supporting young carers

EVALUATION OF THE HAMPSHIRE YOUNG CARERS ALLIANCE (HYCA) - IMPACT ON YOUNG CARERS

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UNIVERSITY OF WINCHESTER
Hampshire Young Carers Alliance
BIG LOTTERY FUND
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Executive Summary

Funding from the Big Lottery Fund was used by HYCA to commission the University of Winchester to undertake an independent evaluation of its work between September 2016 and August 2019[1]. This evaluation had several aims, including evaluating the impact that the HYCA collaboration made to young carers and families, the impact of HYCA's collaborative approach, its value for money and of the progress by HYCA towards sustainability.

Following an initial qualitative study of the impact of the young carer services (Phelps, 2017a) a subsequent study was undertaken to evaluate the impact of the support specifically on *the young carers themselves*. This focused on those impacts that had been identified in the initial research phase. A questionnaire was designed and trialed which included psychometric instruments to assess young carers' general sense of well-being, their perceived stress, the positive and negative outcomes of their caring roles, as well as questions related to other outcomes identified in the initial research phase. The outcomes of young carers being supported by the projects were measured using this questionnaire which was administered at two points in time (pre- and post).

One significant finding is that over half of the young carers had been caring for three or more years (and over three and a half years on average), when they completed the initial questionnaire. Furthermore, almost a third of those who completed the initial questionnaire disengaged from their projects over the course of the study.

A main finding was that the young carers were reporting generally positive outcomes across a range of domains after the support they had received from their projects. However, generally positive outcomes were also reported at the start of their engagement with services. It was only a minority of young carers who reported relatively low outcomes at either evaluation point. Furthermore, although there were lots of small positive changes measured across many of the domains, these were not statistically significant.

Although the high-level outcomes reported by the young carers at the initial evaluation point might truly reflect the outcomes they were experiencing, an alternative explanation has been proposed for why the young carers may be reporting so positively at this early stage. This may be explained by young carers being guarded about reporting negatively on their health and wellbeing due to a fear of services intervening in the families. It is also proposed that a marked change in the young carers' perception might have taken place by the second questionnaire with young carers feeling more comfortable about reporting more negatively. It is proposed that together, these two dynamics *might* have masked any significant effects made by the intervention itself.

Reflecting the findings from the interviews in the initial research phase, projects were found to be important to the young carers. All the young carers who

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[1] On the 29 January 2019 the Big Lottery Fund became known as The National Lottery Community Fund.

responded reported that they would recommend their group to another young carer. A correlation was found between the number of hours of care undertaken by the young carers and how important their project was to them. Moreover, a much higher proportion of young carers who remained engaged with their project, had initially viewed their group as being important to them, compared to those who later disengaged.

Furthermore, as in the initial research, this study also found that the groups (projects) enabled the young carers to make a significant number of new friends, to have fun, to meet and talk with others. Correlations were found between the confidence that young carers reported in themselves and in their caring role, and their mental wellbeing.

This study clearly reflected some of the findings from the initial qualitative phase of the evaluation, specifically that projects were important to them and that projects enabled them to make many new friends. Although lots of further positive impacts were also measured, these were not found to be statistically significant.

The findings in this study are important in a number of ways. Firstly, they highlight the importance of improving our understanding at both local and national level about the level of need of young carers who are referred to young carer projects, as well as how quickly young carers are engaged with services after a caring role has begun.

Secondly, the study offers a questionnaire that can be used to measure the outcomes of young carers on a population level, whilst also contributing to our understanding of the practical challenges in measuring the outcomes for young carers from project support. A key practical challenge was recruiting sufficient numbers of participants.

Recommendations

Future research (at both local and national level) should explore how quickly young carers are referred to support from projects following the onset of a caring role, as well as their level of need at the point of referral. Research could further explore the factors that make projects important to young carers, why young carers disengage from projects, whether there are early indicators to how young carers will engage with projects and whether the confidence that young carers report might be a useful indicator of their health and wellbeing.

Future studies might also explore alternative ways to evaluate health, wellbeing and other outcomes for young carers *when they are initially engaging with services,* to accommodate for any elevated self-reporting by young carers as has been hypothesized. Alternative timings (i.e. evaluating young carers at a later point in time) for acquiring baseline data should be considered.

Finally, since the use of the questionnaire itself was found to be suitable in practice for evaluating the outcomes for young carers at a population level, its further use is recommended, however, to improve the chances of detecting statistically significant changes, studies might well benefit from higher numbers of participants.

Summary Findings

Outcomes

- When the young carers initially engaged with projects, over half had been caring for three or more years (and over three and a half years on average).
- Almost a third of the young carers disengaged from their projects over the course of the study (i.e. within 8.5 - 11.5 months).
- Young carers reported generally positive outcomes across a range of domains after being supported by projects.
- However, generally positive outcomes were also reported at the start of young carers' engagement with services.

Importance of projects and engagement

- Projects were important to young carers and enabled them to make many new friends, to have fun and to meet and talk with others.
- All the young carers who responded reported that they would recommend their young carer project to another young carer.
- There was a correlation between the number of hours of care undertaken by the young carers and how important their project was to them.
- A much higher proportion of young carers who remained engaged with their project, had initially viewed their group as being important to them, compared to those who later disengaged.

Confidence

- Correlations were found between the confidence that young carers reported in themselves and in their caring role, and their mental wellbeing.

List of acronyms and abbreviations

FAQs	Frequently answered questions
HYCA	Hampshire Young Carers Alliance
ONS	Office for National Statistics
SEN	Special educational needs
Q1	Questionnaire 1
Q2	Questionnaire 2

1 Introduction

1.1 Background

1.1.1 The Hampshire Young Carers Alliance (HYCA)

The Hampshire Young Carers Alliance (HYCA) is an alliance of ten young carer services or 'projects' within Hampshire, with the common aim of supporting young carers within the county. One service is part of a national charity, four are local young carer specific charities and the other services form part of other local charities with broader remits.

Originally composed of five young carer projects, the Alliance was formed around 2005 in order for the individual services to work closer together, share good practice and resources, to develop a single county-wide voice, and to advocate and campaign for young carers within the county.

HYCA services are currently funded by a broad range of funding streams, including funding from the local authority. Historically, the services have had different capacities and have worked in varying ways to meet the local needs of young carers. As has taken place nationally over the last ten to fifteen years, some of the HYCA young carer services have complemented the respite activities, clubs and trips that they had generally offered (and that are common to most young carer services), with schools work and a 'whole family approach' to supporting young carers and their families. For some of the HYCA services, this has included employing specific staff to work with families and other staff to provide targeted work in schools.

Between 2011 and 2014, HYCA received funding from the Big Lottery 'Youth in Focus' (YiF) grant for a pilot county-wide project. At the time, only seven of the HYCA services were in a position to join this 'Hampshire Young Carers (HYC)' project. This pilot project employed seven 'Schools Workers' and five 'Family Workers' within the seven funded areas and delivered support to over 1300 young carers and their families. During this period HYCA also developed and advanced what it describes as a **'3-pronged support model'**, with its services offering respite activities, family support and support for young carers in schools.

The 3-pronged support model

This consists of three areas of intervention:

1. Family support: Aims to support the needs of the whole family and not the needs of young carers in isolation
2. Respite support: providing opportunities to young carers to have time away from their caring role, to experience new opportunities and to create peer networks
3. School support: Providing awareness, advocacy and opportunities for young carers to engage positively with education

1.1.2 Current provision of HYCA services

HYCA services are currently in contact with 1596 young carers across Hampshire. They are actively providing support to 1109 young carers, including 570 within schools.[2] Services cover both rural and urban areas, with more urban areas covered by services such as Basingstoke, Fareham and Gosport and Havant and more rural areas covered by the New Forest and Romsey.

1.1.3 Big Lottery Funding 2016 – 2019

In 2016 HYCA was awarded additional funding from The Big Lottery in order to roll out and further embed the '3-pronged' support model across *each* of the ten districts within the county where the HYCA services operated and to bring about a more consistent county-wide service. HYCA aimed to achieve this enhanced and consistent service by further developing and strengthening its collaborative working and through sharing resources, such as a new shared database, whilst still maintaining the support delivered by the individual HYCA services that targeted local needs.

1.1.4 The evaluation and aims

Using an allocation of The Big Lottery funding, HYCA commissioned the University of Winchester to undertake an independent evaluation of the work of the Alliance over the three year period from September 2016 to August 2019. The evaluation presented HYCA with an opportunity to explore their service delivery and how the individual services worked together as an alliance. The evaluation had several aims including evaluating the impact that the HYCA collaboration has made to young carers and families, the impact of the collaborative approach, an evaluation of value for money and of the progress made towards sustainability.

1.1.4.1 The aim of this phase of the evaluation

The aim of this phase of the evaluation was to build on the findings of the initial evaluation phase which explored the most important changes that the young carer services made to young carers, their families and to other stakeholders, as well as what it is about the services that creates changes.[3]

More precisely, this phase of the evaluation aimed to evaluate the impact of the support from the young carer projects specifically on the young carers themselves that had been identified in the initial research phase. It also aimed to trial a questionnaire which included psychometric instruments to assess young carers' general sense of well-being, their perceived stress and the positive and negative outcomes of their caring roles, further questions related to the outcomes identified in the initial research phase and questions related to how the young carers viewed their projects.

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[2] These figures are the most accurate figures that could be currently provided by HYCA .from the database in October 2018. Figures used do not necessarily reflect variations in how individual HYCA services define and record support for young carers

[3] Phelps, D (2017a), Supporting young carers: The provision of county-wide support for young carers, University of Winchester.

2 Method

The outcomes for young carers being supported by the projects were measured using a questionnaire administered at two points in time (pre- and post). The questionnaires were designed to evaluate those outcomes that were identified in the initial research, including young carers' perceived stress, how young carers felt, (wellbeing) how confident young carers felt, as well as evaluating the views of young carers towards their projects.

2.1 Research ethics

Ethical approval for the research was granted under the Research and Knowledge Exchange ethics procedures of the University of Winchester.

Informed, verbal consent was sought prior to the interviews and written consent obtained from their parents. Before the questionnaires were completed participants were given an information sheet that was read out to them, setting out the purpose of the research. Confirmation that they were happy to proceed was sought and participants were informed that participation in the interview was voluntary and that they could withdraw at any time.

No individuals, or specific settings or localities are identified in the research findings and all legislation relating to data protection has been complied with. Please see separate appendices for the materials used with participants which include the questionnaires, information sheets and the consent form.

2.2 Procedure

2.2.1 Recruitment strategy

A recruitment strategy was included in the FAQs developed for the HYCA services (See Appendices).

The target sample was n=80 young carers (n=8 young carers from each service).

No specific criteria were used to screen participants as young carers, apart from the fact that they had been referred to and accepted on to projects because they were deemed to be a young carer (a young person with caring responsibilities). This aligns with the legal definition that states that a young carer is 'a person under 18 who provides or intends to provide care for another person' (HM Government, 2014).

No minimum level of care was screened for (for example by using a dedicated instrument such as the Multi-Dimensional Activities of Caring (MACA) (Joseph, Becker, & Becker, 2009). However, the questionnaire itself contained three questions about caring:

- Who do you help care for?
- How long have you been caring for these people?
- On average, how many hours would you spend supporting this person / these people during one week?

Criteria 1
In order to capture as far as possible, any outcomes from early engagement with a service, the period between joining the project and completing the questionnaire needed to be as short as possible. Therefore, the questionnaire was administered to those young carers who had most recently joined the projects.

- Young carers must have first engaged with the projects between March and May 2018.

Criteria 2
Services were also requested as far as possible to purposively select young carers of mixed gender and ages to complete the questionnaire. Services were requested to recruit young carers in years 7 and above (ages 11/12 – 17).

2.2.2 Questionnaire design

The questionnaire was developed based on the findings from the initial qualitative research phase of the evaluation. This had found a diverse range of outcomes for the young carers including:

- helping them relax and feel less stressed
- improving how they feel
- improving their confidence in themselves and in their caring roles
- helping young carers make friends
- feeling 'OK' about being a young carer

The questionnaire (See Appendices) aimed to explore these diverse outcomes further and contained the following sections:

A demographic section featuring questions for example about age, gender, how long they had cared for, who they cared for and the number of hours they spent caring.

A second section focused on the impacts of caring, the young carers' mental wellbeing and their perceived stress and was comprised of three different instruments:

- The Positive and Negative Outcomes of Caring (PANOC) (Joseph, Becker, & Becker, 2009) which was designed to use specifically with young carers
- The Warwick-Edinburgh Mental Wellbeing Scales (WEMWBS; Tennant et al., 2007)
- The Perceived Stress Scale (Cohen, Kamarack, & Mermelstein, 1983)

A third section focused on some of the other impacts that had been identified in the initial research phase. This included questions about the confidence young carers had in themselves and their caring role, whether the young carers felt OK about being a young carer, about their friends, school, after school activities and how important the young carer group is to them. This section also included four questions used by the Office of National Statistics (ONS, 2018) to measure personal well-being and a final open-ended question about their project.

2.2.3 Pre-test

The questionnaire was pre-tested with four young carers from the Basingstoke young carer project. It was found that the questionnaire took on average 18 minutes to complete. One young carer with special educational needs, (SEN) took 28 minutes to complete the questionnaire and required their support worker to explain some of the questions. This increased the average time it took to complete. Those completing this pilot phase were asked about the comprehensibility of the questions and as a result the language of some questions were modified.

2.2.4 Completion of questionnaires

Young carers completed the questionnaire at two evaluation points:

- Evaluation point 1: April - May 2018
- Evaluation point 2: February 18th - 15th March 2019

The period between questionnaires (and there the duration of support that young carers received between questionnaires) therefore ranged from 8 ½ months to 11 ½ months. There were some minimal variations in these timeframes as a result of operational issues experienced by the young carer projects.

2.2.5 Data collection

The questionnaire was designed to be completed using paper and pencil and each questionnaire was identified using a coding system to ensure young carers are not identifiable from the data. Having completed their questionnaire, young carers were instructed to place it in an envelope and seal it. Envelopes with the questionnaire inside were given to the Researcher to open and enter the answers electronically onto an Access database before being transferred to an Excel database and then into an SPSS Statistics dataset.

The questionnaire was preferably to be completed at the first contact with a young carer (at the first home-visit or on the young carers' first visit to the group). If this was not possible for the services (or they chose not to) then the questionnaire had to be administered as soon as possible and within one month of the young carer joining the project

2.2.6 Data Analysis

Descriptive statistics were used as well as inferential statistics (using SPSS Statistics).

2.2.7 Limitations of the method

- Participants were not randomly chosen but purposively chosen by project staff to:
    1. meet the start date criteria and
    2. ensure a range of ages and genders.
- In addition, it should be noted that depending on the number of referrals fulfilling criteria 1 that HYCA staff may have had some free choice in which young carers were chosen to complete the questionnaires. This choice would also have been determined by operational challenges of being able to undertake the questionnaire.
- Although the young carers would have received similar types of support the exact interventions from the ten HYCA services would not have been identical.
- The Winchester Young Carers project modified their offer to young carers during the study. The n=7 young carers from the Winchester project consequently all

received a more formal intervention programme as well as other general interventions experienced by the young carers attending the other groups.[4]

- Because of the requirement, for practical purposes, to establish a timeframe for the completion of both questionnaires, the duration of the intervention was not identical for all the young carers.
- The level of engagement of the young carers with the projects was not consistent. At the second questionnaire, HYCA staff were requested to state on the Summary Log Sheet whether the young carer had engaged or not (Y/N).

2.2.8 Participants

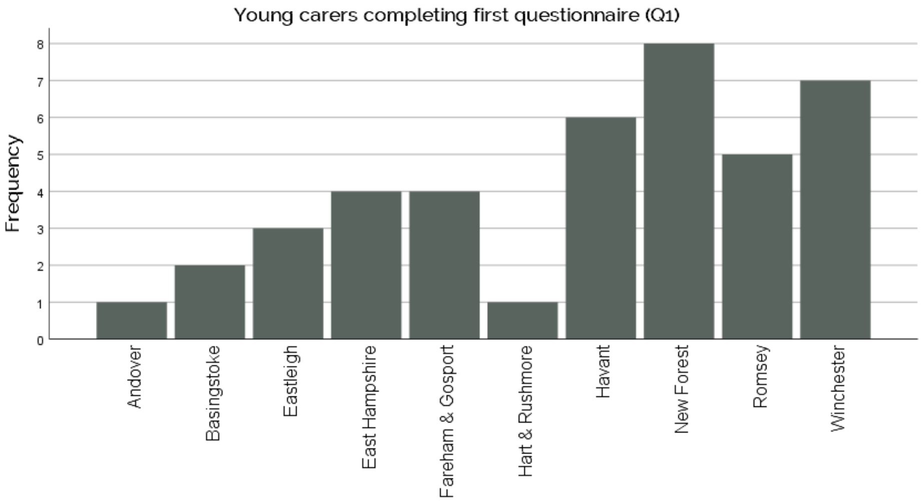
Some of the projects struggled to recruit high numbers of young carers because of practical reasons and as a consequence of the low number of young carers who were referred to some projects during the time-window for completing the first questionnaire who fitted the age criteria.

In total **n=41 young carers** were recruited from the 10 HYCA young carer services and completed the first questionnaire. Of these young carers, **n=30** completed the second questionnaire as well.

The main reason why young carers did not complete the second questionnaire was that they were no longer engaging with the service and were not able to be contacted. One parent refused to allow their child to complete the second questionnaire as they were no longer engaged and another parent reported that their child did not wish to complete the second questionnaire.

Of those 30 young carers who did complete both questionnaires, **n=3** did not engage with their project which left a total of **n=27** young carers who completed both questionnaires and who also engaged with a project.

Young carers from each of the 10 HYCA projects completed Questionnaire 1 (Q1). The highest number of young carers from one project was 8 (New Forest) and the lowest was one (Andover & Hart and Rushmore).



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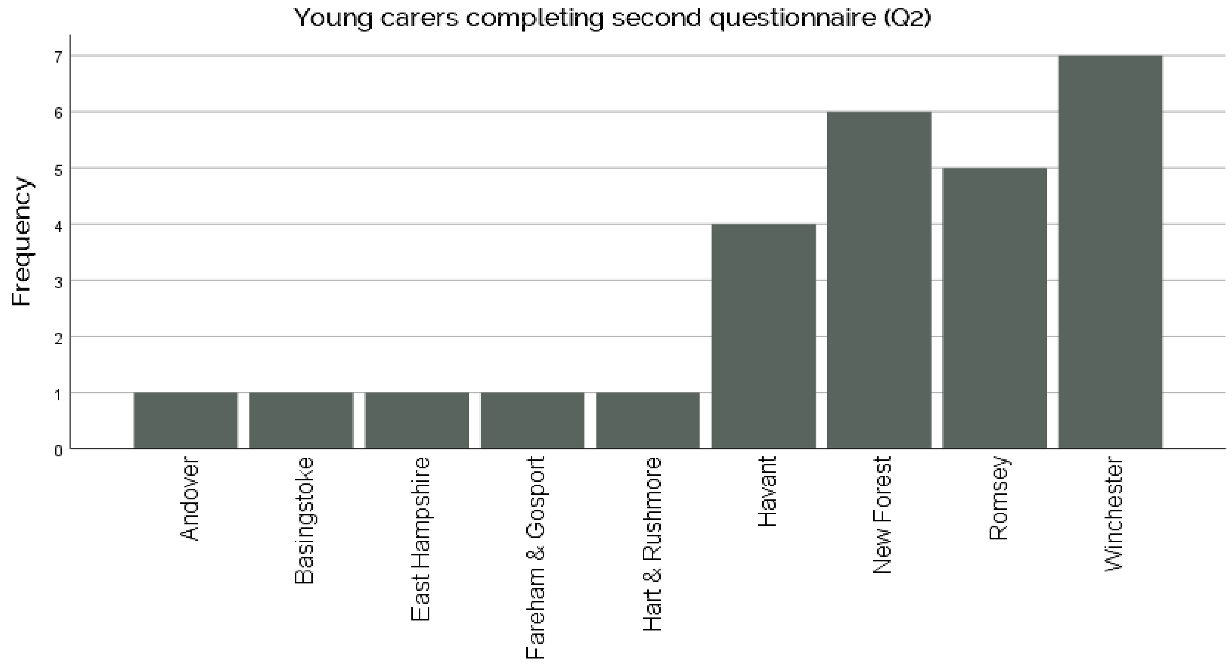
[4] The Young Carer Exploration Programme (See Appendices)

Young carers from each of the 10 HYCA projects completed the Questionnaire 1. The highest number of young carers from one project was 8 (New Forest) and the lowest was one (Andover & Hart and Rushmore).

Young carers from only 9 HYCA projects completed Questionnaire 2 (Q2). The highest number of young carers from one project was 7 (Winchester) and in 5 projects only n=1 young carer completed Q2. No young carers from the Eastleigh project completed Q2.



N=41 young carers completed Q1

N= 28 young carers completed Q1 and engaged with their project

N= 27 young carers completed Q1 and Q2 and engaged with their project

N= 13 completed Q1 but did not engage with their project after that

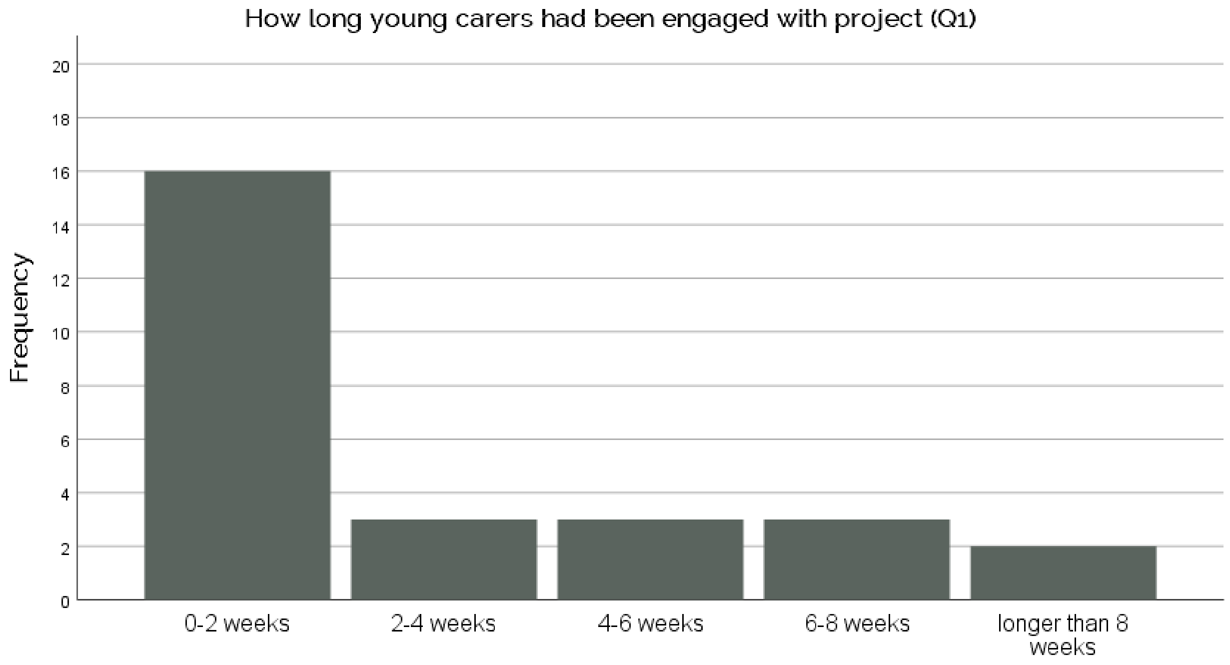
Table 1 Overview of young carers completing Q1

		Questionnaire 1				Questionnaire 2			
		Total	Male	Female	Prefer Not to Say	Total	Male	Female	Prefer Not to Say
1	Andover	1	0	1	0	1	0	1	0
2	Basingstoke	2	2	0	0	1	1	0	0
3	Eastleigh	3	2	1	0	0	0	0	0
4	East Hampshire	4	2	2	0	1	1	0	0
5	Fareham & Gosport	4	2	2	0	1	0	1	0
6	Hart & Rushmore	1	1	0	0	1	1	0	0
7	Havant	6	3	3	0	4	1	3	0
8	New Forest	8	4	4	0	6	3	3	0
9	Romsey	5	2	3	0	5	2	3	0
10	Winchester	7	4	3	0	7	4	3	0
	Total	**41**	**22**	**19**	**0**	**27**	**13**	**14**	**0**

In total 41 young carers from 10 HYCA services completed Questionnaire 1 and 27 completed Questionnaire 2 (and engaged with their project).

2.2.8.1 How long young carers had been engaged with the projects

When completing Q1, the majority of all young carers (n=27, 65.9%) had been engaged with their project between 0 and 2 weeks, whilst 2 reported having been engaged with the project longer than 8 weeks.

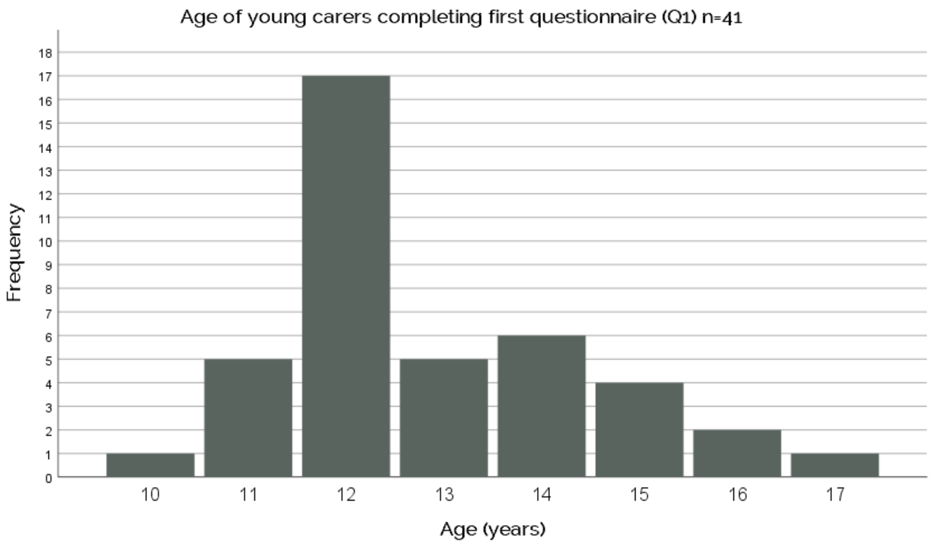


3 Results

3.1 About the young carers completing questionnaire 1 (Q1) and questionnaire 2 (Q2)

3.1.1 Age of young carers completing questionnaires

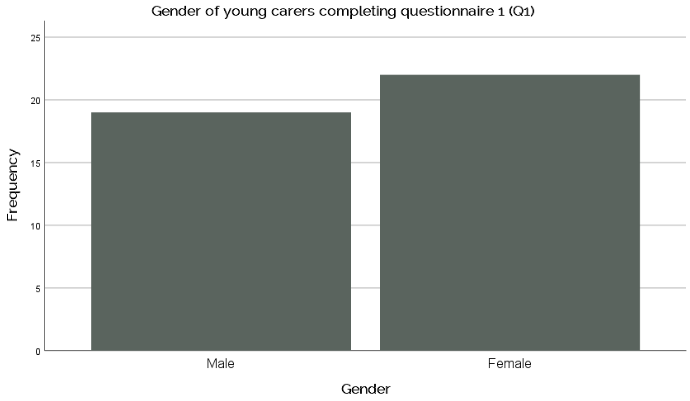
The mean age of all those completing the first questionnaire (n=41) was **12.9** years and the age range was between 10 and 17 years.



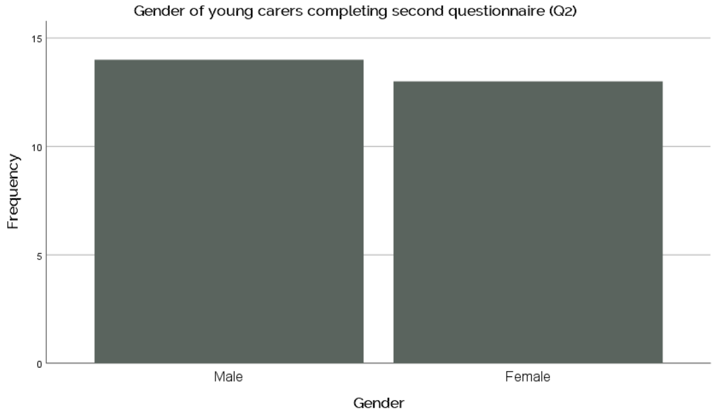
Young carers completing **both questionnaires** were aged between 10 and 16 years old when they completed Q1 and their mean age was **12.5** years. By the time they completed Questionnaire 2 the young carers were aged between 11 and 17 with a mean age of **13.3** years.

3.1.2 Gender

N= 22 young carers completing Q1 (53.7%) were female and n=19 (46.3 %) were male. No young carers identified themselves as 'Other' or chose not to express a gender.

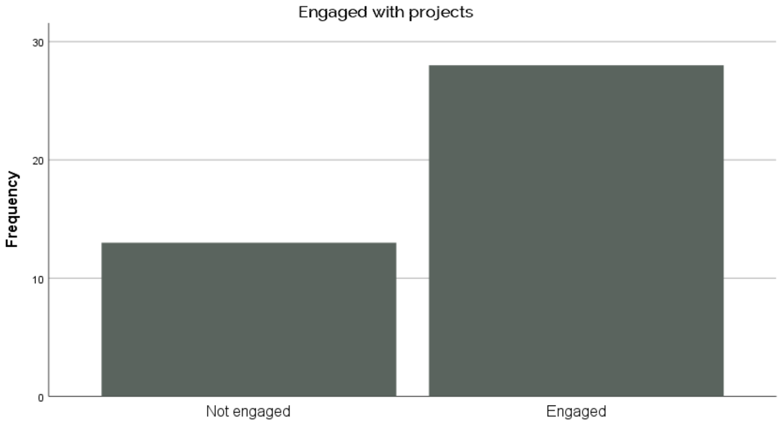


At Q2, n=14 (52%) were male and n=13 (48%) were female.



3.2 Engagement after Q1

N=28 young carers (68.3%) who undertook the initial questionnaire (Q1) also engaged with their young carer project. Therefore 31.7% of the young carers (n=13) did not engage with their project after their initial introduction to the project after having completed the first questionnaire (Q1).

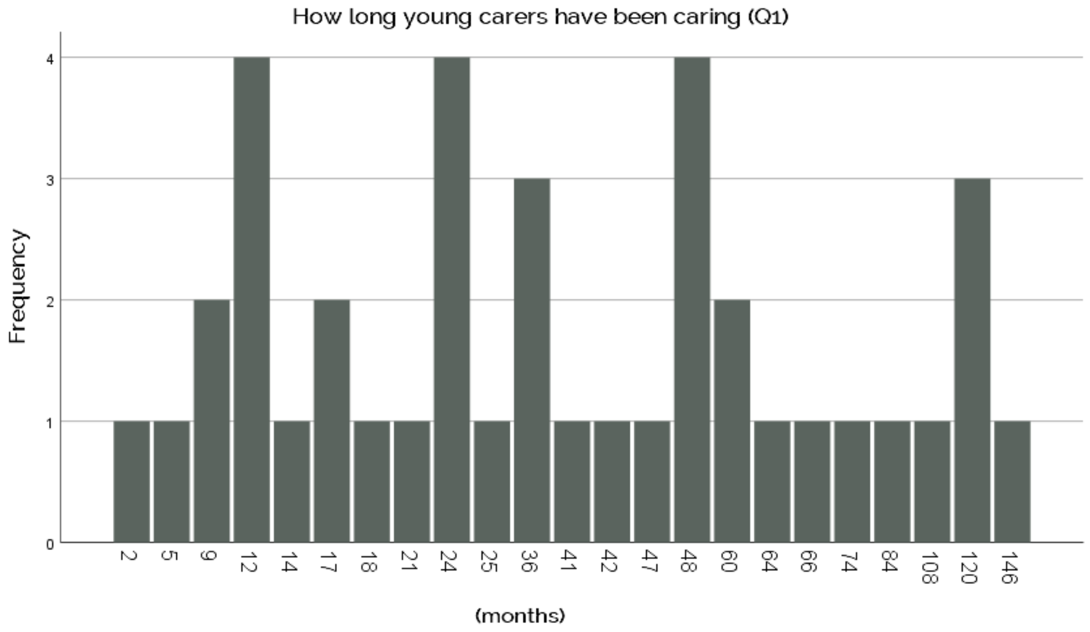


The mean age of all those who did not engage with the projects after completing Q1 (n=13) as reported by project staff, was **13.5** years.

3.3 About the young carers' caring

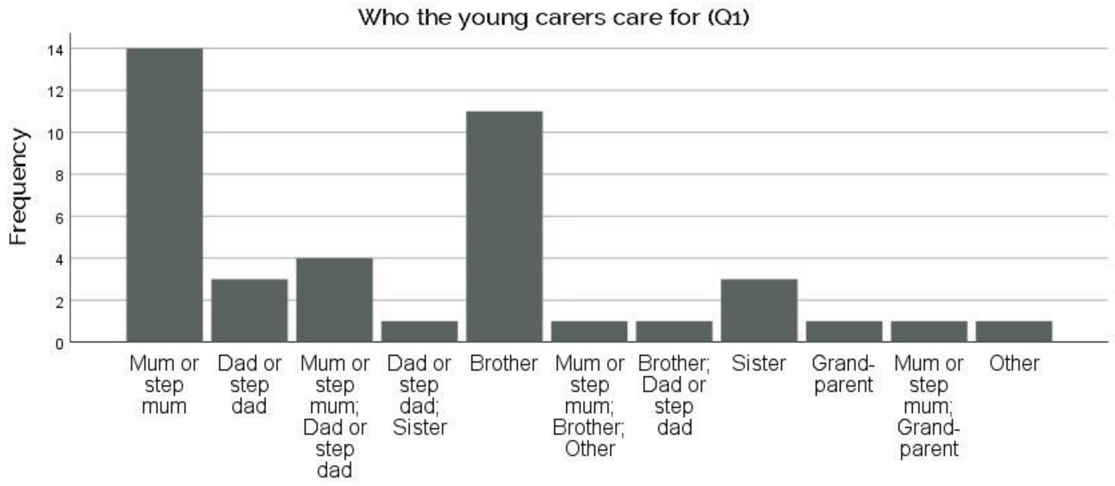
3.3.1 How long young carers had been caring

The young carers had been caring for varying lengths of time ranging from 2 months to over 12 years. The average length of time that the young carers who completed Questionnaire 1 had been caring for was for 3 years 8 months (44 months).
Over half (53.8%) of those who responded had been caring for three or more years.

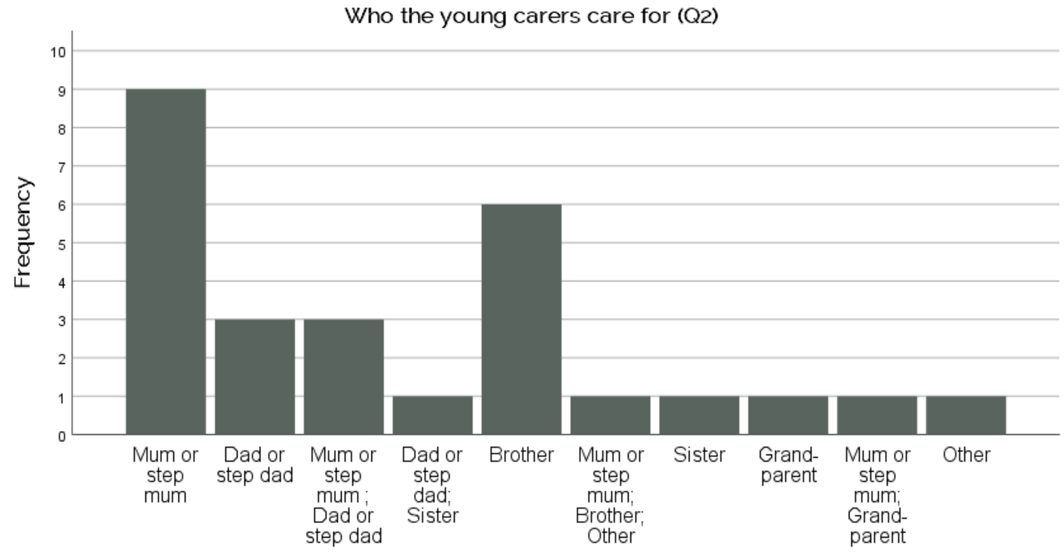


3.3.2 Who the young carers care for

The young carers completing Q1 cared primarily for different family members, with only one young carer reporting that they cared for someone other than a family member. The most frequent family members who were cared for were mums or step-mums (n=14) and brothers (n=11). N=7 young carers reported caring for two or more people and one young carer reported caring for three people a (mum or step-mum, a brother and one other person).



The profile of those who young carers reported caring for at Q2 was similar (as would be expected) to that reported at Q1, with caring for a mum or step-mum or a brother being most common.



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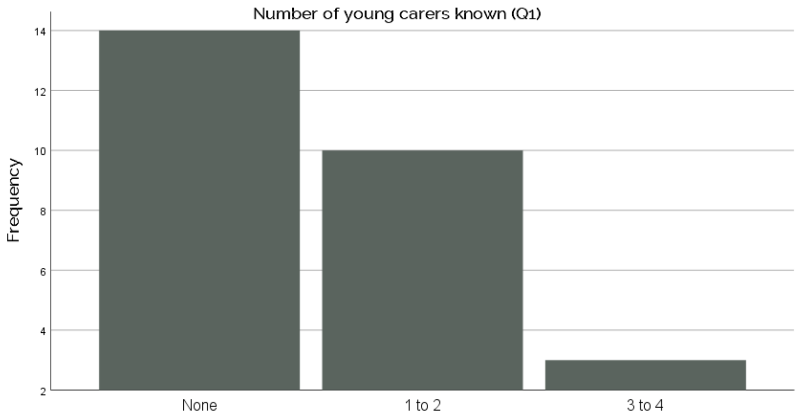
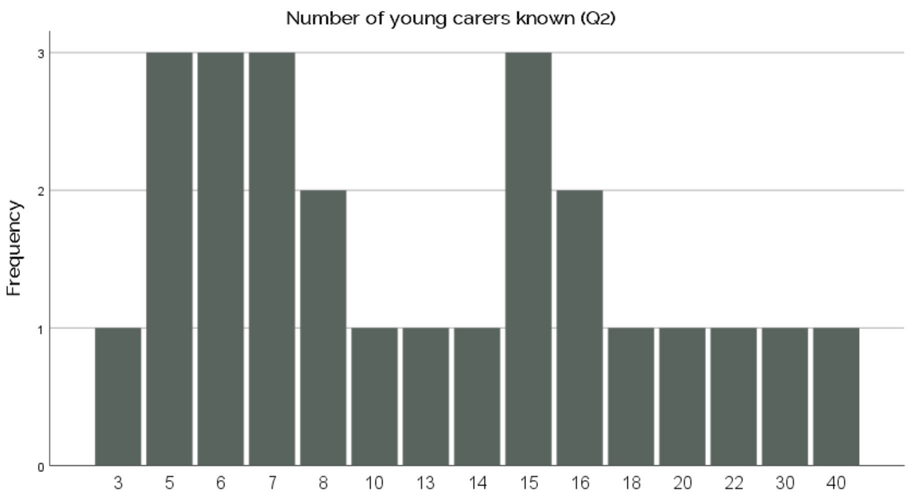
*The majority of the remainder of the results only include the 27 young carers who engaged with the projects **and** who completed **both** questionnaires.*

3.4 Number of young carers known

N=14 (51.9%) of the 27 young carers (who completed Q1 and Q2 and remained engaged) reported that they did not know any other young carers prior to joining their project, n=10 knew 1-2 young carers and n=3 knew 3-4 young carers. No young carers reported knowing more than 4 young carers before they had engaged with their project.

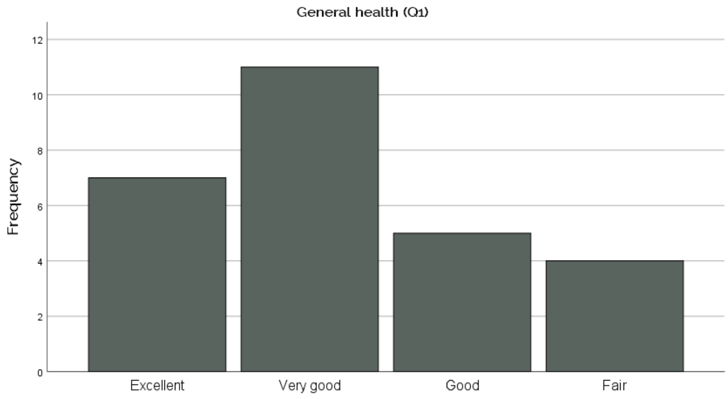


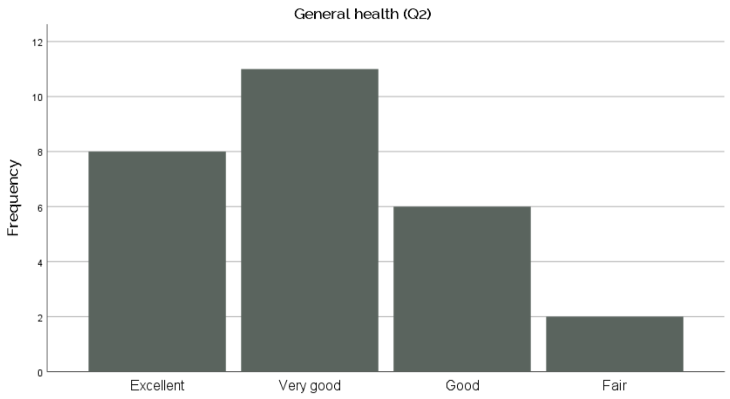
By Q2 there had been a large increase in the number of young carers who were now known by participants. N=2 young carers did not answer this question, however, of those who did, none of the young carers at Q2, reported that they did not know any other young carers. Furthermore, the average number of young carers now known by those completing the questionnaire was 12.7 (ranging from 3 young carers to 40 young carers).



3.5 Health

Responding to the question, ‘In general, how is your health?’ the vast majority of young carers (85.2%) reported their health to be either ‘excellent’, ‘very good’ or ‘good’ in Q1. This had increased to 92.6% in Q2. Furthermore, no young carers described their health on the stand-alone health question as ‘poor’ in either questionnaire.




General health (Q2)
Frequency
0
2
4
6
8
10
12
Excellent
Very good
Good
Fair

3.6 PANOC

The PANOC aims to measure the positive and negative outcomes of caring. It provides a score of the subjective cognitive and emotional impact of caring in young people. One score shows how much caring is experienced negatively and one score shows how much caring is experienced positively.

3.6.1 PANOC (+ve)

At Q1, young carers were already generally experiencing relatively high positive outcomes of caring. The mean PANOC (+ve) score at Q1 was **14.00** and at Q2 this had risen slightly to **15.19** (although this is not statistically significant). Both these scores might be considered as indicating relatively high positive outcomes. Only a quarter 25.9% of the young carers (n=7) scored 12 or less on the PANOC (+ve) score at Q1, indicating relatively few positive outcomes.

PANOC (+ve)		
	Q1	**Q2**
Mean	14.00	15.19
Std. Deviation	3.13	3.42

T-TEST PANOC (+ve)				
N	**Mean**	**Standard Deviation**	**t**	**Sig**
27	1.185	3.991	1.543	0.135

3.6.2 PANOC (-ve)

Here a low score indicates only a few negative outcomes, whereas a high score above 8 raises potential for concern.

At Q1, young carers were generally only experiencing a few negative outcomes of caring. The mean PANOC (-ve) score at Q1 was **4.26** and at Q2 this had risen slightly to **4.81** (although this is not statistically significant). Both these scores might be considered as indicating relatively low negative outcomes. 85.2 % of the young carers scored 8 or less on the PANOC (-ve) score at Q1, again indicating that generally they had relatively few negative outcomes near the start of receiving support.

PANOC (-ve)		
	Q1	**Q2**
Mean	4.26	4.81
Std. Deviation	3.96	4.26

Because the data was skewed for one of the variables, a Wilcoxson Signed-Ranks test was run. The output indicated that the median Q2 scores were not statistically higher than Q1 scores, z=-0.747, p= 0.455.

3.7 The Warwick-Edinburgh Mental Well-being Scale (WEMWBS)

WEMWBS comprises 14 items that relate to an individual's state of mental wellbeing in the previous two weeks.

The WEMWBS scores at Q1 ranged from 34-62, with the mean being **48.41** (standard deviation 7.54). At Q2, the scores ranged from 36-69 and the mean had risen slightly to **50.85,** (standard deviation 9.47) although this is not statistically significant,

WEMWBS		
	Q1	**Q2**
Mean	48.41	50.85
Std. Deviation	6.42	4.99

T-TEST WEMWBS				
N	**Mean**	**Standard Deviation**	**t**	**Sig**
27	2.444	9.736	1.305	0.203

There was an increase in the percentage of young carers responding positively to the statement that they had been feeling relaxed. A quarter (25.9%) said they felt relaxed often, or all of the time at Q1, compared to over a third of young carers (34.6%) at Q2, There was also an increase in the percentage of young carers responding positively to the statement that they had been feeling confident. 40.7% said they felt confident often, or all of the time at Q1, compared to 55.6% young carers at Q2,

3.8 The Perceived Stress Scale (PSS)

The Perceived Stress Scale (PSS) is a classic stress assessment instrument aimed at measuring perceived stress. Individual scores on the PSS can range from 0 to 40 with higher scores indicating higher perceived stress.

There was a slight decrease in the mean stress score between **Q1 (19.15) and Q2, (18.33)** however this was not statistically significant.

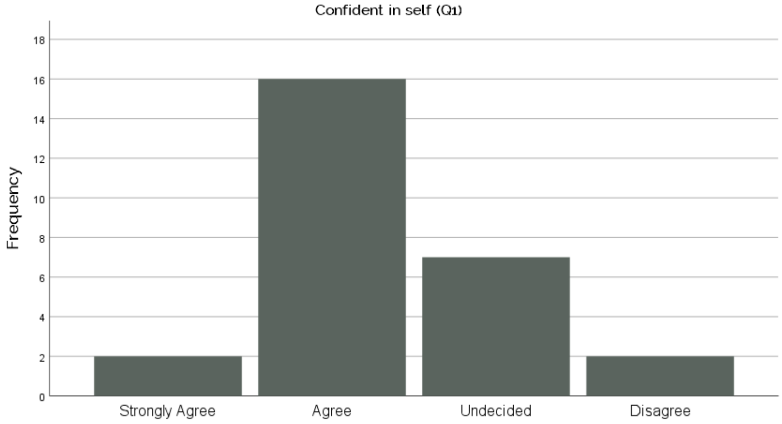
PSS		
	Q1	**Q2**
Mean	19.15	18.33
Std. Deviation	6.42	4.99

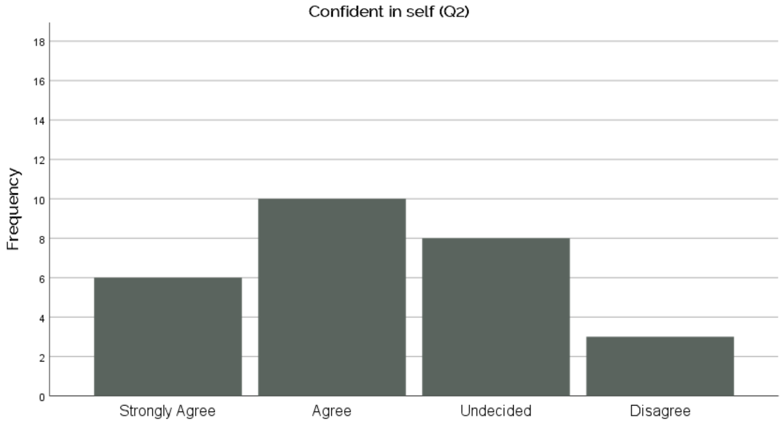
PSS T-TEST				
N	**Mean**	**Standard Deviation**	**t**	**Sig**
27	-0.815	7.179	-0.590	0.560

3.9 Confidence

3.9.1 Confidence in self

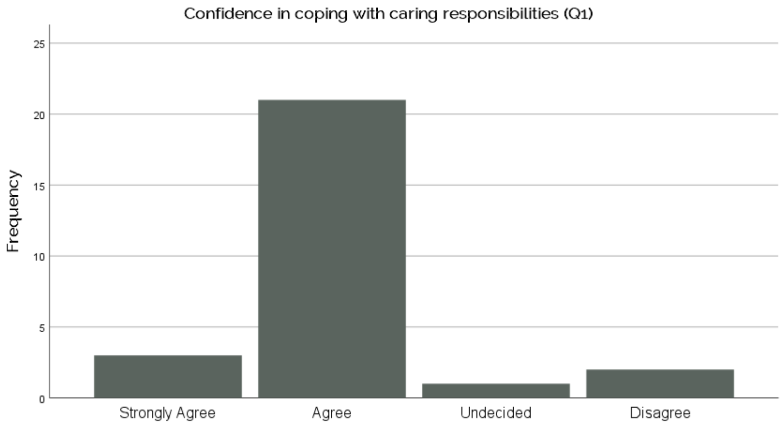
There was little difference in how young carers reported how confident they felt in themselves between Q1 and Q2. Generally young carers reported that they were confident in themselves. In Q1, n=18 young carers, (about two thirds, 66.7%) either 'agreed', or 'strongly agreed' to the statement 'I generally feel confident in myself'. This fell slightly to 59.3% in Q2 although the number reporting they 'strongly agreed' rose. Two and three young carers disagreed that they were confident in themselves in Q2 and Q3 respectively.

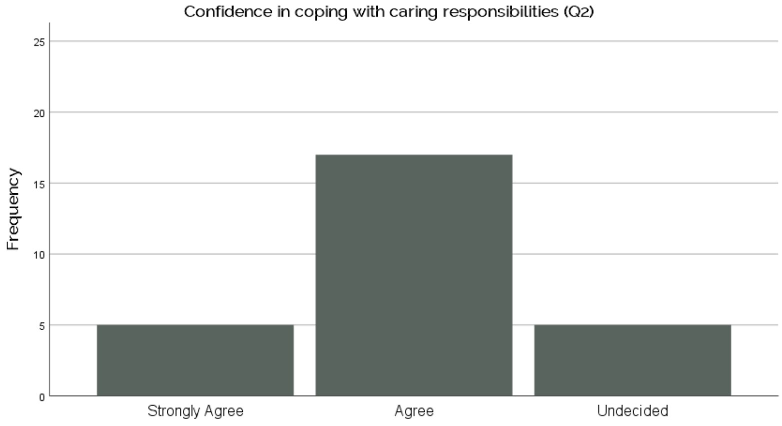




3.9.2 Confidence in caring role

Again, generally young carers reported that they were confident in their caring role. The majority of young carers either 'agreed' or 'strongly agreed that they were confident in coping with their caring responsibilities at both measuring points (88.9% at Q1 and 81.5% at Q2). A few more (n=4) had become undecided by Q2 about whether they were confident, however none disagreed that they had confidence in their caring role at the second questionnaire.

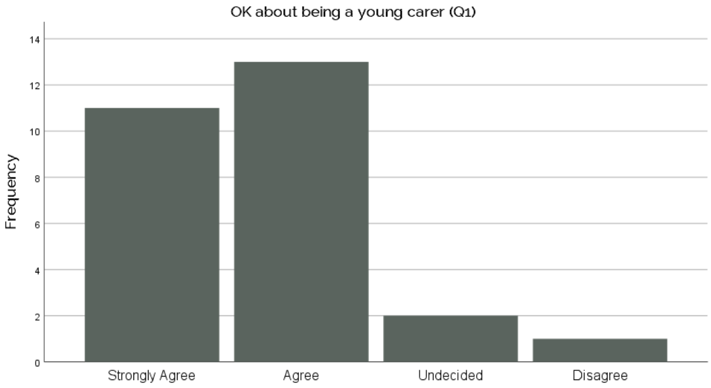


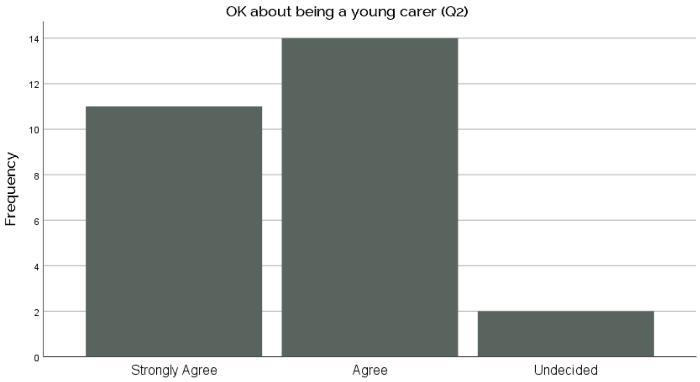


Overall there was little measured change in the how young carers reported their confidence in themselves or in their confidence about coping with their caring responsibilities. It is worth noting that at Q1 a large majority of young carers reported having confidence in themselves and in coping with their caring role.

3.10 OK about being a young carer?

There was little change from Q1 to Q2 as to how young carers responded to the statement 'I feel OK about being a young carer'. At Q1, a large majority n=24 (88.9%) of the 27 young carers agreed or strongly agreed that they felt OK about being a young carer. By Q2 this had risen by one young carer to n=25 (92.6%) with none of the young carers reporting that they were not OK about being a young carer.

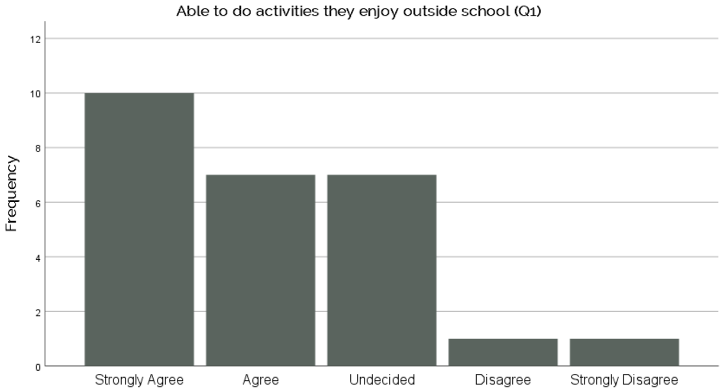


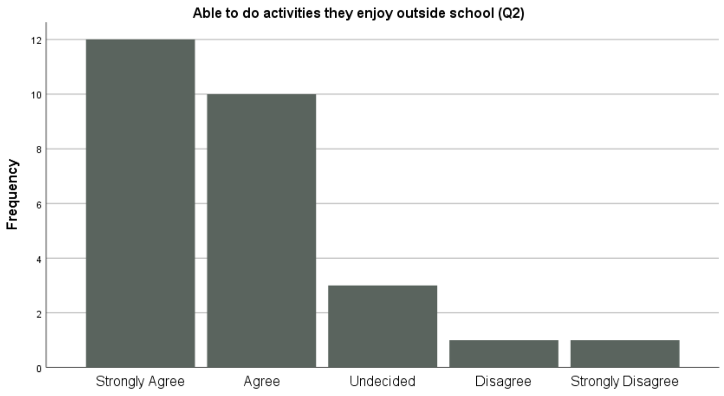


3.11 Activities outside school

Between Q1 and Q2 there was an increase in the number of young carers from n=17 (two thirds of the young carers) to n=22 (65.4% to 81.5%) who either 'agreed' or 'strongly agreed' that they were able to do activities they enjoy outside school.

Only two young carers at both Q1 and Q2 either 'disagreed' or 'strongly disagreed' that they were able to do activities that they enjoyed outside school.

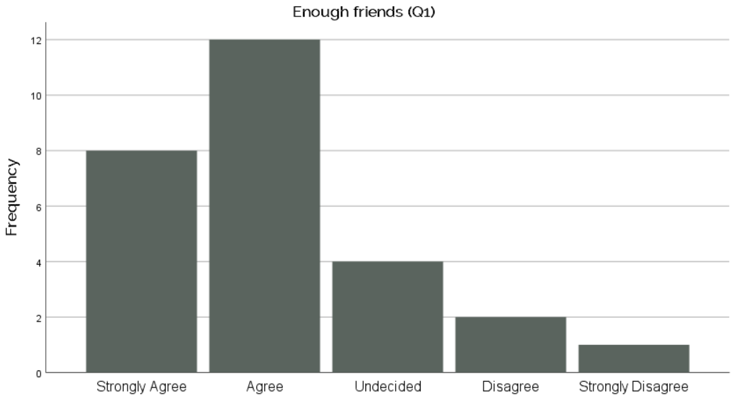


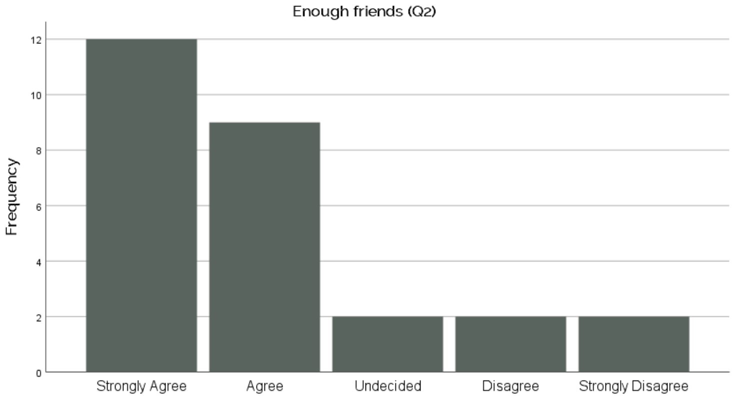


3.12 Friends

3.12.1 Enough friends

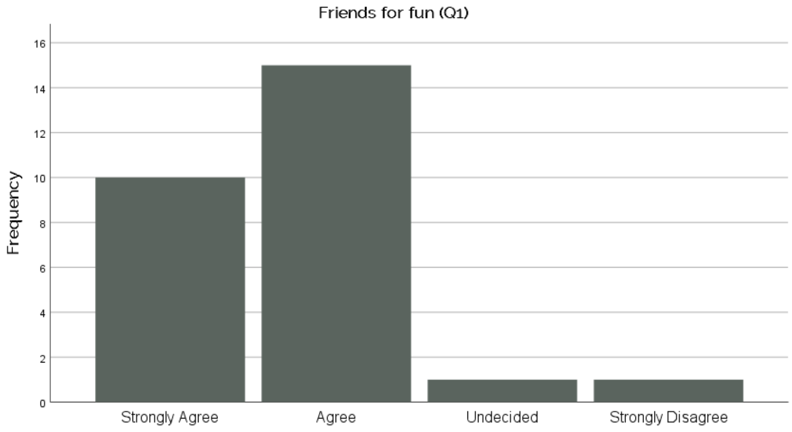
There was little change in how the young carers reported whether they felt that generally they had enough friends. Over three quarters (77.8%) believed that they did have enough friends at Q2 compared to 74.1% at Q1. The number of young carers who strongly agreed that they had enough friends however increased from 29.6% to 44.4% (n=8 to n=12).

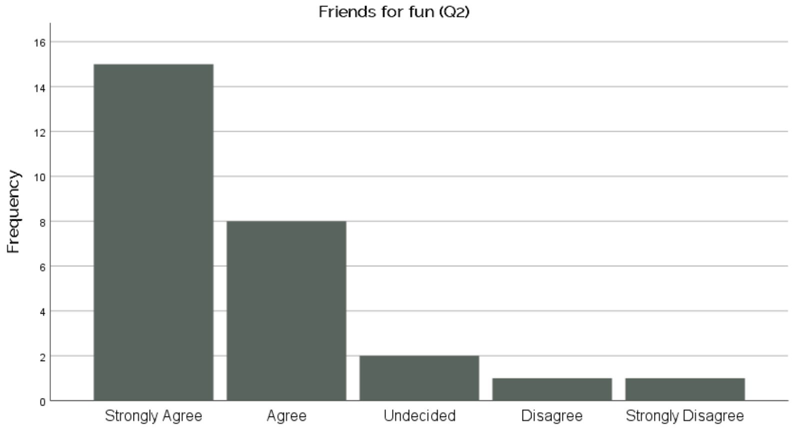




3.12.2 Friends for fun

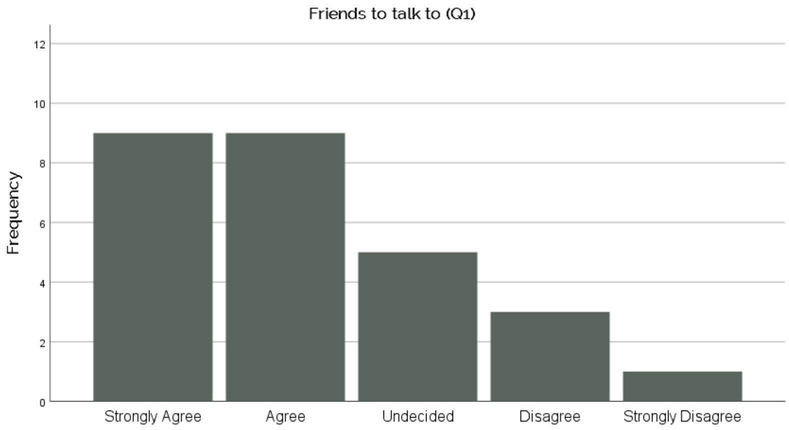
At Q1 the majority of young carers, n=25 (92.6%) either agreed or strongly agreed that they had enough friends for fun, this compared to only n=1 young carer who strongly disagreed this was the case. The situation was very similar, although slightly lower, at Q2 where n=23 (85.2%) young carers reported having enough friends for fun.

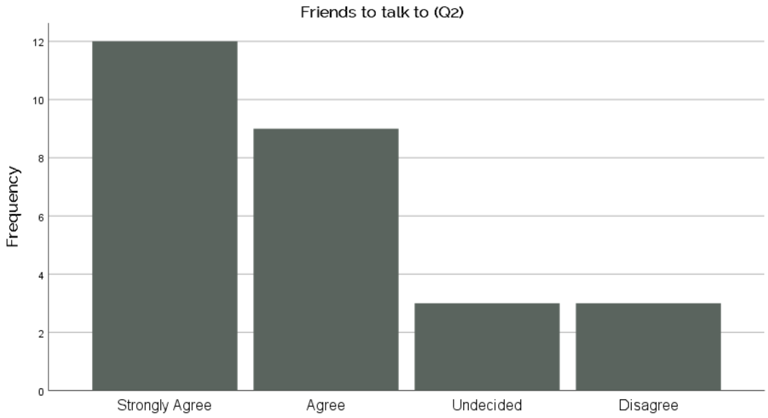




3.12.3 Friends to talk to about things they are worried about

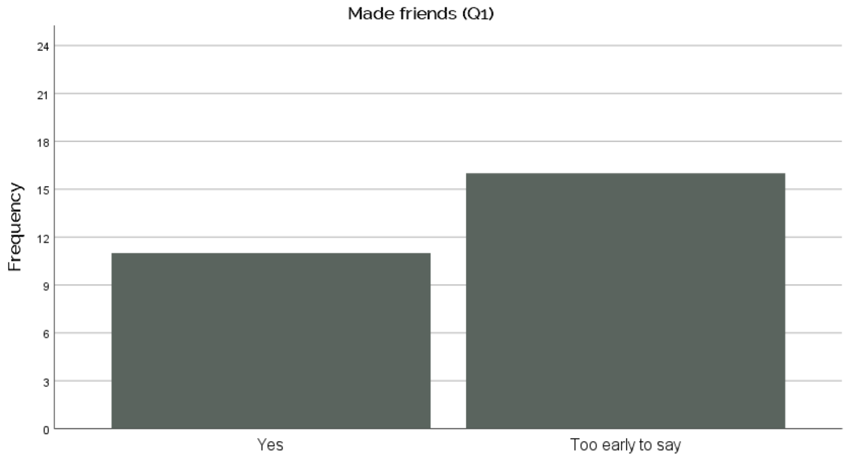
Between Q1 and Q2 there was a slight increase in the number of young carers from n=18 to n=21 (66.7% to 77.8%) who either 'agreed' or 'strongly agreed' that they had enough friends to talk to about things they are worried about.

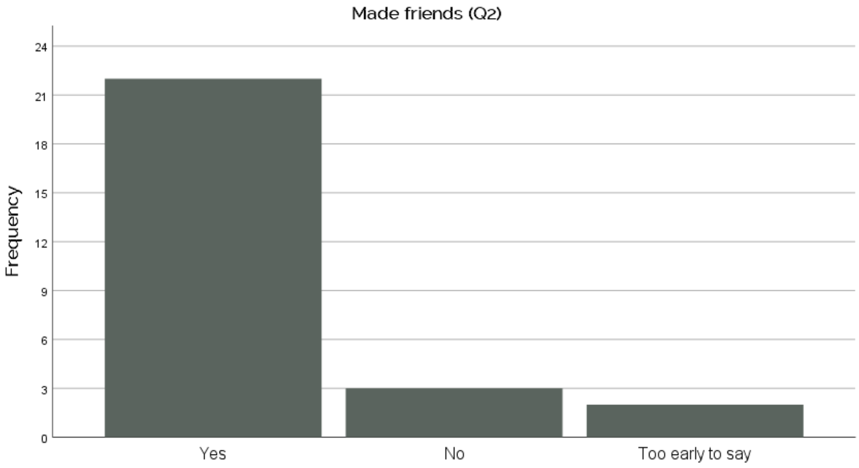




3.12.4 Friends young carers have made

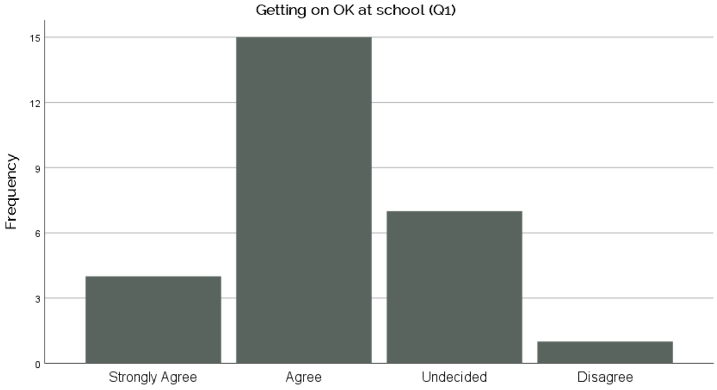
At Q1, n=16 young carers felt it was too early to say whether they had made friends since joining the young carers' group, however, n=11 (40.7%) reported that they already had made friends. By Q2, the number of young carers reporting that they had made friends had doubled to n=22 (81.5%) with only n=3 young carers reporting that they had not made friends.

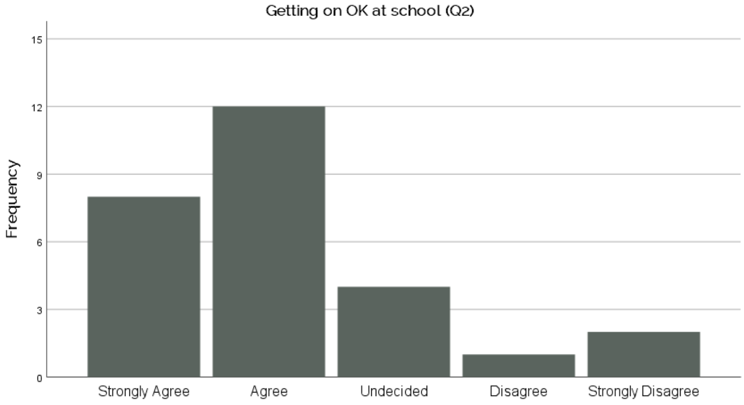




3.13 School

At Q1, a fairly high number n=19 (70.4%) of the young carers agreed or strongly agreed that they were getting on OK at school. By Q2 this had risen very slightly to 74.1% (n=20). However, whereas at Q1 no young carers had strongly disagreed that they were getting on OK at school, two young carers at Q2 reported this.





3.14 Office for National Statistics (ONS) personal wellbeing questions

Overall, how satisfied are you with your life nowadays?
The mean score to the question **'Overall, how satisfied are you with your life nowadays?'** at Q1 was **7.00** and at Q2 this had risen minimally to **7.04** (although this is not statistically significant).

ONS 'How satisfied'		
	Q1	**Q2**
Mean	7.00	7.04
Std. Deviation	1.64	2.23

Overall, to what extent do you feel the things you do in your life are worthwhile?
The mean score to the question **'Overall, to what extent do you feel the things you do in your life are worthwhile?'** at Q1 was **6.85** and at Q2 this had risen to **7.33** (although this is not statistically significant).

ONS 'How worthwhile'		
	Q1	**Q2**
Mean	6.85	7.33
Std. Deviation	1.75	1.96

Overall, how happy did you feel yesterday?
The mean score to the question **'Overall, how happy did you feel yesterday?'** at Q1 was **7.30** and at Q2 this had risen slightly to **7.78** (although this is not statistically significant).

ONS 'How happy'		
	Q1	**Q2**
Mean	7.30	7.78
Std. Deviation	2.03	1.67

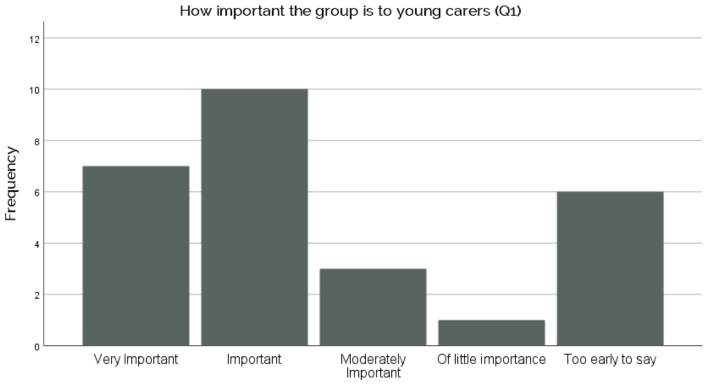
On a scale where nought is 'not at all anxious' and 10 is 'completely anxious', overall, how anxious did you feel yesterday?
The mean score to the question **'On a scale where nought is 'not at all anxious' and 10 is 'completely anxious', overall, how anxious did you feel yesterday?'** at Q1 was **3.81** and at Q2 this had fallen slightly to **3.44** (although this is not statistically significant).

ONS 'How anxious'		
	Q1	**Q2**
Mean	3.81	3.44
Std. Deviation	2.82	2.64

3.15 Young carers' views of their project

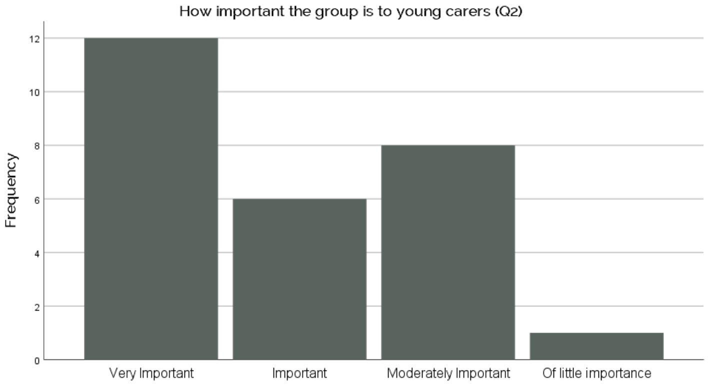
3.15.1 How important is the group to the young carers

Views on the projects were positive at both assessment points (Q1 and Q2). At the start (Q1) n=17 (63%) of the young carers reported that the young carer group they attended was either 'important' or 'very important'.

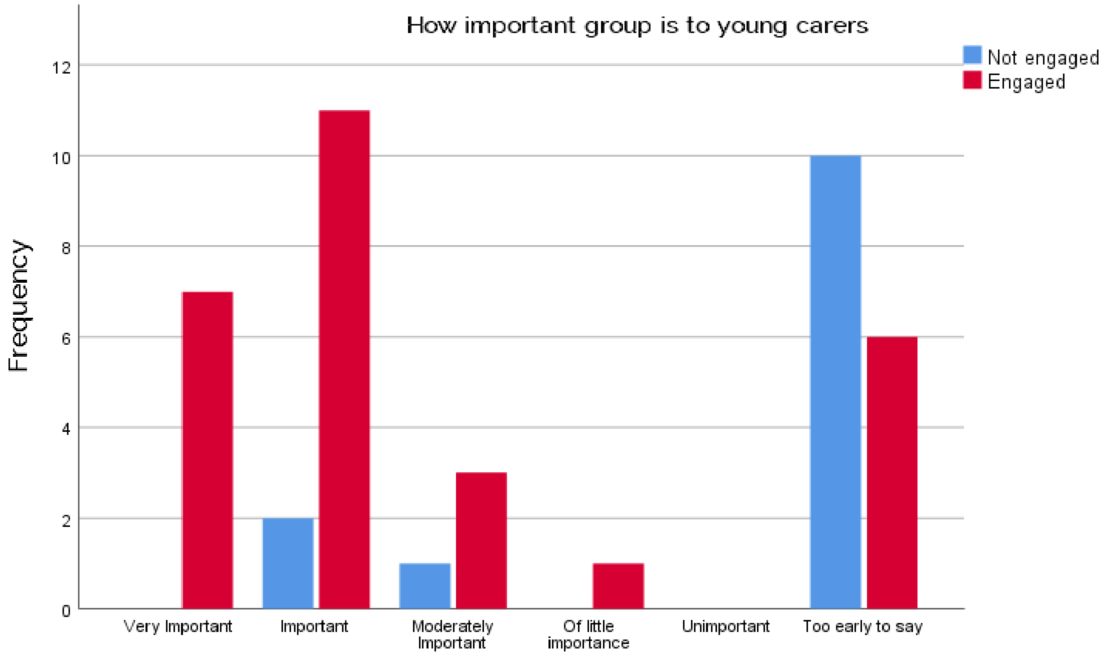


By Q2 this had risen by one young carer to two-thirds (66.7%). The numbers reporting their group to be 'very important', 'important' or 'moderately important' rose from 74.1% at Q1 to 96.3% at Q2. There was also a rise in the number of young carers reporting the group to be '*very* important' from n=7 to n=12 (although this coincided with a drop in reports of the group being 'important').

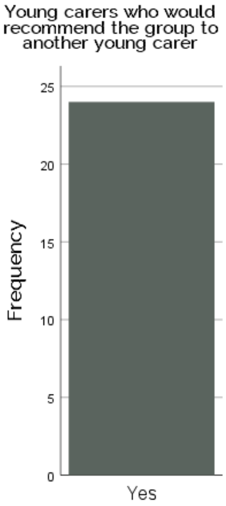
Overall, for those young carers who remained engaged with their project over the duration of the intervention, the importance of how they viewed their project had increased and more of them (a quarter) viewed their project as being 'very important' to them, with only one reporting it was 'of little importance' to them.



Of particular note, a much higher proportion of those young carers who remained engaged with their projects viewed their group as being important to them compared to those who disengaged. At Q1, the majority of those who later engaged with their project (64.3%) reported that their project was either 'very important' or 'important' to them. This is in contrast with those who did not subsequently engage with their project and who predominantly reported that it was too early to say how important the project was to them. For this group who did not engage, only 15.4% reported at Q1 that their project was either 'very important' or 'important' to them.



3.15.2 Would young carers recommend their project?



24 young carers out of the 27 who completed Questionnaire 2 responded to the question to whether or not they would recommend their young carer group to another young carer. Of those responding, 100% reported that they would recommend their project, which reflects the previous finding about how important the project was to them.

3.15.3 Open question about projects

Both questionnaires asked the young carers whether there was anything else that they wished to say about the young carers' group. Young carers were generally positive about their initial engagement with projects and several of the young carers reported that they were looking forward to continuing engaging with them. There were some general positive comments as well, including 'It has a very nice atmosphere' and 'it seems nice'. A few young carers also reported some early positive outcomes including, 'It has been helping me relax' and 'They helped the fastest'. Others highlighted the opportunity to meet and talk with others, that projects were fun and that the staff were amazing. Comments from the second questionnaire were also positive and included some very positive language such as 'It's amazing', 'One of the nicest places I have ever been to', 'Very supportive', 'Very fun' and 'amazong' [sic]. As in Q1, young carers positively reported the opportunity to meet and talk with others, and that the projects were fun. Two young carers highlighted the role of staff as positive and another two reported that their project had helped them with their confidence.

Table 2 Open question about projects

Questionnaire 1 (N= 41)	Questionnaire 2 (N= 28)
Early engagement • I've only just started • I am looking forward to starting properly this week • It's too early to say. I haven't started yet • They're good they help out a lot. But only seen them once! • I have been to lunch club. It was good. I am going to club next week. • I'm really enjoying it and want to come again • I am thankful that I am now in the young carers group	
Positive general comments • It has a very nice atmosphere • It is very helpful to have them by my side when I'm caring • It seems nice	**Positive general comments** • I think that young carers is a really lovely idea so that people can get together and help each other out [YC did not engage] • It's amazing and I'm so happy I'm part of it • Useful • Young carers is one of the niceest [sic] places I have ever been to and I thoroughly enjoy it • Very supportive and very helpful!
Fun • I like coming here because it is very fun • Fun	**Fun** • Fun nice to talk to about problems • It's fun, most of the activities I have done has been very fun and interested
Meeting others and talking with others • New friends and less dealing with my brother • I think that it is a good idea to do young carers because you get to meet people that has been through the same thing as you and they can understand what you are feeling • Could help me speak to people a bit more • I enjoy being able to talk to people that are the same as me because they understand more • It's cool to express myself	**Meeting others and talking with others** • It is helpful because whenever I have a problem I have more friends to go to • It is nice to have people to talk to who understand you • It is grate [sic] to talk to people • Good for helping how support others
Staff • Staff is amazing	**Staff** • They are very friendly and the leaders are amazong [sic] at what they do • They're really lovely and helpful
Helped young carers • It has been helping me relax • It's helped me a lot • They helped the fastest	**Confidence** • It has helped me to get a lot more confident • Young carers has made me more confident. What I want **Other** • They're good there is yummy food :)

3.16 Correlations

3.16.1 Number of hours caring

A Spearman's correlation was run to determine the relationship at Q1 between the number of hours of care undertaken by the young carers and their perceived stress as measured by the PSS. There was a moderate positive correlation between number of hours caring and stress (at Q1) ($r_s = .434$, $n = 27$, $p < .05$).

A Spearman's correlation was run to determine the relationship at Q2 between the number of hours of care undertaken by the young carers and how important they reported their young carer project to be. A moderate positive correlation between number of hours caring and how important (at Q2) ($r_s = -.448$, $n = 27$, $p < .05$).

3.16.2 Confidence

A Spearman's correlation was run to determine the relationship at Q1 between the young carers' confidence in themselves and their subjective wellbeing as measured by the WEMWBS. A moderate positive correlation was found between their confidence in themselves and their WEMWBS score (at Q1) ($r_s = .0.537$, $n = 27$, $p < .01$). At Q2 a strong correlation was found between the young carers' confidence in themselves and their subjective wellbeing as measured by the WEMWBS. ($r_s = .0.637$, $n = 27$, $p < .01$).

A moderate positive correlation was found between the young carers' confidence in caring and their subjective wellbeing and psychological functioning as measured by the WEMWBS.at Q1 ($r_s = .0.553$, $n = 27$, $p < .01$).

A moderate positive correlation was also found between the young carers' confidence in caring and their subjective wellbeing and psychological functioning as measured by the WEMWBS.at Q2 ($r_s = .0.537$, $n = 27$, $p < .01$).

4 Discussion

Using an allocation of The Big Lottery funding, HYCA commissioned the University of Winchester to undertake an independent evaluation of the work of the Alliance over the three-year period from September 2016 to August 2019. This phase of the evaluation aimed to evaluate the impact of the support from the young carer projects specifically on the young carers themselves that had been identified in the initial research phase. It also aimed to trial a questionnaire which included psychometric instruments to assess young carers' general sense of well-being, their perceived stress and the positive and negative outcomes of their caring roles (See Appendices).

Challenges with recruitment and disengagement from projects

The first noteworthy finding was that the number of young carers who completed both Q1 and Q2 was lower than had been expected. A combination of operational reasons (e.g. projects having difficulties arranging times to undertake the questionnaires and project staff not deeming the questionnaire appropriate to use with certain young carers), as well as lower numbers of young carers than anticipated being referred during the timeframe within the 11-17 age range, meant that some projects recruited very low numbers of young carers. In addition, 13 young carers (almost a third) disengaged from their projects between the two questionnaires, further reducing the numbers completing both Q1 and Q2. Further research is needed to determine why young carers who are referred to services are disengaging from them and whether those young carers who are disengaging have particular characteristics. Depending on why young carers disengage from services, there are potential implications in relation to the referral process and criteria that projects use, the initial assessment and induction processes that services carry out, how services generally support engagement, as well as the cost-effectiveness of services.

Participants

A second noteworthy finding was that over half of the young carers had been caring for three or more years. Previous research has showed that children who care for longer than two years are more likely to experience poorer negative emotional outcomes (Abraham & Aldridge, 2010). Going forward, this might be useful data to monitor for the HYCA young carer services as well as for services a national level, in order to gauge how quickly young people are being referred to them and engaging with them following the onset of their caring roles. Although the duration of caring (compared with impact of caring) is perhaps not the most important factor in engaging young people with support from services, reducing the time between the onset of a caring role and engaging young people with support is in line with the preventative principle that the projects follow.

High level outcomes

Taking the findings together, the young carers are reporting generally positive outcomes at both evaluation points (Q1 and Q2) across the range of domains (i.e. the outcomes of caring, subjective wellbeing, perceived stress, health, confidence, being OK about being a young carer and friends). It is only a minority of young carers who are reporting relatively low outcomes.

What is of particular note is that the young carers are generally reporting positive outcomes across all the domains at Q1, i.e. when they had only recently begun engaging with the projects and before the majority of any intervention had occurred. This finding is encouraging in that it would appear that most referrals to the projects are not occurring at a point when young carers are being significantly negatively impacted by their caring roles. It is encouraging in the sense that this aligns with the preventative approach that the projects adhere to. There is also the possibility however that young carers experiencing more negative outcomes are not being referred to projects or engaging with them.

These findings might well be a true reflection of the outcomes experienced by the young carers when they first engaged with services. If so, then it is worth noting that despite the young carers having cared on average for over three and a half years, they are not reporting particularly low outcomes. This contrasts perhaps with other evidence that strongly points to caring roles leading to a range of negative impacts on a child's health and wellbeing, and education, (e.g. Aldridge & Becker, 2003; Dearden & Becker, 2004; The Children's Society, 2013) and in Scotland, where a survey found that pupils who had some form of caring responsibility at home, were more likely to have lower mental wellbeing than those who did not (Scottish Government, 2015). It should also be noted however that although reported outcomes were generally positive for the young carers in this study, there is no comparative group of non-carers.

One alternative explanation of these findings however is that at Q1, the young carers had only recently been linked to the service and therefore were experiencing many new things, including meeting with new people, having new conversations (e.g. about young caring and how they feel), undergoing an assessment carried out by the project and being asked to complete the questionnaire. It is widely acknowledged that young carers are often concerned, or even fearful about sharing their situation in case this leads to intervention by social services. For example, as Aldridge et al. (2016, p.10) report "both children and their parents were reluctant to disclose information about caring responsibilities for fear of potential repercussions in the form of interventions that might lead to family separations". This should be acknowledged when considering the novel situation in which young carers completed the initial questionnaire Q1. It is possible therefore that in this study, where young carers are completing questionnaires early on in their engagement with services, that they are hesitant or reluctant to report negatively on their health and wellbeing.

Small changes in outcomes

There were small positive changes in the mean scores for the three psychometric instruments, the PANOC (+ve), the WEMWBS and the Perceived Stress Scale, however these were not found to be statistically significant. Additionally, there were other small positive changes across other domains including general health, being 'OK' about being a young carer, having friends to talk to about things that worry them, how they were getting on at school and on the ONS questions about personal well-being. However, the fact that the baseline level across the domains is relatively high reduces the likelihood of observing statistically significant changes in the outcomes.

It is worth noting that the conditions under which the young carers completed the two questionnaires may have differed markedly. These different conditions may be principally one of perception. At Q1, as described above, because of their novel situation of being involved with a young carer service, and a potential fear of the intervention of services that young carers are often reported to experience, young carers may have been particularly guarded with their responses (e.g. Aldridge et al., 2016).

In contrast, at the point of completing the second questionnaire Q2, the young carers are likely to have perceived their situation very differently. In the UK it has become common practice for young carer services to provide a platform for the voices of young carers "through informal research methods such as online questionnaires, focus groups, feedback forms, the collation of views at workshops and larger events" (Phelps, 2017b, p. 114). The young carers therefore are likely to have become more familiar with, and experienced in providing feedback about how they feel, and would have understood that this is as a common activity of being part of a young carer project. Secondly, it is likely that they would have seen and heard other young carers talking candidly about their feelings and about issues they may be struggling with. Thirdly, the initial qualitative interviews found that young carers felt safe, accepted and supported at their groups, that services built trust with young carers and that young carers viewed staff very positively. Therefore, it is possible that by the time the young carers completed the second questionnaire their perception of this activity was very different than when they completed the initial questionnaire. Consequently, they might have felt significantly more comfortable when completing Q2 and less guarded about their feelings and struggles.

This change in perception when completing the questionnaire (or the 'internal conditions' under which this second questionnaire was completed) along with the generally high outcomes reported in the initial questionnaire, might have been enough to mask any significant effects made by the intervention itself.

The questionnaire

The questionnaire was designed to further explore the outcomes that were found in the initial phase of the evaluation (Phelps, 2017a) and included three main psychometric instruments to assess young carers' general sense of well-being, their perceived stress and the positive and negative outcomes of their caring roles. The outcomes of young carers are commonly assessed using the PANOC instrument which was developed for this purpose (Joseph, Becker, & Becker, 2009). Although it has been used by the Scottish Government (2015) the WEMWBS has been less commonly used with young carers for this purpose, and although Early et al. (2006) developed a Young Carers Perceived Stress Scale, (YCPSS) use of the PSS with young carers was not found.

No specific issues were found in the use of the questionnaire itself and there is no evidence against including the three main instruments in future studies to measure outcomes for young carer services at a population level. However, to improve the chances of detecting statistically significant changes, studies might well benefit from higher numbers of participants.

Alternative timings (i.e. evaluating young carers at a later point in time) for acquiring baseline data might also be considered in order to mediate the theorised masking effect described above. However, as discussed, this would risk missing any outcomes resulting from early engagement with services.

The importance of projects

Reflecting the findings from the initial phase of the evaluation, it is clear that the projects are very important to some young carers. How young carers viewed their projects was generally very positive and reflective of the findings from the initial qualitative interviews (Phelps, 2017a) and of other studies (e.g. Children's Commissioner for England, 2016; Aldridge et al., 2016). As in the initial research phase, young carers reported that their projects were helpful and supportive to them and were somewhere they could go to have fun and to meet and talk with others.

Also reflecting the initial research, some young carers reported positively about staff and that projects had helped them become more confident. The importance of the projects to these young carers is also highlighted by the fact that 100% of those who responded stated that they would recommend the project to another young carer. It should be noted however that these are the views of young carers who remained engaged with projects.

Further research would be helpful to explore the reasons why some young carers view the projects as 'important', or 'very important', and others less so. For example, does the correlation found in this study between the number of hours of care undertaken by the young carers and how important they reported their project to be, point to the amount of care that young carers provide, being one of these factors?

The fact that at Q1, a much higher proportion of those young carers who subsequently remained engaged with their project, viewed their group as being important to them, compared to those who later disengaged, might be a hint to one early indicator for determining the future engagement of young carers with their services.

Friendships

The young carers had been generally positive about their friendships near the beginning (at Q1). However, it is also clear that being part of a project enables the young carers to form many friendships. This appeared to happen relatively quickly with a number of young carers already reporting they had made friends by the time they had completed the first questionnaire. At Q2, the majority reported they had made friends. Making friends was one of the important outcomes that the young carers had highlighted in the initial research phase and which is commonly reported by young carers. Making friends is especially important for young carers since research has found that being a young carer can often be socially isolating and linked to being bullied (e.g., Green, Collingwood, and Ross, 2010; Katz, 2015; Lindley and Phelps, 2016). The fact that a number of the young carers had made friends by the time they completed the first questionnaire justifies the aim of the current study to capture any outcomes from early engagement with the services. Similarly, the fact that (as expected) all the young carers at Q2 now knew other young carers, highlights the importance of the projects in enabling young carers to meet others in similar situations.

Confidence

The correlations found between the confidence that young carers reported in themselves and in their caring role, and their mental wellbeing, (as measured by the WEMWBS) are interesting. Research could explore further whether the reported confidence of young carers might be a useful indicator of their wellbeing.

Limitations

As described in the procedure section, this study had several limitations resulting from the practicalities of measuring outcomes of young carers engaging with 10 different services. Firstly, it needs to be recognised that participants were not randomly sampled. They were chosen purposively, in line with set criteria, whilst also subject to practical restrictions. A second limitation was that although generally the projects were aiming to provide a similar intervention, the interventions received by young carers varied across the ten projects. Furthermore, the Winchester project modified their offer to young carers following the design of the study and as a consequence, young carers from this project received a more formal intervention programme (in addition to the other general interventions experienced by the young carers attending the other groups).[5] Although the outcomes of those supported by the Winchester project appear positive, the participant numbers are too low to draw any hard conclusions about this variation in intervention.

Lastly, a significant limitation to finding statistically significant outcomes might have resulted from the low number of participants that were able to be recruited that met the criteria. One factor limiting the numbers of young carers meeting the criteria was the recruitment timeframe. This had been set in order to explore outcomes from initial engagement with projects. Future research could look at ways to increase the number of participants whilst still being able to explore outcomes resulting from initial engagement with projects.

The importance of the study

This study contributes to the understanding of the challenges and practicalities of recruiting sufficient numbers of young carers for studies that effectively measure the outcomes for young carers and that span several months. It also highlights the additional restriction from recruiting only young carers who have recently engaged with a young carer service in order to assess outcomes from their initial engagement with services.

This study also highlights the need for better understanding at a local and national level about the level of need of young carers who are being referred to services and how quickly support is being initiated by referring agencies and local authorities. Both these have implications for how quickly young carers are identified by professionals and the criteria that services set for supporting young carers.

Lastly, this study highlights several interesting areas for future research. One area is related to engagement of young carers with their services, including why young carers disengage from projects and potential early indicators of engagement with

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[5] The Young Carer Exploration Programme (See Appendices)

projects. A second area of potential exploration is to explore the factors that make a young carer service important to young carers and why. A third area of research could further explore whether confidence (as reported by young carers) might be a useful indicator of their wellbeing and a fourth (with wider implications) is related to the timing and methods of assessing young carers once they have been identified and measuring their health and wellbeing especially in order to attain baseline data.

Finally, this study presents a questionnaire which can be used and adapted with appropriate permissions, to assess the outcomes for young carers and evaluate the impact of young carer services.

5 Conclusions

This phase of the evaluation aimed to evaluate the impact of the support from the young carer projects specifically on the young carers themselves that had been identified in the initial research phase. This involved trialing a questionnaire which included psychometric instruments to assess young carers' general sense of well-being, their perceived stress, the positive and negative outcomes of their caring roles as well as questions related to other outcomes identified in the initial research phase.

A main finding was that the young carers were reporting generally positive outcomes across a range of domains not only after being supported by the services, but also at the start of their engagement with services. It was only a minority of young carers who reported relatively low outcomes at either evaluation point. Although there were many small positive changes measured across many of the domains, these were not statistically significant.

However, reflecting the findings from the interviews in the initial research phase, projects were found to be important to the young carers and this was highlighted by the fact that all the young carers who responded, reported that they would recommend their group to another young carer. Furthermore, as in the initial research, this study also found that the groups enabled the young carers to make a significant number of new friends.

Another interesting finding was that over half of the young carers had been caring for three or more years (and over three and a half years on average) when they completed the initial questionnaire. Furthermore, almost a third of those who completed the initial questionnaire disengaged from their projects over the course of the study.

The findings in this study are important in a number of ways. Firstly, they highlight the importance improving our understanding at both local and national level about the level of need of young carers who are referred to young carer projects for support, as well as how quickly young carers are engaged with services after a caring role has begun.

Secondly, the study offers a questionnaire that can be used to measure the outcomes of young carers on a population level, whilst also contributing to our understanding of the practical challenges that exist in measuring the outcomes for young carers from the support of young carer services. These practical challenges led to limitations of the study including recruiting sufficient numbers of participants, not having a random sample of young carers and the variations in intervention delivered by the different projects.

This study has also highlighted some interesting areas for future research. As well as exploring how quickly young carers are referred to support from projects and their level of need when they are referred, future research might explore the factors that make projects important to young carers, why young carers disengage from projects and whether there are early indicators to how young carers will engage with projects. Another potential area for further research is whether the confidence that young carers report might be a useful indicator of their health and wellbeing. Finally, future studies might explore alternative ways to evaluate health and wellbeing (and other) outcomes for young carers when they are new to services in order to accommodate for the hypothesized elevated self-reporting by young carers.

6 Summary recommendations

- Monitor (at a local and national level) how quickly young people are being referred to and engaging with services following the onset of their caring roles.

- Consider alternative timings for assessing/evaluating young carers (i.e. assessing/evaluating at a later point in time, after an initial settling in period with their services).

- Promote the benefit that young carer services enable young carers to make friends.

- Promote the fact that 100% of young carers who responded would recommend their young carer service to another young carer.

- Undertake further research to determine why young carers referred to services are disengaging and whether those young carers disengaging have particular characteristics.

- Undertake further research to explore the reasons why some young carers view the projects as ‘important’, or ‘very important’, and others less so.

- Undertake further research to explore whether reported confidence might be a useful indicator of the wellbeing of young carers.

- Use the questionnaire to measure outcomes at a population level. However, to improve the chances of detecting statistically significant changes, studies might well benefit from higher numbers of participants.

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