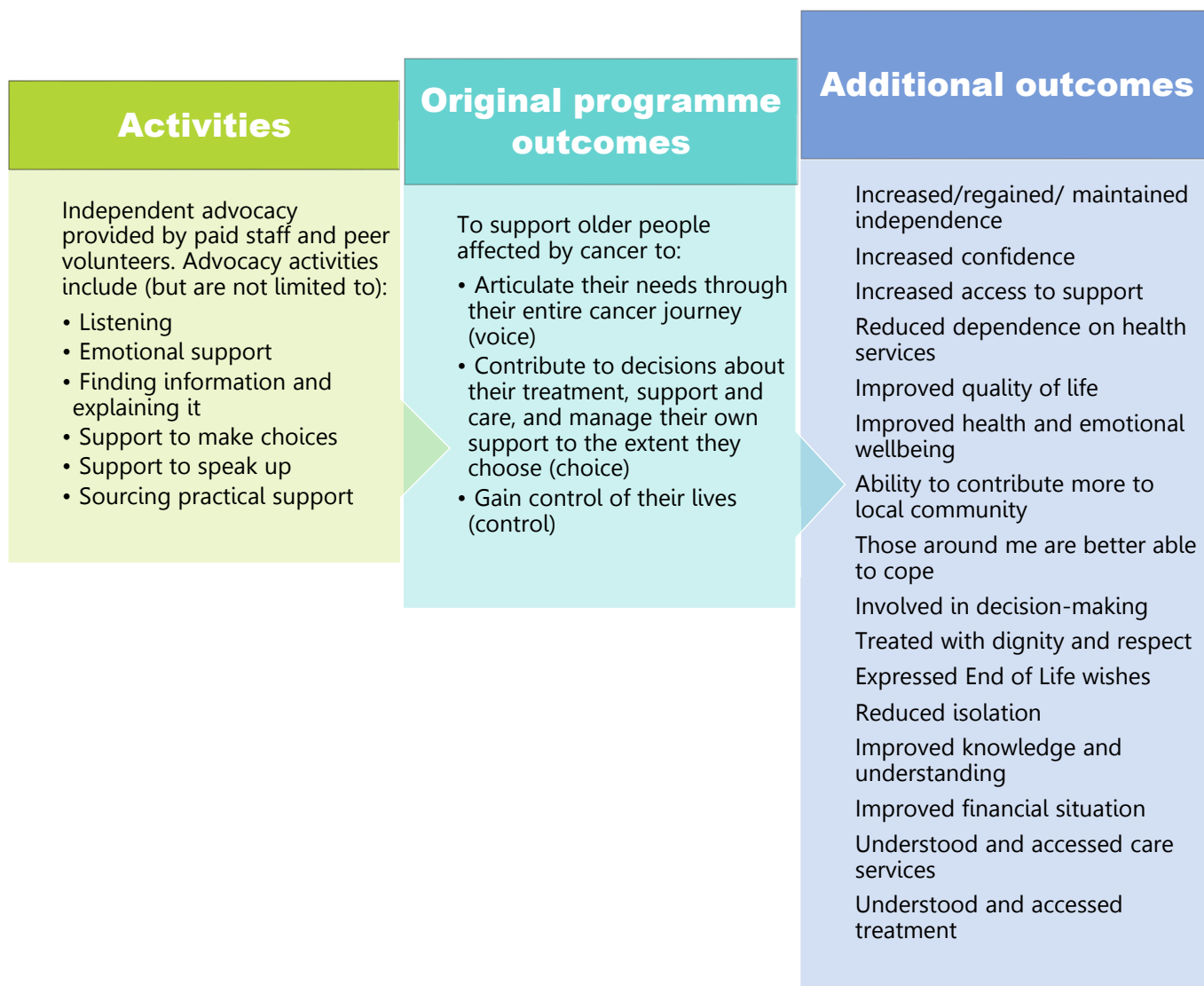


Evaluation of the Cancer and Older People Advocacy Project

APPENDICES

Appendix 1: Activities and outcomes of the COPA programme



Appendix 2: Methodological issues

1. Methodological considerations

With multi-site evaluations, differences in local context across sites and in the way programme requirements are interpreted and delivered by different participating organisations can make it harder to draw conclusions about overall impact (Stainbrook et al. 2015). In particular, this variation between sites makes it difficult to generalize across different parts of the programme. Thus in this study we sought to combine an analysis of quantitative outcome data across the whole programme with a more focused qualitative examination of six local delivery partners engaged in the COPA programme. Six sites were chosen that would provide a (non-generalisable) snapshot of the relationships between advocacy activities, outcomes and (where relevant) the local context within which the service was being delivered. In each of these six sites a range of stakeholders were interviewed (older people affected by cancer, advocates, health and social care professionals and local community groups) to understand outcomes of the programme in a range of different contexts and the factors that influenced this.

COPA sites that kindly agreed to participate included:

- Dorset (Dorset Advocacy / Help and Care)
- Cardiff (Age Connects Cardiff)
- Oxfordshire (Getting Heard)
- Sandwell (Sandwell Advocacy)
- Sefton (Sefton Pensioner's Advocacy Centre)
- Stoke on Trent / Wolverhampton (Beth Johnson Foundation)

With the support of OPAAL and Macmillan, COPA staff from each site supported recruitment of respondents from the following groups: older people affected by cancer; advocates, local health and social care professionals. Access to certain groups of respondents varied in each site and was lower in some sites due to factors such as: poor health or mobility; overlap with other local evaluation activities; lack of time; lack of access to or availability of potential respondents. Thus the original target sample was also supplemented with other respondents with relevant experience (e.g. national stakeholders and community groups working with older people in neighbouring areas). An overview of the final sample is provided below:

In order to ensure focus group and interview transcripts were appropriate we piloted some with a group of COPA staff and advocates from Beth Johnson Foundation. We also sought to establish potential support that older people affected by cancer might require when participating in the research and how that support would be best provided. A summary of research topics for each set of research participants (older people affected by cancer; advocates; COPA staff, community groups and Macmillan staff; and health and social care professionals) is included below. When designing the study, we also discussed with COPA staff some of the ethical considerations of the work. In particular, when piloting research instruments we discussed how it would likely be much harder to speak to people who were

not well or unlikely to recover from cancer. As part of the participant recruitment process, we shared a simple information sheet and stressed as part of the consent process that participants' contributions would be reported anonymously and that participation was completely voluntary. When conducting primary research, on the few times that participants showed signs of emotional stress, researchers ensured that participants were supported directly or by their advocate (if they were present).

2. Sampling

Indicators used to identify appropriate COPA sites for study.

INDICATOR		MEASURE	RATIONALE
	No of active service users	No of open cases	Provides an indication of the number of active participants on each site
	Repeated use of service	No of open cases by date opened No of case reopenings	Provides an indication of the number of repeat users on each site
	Age	60 \geq pop of site (%)	Allows an assessment of whether services in an area have in any way developed to meet the needs of an older population
	Cancer outcomes	% cancer mortality rate higher/lower than Eng av	Assesses current capacity of system to delivery particular outcomes Allows us to assess sites that are broadly similar in terms of performance
	Ethnicity	BME pop of site (%)	Noting the correlation with ethnicity and poorer health outcomes and experiences, this indicator allows an assessment of how different communities may benefit from empowerment. Note that ethnicity data within SAM database is sparse: area data therefore provides a useful proxy
	Deprivation	% of neighbourhoods in site that are highly deprived	Recognises importance of social determinates on health inequalities.
	Patient experience	No. of times trusts in the area fall within top/bottom 20% of answers to Cancer Patient Survey	See point 4.
	Rurality	% pop living in rural/rural-related areas	Assessment of rural and urban areas may help understand significance of local infrastructure, transport, etc

An overview of the number, location and type of respondents that participated in the research is provided below.

Interviews:

WHO	NUMBERS							
	Total	BJF	Cardiff	Dorset	Oxfordshire	Sandwell	Sefton	Other
Service users and carers	13	-	4	1	-	4	4	-
Volunteer advocates and staff working with advocacy services	17	-	2	9	1	-	5	-
Senior Macmillan Development Managers and Macmillan Development Managers	5	2	-	1	1	1	-	-
Health and social care staff (including Clinical Nurse Specialists, Cancer Information Support Services, hospice workers, etc)	14	2	2	2	2	2	3	1
Misc (including national cancer champion board members, local equality organisations, etc)	7	-	-	1	1	-	-	5
	56	4	8	14	5	7	12	6

Focus groups

WHO	NUMBERS							
	Total	BJF	Cardiff	Dorset	Oxfordshire	Sandwell	Sefton	Other
Mixed groups: advocacy partners and / or advocates	7	1	1	2	1	1	1	-
COPA staff	1					1		-
Health and social care staff (including Clinical Nurse Specialists, Cancer Information Support Services, hospice workers, etc)	6	1	1	1	1	1	1	-
Community organisations supporting older people	1							1
	15	2	2	3	2	3	2	1

Appendix 3: Quantitative overview of outcomes

This section outlines findings based on an analysis of the online project database, 'SAM'. Data was accessed at various times during the first week of November 2016. The data outlined in this section provides useful context for the qualitative findings outlined in section 3.1.2 of the main report. However, it is important to note that for some indicators the number of 'undefined' or 'unknown' entries significantly reduces the sample size and, as such, care should be taken if extrapolating from the figures presented here.

ADVOCATE PROFILE

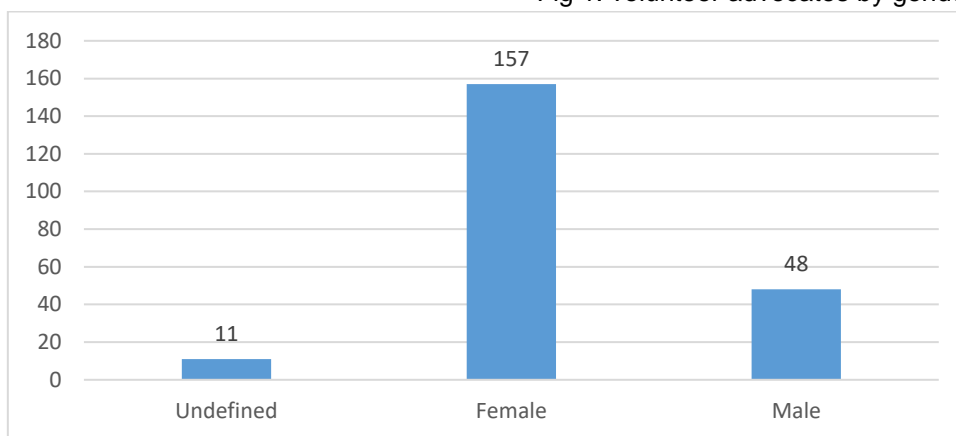
OVERVIEW

There are 216 volunteer advocates registered on the project database. The average volunteer advocate provided 16.6 hours of support in total.

GENDER

72.6% of volunteer advocates are women. 22.2% are men.

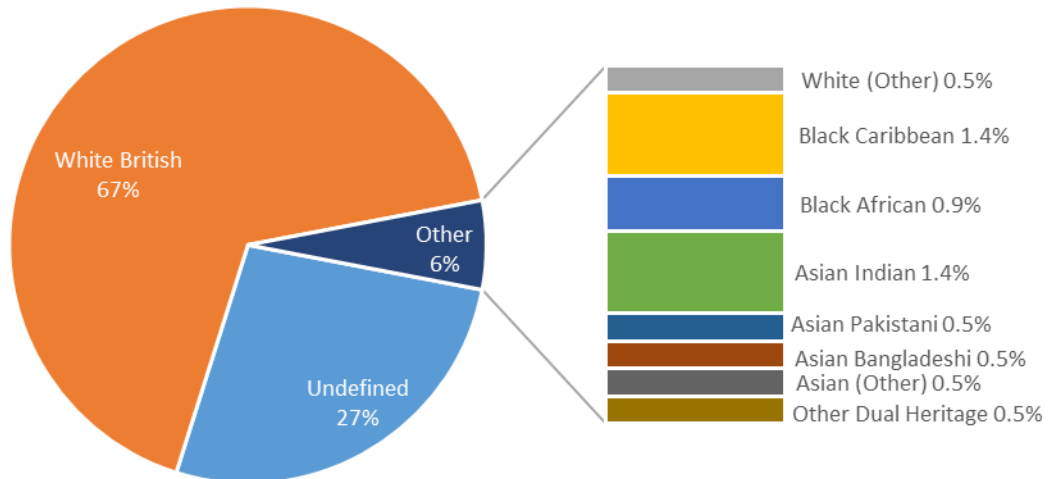
Fig 1: volunteer advocates by gender (all sites)



ETHNICITY

The majority of volunteer advocates – 67% - are White British. A large proportion (27%) chose not to reveal their ethnicity. Six per cent of the remaining advocates are from a BME background.

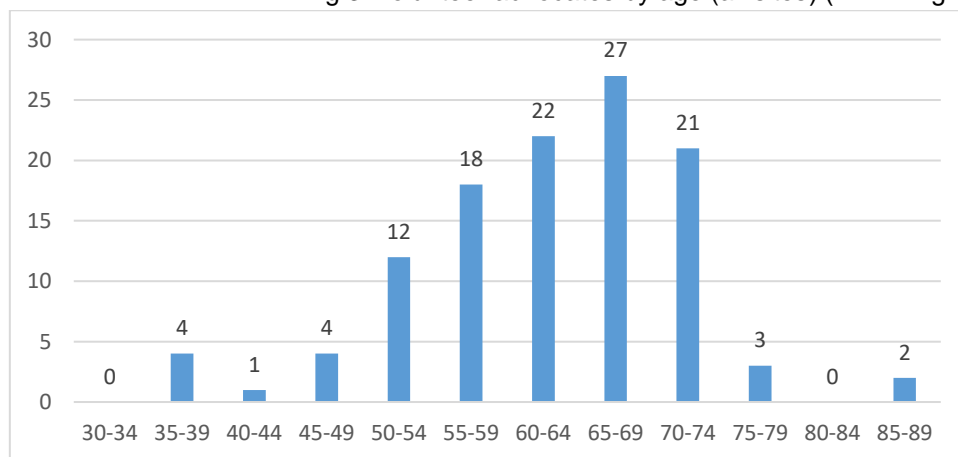
Fig 2: volunteer advocates by ethnicity (all sites)



AGE

The age of a significant proportion of advocates (47.2%) is not recorded. Figure 3, below, only shows data for those advocates for whom age is recorded. As can be seen, about 12% of advocates are aged 65-69; about 10% are 60-64; and about 9% are 70-74.

Fig 3: volunteer advocates by age (all sites) (excluding 'undefined')



CLIENT PROFILE

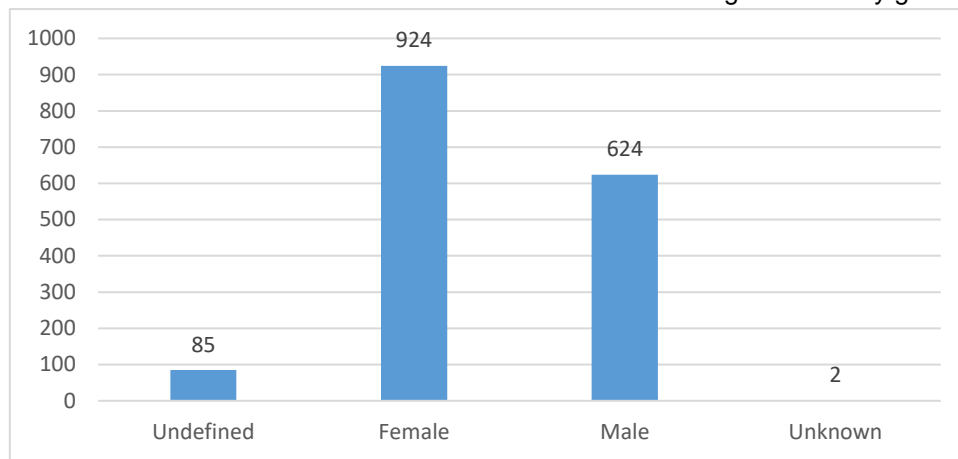
OVERVIEW

There are 1,635 cases on the project database. This equates to 1,584 individual clients (people can have multiple cases). It is important to note that demographic information is broken down by cases rather than person, so the data below will inevitably count some clients twice.

GENDER

Just of half (56.5%) of cases are women; 38.2% are men.

Fig 4: Cases by gender (all sites)



ETHNICITY

The majority of cases (72.7%) are White British. 7.2% are from BME backgrounds (see fig 5). If cases are broken down by site, it can be seen that in areas where the proportion of White British cases is lower than this average it is often because the proportion of 'Undefined/unknown' cases is higher (rather than the proportion of BME cases being higher) (see fig 6). The exception to this is Barnet, where 21% of cases are either Irish or Black (albeit with a smaller sample than other sites).

Fig 5: Cases by ethnicity (all sites)

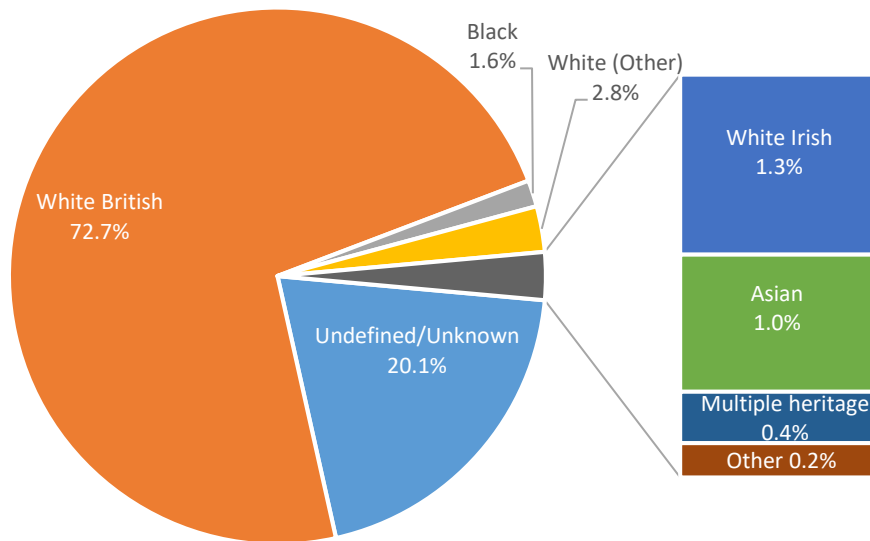


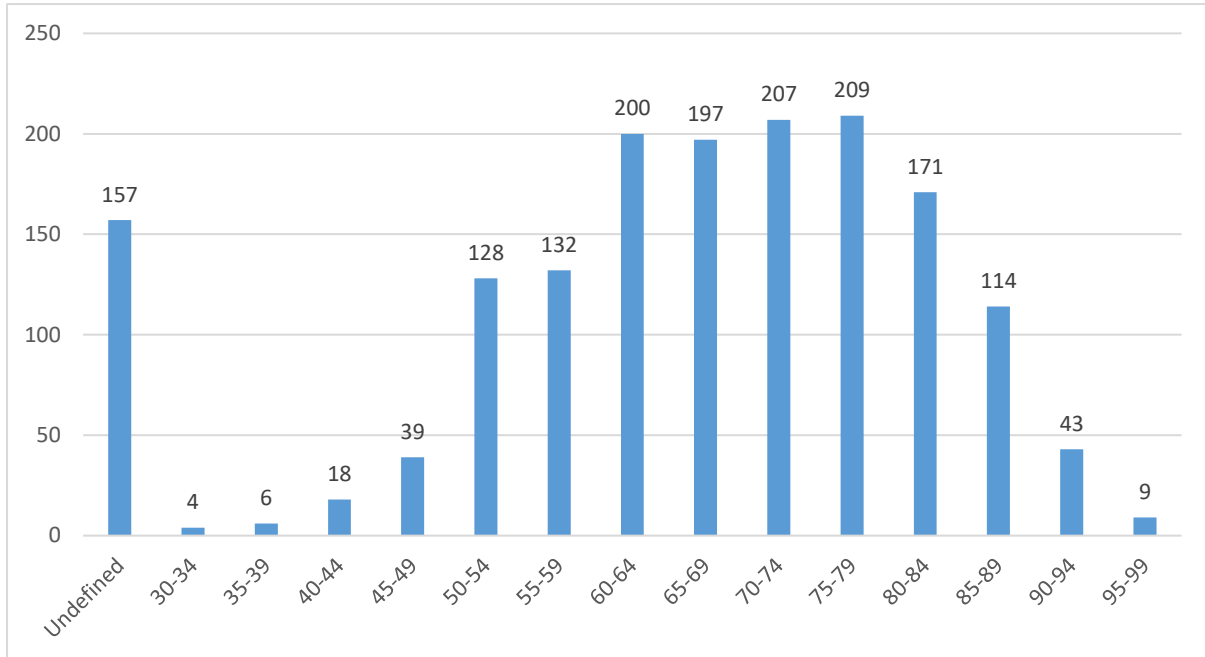
Fig 6: Cases by ethnicity and site

	Undefined /Unknown	White British	White Irish	White Other	Black	Asian	Other	Multiple heritage	n=
Sandwell	2.5	84.8	6.3	1.3	3.8	1.3	0.0	0.0	79
Cardiff	2.8	88.1	0.9	8.3	0.0	0.0	0.0	0.0	109
Bristol	3.2	84.1	3.2	1.6	6.3	0.0	0.0	1.6	63
Gateshead	6.7	86.7	0.0	6.7	0.0	0.0	0.0	0.0	30
Northumberland	8.3	83.3	0.0	0.0	8.3	0.0	0.0	0.0	36
ICANN	9.8	72.8	3.3	4.3	2.2	5.4	0.0	2.2	92
Sefton	11.6	87.4	1.1	0.0	0.0	0.0	0.0	0.0	95
Barnet	15.8	52.6	10.5	5.3	10.5	0.0	5.3	0.0	19
BJF	19.8	76.3	0.5	1.7	0.9	0.9	0.0	0.0	587
Oxfordshire	26.4	55.7	1.9	5.7	4.7	2.8	0.9	1.9	106
Dorset	33.0	60.9	0.8	3.8	0.8	0.4	0.4	0.0	261
IMPETUS	45.5	48.5	0.0	3.0	0.0	0.0	3.0	0.0	33
KPAIS	51.9	48.1	0.0	0.0	0.0	0.0	0.0	0.0	79

AGE

As can be seen in figure 7, below, 60.2% of cases were aged between 60-84.

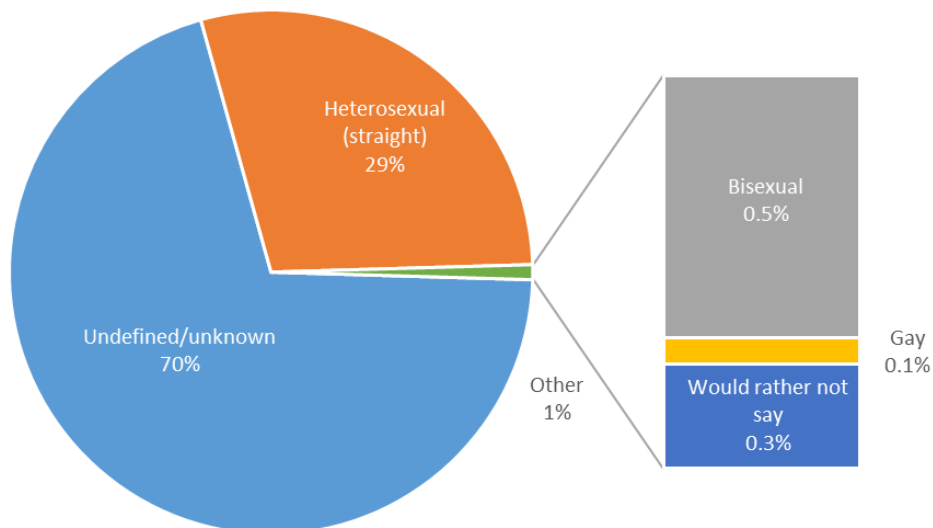
Fig 7: Cases by age (all sites)



SEXUAL ORIENTATION

As with many other projects of this type, there are significant challenges collecting data relating to clients' sexual orientation. Information on sexual orientation has only been collected by the SAM database since January 2016.

Fig 8: Cases by sexual orientation (all sites)

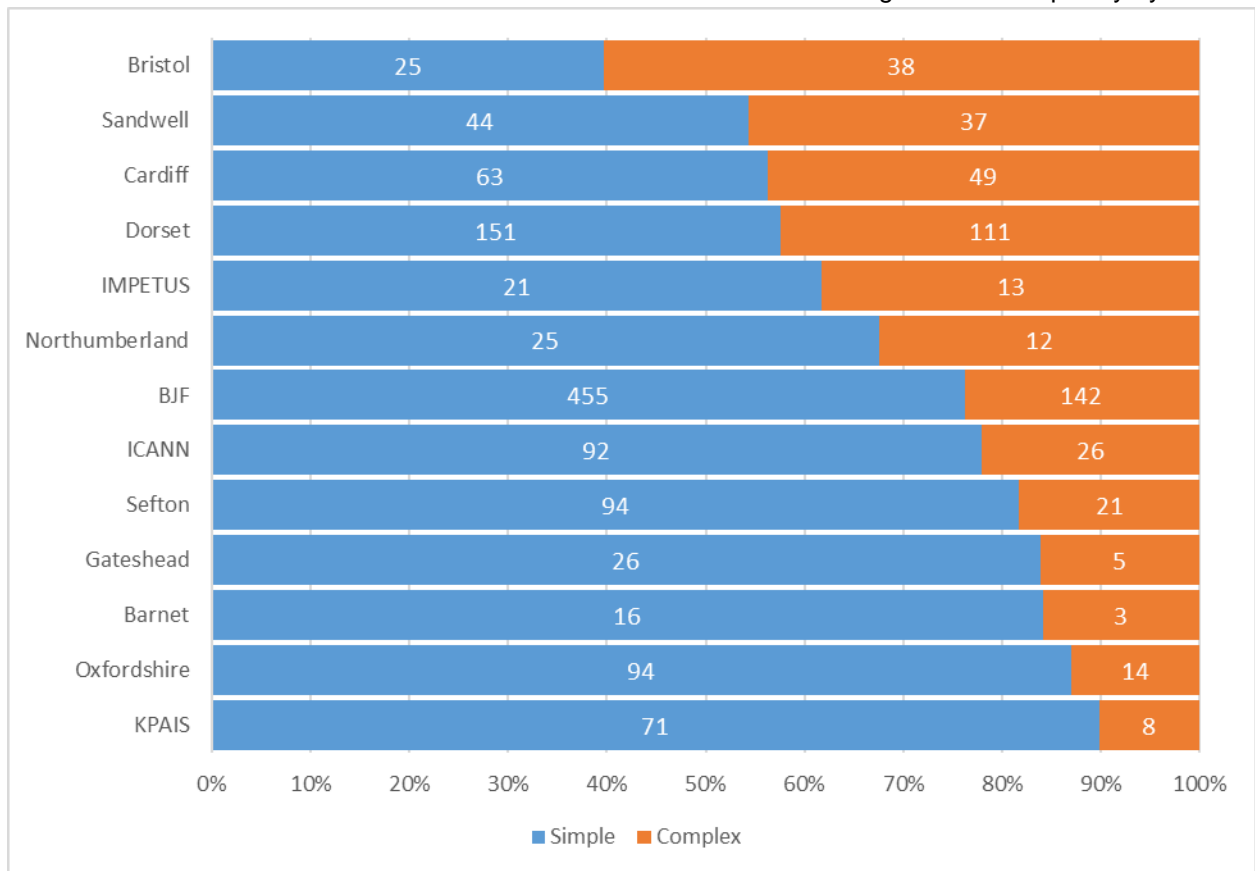


CASE COMPLEXITY

Complex Cases are defined as cases with three or more advocacy issues. Figure 9 below shows the proportion of cases for each site that are complex and simple. Note that an individual can have multiple cases

Bristol has an unusually large proportion of its caseload made up of complex cases (60.3%). Complex cases make up 45.7% of all cases in Sandwell, 43.8% of cases in Cardiff, and 42.4% of cases in Dorset. In contrast, only 10.1% of cases dealt with by KPAIS are complex.

Fig 9: Case complexity by site



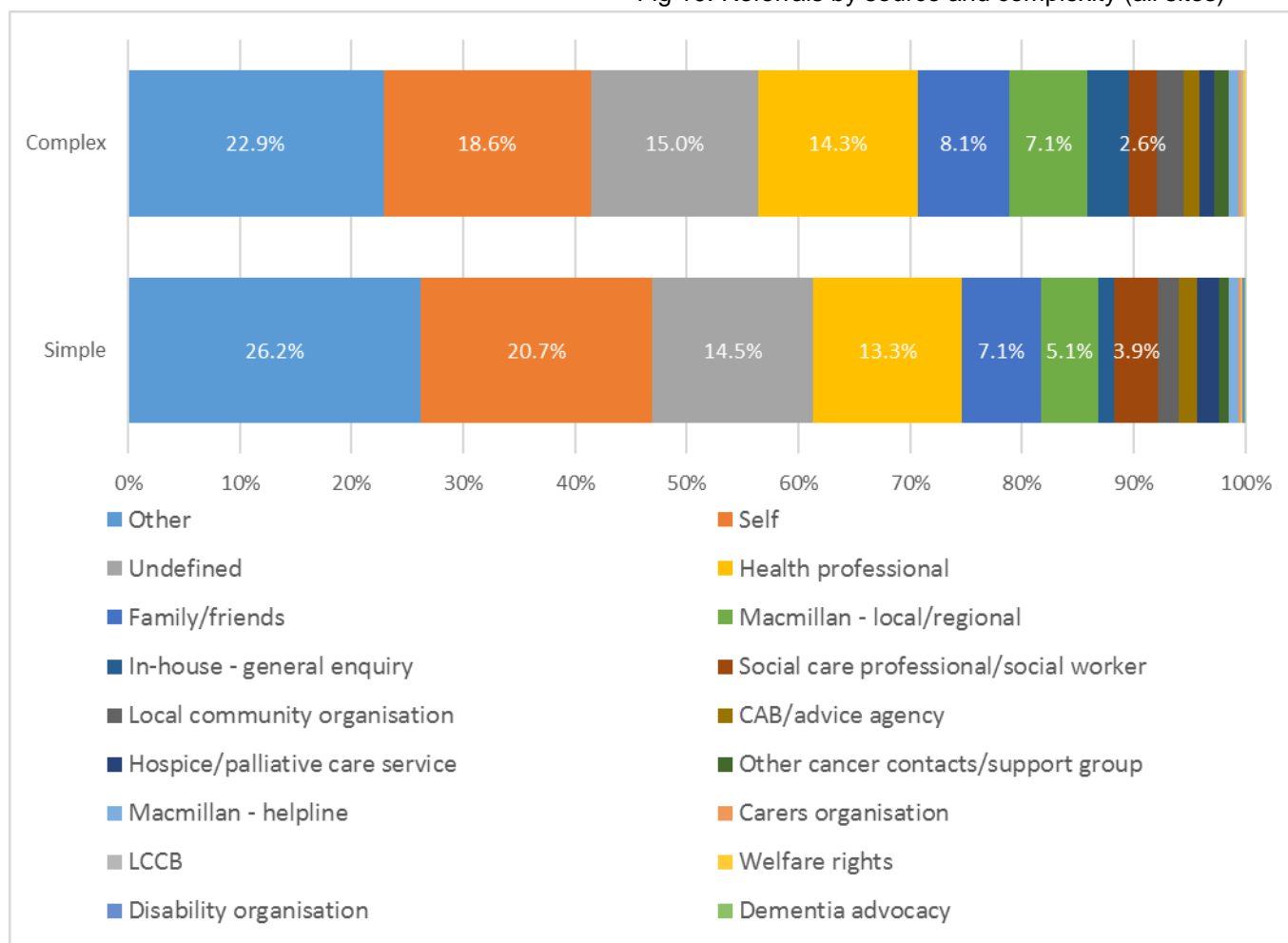
REFERRALS

SOURCES

One in five people referred to an advocate self-referred. 13.6% of cases were referred by a health professional.

Figure 10 below shows referral sources for simple and complex cases. The largest differentials occur for self-referrals (20.7% of simple cases, 16.6% of complex cases); referrals from social care professionals (3.9% of simple cases, 2.6% of complex cases); referrals from Macmillan (5.1% of simple cases, 7.1% of complex cases); and referrals coming from general enquiries (1.5% of simple cases, 3.6% of complex cases). It is important to note the largest differential is for referrals from 'other' sources (26.2% of simple cases; 22.9% of complex cases).

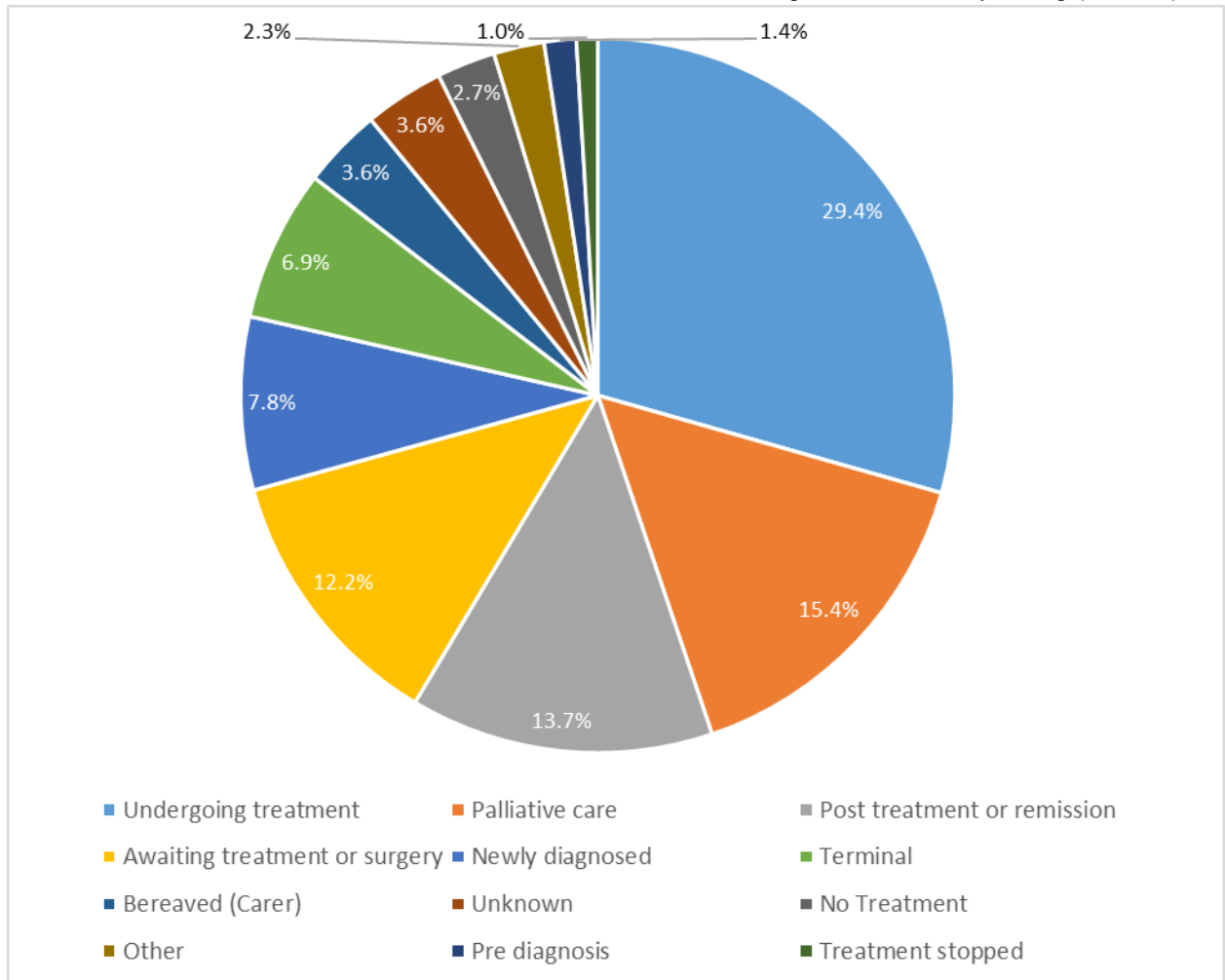
Fig 10: Referrals by source and complexity (all sites)



TIMING

Most people (29.4%) are referred to an advocate when they are undergoing treatment. Significant proportions are referred during palliative care (15.4%); post treatment (13.7%); and when awaiting treatment or surgery (12.2%).

Fig 11: Referrals by timing (all sites)

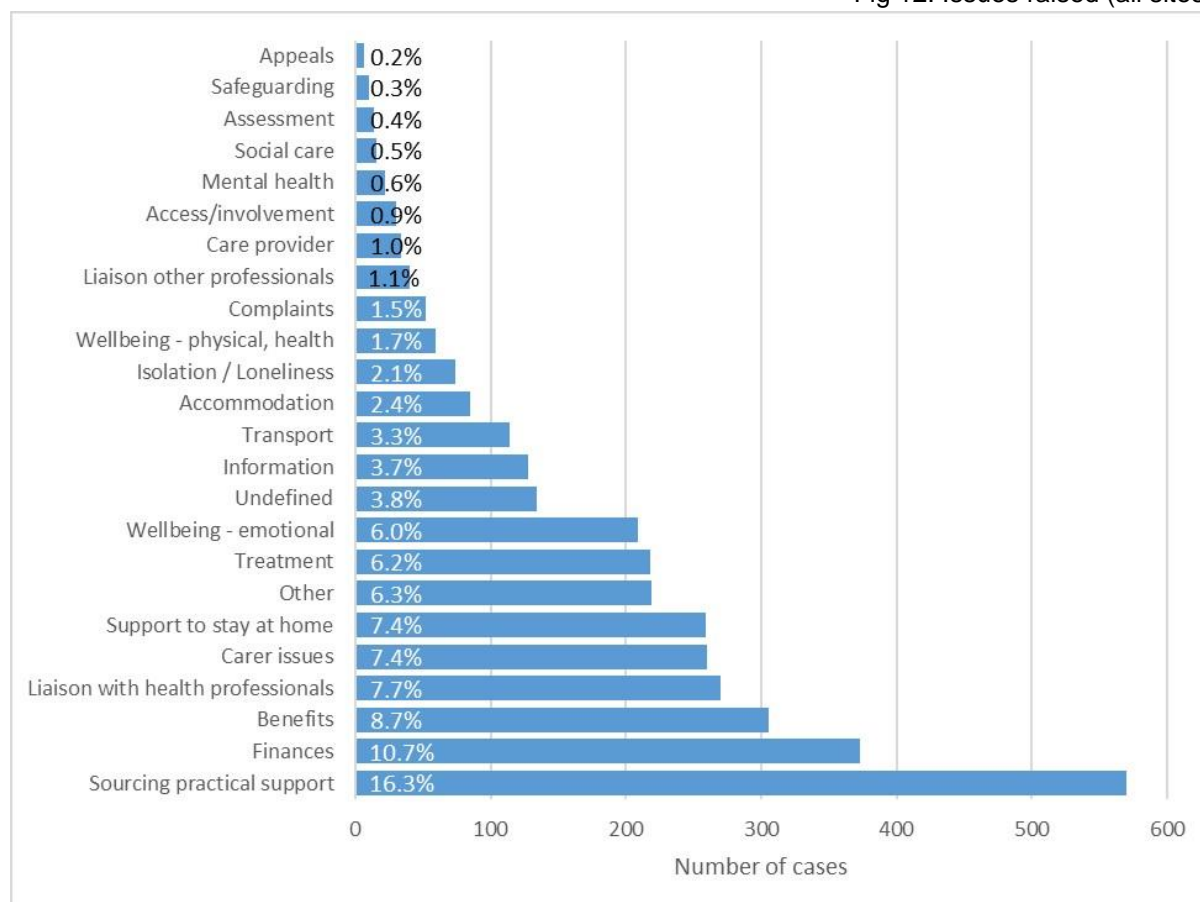


ISSUES AND OUTCOMES

ISSUES

The single most common reason for accessing advocacy support is for ‘sourcing practical support’ (16.3%). 10.7% of all issues raised relate to people’s finances, 8.7% relate to benefits, and 7.7% are connected with liaising with health professionals.

Fig 12: Issues raised (all sites)



As figure 13 shows, the issues raised by patients and carers can vary significantly from site to site (the table shows each individual issue as a proportion of the total number of issues raised in the six sites selected as part of this research project). Issues around finances and benefits are more common in Sefton than in other sites, and more common than the national aggregate (shown in figure 12). These issues are also slightly more common in the area covered by the Beth Johnson Foundation than in the national picture. In contrast issues with finance are less common in Dorset (4.6% of all issues), Cardiff (5.6%), and Sandwell (6.7%). Finally, some areas appear to experience issues around treatment and care more than others. For example, issues with liaising with health professionals make up 17.3% of all concerns in Oxfordshire and 11.6% in Cardiff. Similarly, concerns with treatment comprise 10.3% of all issues in Cardiff and 9.8% in Oxfordshire. It is important to note that OPAAL have been discussing with deliver partners that there may be inconsistency in how issues are being recorded across sites and individuals within those sites. A guide for each entry

option is being developed to improve consistency and this will be applied in the next phase of the COPA programme.

Fig 13: % of cases raising specific issues by site

	Dorset	Sefton	BJF	Cardiff	Oxfordshire	Sandwell
Access/involvement	0.3	0.0	0.4	0.3	1.2	1.3
Accommodation	1.2	6.3	2.7	1.0	0.6	2.2
Appeals	0.0	0.5	0.1	0.3	0.0	0.4
Assessment	0.5	0.5	0.2	0.0	0.0	0.0
Benefits	6.1	13.0	7.7	4.0	6.9	5.3
Care provider	0.3	1.0	2.2	0.7	0.0	0.0
Carer issues	9.2	1.9	9.4	4.0	2.3	6.7
Complaints	1.2	3.9	1.5	1.3	0.0	1.3
Finances	4.6	22.7	14.3	5.6	11.6	6.7
Information	4.5	0.0	3.0	5.3	4.6	5.8
Isolation / Loneliness	2.5	1.0	1.8	3.3	1.7	4.0
Liaison other professionals	0.5	1.0	1.1	1.7	0.0	0.9
Liaison with health professionals	9.2	2.4	6.1	11.6	17.3	4.0
Mental health	0.8	0.0	0.5	0.7	0.6	0.4
Practical support	18.0	18.4	15.7	15.6	14.5	23.6
Safeguarding	0.2	0.0	0.0	0.0	0.0	3.6
Social care	0.2	1.0	0.4	0.0	0.0	0.0
Support to stay at home	6.1	8.7	7.0	11.6	2.9	7.1
Transport	5.2	2.9	3.0	4.3	4.0	0.9
Treatment	9.8	3.9	4.8	10.3	9.8	3.6
Undefined	4.0	0.0	1.6	6.3	4.0	0.0
Wellbeing - emotional	7.4	4.8	6.0	4.0	8.1	14.2
Wellbeing - physical, health	1.4	1.9	2.7	0.3	3.5	1.3
Other	6.9	4.3	7.7	7.9	6.4	6.7
n=	651	207	1188	302	173	225

It does not appear that complex cases are the result of particular issues or concerns more than others. For example, complex cases are only 1.6 times more likely to be about social care: the area with the largest differential.

OUTCOMES

Before outlining outcomes, it is important to note that outcomes recording is a relatively new category for entry on the SAM database. Information about COPA outcomes was only collected from January 2016. Similarly, there is a risk that outcomes are being recorded differently across sites because of differences in interpretation of what those outcomes

mean. This is something OPAAL is seeking to address in the next phase of the COPA programme.

As the data in Fig 14 suggest, outcomes in 26.1% were undefined. About one in ten of the remaining cases (9.9%) resulted in increased access to support; 9.1% resulted in greater or maintained independence, and 9.0% in improved knowledge and understanding.

Fig 15 shows outcomes in the six sites selected as part of this research project. As can be seen, the pattern of outcomes differs significantly from the national aggregate. Some of the largest differentials relate to 'improved access to support' (18.5% of outcomes in Dorset; 7.6% in Cardiff and Sefton); 'being treated with dignity and respect' (13.8% of outcomes in Dorset, 5.7% in the area covered by the Beth Johnson Foundation); and 'improved health and emotional wellbeing' (13.0% of outcomes in Sefton, 5.2% in Oxfordshire).

Simple cases do not result in significantly different outcomes to complex cases (with the exception of 'being able to contribute to my community', which is twice as likely to be the outcome of a simple case compared with a complex case).

Fig 14: Case outcomes (all sites)

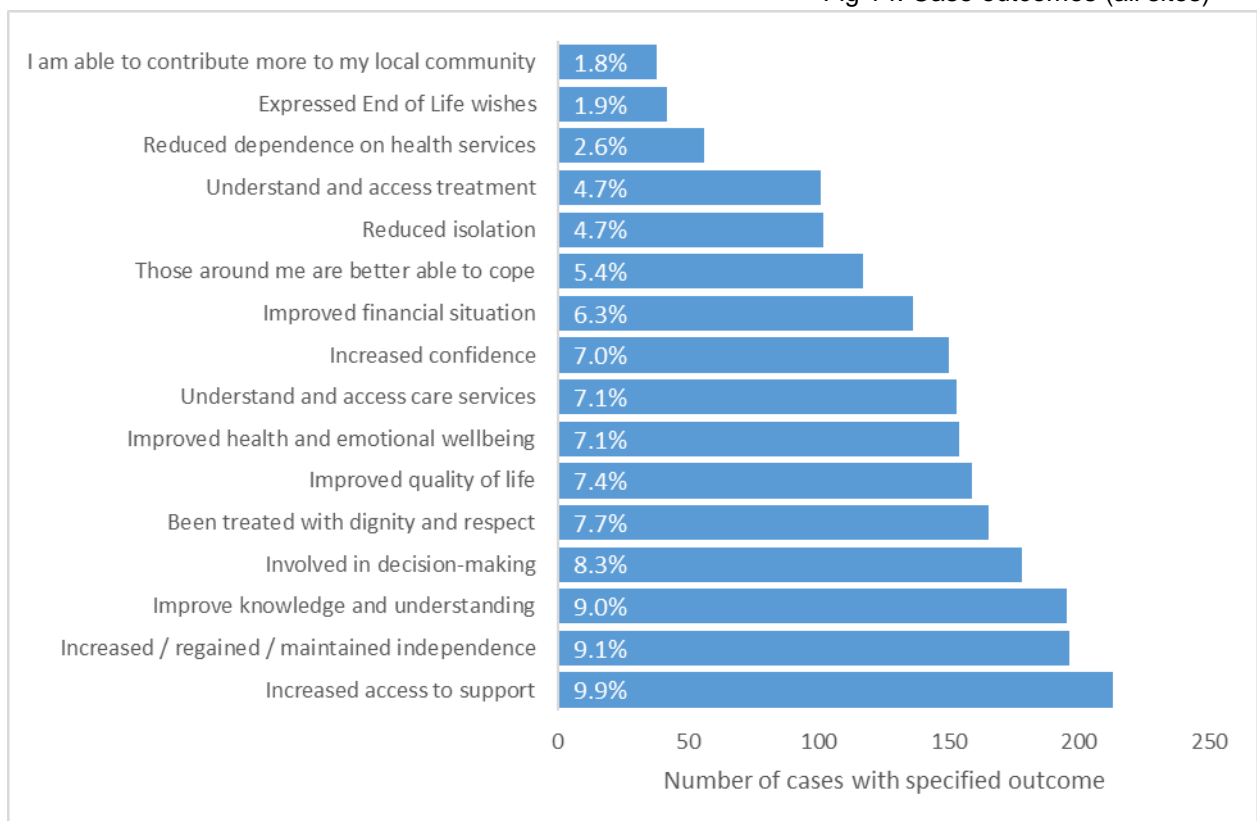


Fig 15: % of cases with specified outcome by site

	Dorset	Sefton	BJF	Cardiff	Oxfordshire	Sandwell
Been treated with dignity and respect	13.8	8.2	5.7	7.3	10.8	11.0
Expressed End of Life wishes	1.5	0.0	2.8	2.3	2.6	2.4
I am able to contribute more to my local community	0.0	2.2	0.3	3.0	3.1	1.0
Improve knowledge and understanding	6.2	11.4	9.6	6.9	8.2	7.6
Improved financial situation	7.7	7.1	7.1	3.6	3.6	3.1
Improved health and emotional wellbeing	12.3	13.0	5.8	7.9	5.2	8.6
Improved quality of life	3.1	8.7	7.4	7.9	6.2	9.3
Improved/regained/maintained independence	7.7	9.2	11.9	7.6	4.1	10.0
Increased access to support	18.5	7.6	10.4	7.6	11.9	10.3
Increased confidence	4.6	8.7	6.7	6.3	7.2	7.9
Involved in decision-making	3.1	6.5	9.3	7.6	7.7	7.2
Reduced dependence on health services	1.5	0.0	1.6	6.6	3.6	1.0
Reduced isolation	4.6	4.3	3.2	5.9	9.3	4.8
Those around me are better able to cope	1.5	2.7	5.5	6.3	6.7	6.2
Understand and access care services	7.7	9.8	7.2	6.3	4.6	7.6
Understand and access treatment	6.2	0.5	5.7	6.9	5.2	2.1
n=	65	184	690	303	194	291