	<b>27%</b>



## 2. Clients (OPABC who used the advocacy service)

A total of 670 clients were supported by the service across all the partner organisations. Their ages, gender and ethnicity are summarised in Tables 4-6.

**Table 4: Age of clients**

<b>Age</b>		
	Number of clients	% of total clients
25-34	2	<1%
35-44	12	2%
45-54	56	8%
55-64	148	22%
65-74	163	24%
75-84	168	25%
85 and over	56	8%
Not specified	65	10%

**Table 5: Gender of clients**

<b>Gender</b>		
	Number of partners	% of total
Female	356	53%
Male	249	37%
Not specified	65	10%

**Table 6: Ethnicity of clients**

<b>Ethnicity</b>		
	Number of clients	% of total clients
White British	447	67%
White (Other)	18	3%
White Irish	8	1%
Black Caribbean	6	1%
Black African	1	<1%
Black (other)	1	<1%
White and Black Caribbean	1	<1%
White and African	1	<1%
Asian Indian	5	1%
Asian Pakistani	1	<1%
White and Asian	1	<1%
Asian other	1	<1%
Other dual heritage	2	<1%
Any other	1	<1%
Not specified	176	26%

### 3. Type of advocacy support provided to clients

The type of advocacy support provided to clients is described in terms of the nature of the advocates' activities (Table 8). There were 5514 occasions in total when these different activities were carried out. This amounted to 5800 hours of advocacy support, an average of 1 hr and 3 mins per activity. Table 9 describes the type tasks that advocates carried out in completing these activities.

**Table 8: Activities**

Activity	Number of occasions when this activity was carried out	% of total
General support	1554	28%
Arranging services	1123	20%
Visit to service user at home	678	12%
Pre-allocation tasks	462	8%
First meeting with service user following referral	457	8%
Independently researching information	447	8%
Emotional support	381	7%
Visit to service user on ward	108	2%
Meeting with consultant	106	2%
Introductory meeting with potential advocate	75	1%
Meeting with clinical nurse specialist	61	1%
Meeting with GP	26	<1%
Meeting with benefits agency	21	<1%
Meeting with lawyers	15	<1%

**Table 9: Nature of the tasks carried out by advocates**

Nature of the task	Number of times advocates carried out this work*	% of total activity
Telephone calls	3632	38%
Listening and reassurance	1630	17%
Research and information gathering	880	9%
Admin	815	9%
Travel	798	8%
Emails	682	7%
Signposting	305	3%
Form filling	265	3%
Referrals	210	2%
Letter writing	193	2%
Supervision	96	1%
<b>TOTAL</b>	<b>9506</b>	

\* during any single activity more than one kind of task may have been carried out.

## Appendix 3: Findings from the interviews with volunteer advocates

### 1. Introduction

A series of in-depth, face-to-face interviews were conducted by OPAAL between June and September 2015 with volunteer advocates (28 in total). Thirteen were volunteering for organisations which have been part of the COPA programme since the pilot project, which started in 2012. The other 15 interviewees were advocates volunteering with new delivery partners all of whom joined the COPA programme on 1 May 2014. The findings are summarised here with direct quotes from volunteers in italic.

### 2. Were the volunteers' expectations met?

Twenty-four of the 28 (86%) stated that their expectations of being an advocate had been met whilst 3 (11%) said that their expectations had been partly met, with 1 (3%) saying that their expectations had not been met. The 3 volunteers whose expectations were only partly met stated:

*Mostly met, completely different each partners. Some 'light touch' others quite emotional.*

*Don't feel as busy as you could have been. Only working with one partner at a time.*

*Make a difference, quality of life for others. One partner has died. Wider remit than expected, realised this after training.*

The volunteer whose expectations had not been met stated: *Hoped to get experienced quickly, this has not happened due to lack of referrals. First case sitting with client's carer with Parkinson's whilst wife went to hospital.*

### 3. Developing skills in the advocate role

The number of advocates who reported improving their skills through advocacy work is shown in Table 1. Many of the volunteers brought these skills from their previous professional roles, and did not feel the need, or expect to develop these further.

**Table 1: Skill development**

<b>Skills</b>	<b>No. of advocates reporting an improvement in this skill</b>	<b>% of total</b>
<b>People skills</b>	18	64%
<b>Communication or social skills</b>	21	75%
<b>Team working skills</b>	15	54%
<b>Management skills</b>	10	36%
<b>Organisational or time management skills</b>	11	39%

Additionally 6 volunteers (22%) noted improvements in other areas including:

*..increased empathy with others*

*confidence improved*

*I've learned a great deal about the bureaucracy of social services etc.*

*my appreciation of things that matter to other people*

#### 4. Knowledge and awareness of cancer

The interviewees were asked whether their awareness of cancer had changed as a result of their experience and whether they felt any difference in their ability to provide advocacy support to OPABC. The results are shown in Table 2. As many of the volunteers had previous experience of cancer, they already had considerable knowledge of their cancer, but reported improving their awareness of other types of cancer.

**Table 2: Awareness and ability**

	Number of interviewees reporting a change in levels of awareness or ability				
	Greatly decreased	Slightly decreased	No change	Slightly increased	Greatly increased
<b>Awareness of different types of cancer</b>			<b>5</b> (18%)	<b>15</b> (54%)	<b>8</b> (28%)
<b>Ability to relate to a person affected by cancer</b>			<b>5</b> (18%)	<b>13</b> (46%)	<b>10</b> (36%)
<b>Ability to provide support to a person affected by cancer</b>			<b>3</b> (11%)	<b>7</b> (25%)	<b>18</b> (64%)

A volunteer who is a retired nurse commented: *Because of COPA I am learning more about cancer and the services & support offered by Macmillan and others.*

## 5. Feeling and thoughts about being an advocate

**Table 3: Advocates reports of well-being**

	Number of interviewees who reported this thought / feeling				
	None of the time	Rarely	Some of the time	Often	All of the time
<b>I've been feeling optimistic about the future</b>	1 (3%)	-	5 (18%)	12 (42%)	10 (36%)
<b>I've been feeling useful</b>	-	-	5 (18%)	9 (32%)	14 (50%)
<b>I've been feeling relaxed</b>	1 (3%)	1 (3%)	3 (11%)	15 (54%)	8 (28%)
<b>I've been dealing with problems well</b>	-	-	2 (7%)	14 (50%)	12 (42%)
<b>I've been thinking clearly</b>	-	1 (3%)	3 (11%)	9 (32%)	15 (54%)
<b>I've been feeling close to other people</b>	-	1 (3%)	2 (7%)	7 (25%)	18 (64%)
<b>I've been able to make up my own mind about things</b>	-	-	1 (3%)	10 (36%)	17 (61%)

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## 6. Continuing in an advocacy role

Twenty-seven (97%) of the interviewees said they would like to continue as peer advocates. The one person who said they wouldn't want to continue explained this was because they had other caring responsibilities.

The main reasons people gave for wanting stay on was because they felt they were making a real difference, they felt they were well-trained and supported which gave them confidence and they enjoyed being part of their advocacy team:

*I can help people practically and personally. I have a good idea of what people are going through. I can help them with their concerns or fears for the future. I enjoy being part of a team, and I enjoy the training offered to us all.*

*I feel I can relate to my advocacy partner very well due to my own experiences. I find it useful to have something in common with my partner in addition to the cancer. I am an empathetic person, a good listener and able to support others to express their concerns and worries.*

*Want to help people affected by cancer because I feel there is a gap in services to support people personally and allowing their voice to be heard and express their own feelings, wishes and concerns. Someone to 'be there for them'. Lonely experience for OPABC.*

*I enjoy being with COPA staff, like helping other people. It's a fantastic opportunity to give something back, my Grandad was lucky, he had me. Too many people have no one to help them.*

## **7. What's working well?**

When asked what was working well for them in the project, the interviewees gave a range of responses that included:

- High quality training and support from COPA staff
- Having a positive impact on the lives of clients
- Developing relationships with clients

## **8. What is not working well?**

There was a general consensus that the main issue facing the project was the limited number of referrals. This is frustrating for volunteers as it means they are not as busy as they had anticipated or would like to be.

Volunteers remain keen in spite of these issues. In summing up their overall volunteering experience to date peer advocates made the following comments:

*It helped me feel useful and increase confidence. Been a godsend to feel useful again.*

*Very gratifying when people acknowledge help and support they've been given, one clients' son said 'Thank you very much. I don't know if Dad would have come through this without you.'*