

Older People's Cancer Voices: Final Evaluation

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Contents

- 1. Introduction 2
- 2. Methodology 3
- 3. Background 4
- 4. Findings 5
- 5. Conclusion 12

- Appendix 1: Contacts and Interviewees 14
- Appendix 2: A Commissioner’s View 15
- Appendix 3: Diary of a Project Lead / Volunteer Cancer Advocate 16
- Appendix 4: Dorset Appointments Advocacy Service 17

Introduction

Older People's Cancer Voices (OPCV) is a project funded by the Department of Health and managed by OPAAL UK which ran from October 2014 to September 2017. The project is closely related to a wider programme called Cancer, Older People and Advocacy (COPA), which provided one-to-one advocacy for older people affected by cancer.

The starting point for both projects was the realisation that there appeared to be some 'under-treatment' of older people affected by cancer.¹ The Department of Health acknowledged the need to 'improve intervention rates for older people who could benefit, ensuring that age alone is never a barrier to the most appropriate treatment.'² Macmillan Cancer Care described the lack of support many older people experienced both during and after cancer treatment.³

According to the NHS, nearly two thirds of cancer diagnoses occur in the over 65s.⁴ If NHS cancer services are failing older people, they are failing the group that needs them most. Advocacy aims to redress the balance in favour of the older person's needs and wishes. In this report we will be evaluating OPCV rather than COPA, but there is considerable overlap between the two.

1 Macmillan Cancer Care, 'The Age Old Excuse: the Under Treatment of Older Cancer Patients', 2012.

2 Department of Health, 'Improving Outcomes: A Strategy for Cancer', 2011, p.55.

3 Macmillan Cancer Care, 'Walking into the Unknown', 2011.

4 http://www.ncin.org.uk/publications/older_people_and_cancer#. Accessed September 2017.



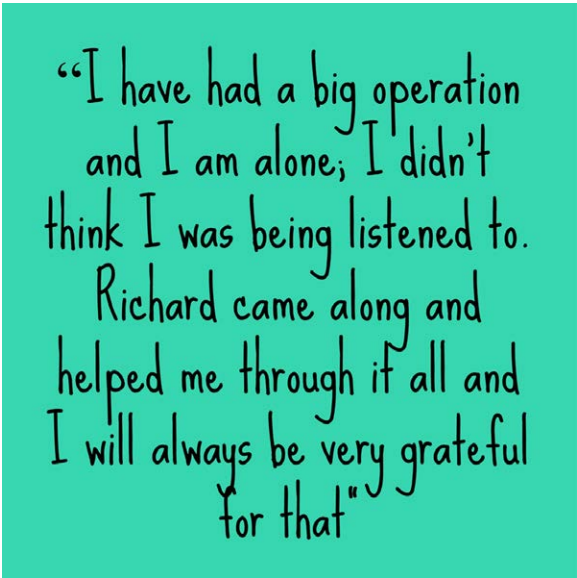
Methodology

The evaluation was undertaken in two stages, with an interim evaluation produced in January 2016 and the final evaluation before you. The main research method employed in the evaluation consisted of semi-structured interviews with key stakeholders in each area and with relevant OPAAL staff. Semi-structured interviews are designed to be flexible and to respond to the perspective of the interviewee rather than follow a rigid questionnaire format.

Interviews for the interim evaluation were carried out in October, November and December 2015 and for the final evaluation in July, July and August 2017. There was a mixture of face-to-face and telephone interviews, which were recorded to facilitate accurate note-taking. The

consultant attended three meetings of the Project Management Group in June 2015, February 2016 and May 2017, as well as the Launch Event which took place in Manchester in August 2017.

In both reports we sought to capture the experiences of stakeholders at each of the four project locations. For the interim evaluation we were aiming to draw out expectations and potential challenges to help shape the project. In this final evaluation we look back over the project to see whether it achieved its overall aims. The research findings are augmented by our own independent analysis, leading to a conclusion and recommendations. Interviewees and contacts are listed at the end of the report.



“I have had a big operation and I am alone; I didn't think I was being listened to. Richard came along and helped me through it all and I will always be very grateful for that”

Background

COPA aimed to recruit and train people over 50, themselves older people affected by cancer, to be Peer Volunteer Advocates. COPA operated in thirteen locations in England and Wales. It was funded by the Big Lottery Silver Dreams fund and Macmillan Cancer Support. This national funding for COPA came to an end in March 2017.

OPCV is funded by the Department of Health's Innovation, Excellence and Strategic Development Fund (IESD). Funding over 3 years is just over £270k. Rather than delivering one-to-one advocacy itself, OPCV seeks to 'build relationships' in four areas of England between Clinical Commissioning Groups and four of the COPA organisations who agreed to be OPCV Project Partners:

- ICANN - a small generic advocacy project covering the Central Lancashire area. The Project Lead for OPCV is the ICANN Services Manager who also managed the COPA programme for the charity.
- Dorset Advocacy - a larger generic advocacy project. The Project Lead is the Macmillan Project Coordinator for Dorset Advocacy.
- Help and Care - a larger Dorset-based charity working with older people to offer a range of services, including cancer advocacy. The Project Lead is the manager of the charity's Partnerships for Older People programme, which supports older people in their own homes. Also involved is a Volunteer Cancer Advocate who liaises with the Project Lead so that cancer advocates are at the heart of the process.

- Beth Johnson Foundation - a sizeable charity working primarily with older people, for whom advocacy is a key component of their work. The Project Lead manages the COPA programme across the localities of Stoke-on-Trent and Wolverhampton.

The charity needs to show it has developed strategic strengths through running the project. The key strengths to be developed were stated on the application form as:

- National project management skills.
- Partnership development work.⁵

As well as the overall strategic aims a number of subsidiary objectives were stated:

- Increase health and care professionals' and commissioners' understanding of advocacy.
- Increase referral numbers.
- Increase numbers of peer advocate volunteers.
- Support the longer-term sustainability of COPA.⁶

⁵ OPAAL, 'Application Form for Innovation, Excellence and Strategic Development Fund', 2014-15, p.8.

⁶ <http://opaal.org.uk/older-peoples-cancer-voices/>

Findings

We will use our findings from interviews and analysis to ascertain to what extent OPAAL has been able to achieve the objectives described above.

PROJECT MANAGEMENT

Project Partners enjoyed working with OPAAL on OPCV and believed the project was managed effectively:

'The Project Manager did everything that was asked of her and more'

'OPAAL seemed to run the project quite smoothly.'

'With OPAAL there is not a lot of pressure. They know there will be problems from time to time.'

To a large extent OPAAL has been very much dependent on the Project Partners for the delivery of the outcomes. Funding to each partner was £3,225 per annum, so a relatively small amount of income in organisational terms. There was no power to compel partners to do what was required other than through negotiation.

PARTNERSHIP DEVELOPMENT

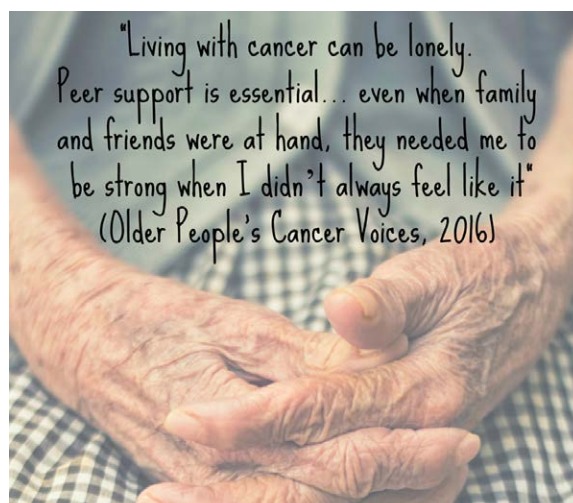
OPAAL took considerable pains to ensure that Project Partners were kept on board and that there were plenty of opportunities to discuss relevant issues. Early in the project OPAAL established a Project Management Group (PMG) consisting of Project Leads and the OPCV Project Manager). In addition a 'Steering Group' was set up comprising individuals nominated by Project Partners who could

'open doors' for OPCV with health commissioners and others.⁷ Both groups met regularly through the life of the project, which required considerable project management skill to organise successfully.

The initial idea behind the bid was to have four partners in four separate locations - Dorset, Stoke on Trent, Gateshead and Sefton. However, this proved to be not possible in practice since two areas decided not to sign up to OPCV.

This illustrates one of the difficulties of partnership development work. OPAAL had agreed to run OPCV with a sub-group of COPA organisations, so was very much dependent on securing the agreement of four partners to participate. Given the need to get the project off the ground in the early stages, and a relatively small number of COPA projects to choose from, OPAAL probably did the best it could in the circumstances in identifying two replacement partners. But it was not ideal that two of the final Project Partners were in the same location (Dorset).

⁷ OPAAL UK, 'Minutes of the Older People's Cancer Voices Steering Group', August 2015.



MAKING THE PARTNERSHIP WORK

Having said this, OPAAL clearly made the partnership work by making OPCV complementary to the activities of the COPA partners. As Project Partners commented:

'OPCV has been an important project because cancer advocacy has been a difficult thing to explain. It has helped us to promote the cancer advocacy service and communicate what this service is.'

'OPCV has done a great job in promoting advocacy'.

'We have been lucky to have OPCV as the parallel programme to COPA'.

Partnership work can be risky. To some extent the responsibility for the success of a partnership project depended upon the Project Partners, who were not always able to deliver what was expected. For example, one Project Partner did not take part in either of the two rounds of filming.

FIRST GROUP OF FILMS

OPCV aimed to produce resources that would support Project Partners to influence health professionals and commissioners. One of the key outputs was a series of short films, four in the first half of the project and a further four in the second.

In the first year of operation OPCV worked with Partners to create four short films describing the benefits of peer advocacy support for older people affected by cancer. The films were based on footage recorded with Project Partners in April and May 2015. One film was to serve as a general introduction to cancer advocacy.

The three other films were designed to appeal to three separate audiences: commissioners, potential new volunteers and health professionals.

Whilst the films were fine technically, and contained much excellent material, feedback from the interim evaluation suggested that Project Partners did not find them particularly useful. They were felt to be too long, with too much voiceover, and insufficiently focused on telling older people's stories. There was prominent Macmillan branding in the films even though they were not directly funded by Macmillan. To its credit, OPAAL took these ideas on board and took a different approach to the second round of filming.

SECOND GROUP OF FILMS

The second group of films focused much more closely on providing a platform for 'older people's cancer voices'. The idea was to be 'brave' about telling these stories, not shying away from complex or sensitive issues. Unlike the first group of films, which incorporated footage from each of the Project Partners, each film in the second group focused on a different individual client linked to one advocacy organisation. The four films are:

- 'Mike's Story' (produced with Dorset Advocacy). Released November 2016.
- 'David's Story' (produced with Help & Care). Released November 2016.
- 'Suzanne's Story' (produced with Sefton Pensioners Advocacy Centre). Released May 2017.
- 'Rosie's Story' (produced with Oxfordshire Advocacy). Released September 2017.

To a large extent, the second group of films

were felt to be ‘much better’ and more ‘powerful’ by Project Partners and other interviewees. They are on average much shorter than the first batch, which helps them have more impact.

BRINGING ADVOCACY TO LIFE

The films demonstrate what advocacy is ‘about.’ They show how the advocate works with the person in the round; they do not limit themselves to medical issues. They show cancer sufferers in their own homes - real people with real concerns:

‘My advocate asks all the simple questions that I don’t think of asking. I would be lost without her’ (Rosie).

‘I’m not afraid of dying. It’s not part of my daily routine to think about it’ (David).

‘It’s horrible being human sometimes - but that is what we are!’ (Mike)

Suzanne gives us a hint of the difficulties she has experienced:

‘In desperation, I turned up at my doctor’s surgery. I tried to get across how I was feeling to the receptionist, but I was told that it wasn’t a walk-in centre and I was turned away. They rang me two hours later to come back for an appointment. I found myself wandering around on the beach in a terrible state. I didn’t know where to turn.’⁸

We can immediately appreciate advocacy as essentially a community activity. One cancer nurse specialist viewing ‘David’s Story’ was apparently moved to tears, having not previously appreciated what

advocacy meant to him and his family. Showing how advocacy works in practice (rather than explaining this through a voiceover) is much more in line with what advocacy projects are looking for.

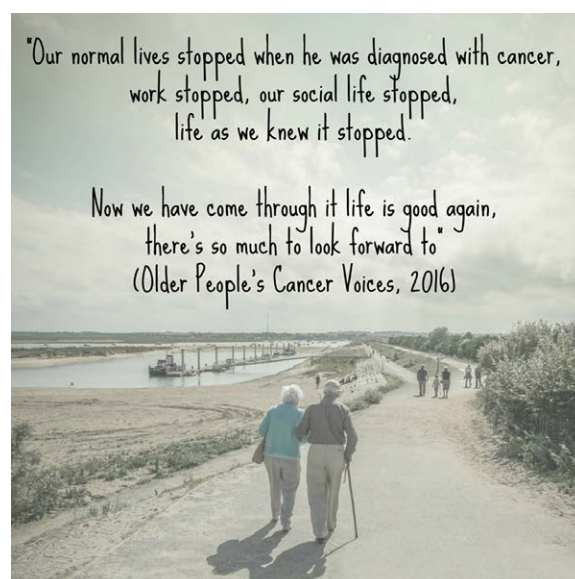
Advocacy organisations found the new films useful:

‘The films in particular are an easy way of showing what we do. If we don’t keep up the publicity we find our referrals drop. So the films are very useful.’

‘To listen to people talking about their experience on the cancer journey is much more powerful than just getting project reports.’

Because each film is linked to an organisation, it can be readily used to help promote the service, generating referrals and helping volunteers and others understand the work. It is a shame, however, that two of the films were not completed until after the national COPA funding had already run out.

⁸ OPAAL UK, ‘Facing cancer together’, 2016.



ISSUES RAISED BY FILMING

Filming with real clients does raise a number of issues. One is the difficulty of finding suitable people to take part:

'There are not many people who are willing, articulate and don't mind telling their story.'

'It was hard to find volunteers who wanted to do the films.'

A second issue is that the films are dealing with older people who have experienced cancer and who may be fragile physically and mentally as a result. As one Project Partner commented:

'People can be very vulnerable with cancer and it can be difficult to make informed decisions about things like this.'

One client agreed to be filmed but got cold feet as the filming was about to begin:

'She became very self-conscious after having facial reconstruction surgery and decided not to go ahead.'

The advocate must ensure they are not inadvertently putting pressure on the client, who may be grateful for the advocacy help they receive:

'I had a very good relationship with my client. She confided in me, and I didn't want to seem to be taking advantage of that.'

Many people will simply not wish to take part in filming because they see it as a potential infringement of their privacy:

'I've got nothing to hide but I'm a very private person. For me it was the idea that you would have no control of the material once you'd agreed to take part.'

'Lots of older people we spoke to did not want to be filmed.'

HEALTH PROFESSIONALS

One of the novel aspects of OPCV is that it was specifically targeted at influencing NHS health professionals and commissioners (as opposed, for example, to local authority commissioners). No doubt this is one of the reasons why the Department of Health chose to fund it. By targeting health professionals and improving their 'understanding of advocacy' the hope was this would translate into sustainable health funding for COPA, more referrals and more peer advocacy volunteers coming forward in the Project Partner areas.

"Appointments with doctors become something you look forward to, isn't that funny? It's the days where you're waiting, nothing is happening, you're on the "watch and wait" that you really hit rock bottom, because there's no progression, only you trying to live your life, which is quite different to the life you lived before cancer"
Older People's Cancer Voices, 2016

The overall experience of seeking to engage NHS professionals has been a rather bruising one:

'There is huge difficulty in raising awareness of cancer advocacy amongst professionals.'

'It's been a huge challenge trying to get GPs to refer. We've done a lot of work with district nursing teams too but don't think we've ever had a referral from either.'

'It is very difficult to reach commissioners as there have been so many changes of staff in the past few years. The whole landscape has been complex and changing and difficult to work with.'

'We are really struggling to engage with health professionals. Approaches have been tried through practice managers, and with Cancer Nurse Specialists, but none of this has resulted in any referrals.'

As one Project Partner said:

'Our challenge seems to be showing where our support for an older person affected by cancer will align with a health professional's job description.'

In the circumstances it is perhaps unsurprising that few health professionals were available to interview for this report (though several appeared in the OPCV films and made clear their support for cancer advocacy). None of the Project Partners had developed strong enough links with NHS commissioners to be able to put them forward as interviewees for this research. This is disappointing

because it is simply not possible to assess the impact of OPCV on commissioners without this evidence.

We did manage to secure an interview with an NHS commissioner outside the OPCV areas who did not wish to be named but whose views help to put this into perspective (Appendix 2).

INCREASING REFERRALS AND SUPPORTING VOLUNTEER RECRUITMENT

There is some evidence that OPCV resources have led to increased referrals. For example, the OPAAL Annual Report says that referrals from Macmillan's helpline and support teams increased by 84% following a talk by peer volunteer advocates.⁹ One Project Partner commented:

'The volunteer peer advocates gave a talk to a team meeting of cancer nurses. It had taken us a long time to secure a meeting with them. One nurse said after the presentation she felt much more confident about referring to the service after meeting the volunteers.'

Similarly, there is some evidence that having OPCV resources available (particularly the recent films) has supported volunteer recruitment for the advocacy projects:

'I'm going to be using the films in training for new volunteers.'

However, it is not easy to quantify the overall effect of OPCV in numerical terms on volunteer recruitment or overall referral numbers from the NHS.

⁹ OPAAL UK, 'Annual Report for the Year Ended 31 March 2017', p. 9.

OTHER INFLUENCING RESOURCES

Another key element of the project, in addition to the films, is the production of a number of online documents and materials to support advocacy organisations to 'influence' commissioners and decision-makers. Currently the resources are:

- 'Asset-Based Community Development: A learner pack for advocates supporting older people'.
- 'Engaging with health services and establishing advocacy on the cancer pathway'.
- 'Supporting older people to engage with decision makers'.
- 'Outcomes for older people affected by cancer'.
- 'What older people told us about their experience of cancer'.
- 'Defining advocacy cases as complex'.
- Media resources.
- My Cancer Advocacy Story Films.

These are hosted on a single OPAAL webpage containing more than 7,500 words of text.¹⁰ Interviewees said they had used the resources in a number of ways:

'I have used them as a point of reference for funding applications'.

However it is not always clear whether interviewees were referring to the OPCV resources or to other COPA resources. There was no doubt that online resources were felt to be preferable:

'Printed reports sometimes just go on a shelf and it is often easier to access things online and search for things in a digital version.'

We felt that the current presentation of the influencing resources could be improved. En masse they appear a little daunting, which perhaps accounts for the mixed reactions they have encountered.¹¹ We believe there is a great deal of valuable material here which would benefit from a more synoptic overview and presentation.

¹⁰ <http://opaal.org.uk/older-peoples-cancer-voices/>

¹¹ For example, from the audience at the Launch Event in Manchester on 1st August 2017.

"If you're older, isolated and alone, cancer throws up all sorts of worries and fears...advocacy is the only thing that gives you someone you can talk to... someone who has been there... Your family and friends will love you, but there are some things you just can't talk about with them"
(Older People's Cancer Voices Film 2015)

TIMES OF 'AUSTERITY'

One of the chief problems faced by OPCV has been that the project took place during a time of 'austerity' in which NHS funding for new projects has not been available. As Project Partners commented:

'The OPCV resources are designed to aid you when you already have a relationship with health commissioners. But if you can't get your foot in the door and you're just told 'we've got no money' it doesn't matter how fantastic the films or the toolkit are. They are not going to talk to you anyway.'

'We have found it very difficult to reach commissioners to present our case to them. So it has been impossible to directly influence any increases in funding'.

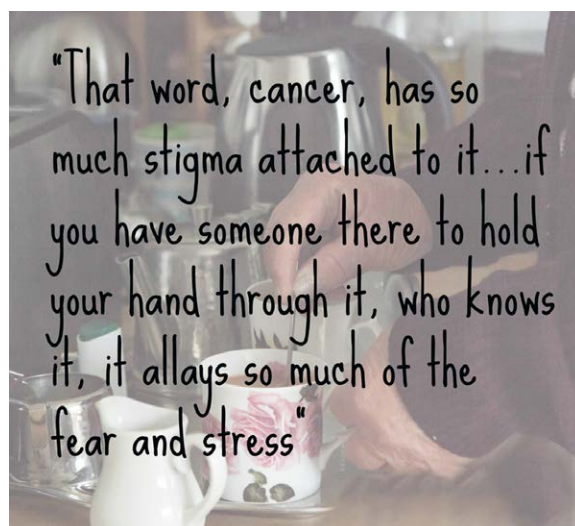
Nonetheless it is clear that some areas made strenuous efforts to influence health care professionals. Probably the most successful area in terms of activity levels was Dorset - perhaps because two Partners covered this large area and were able to support one another's efforts. In Appendix 3 we give an account of the activities of the joint Project Lead for Help and Care who is himself a Volunteer Cancer Advocate.

In Appendix 4 we describe the Dorset Appointments Advocacy Service at Royal Bournemouth Hospital developed by Dorset Advocacy. This appears to have come about as a direct result of 'influencing' activities of just the kind that OPCV is all about:

'Two of our paid advocates presented to a commissioner at Dorset CCG about getting advocacy on the lung cancer pathway. That gave us a really good link with the cancer lead in the CCG. We were then asked to be part in the national pilot. They've agreed to fund this until April 2018.'

These are positive developments within an overall context which has not been conducive to funding cancer advocacy. We must bear in mind that none of the thirteen COPA projects have received mainstream CCG funding to continue their work. It is hoped that the OPCV resources will continue to be utilised. As one interviewee commented:

'It's not a case of just sending it out there and waiting for people to see it. There's another piece of work that has to go alongside that. Now it needs to be shown to the right people at the right meetings to get them engaged.'



Conclusion

We saw in the Background section above that OPCV was closely related to COPA right from its inception. One interviewee summarised this by remarking:

'This is a means to an end. We are publicising the cancer advocacy service which actually helps ensure individuals affected by cancer get their voices heard.'

There is no doubt that COPA has achieved a great deal for older people affected by cancer.¹² But there was clearly no guarantee that COPA projects would receive mainstream CCG funding once the original funding came to an end.

This does not mean that OPCV has been a wasted project - far from it. There is much that is positive to be acknowledged. OPCV has succeeded in achieving the objectives it agreed with the DoH (to the extent that this was possible in the current economic climate). The project has bolstered OPAAL's experience of

partnership working. It has produced some great stories. The films in particular will continue to be powerful promotional tools for cancer advocacy and indeed advocacy in general. The influencing resources are thoughtful and considered.

Working with the health sector has not been easy. As one Project Partner commented, 'it can take a long time to turn a big ship around.' The NHS clearly regards advocacy as something funded by local authorities and not by health bodies.¹³ But OPAAL has worked hard to make the case for independent advocacy and should be proud of what it has achieved.¹⁴

¹² See OPAAL UK, 'Every step of the way', 2015, and 'Time - our gift to you', 2017.

¹³ <http://www.nhs.uk/Conditions/social-care-and-support-guide/Pages/advocacy-services.aspx>

¹⁴ For example, OPAAL is one of the few voluntary organisations to be shortlisted for a prestigious award from the Health Service Journal. See <https://www.hsj.co.uk/quality-and-performance/shortlist-forhsj-awards-2017-revealed/7020522.article>



As we said at the beginning of this report, the starting point for both OPCV and COPA is that so often older people are being let down by the health and care system. Now more than ever older people need someone on their side who understands this system but who is not in thrall to it.

We believe OPAAL can learn a number of important lessons from OPCV:

- Partnership working can be successful so long as the objectives meet the requirements of all partners. Where this does not happen (e.g. the first set of films did not meet the requirement of advocacy partners for local promotional material) partners can become disengaged.
- The choice of Project Partners and Project Leads happened quickly at the start of OPCV but the consequences were felt throughout the project. It was difficult in practice for Project Leads to engage with commissioners since none were chief officers, who are normally responsible for this kind of high-level negotiation (though they had many other skills).
- OPCV and COPA have shown that advocacy promotion can benefit from the use of digital media such as films, photographs, case studies and blog

posts. It is not always easy to judge the overall impact of such activities but they have helped to create a 'buzz' about the project.

- OPCV has demonstrated OPAAL's strength as a campaigning body with a national leadership role. There is much here to build upon and develop.
- Older people themselves are a key asset in promoting advocacy for older people. OPCV could form the basis of a strong national network of 'influencers' who can act as a virtual promotion community.
- A great deal of effort has been expended by OPCV to persuade health professionals of the benefits of advocacy but the results have been mixed. OPAAL needs to consider carefully how to take this forward.
- We felt that there was pressure to present advocacy in health contexts as contributing to 'clinical outcomes' or the 'cancer care workforce'. This needs to be balanced against the requirement to ensure that advocacy is independent.
- OPAAL should continue to be brave in promoting independent advocacy and not shy away from the realities of ageing under our health and social care system.

Appendix 1: Contacts and Interviewees

Aneesah Bana, Advocate, I-CANN

Andrew Booth, Director, SPAC

Angela Broadbridge, National Development Officer, OPAAL UK

Janet Cullingford, Services Manager, I-CANN

Angela Clarkson, Volunteer Coordinator, SPAC

Kath Curley, Staffs & Wolves Cancer Advocacy and Support Project Manager, Beth Johnson Foundation

Gary Finch, Dorset POPP Service Manager, Help and Care

Kathleen Gillett, Coordinator, Help and Care, Dorset Macmillan Advocacy

Genevieve Holmes, Macmillan Project Coordinator, Dorset Advocacy

Marie McWilliams, Operations Manager, OPAAL UK

Kath Parson, Chief Executive, OPAAL UK

Richard Rogers, Volunteer Cancer Advocate, Dorset Advocacy

Dr Lavina Sakhrani-Clarke, Dorset Macmillan GP

Bob Smith, Volunteer Cancer Advocates, Help and Care

Maddy Smith, Volunteer Cancer Advocates, Help and Care

David Strange, Volunteer Cancer Advocate, Help and Care

Marion Summers, Volunteer Cancer Advocate, Help and Care



Appendix 2: A Commissioner's View

'I get advocacy - I understand it. But I struggle talking to colleagues about it. Commissioners who are not involved in the voluntary sector often don't get it. Advocacy is not well understood amongst health professionals in general.

'To my mind advocacy is about empowerment, not simply signposting, but the two are often confused. If everything worked as it should we would not need advocacy. But that's not always the case. Empowering people may involve dealing with a range of issues facing them, such as financial security or quality of life.

'Anyone diagnosed with cancer is likely to feel quite fearful. Older people may feel they don't want to have treatment because of their age, but they shouldn't feel like that. Cancer advocacy is an opportunity to support older people through a critical period in their lives.

'From a commissioning perspective we are in times of austerity. This year we have reluctantly had to reduce funding across the voluntary sector to make ends meet. So at the moment we are not in a position to commission new services. In fact we need to make savings year on year. To commission new services we would have to take money from existing budgets.

'Not all commissioning needs to be done by ourselves or the local authority. A project supporting patients to attend hospital appointments might be a good idea, but we already fund our Acute Trusts through block contracts. They may wish to commission it themselves if they can save money, but we'd struggle to justify new funding if the CCG itself cannot make the savings.

'CCG management structures can be different in each area, so to understand who to go to and talk to about advocacy can be difficult. From a health and care perspective each CCG area should have someone who leads on cancer. CCGs should also have a clinical lead for cancer, as GPs are commissioners within CCGs too.

'Empowerment isn't the same as saving money or showing clinical outcomes. But if advocacy can show how it might have potential benefits along these lines, that would help to make the case.'

Appendix 3: Diary of a Project Lead / Volunteer Cancer Advocate

- 5.10.16 Interview with Forest Radio (East Dorset)
- 16.11.16 Talk to Ward Sisters from across Dorset at Wareham Hospital
- 7.12.16 Talk to Heads of Departments at Swanage Hospital
- 11.1.17 Two presentations to Macmillan HQ in London:
Customer Support telephone team
Macmillan UK-wide Mobile Support Team
- 1.3.17 HANDS patient support group in Dorchester
- 20.3.17 Presentation to Dorset Cancer Centre presentation
- 20.3.17 Presentation to Forest Holme Hospice
- 4.4.17 Talk to About Face patient support group in Poole
- 10.4.17 Talk to Afterglow Patient Support Group in Bournemouth
- 31.5.17 Talk to Wessex Cancer Trust in Bournemouth
- 24.7.17 Presentation to 'Older People's Cancer Voices' Launch Event in Birmingham
- 25.8.17 Talk to Poole Hospital Radiology Team
- 31.8.17 Presentation to Dorset CCG Commissioners
- 12.9.17 Presentation with OPAAL to Health Service Journal Awards Panel

Appendix 4: Dorset Appointments Advocacy Service at Royal Bournemouth Hospital

Dorset Advocacy is working in partnership with Royal Bournemouth Hospital as part of their Faster Diagnostic Standards pilot. Bournemouth is one of 5 local areas given pilot funding by NHS England to test out the best way to ensure all patients referred for diagnostic cancer tests by their GP get a result within 28 days.

Advocates support individuals to better prepare for appointments, gather information from the right sources, make more appropriate use of services and -

where necessary - cancel or rearrange appointments. Advocacy can provide vital support in this situation, helping individuals to engage with the process, overcoming practical and emotional difficulties.

The pilot is still in its initial stages but has already supported individuals to take part in the diagnosis process more fully and helped the hospital provide a more person-centred service. It runs until April 2018.



“There are a lot of decisions patients have to make and we try to help them as much as we can, but sometimes I think to have someone one to one at home with a lot of time to do that...it’s another pair of ears, you don’t take everything in when you’re seen in clinic” (Older People’s Cancer Voices Films 2015)