



The COPA Volunteer Experience

Report of OPAAL internal evaluation of the
Volunteer Cancer Support Advocates Role within
the Cancer Older People and Advocacy
Programme

**Internal evaluation conducted by Kath Parson
OPAAL Chief Executive**

Report compiled by Marie McWilliams
October 2015

The COPA Volunteer Experience

Cancer, Older People and Advocacy (COPA) is different from most other volunteer recruiting services. It has quite specific criteria for those it seeks to recruit. The service is designed to provide **peer** advocacy support. This means that the majority of volunteers recruited, trained and supported are older people over 50, who have themselves been affected by cancer.

Because of the nature of this group of people it's more likely that they will present with characteristics not present in the usual cohort of volunteers in the over 50 age bracket. During the course of volunteering they may fall ill again themselves, have to resume caring responsibilities, come up against memories that make it difficult for them to deal with or even die. All of these are very real situations which impact on the volunteering experience and which help place this evaluation report in context.

OPAAL's Chief Executive Kath Parson interviewed 28 peer volunteer advocates from the Cancer, Older People and Advocacy (COPA) programme in evaluation meetings held between June and September 2015. The resultant findings from those interviews will inform the whole programme evaluation being conducted by TwoCan Associates. 13 of the peer advocates interviewed volunteer for delivery partners who have been part of the COPA programme since its inception as a pilot project which began on 1st July 2012. The other 15 interviewees are peer advocates volunteering with new delivery partners all of whom joined the COPA Flagship programme as service providers on 1st May 2014.

Kath provided all interviewees with an information sheet (appendix 1) ahead of time which noted:

The aim of this evaluation is to find out:

- *What experiences you have had as a Peer Volunteer Advocate and whether you have learned anything new.*
- *What difference does this service make to you as a Peer Volunteer? How does it benefit older people affected by cancer?*
- *What factors help the advocacy service to work well?*
- *What are the barriers to a successful service? How you think these can these be overcome.*

The evaluation will capture the experiences of Peer Volunteers at each of the locations and draw out the lessons for others, so that they can then establish similar services in other parts of the country. A copy of the questions to be asked at interview was also provided ahead of time. A copy of those questions and responses is available in Appendix 2.

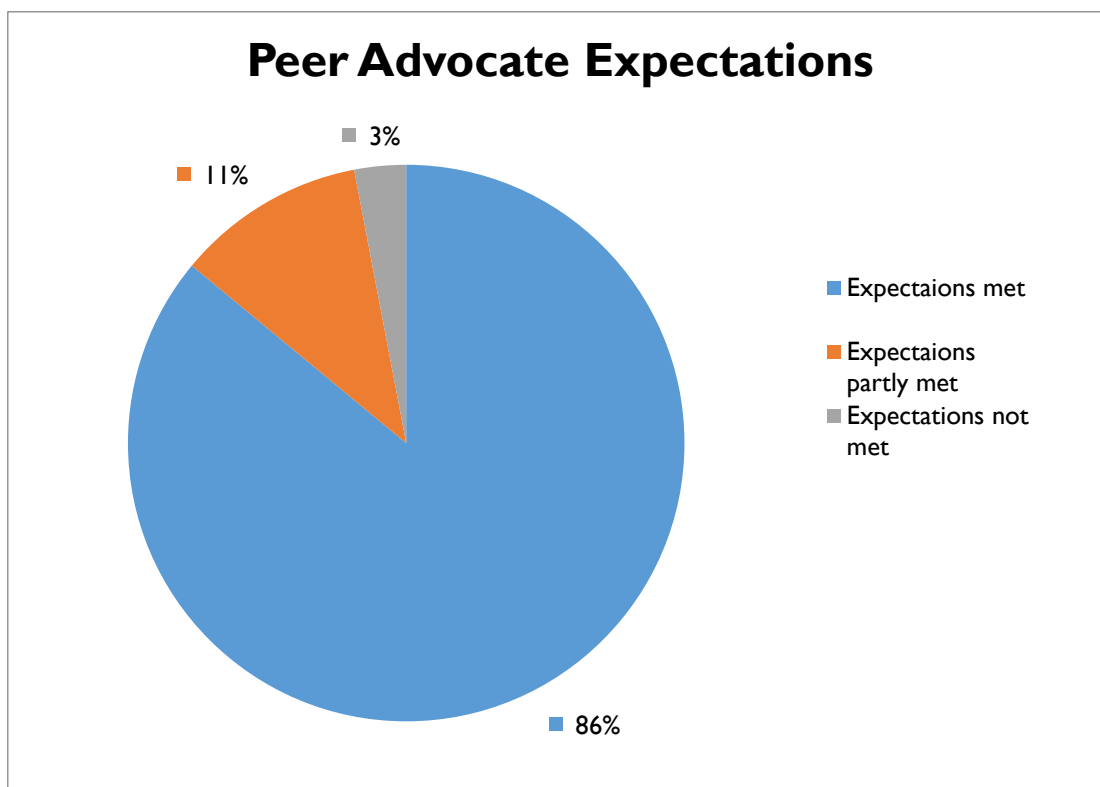
27 of the volunteers interviewed (97%) are keen to keep up their volunteer advocate role in the future:

"Makes a real difference to those we support. It ticks lots of boxes for me, I wanted to continue to use skill, experience & knowledge to help others, to make a positive difference to people's lives."

“I want to help people affected by cancer, and am happy to help people through the ‘cancer experience’. For me it’s all about putting something back, I was well cared for and I’m aware that a lot of other people are not so fortunate.”

The other 1 (3%) volunteer wants to be an advocate in the future but has no fixed plans at the moment. She explained that: *“We have carers’ responsibility for an uncle aged 96, also sister-in-law needs practical support. I’m unsure I will be available in future for the time I used to support the project.”*

24 of the 28 (86%) stating 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.”*

The volunteers interviewed came to the project with a range of skills but **18** (64%) identified improved people skills, **21** (75%) improved communication or social skills, **15** (54%) improved team working skills, **10** (36%) improved management skills and **11** (39%) improved organisational or time management skills as a direct result of being involved with the project.



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

“..increased empathy with others”

“confidence improved”

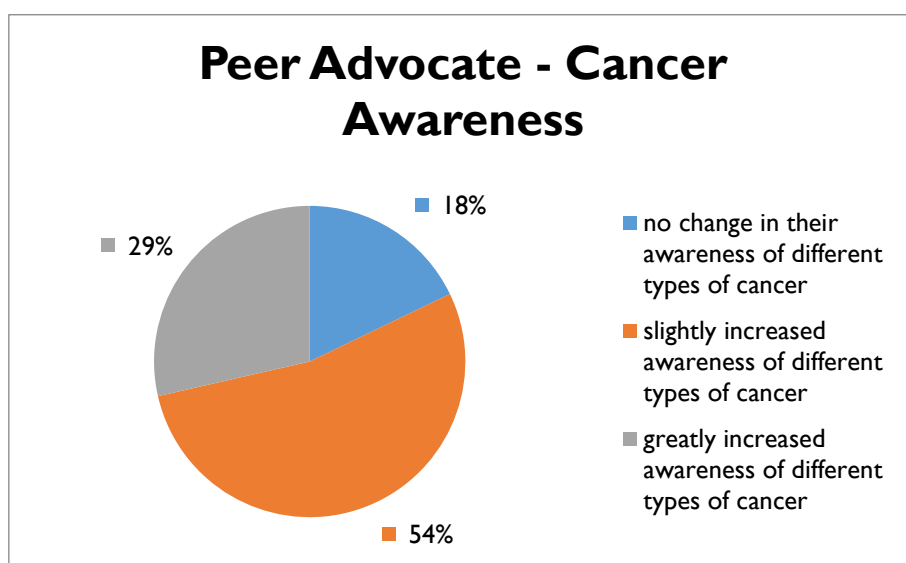
“I’ve learned a great deal about the bureaucracy of social services etc.”

“my appreciation of things that matter to other people”

Volunteers were also asked about their levels of knowledge and abilities as a result of their participation in the COPA programme:

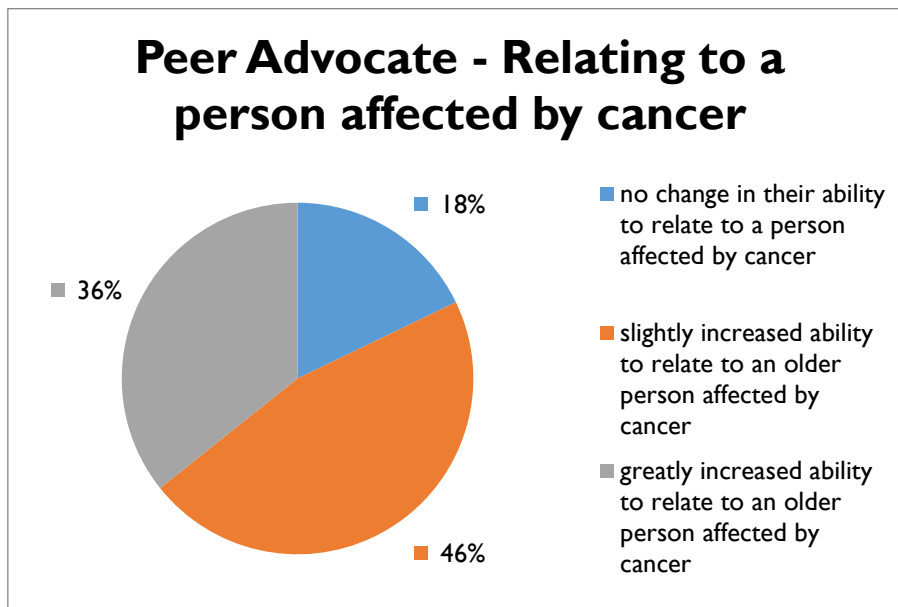
5 (18%) recorded no change in their awareness of different types of cancer,

15 (54%) recorded slightly increased awareness of different types of cancer whilst **8** (28%) recorded that this had greatly increased;



5 (18%) recorded no change in their ability to relate to a person affected by cancer,

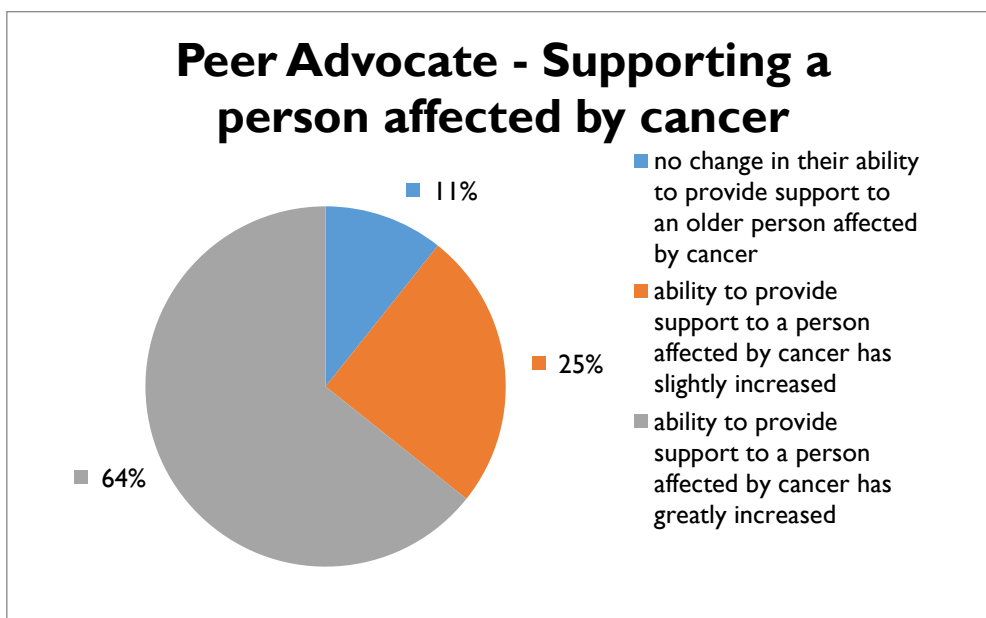
13 (46%) recorded a slightly increased ability to relate to an older person affected by cancer with 10 (36%) saying that this has greatly increased;



3 (11%) recorded no change in their ability to provide support to an older person affected by cancer,

7 (25%) said that their ability to provide support to a person affected by cancer has slightly increased with 18 (64%) saying that this has greatly increased.

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.”*



Volunteers were also asked a range of questions about their feelings and thoughts after being involved in the programme:

1 (3%) recorded **never** feeling optimistic about the future, **5** (18%) **sometimes** feel optimistic about the future, **12** (42%) **often** feel optimistic about the future whilst **10** (36%) feeling optimistic **all of the time**;

5 (18%) feel useful **some of the time**, **9** (32%) feel useful **often** and **14** (50%) feel useful **all of the time**;

1 (3%) recorded **never** feeling relaxed, **1** (3%) **rarely** feels relaxed, **3** (11%) feel relaxed **some of the time**, **15** (54%) **often** feel relaxed whilst **8** (28%) feel relaxed **all of the time**;

2 (7%) recorded dealing with problems well **some of the time**, **14** (50%) **often** deal with problems well and **12** (42%) deal with problems well **all of the time**;

1 (3%) recorded **rarely** thinking clearly, **3** (11%) think clearly **some of the time**, **9** (32%) **often** think clearly and **15** (54%) think clearly **all of the time**;

1 (3%) recorded **rarely** feeling close to people, **2** (7%) feel close to people **some of the time**, **7** (25%) **often** feel closer to other people and **18** (64%) feel closer to other people **all of the time**;

1 (3%) recorded being able to make up their own minds about things **some of the time**, **10** (36%) are **often** able to make up their own minds about things and **17** (61%) make up their own minds about things **all of the time**.

As mentioned previously **27** (97%) of volunteers would like to continue as peer advocates but **1** (3%) has caring responsibilities which are likely to preclude that.

Comments made by volunteers on why they want to stay involved include:

“Because I believe I can make a real difference, I can help people practically & 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 & worries.”

“Recently trained, increased confidence, enjoy making a difference, good inter-personal skills.”

“Something I need to do, being told as much by others, helping people and feel fulfilled. Other people tell me I make a real difference to their lives.”

“Want to help other people. I’ve enjoyed what I have done so far and wish I could do more.”

“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 & 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.”

“I want to be able to support someone in need of support at a difficult time in their lives. I have the right skills & attitude to offer this support. In doing so the reward for me will be to feel I am available to support them when they need someone.”

Volunteer views on **what is working well** in the COPA programme were varied but the consensus was on the quality of training and support offered by COPA delivery partners. Volunteers commented:

“The training offered ... is excellent”

“Training to gain knowledge of advocacy the role & other cancer information & guidelines”

“The team of staff & volunteers, being able to learn from them”

“Being supported through the staff team”

“Level of support from staff appears to be very good. Also set up system of mutual support between volunteers”

In addition, feeling able to make a difference in the lives of older people affected by cancer seems to be a major driver in what’s working well for volunteers:

“Results that you see in partners, positive changes”

“When I’m with people I’m supporting, feel able to help, it’s a very positive experience for both of us”

“I enjoy helping the people we support “

“Being able to support people by myself, and start to develop a ‘bond’ with that person”

There were several suggestions as to what is **not working so well** for volunteers in the COPA programme and universally volunteers offered suggestions as to what might help.

The **lack of referrals** is frustrating for volunteers as it means they are not as busy as they anticipated or would like to be:

“I think it would be helpful if Macmillan could do more to help us, perhaps by sending us more patients and carer’s to support”

“Not being as busy as you expected”

“I’m ready for another client now”

“Waiting for referrals”

Additionally, volunteers perceive a problem with **insufficient publicity** for the COPA

service which might be one of the reasons for low referral rates:

“Publicity – we need to do more to inform professionals about the service. Participating in local fairs and events”

“Need to do more to let older people know that the service is here.”

“Marketing needs to improve, how to use loop videos in GP surgeries – could we do this with the new films? Accident & Emergency and Outpatients screens – investigating how we could use these in hospitals too”

“Marketing & publicity – not happening quickly enough”

“Only got one person, more promotion needed”

Volunteers also stated concerns about **engagement with health professionals** and being able to **explain what’s unique about advocacy** compared to other available services:

“Very difficult to engage with medical profession”

“Plethora cancer charities, difficult to put over our unique selling point, i.e. advocacy”

“Need to do more work with health professionals”

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 & 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.’”

“I’m happy with the role as it enables me to continue my interest in health & supporting others less fortunate than myself. I feel my own experience of cancer coupled with my nursing background gives me a unique insight into supporting OPABC living with cancer.”

“I have a disabled son and husband at home and I regard my volunteering time as my time, a time for me to give something back to support others who have no one else to help them. In return I get out of the house, meet some amazing people and am able to work closely with my fellow volunteers as part of a team. We also socialise a lot so this helps me to keep in touch with my local community. It saves me from becoming isolated due to my carer’s role.”

“I enjoy the role”

“Enjoying it very much, good use of your skills”

“I find it very rewarding as well as helping others”

The COPA Volunteer Experience, then and now

During August 2013 Kath Parson conducted interviews with 11 volunteer advocates as part of the evaluation of the earlier COPA pilot project, which ran from July 2012 until March 2014. OPAAL thought it might be useful to compare and contrast some of the findings from those earlier interviews with those noted above.

27 (97%) of peer advocates interviewed recently want to continue in their volunteering role with the other **1** (3%) unable to commit because of caring responsibilities. This compares to **11** (100%) in the earlier study. This indicates a real commitment from peer advocates and a desire to support their peers to the best of their ability.

In the most recent interviews **24** of the 28 (86%) stating 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. This compares to **9** (82%) stating that their expectations of being an advocate had been met whilst the other **2** (18%) said that their expectations had been partly met. Comments made by those not fully satisfied in each study indicate a common theme of **lack of referrals** having a negative impact on satisfaction levels. This continues to be an area of concern for OPAAL and is the rationale for the creation of the National Health Professionals Board.

Both the earlier and most recent study show a recognition amongst volunteers that skills levels have improved in a number of areas as a direct result of being involved in the COPA programme.

In the most recent study **18** (64%) identified improved people skills, **21** (75%) improved communication or social skills, **15** (54%) improved team working skills, **10** (36%) improved management skills and **11** (39%) improved organisational or time management skills. This compares favourably with the pilot where **6** (55%) identified improved people skills, **7** (64%) improved communication or social skills, **2** (18%) improved team working skills, **1** (9%) improved management skills and **4** (36%) improved organisational or time management skills.

Whilst volunteers were asked in both studies about their feelings and thoughts after being involved in the COPA programme OPAAL has decided against comparing and contrasting such subjective views.

Our appreciation and thanks go to the following:

Andy Lester, Sandwell Advocacy (SCOPA)
Barry Senior, Sefton Pensioners' Advocacy Centre (SPAC)
Bob Smith, Help & Care, Dorset
Carol Wood, Independent Community Advocacy Network North (ICANN)
David Strange, Help & Care, Dorset
Geoff Allan, AgeUK Bristol
Janice Deane, Help & Care, Dorset
June Palfreyman, Knowsley Pensioners Advocacy Information Service (KPAIS)
Karen Bower, AgeUK Northumberland
Kathryn Walton, AgeUK Bristol
Leanne, Knowsley Pensioners Advocacy Information Service (KPAIS)
Lisa Labrey, Sefton Pensioners' Advocacy Centre (SPAC)
Lorraine Toker, Sefton Pensioners' Advocacy Centre (SPAC)
Maddy Smith, Help & Care, Dorset
Margaret O'Donohue, Independent Community Advocacy Network North (ICANN)
Margaret Sanderson, Age Connects Cardiff
Mary Ripley, Help & Care, Dorset
Michael Worthington, Oxfordshire Advocacy (OA)
Neil Topping, Oxfordshire Advocacy (OA)
Pauline Wood, Beth Johnson Foundation (BJF)
Richard Rogers, Dorset Advocacy
Richard Timson, Independent Community Advocacy Network North (ICANN)
Rod Penny, Dorset Advocacy
Sandra Casey, Independent Community Advocacy Network North (ICANN)
Sherry Chudyk, Sandwell Advocacy (SCOPA)
Susan Mackie, Oxfordshire Advocacy (OA)
Wendy Sandbrook, Beth Johnson Foundation (BJF)

Appendix 1

An OPAAL evaluation of the CANCER OLDER PEOPLE'S ADVOCACY PROGRAMME 2015

Peer Volunteer information sheet

About this evaluation

The Cancer Older People's Advocacy programme (COPA) is aiming to provide advocacy support to older people affected by cancer to help them make decisions and access care throughout their cancer journey. The project is led by the Older People's Advocacy Alliance.

The aim of this evaluation is to find out:

- What experiences you have had as a Peer Volunteer Advocate and whether you have learned anything new.
- What difference does this service make to you as a Peer Volunteer? How does it benefit older people affected by cancer?
- What factors help the advocacy service to work well?
- What are the barriers to a successful service? How you think these can these be overcome.

The evaluation will capture the experiences of Peer Volunteers at each of the locations and draw out the lessons for others, so that they can then establish similar services in other parts of the country.

Who is carrying out this evaluation?

The Older People's Advocacy Alliance is carrying out this part of the evaluation. Kath Parson OPAAL's Chief Executive will carry out these interviews.

How and when is this evaluation being done?

Interviews will be held with Peer Volunteer Cancer Support Advocates in each of the locations during June, July and August 2015.

Do I have to take part?

It's up to you to decide whether or not to take part. If you agree to be interviewed, you are free to change your mind at any time without giving a reason.

What will be involved if I agree to take part?

One of your local project team members will arrange a time and date to interview you. This will be a face to face interview, or if more convenient a telephone interview. They will ask you for permission to record the interview. This is to help with note-taking and to make sure we get accurate quotes.

What kind of questions will I be asked?

OPAAL are not going to be assessing you or the organisation you work with. You're not being tested. The aim is to draw out lessons for other organisations, so that they can learn from your experience. So the questions OPAAL will ask will be about what has worked well, what has not worked well and what could have been done better. It would be helpful if you can be as open and honest as you can, especially about the challenges and difficulties – as often this is where the most useful lessons come from.

Will my information be kept confidential?

Only OPAAL will have access to the recordings and written notes from the interviews. The notes will be stored on their computers, so no one else will be able to access them. One month after the end of the evaluation, when the final report has been written and published, the recordings and transcripts will be deleted.

Your name will not be used in any of the reports – except in the acknowledgements section, and only if you have given your permission. Any quotes will not be attributed to named individuals but to a general description of the person such as 'advocate'. So as far as possible all quotes will be anonymous. You will be able to check drafts of the reports to ensure you are happy with the way you have been quoted, before any of the reports are made available to other people.

What will happen to the information I give?

The notes from all the interviews from all sites will be used to write a report, this internal report will be passed to OPAAL's external evaluators who will use the information to inform a final project evaluation report due to be published in November 2015. This will include lessons about the ongoing management of the service, for example supporting advocates and overcoming any barriers to advocacy support.

The reports will be shared with all the stakeholders in the project. This will include:

- People working at all delivery sites, staff and volunteers
- Local and national cancer champions
- The new National Health Professionals Board
- OPAAL (The Older People's Advocacy Alliance) and the advocacy organisations who form the national partnership
- Macmillan Cancer Support and the Big Lottery Fund who have funded this project

Who is overseeing this evaluation?

There is a Project Management Group overseeing the project as a whole and the evaluation. The Project Management Group consists of a senior staff member from each of the delivery advocacy organisations and OPAAL. The evaluation is also overseen by local and national cancer champions.

Who should I contact for more information?

In the first instance please contact Kath Parson

Email: kath@opaal.org.uk

Tel: 07966039797

Thank you

Thank you for taking the time to read this information sheet.

Kath Parson
Chief Executive
May 2015.

Appendix 2

OPAAL – Cancer Peer Advocate questions & responses

1. Have your expectations of being an advocate been met?

- Yes - **24** (1 comment: "surpassed")
- No - **1**
- Partly - **3** **Total interviews = 28**

2. Please explain your answer if the box below:

Exceeded a bit, mother and other family died of cancer. Expecting it to be like a befriending role. Pleased that it's much more than this, particularly contact with other professionals.

Mostly met, completely different each partners. Some 'light touch' others quite emotional. Thai man being supported with dentures and spectacles, Npower gas man.

Cared for father who had cancer. Previous advocacy volunteer so know what to expect.

From a training background, impressed.

Done shadowing with Angela, done first visit, used system to log case record.

Done training, team orientated, have support you need. Trained counsellor & mentor. Got a new client to meet soon.

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

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.

Opportunity to put something back, I have shadowed the professional advocate. My background is working with people with learning disabilities, this has helped me to be a good listener, and to pick up sudden changes in behaviour.

Had two training sessions, one on advocacy and one on cancer, not as practical as expected due to needs of OPABC being paramount. My brother died of cancer so I know & understand the impact of cancer on one's life.

Joined to help OPABC, I've had cancer and nursed mum & aunt through cancer. Used to be an office worker, since coming to work with COPA a lot of my people skills have returned.

Background as a nurse. Also volunteers as End Of Life befriender.

Useful training preparing me for the role, particularly second day when we worked at what an advocate is and is not.

Completed two volunteer courses re: advocacy & cancer. Patient with cancer 2013 had skin and breast cancer, Macmillan volunteer – information & signpost. Volunteer patient tutor represent ladies who've had breast cancer, so lots of volunteering experience.

Lost Grandad to cancer, so it motivated me to volunteer. I've very much enjoyed the training, especially the one page profiles. I don't have a lot of confidence but I do have a lot of knowledge on how it is to live with cancer and I need to use this to support other people

In my previous role as a health visitor & cancer support nurse you found that advocacy is very important. I found that when treatment ended support ceased leaving patients in an abyss. I was a founder member of St Catherine's Hospice, established cancer help local charity who saw 6000 patients (included a Macmillan info base). I expected to be able to continue to use knowledge to inform advocacy role.

Also a volunteer at a local hospice palliative care. Had 3 referrals. Be able to feel useful.

Been volunteering 3 and a half years. I thought there would be more health apt, in fact been supported in lots of other ways, practical ways getting a boiler fixed, sorting out administration & paperwork, accompany to hospital. Blind 80 year old accompany to hospital, sorting out admin, accompany to CAB etc., cancer & Alzheimer's – arrears with rent – bailiffs etc.

Help people at critical moments in partners lives, I know this is the case. Man, 63, bowel cancer, Danish so language issues, needed financial support – access bank account, owned property needed to decide whether to sell it & also issues relating to his care arrangements. Support him with all these issues over 4 months – worked in partnership with community social worker & care home manager. Had to build a picture re: funeral arrangements. Now allocated long term & complex cases.

I was well matched with my client. Background in drug/alcohol & mental health

I've learned more about cancer, good to go back to one to one support & re-learn earlier skills. I enjoy being part of BJC team & with other volunteers.

I've had cancer of throat and treated at Castlebridge & Aintree. I had desire to put something back, so I looked on the MAC Cancer Voices website and contacted Janet, who interviewed me and offered me training. I was fortunate in that I had support, I am keen to support those people who don't have anyone.

I've enjoyed it, it's given me something to do. I especially enjoy working with Janet as she always remembers we are volunteers and doesn't pressurise us. If I tell her I can only work on certain days this is fine. I'm able to 'give something back' and really believe I make a positive difference to the lives of the people I support.

Retired staff nurse had a good idea of what was expected. I've been able to provide emotional support, which was appreciated.

Training helped bring the role into focus. Making sure OPABC voice is heard. Some people get tongue tied with authority figures, I helped instil confidence. Help with understanding information in forms and filling these out for them, making telephone calls. Very satisfied that we can help get stuff sorted out for people. Making sure meds are up to date, have benefit people are entitled to.

Had befriending & respite volunteer with mum. Ad appeared in local paper so replied. Explained expectations on both sides. Work with John – complex needs, boundaries getting blurred with carers. 1 visit a week – hospital every 3 weeks, each visit up to 7 hours. Bigger commitment than expected.

Partner 4-5 months early days, a little in denial

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

Not had any expectations - had 3 lots of cancer, use this experience to relate to others. Already had wide ranging experience of working with the public.

Came into it like a campaigning issue, i.e. people expect difference with NHS, largely to do with information, feelings of neglect, a voice for voiceless. Found it was about negotiating relationships within families or other agencies. Die with it, not of it...what did this mean? Found that local medical experts not always gone with interests of the patient.

I expected to be able to support partners along a cancer journey and I've been able to do that. Client in 80's with endometrial cancer, no family support, developed close professional relationship, supported with appointments CNS, specialist, therapy & treatment. Three months of intensive care. Did everything COPA was set up to do. Lady passed away. Documentation

3. As a result of being a Peer Volunteer advocate, have you improved any of the following skills? (select all that apply)

- People skills - **18**
- Communication or social skills - **21**
- Team working skills - **15**
- Management skills - **10**
- Organisational or time management skills - **11**
- Other - **6**

Comments on skills:

Communication or social skills:

- appreciate how cancer impacts on their lives
- definite improvement because involves talking about difficult subject

- vastly increased confidence levels
- improved greatly

Team working skills:

- not many meetings of volunteers

Management skills:

- Using SAM
- using SAM

Organisational or time management skills:

- more organised

Other:

- my appreciation of things that matter to other people
- I've learned a great deal about the bureaucracy of social services etc.
- my appreciation of things that matter to other people. Been able to apply pre-existing skills to new field and develop
- confidence improved
- already arrived with these skills. Some of these improved over time
- increased empathy with others

General comments:

- Not really as these are skills I already have
- Understanding and enlightenment improved at this stage rather than skills
- Not yet supported OPABC
- Completed training to be a Tutor Volunteer and now started a counselling course in September with a view to a career helping others
- I've been able to maintain a lot of my skills and improve many of these
- I've been able to retain all these skills since I've retired
- Maintained people skills, communication or social skills and team working skills

4. For each of the following statements, please circle the number that best describes your level knowledge and abilities as a result of being an 'advocate.

	Greatly decreased	Slightly decreased	No change	Slightly increased	Greatly increased
Awareness of different types of cancer			5	15	8

Ability to relate to a person affected by cancer			5	13	10
Ability to provide support to a person affected by cancer			3	7	18

5. Below are some statements about feelings and thoughts after being an advocate. Please circle the number that best describes your experience of each over the life of the project (please circle one number for each)

	None of the time	Rarely	Some of the time	Often	All of the time
I've been feeling optimistic about the future	1		5	12	10
I've been feeling useful			5	9	14
I've been feeling relaxed	1	1	3	15	8
I've been dealing with problems well			2	14	12
I've been thinking clearly		1	3	9	15
I've been feeling close to other people		1	2	7	18
I've been able to make up my own mind about things			1	10	17

Warwick Edinburgh Mental Well-Being Scale (WEMWBS) © NHS Health Scotland, University of Warwick and University of Edinburgh, 2006, all rights reserved.

6. After being an advocate in the Cancer, Older People and Advocacy project, do you plan to continue your role as an advocate?

Option 1 Yes I will definitely want to continue my role as an advocate
- 27

Option 2 Yes I want to be an advocate in the future but have no fixed plans at the moment - 1

Option 3 No - 0

7. If you selected option 1 or 2 for question 6 please explain your reasons for wanting to continue your role as an advocate in the box below:

Like working with people. Industrial relations, HR Manager, quality background. Lots of people skills. Motivated by a real interest in other people.

Something I need to do, being told as much by others, helping people and feel fulfilled. Other people tell me I make a real difference to their lives.

Recently qualified as L3 Advocate – Certificate

Increased confidence

Recently trained, increased confidence, enjoy making a difference, good interpersonal skills.

Became mother late in life, still has school aged child. 6 years ago wanted to volunteer to maintain skills and confidence. Been very satisfactory for you in this respect.

Have taken on other roles e.g. chair of LCCB, proud of this board. Represent board at National level.

Very good with different ages. Using your own cancer experience, helps to make a connection with others.

I'm a caring person, empathetic & intuitive & enjoying helping people.

Being able to understand where people are at in their lives and support them to achieve their goals

Want to help other people

I've enjoyed what I have done so far and wish I could do more.

Started volunteering with others, Advocacy in Care Homes with RVS & Age Cymru – 'Add to your life' NHS project people over 50. Also interested in pursuing a career in Advocacy and training opportunities.

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 & worries.

I want to fill up my time with fulfilling and rewarding activities. I have relevant experience of issues & problems older people face. My background is in legal advocacy and I feel there are many parallels between the roles. I believe I have the skills & motivation to support others.

Because I believe I can make a real difference, I can help people practically & 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 want to be able to support someone in need of support at a difficult time in their lives. I have the right skills & attitude to offer this support. In doing so the reward for me will be to feel I am available to support them when they need someone

Project manager at Macmillan recommended Kathryn to Bristol. 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 & 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.

I think it's selfish for me not to continue to be involved caring and supporting patients in my retirement. I also feel I have something valuable to offer them. Because of COPA I am learning more about cancer and the services & support offered by Macmillan and others. I also enjoy being involved with a national organisation like OPAAL, and hope that this involvement will ultimately improve services for patients.

I'm enjoying the experience, believe it's worthwhile, I have the time to offer

Because for a limited time period I can make a real difference to other people's lives. Want to continue to direct energies into caring for others.

I like to keep busy. I like working with people, I enjoy the diversity. I enjoy giving something back. Enjoy training on offer and the social aspects of volunteering.

It allows me to exercise my brain, I feel very much a part of the team & the organisation as a whole. It's a very worthwhile project, I can see lots of value for OPABC and their families. Other professionals are now beginning to value the project.

I want to help people affected by cancer, and am happy to help people through the 'cancer experience'.

For me it's all about putting something back, I was well cared for and I'm aware that a lot of other people are not so fortunate.

We've recently moved house and I've been supporting my sister in law with cancer who lives in Scotland, so I haven't done as much as I would have wished to recently. I'm looking forward to doing more now as my sister in law is out of hospital. I enjoy the role meet some very nice people.

Janet is so supportive, always there for me if I need advice and support and never takes advantage of any of us volunteers.

I like to keep in touch with the people I've supported, just to make sure they are going on alright. It makes a big difference, working for a service that is appreciative of the time and commitment we give to the service. It's good that this is recognised.

I feel I am able to be useful to others. I'm also motivated to continue to use my knowledge & skills to give something back to those who need my help.

Option 2: We have carers' responsibility for an uncle aged 96, also sister-in-law needs practical support. I'm unsure I will be available in future for the time I used to support

the project. Have learned about housing, DWP and a lot of other information

Seen positive impact on people needing help. Able to support people to help themselves. Empowerment.

Terminally ill partner, got to do an Advanced Care Plan. A client sees Advocates not about cancer because it is voluntary.

My awareness raised about lot of people not having quality of life they should have. Not want to feel people are alone & isolated, no one wouldn't listen. Not wish to live next door to someone going through it.

Quite enjoy work, meeting people, helping people. Supported 8 people

I want to be useful & important in present political climate, the agencies/charities that support older people are vital. Even the smallest thing I can do to help is what I feel. Desire to fight negligence, arrogance etc. Angry with government. Degree of self-worth, act of feeling I can assist others. It's an opportunity to meet people I would not usually meet. It's a learning experience.

Makes a real difference to those we support. It ticks lots of boxes for me, I wanted to continue to use skill, experience & knowledge to help others, to make a positive difference to people's lives. Only there for her and able to support her to make difficult decisions e.g. refusing chemo. Felt very welcome by professional health staff, radiotherapists, oncologist, CNS, pre-op assessment staff – all of whom recognised the advocacy role.

8. If you selected option 3 for question 6 please explain your reasons for not wanting to continue your role as an advocate in the box below:

9. What are the top two things that are working well for you?
1. Contact with people
 2. Research I have to do to find out about services for older people
-
1. Results that you see in partners, positive changes.
 2. Support & Training from staff
-
1. Meeting clients, one cancer client and two others e.g. benefits & physically disabled young woman
 2. Part of a team
-
1. Relationship with Angela & the team is very good
 2. Access system from home so don't have to come into office

1. The team of staff & volunteers, being able to learn from them
 2. Good training, looking forward to End of Life training
1. Support is very good, always able to go through problems
 2. Training Sessions
1. When I'm with people I'm supporting, feel able to help, it's a very positive experience for both of us
 2. Feel supported & appreciated
1. Being able to support people by myself, and start to develop a 'bond' with that person
 2. To be given the tools & support to do the job
1. Positive impression Age UK Bristol staff
 2. Supportive induction programme. Shadowing with Juliet prior to taking on own case
1. I enjoy helping the people we support
 2. Being supported through the staff team
1. Level of support from staff appears to be very good. Also set up system of mutual support between volunteers.
 2. Written information very good
1. Training to gain knowledge of advocacy the role & other cancer information & guidelines
 2. Being part of new project
1. Support of the COPA team
 2. Relaxing being with others that want to help people
1. The training offered by OPAAL & ICANN is excellent
 2. The local & national support is also excellent
1. Works well that I also volunteer in our local palliative care hospice as this generates referrals for COPA
1. Good support from Oxfordshire Advocacy
 2. Excellent training opportunities – monthly meeting with peers from south east group
1. I'm able to maintain contact & receive support which is always available from the team.
 2. The ongoing training opportunities
1. Feeling part of a team
 2. Fulfilling a necessary role for the client

1. Training experiences are working really well
2. Supportive staff at ICANN

1. Support from Janet and the rest of the staff team. The way she runs the scheme is very flexible I have disabled son and husband and am the main carer in our home so sometimes I'm needed there.
2. I regard my volunteering as 'me time' I'm able to keep learning new things, socialize with other volunteers and also be useful to others.

1. The support offered to me by COPA staff
2. The training was very good

1. The BJB network staff & volunteers
2. I've learned a lot and know I could find a way in to new learning

1. Support & regular meetings, can phone with problems re cases
2. Ongoing training

1. Able to feel useful and helping people
2. Support from project staff & training for volunteers

1. Really liked person paired with, regret did not know her sooner
2. Learned to be sensitive enough to 'back off' when daughter appeared

1. Get interesting cases. Can be complex, needs investigating as to suitable outcome

1. People who offer support to me are very positive, enthusiastic, genuinely caring people, especially to volunteers

1. Support from Oxfordshire Advocacy
2. Enjoy being part of the professional board

10. What are the top two things that are not working so well for you?

1. Cannot think of anything

1. Frustration to do with the role, I can see partners need help – not making decisions when they need to
2. Marketing & publicity – not happening quickly enough

1. Challenging client, personality disorder, can be verbally aggressive, aged 85, multiple conditions, can be unreasonable

1. Only got one person, more promotion needed. Use blog for volunteers

1. We could look at safety of volunteers working in people's homes

1. Not being as busy as you expected
2. Challenges associated with people need(ing?) to make a decision

1. Lack of referrals
1. Broaden out the training to include signposting into health services
1. There will be a big learning curve i.e. types of support
1. Very difficult to engage with medical profession
2. Plethora cancer charities, difficult to put over our unique selling point. i.e. advocacy
1. I'm ready for another client now
1. Waiting for referrals
1. In the beginning for my first training the online Macmillan training not easiest site to navigate, however I managed.
1. Because complex situation, can need help 7 days a week so more of a commitment than expected. So if need weekend help can impact on our chores at home. Trying to bring back into Mon-Fri role.
1. Offered to speak to group of carers, this was not yet taken up.
1. Backed away a little for personal reasons, and not what I expected. Felt a little powerless.
11. What two things would you like to see in the future (to improve the service)?
 1. Need to publicise the service more
 1. Royal Bournemouth session on expert subjects. Could we have someone from our service to present information about advocacy at one of these sessions?
 1. SAM needs improving – more user friendly
 2. Too many blogs – needs to be more informative to directly benefit advocacy work, raise awareness of advocacy issues
 1. More use of social media platforms
 2. Could have access to benefits training
 1. Marketing needs to improve, how to use loop videos in GP surgeries – could we do this with the new films?
 2. Accident & Emergency and Outpatients screens – investigating how we could use these in hospitals too
 1. Don't appear to be getting referrals from Macmillan

1. I'd like to learn more about how we can help others e.g. signposting
1. Need to do more to let older people know that the service is here
2. Need to do more work with health professionals
1. Publicity – we need to do more to inform professionals about the service
2. Participating in local fairs and events
1. Continue to recruit more men to the service to maintain balance of skills, experience & background
1. Recruit more volunteers. It would make it easier for the team to manage when new referrals come in.
1. Improvements to use of the films and to use case studies
1. I think it would be helpful if Macmillan could do more to help us, perhaps by sending us more patients and carer's to support.
2. Asked for advice from Macmillan Helpline as I had a client with severe financial problems. They sent us the wrong forms, so we had to ring again to get the right ones. Eventually and with Janet's help we managed to secure some money for the client. Janet was very good and made sure she fed back to Macmillan the problems we had had.
1. When first involved, try to keep within agreed boundaries & be aware that OPABC can seek to extend these. Can say no.
2. If find this is happening, bring back into supervision.
1. Offering more support for carers, can feel isolated & lonely
1. Needs investigating into some cases, advocate referring to POP when could have been directly referred.
2. People should ask if they want an advocate
1. Training was on theory – more practice & case histories. What does it mean? For me, for others etc. Common themes
2. Attracted by autonomy
1. More promotion of the service
12. Is there anything else you would like to share about your experience of being a Peer Volunteer Advocate?
 1. Improving people skills. Giving people options and letting them make their own decisions. Longer process, more involved, diplomatic skills also needed. Always need to work around clients' needs.
Learned from other volunteers who themselves have had cancer
Visit to hospice for 4.5 hours for 3 days looking at palliative care.

1. Benefits of being involved in LCCB & NCCB – meeting with other delivery partners.
Also meet lots of people locally who are involved. All of which helps broaden my experience & knowledge.

1. Would like more people to help
Like to put hours through electronically & be able to claim expenses and be paid by BACS
Would like to do paid part-time Advocate

1. Enjoying it very much, good use of your skills

1. I still have a passion to support people with learning disabilities. There are a lot of care providers in this area including supported living & community homes.

1. I'm very happy to put myself forward to be filmed at a future date if required to assist in promoting the service

1. Concerned about how transient relationships might be.

1. I find it very rewarding as well as helping others. I have a case where I suspect financial abuse and have reported this to my supervisor in the hope that this will be properly investigated, as the person I am supporting is a vulnerable adult with cancer of the throat.

1. Could set up a referral mechanism from welfare officer construction industry. Need to get message across about the service, access to the service & how people can be supported.

1. BJF is a very good organisation to be involved with. They are well structured, excellent role description and ongoing support. It's nice to be asked to be involved in this evaluation.

1. I enjoy the role

1. Richard saw DVD and offered Angela a lot of useful feedback
2. Wife advertises in local GP on TV so will ask her how she went about it

1. I have a disabled son and husband at home and I regard my volunteering time as my time, a time for me to give something back to support others who have no one else to help them. In return I get out of the house, meet some amazing people and am able to work closely with my fellow volunteers as part of a team. We also socialise a lot so this helps me to keep in touch with my local community. It saves me from becoming isolated due to my carer's role.
Sometimes I don't think I do enough and am looking forward to doing more when I'm able to

1. I'm happy with the role as it enables me to continue my interest in health & supporting others less fortunate than myself. I feel my own experience of cancer coupled with my nursing background gives me a unique insight into supporting OPABC living with cancer.

1. I am a first time volunteer, however knew about BJC through my professional life (ex-social care & health worker).
Very gratifying when people acknowledge help & 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.'
The training received was excellent, very comprehensive. They do lots of additional training covering a wide variety of subject areas.

1. Has a lot of time to spare – not at beck & call
2. Very rewarding, enjoyed it. As develop in role get into watching.
3. In contact with the family in a liaison role etc.
4. Update re: progress

1. It helped me feel useful and increase confidence. Been a godsend to feel useful again
2. To use existing skills to help other people
3. As an ex nurse made me realise how little information patients are given. Advocates have the time to explain what the consultants have said, can offer reassurance – situation not always as bad as they fear

1. Enjoyed the experience
2. Meet regularly
3. Training available
4. Jo & Kath available
5. Easy discussing material
6. Peer training & support
7. Social activity – team aspect
8. Welcome opportunity to use existing skills to benefit additional services

1. Used to sharing issues with others, welcomed more frequent practice – case discussions

1. Can we get information out there?