

Manual for Measures of

Caring Activities and Outcomes

For Children and Young People

Stephen Joseph, Fiona Becker, Saul Becker



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2nd Edition

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1. Context for the development of the measures

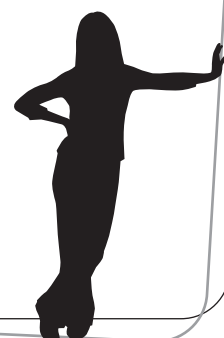
1.1 Introduction

This Manual is intended to provide researchers and practitioners in the field of caring with relevant and accessible instruments for the assessment of caring activities and caring outcomes in children and young people. The instruments can be used on a one-off basis for the purpose of assessment, or pre- and post-intervention to measure change and the impact of support. If used pre- and post-intervention, then practitioners working with young carers will be able to inform their funders and other partners about whether or not their work has made a measurable difference. The instruments can measure the extent and nature of caring and its impact on the emotional and social well-being of a young person.

1.2 Recognising the needs of young carers

Many children and young people are involved in caring for parents, siblings, or other relatives who have an illness, disability, mental health condition or other need for care or supervision (Aldridge and Becker, 2003; Becker, 2008; Becker and Becker, 2008a and 2008b; Dearden and Becker, 2000, 2004). These 'young carers' are defined as "children and young persons under 18 who provide or intend to provide care, assistance or support to another family member. They carry out, often on a regular basis, significant or substantial caring tasks and assume a level of responsibility that would usually be associated with an adult. The person receiving care is often a parent but can be a sibling, grandparent or other relative who is disabled, has a chronic illness, mental health problem or other condition connected with a need for care, support or supervision" (Becker, 2000, p 378).

There is growing recognition of young carers amongst governments in the UK and overseas as well as policy makers and practitioners working in health, social care and education (Becker, 2007). These different professional domains have recognised that children with caring responsibilities are also their concern whether they be in the classroom, attending their GP or living in a family receiving health and social care interventions. Two central government strategies (HM Government, 2008; HM Government 2010) have also highlighted the needs of young carers and what should be done to support them.



1.3 Growth in services for young carers

From just a handful of dedicated young carers projects in the early 1990s there are now over 350 projects/services across the UK in contact with around 30,000 young carers (Becker, 2008). This growth in awareness and identification of young carers and in the number of specialist young carers services and projects was triggered and has been maintained by three key factors: first, a growing research literature on young carers and their families; second, the work of charitable organisations that helped to promote public, political and professional awareness, and finally, changes in legislation¹, guidance and policy initiatives (Department of Health, 1999; HM Government, 2008) which have placed greater emphasis on the need for services to assess and support young carers in order to improve their welfare, health, education and general well-being.

Census data in 2001 (Office for National Statistics, 2003) revealed that there were 175,000 young carers (aged 0-18) in the UK, which is 2.1% of all children. Although this figure was higher than expected it is likely to be an under representation since many families will not identify that they have a young carer in their household, rather caring is seen as a 'normal' or routine part of their everyday experiences and relationships; or families might not wish to disclose that they have a child caring, especially where there is parental mental illness, substance misuse or other stigmatising conditions such as HIV and AIDS (Aldridge and Becker, 2003; Evans and Becker, 2009).

In 2010 the BBC surveyed more than 4000 UK school pupils using the MACA from this Manual and found 1 in 12 had moderate or high levels of caring responsibility. For the UK this would equate to 700,000 young carers, more than four times the 2001 census figure.

1.4 Need for robust measures

There has been limited research into the outcomes produced by support services for young carers. Given the significant investment of governmental and charitable resources, and health and social care services for young carers, it is critical that service providers, including the 350 young carers projects in the UK, have robust measures which can be used in this context. Indeed funding organisations are increasingly demanding robust evidence on outcomes. The 2008 national carers strategy (HM Government, 2008) recognised that "a detailed evaluation of the different approaches and their impact on young carers and their outcomes is lacking" (HM Government, 2008, p 131). The more recent shift to an outcomes-based approach to commissioning and procurement also highlights the need for robust measures that focus on outcomes for all children and young people.

¹ The Carers (Recognition and Services) Act 1995 gives carers of any age the right to an assessment of their 'ability to provide and to continue to provide care'; The Carers and Disabled Children Act 2000 gives family carers over the age of 16 a right to request an assessment of their own needs and to receive services and support, even if the cared for person does not wish to have an assessment; The Carers (Equal Opportunities) Act 2004 requires local authorities to inform carers of their rights to an assessment in certain circumstances and to consider whether the carer works, undertakes education or training, leisure activities or wishes to do any of these things (see Frank and McLarnon, 2008, for a fuller description of the legal entitlements of young carers).



1. Context for the development of the measures

Furthermore, while many countries in the world are now recognising and responding to the needs of young carers few have developed systematic responses including a network of dedicated support projects as in the UK. Research has shown (Becker, 2007) that the experiences and needs of young carers in developed countries such as the UK, Australia and the USA are very similar. The instruments in this Manual will consequently be useable in these countries. Professionals working with young carers outside of specialist young carers projects could also utilise the instruments as they would generate useful information both for assessment and evaluation purposes.

Some young carers services have sought to use generic outcome measures or measures that have been developed for other groups of young people. However, the results generated by the use of non-specific measures may not be reliable when applied to work with young carers. The instruments in this Manual have been developed and tested with young carers so can be used with greater confidence.

1.5 A note for users

The two instruments (MACA-YC18 and PANOC-YC20) in this Manual are intended to be used by professionals in the fields of health and social care (e.g., psychologists, psychiatrists, social workers, nurses, youth workers, young carers workers) as well as those researching informal caring, and caring organisations themselves. As such we expect users to adhere to their organisational child protection and confidentiality policies, their own professional Code of Ethics and to ensure that they are working within their competence. Practitioners should discuss planned use of the instruments with young people, managers and other relevant stakeholders. It should be made clear to young people and their families what will happen to their personal information and how services might respond if answers to the questionnaires raise concerns.

We have endeavoured to compile this Manual so that it is easy to follow and the instructions for use are clear. A fuller explanation and details of the development of the two instruments are available in Joseph, Becker, Becker and Regel (2009).

The 2012 edition also includes a new "About me and my family" questionnaire. This has been included to help young carers' services collate identifying details and user data for those young carers who complete the outcome measuring tools.

We have also included an "identifying detail" box for young carers support workers to complete so services can track who the questionnaire belongs to and at what stage it was completed. Please ensure that this box is always completed.



1.6 About me and my family

We are asking for your views so we can find out more about what you do, how it makes you feel and what difference a young carers project makes to your life. The information we collect from you, and many other young carers, will be used to improve services for all young carers and their families.

What you need to do

Step 1: Please read all parts of the questionnaire and answer everything as honestly as you can. There are no right or wrong answers; we just want to know what you think.

Step 2: If you are stuck with any questions or need someone to explain it please ask a member of staff to help.

We would like to know some information about you and your family

Name of your Young Carers' Service:

Are you a girl or a boy ? (please tick)

Initials: Date of birth: / /

Who is it you provide help to?

Mother	No <input type="checkbox"/>	Yes <input type="checkbox"/>	
Step Mother	No <input type="checkbox"/>	Yes <input type="checkbox"/>	
Father	No <input type="checkbox"/>	Yes <input type="checkbox"/>	
Step Father	No <input type="checkbox"/>	Yes <input type="checkbox"/>	
Brothers/Step Brothers	No <input type="checkbox"/>	Yes <input type="checkbox"/>	If yes, how many:
Sisters/Step Sisters	No <input type="checkbox"/>	Yes <input type="checkbox"/>	If yes, how many:
Grandparents	No <input type="checkbox"/>	Yes <input type="checkbox"/>	If yes, how many:
Other adult relative (please specify)	No <input type="checkbox"/>	Yes <input type="checkbox"/>
Family friend	No <input type="checkbox"/>	Yes <input type="checkbox"/>	
Other (please specify)	No <input type="checkbox"/>	Yes <input type="checkbox"/>

Why does the person(s) you care for need your help? (please write your answer below)

Which of these statements best describes you? (Tick all that apply to you)

I am caring for someone ...

- | | |
|--|---|
| <input type="checkbox"/> With a substance misuse problem | <input type="checkbox"/> From the lesbian, gay, bisexual or transgender community |
| <input type="checkbox"/> With a physical disability | <input type="checkbox"/> From a travellers community |
| <input type="checkbox"/> With a learning disability | <input type="checkbox"/> From a rural community |
| <input type="checkbox"/> With a life limiting condition | <input type="checkbox"/> From an ethnic minority community |
| <input type="checkbox"/> With a mental health illness | |

please turn over...



What is your ethnic background?

Our ethnic background describes how we think of ourselves. This may be based on many things, for example, our language, culture or family history. **Ethnic background is not always the same as nationality or country of birth.** Please tick which is closest to how you see yourself, or write in a more specific group if you wish.

White

- British
 - Irish
 - Traveller of Irish heritage
 - Gypsy Roma
 - Turkish Cypriot/Turkish-speaking (including Kurdish)
 - Greek/Greek Cypriot
 - White Eastern European
 - White Other European
 - Jewish
 - Charedi (Orthodox Jewish)
 - Any other White background
 - Please specify below (if you wish)
-

Black or Black British

- Black British
 - Caribbean
 - African – Somali
 - African – Congolese
 - African – Nigerian
 - African – Ghanaian
 - Other West African
 - Any other Black or Black British background
 - Please specify below (if you wish)
-

Mixed

- White and Black Caribbean
 - White and Black African
 - White and Asian
 - Please specify below (if you wish)
-

Asian or Asian British

- Asian British
 - Indian
 - Pakistani
 - Bangladeshi
 - Any other Asian background
 - Please specify below (if you wish)
-

South East Asian or South East Asian British

- Chinese British
 - Chinese
 - Japanese
 - Malaysian
 - Vietnamese
 - Any other South East Asian
 - Please specify below (if you wish)
-

Any other ethnic group

- - Please specify below (if you wish)
-

Thank you and well done for completing this information!



2. Measures of Caring Activity and Caring Outcomes

2.1 Introduction to the measures

The Manual introduces two instruments for the assessment of caring:

The **Multidimensional Assessment of Caring Activities (MACA-YC18)** is a questionnaire (an 18-item self-report measure) that can be used to provide an index of the total amount of caring activity undertaken by the young person, as well as six subscale scores for domestic tasks, household management, personal care, emotional care, sibling care, and financial/practical care. The MACA-YC18 can be used before, during and after receiving support in order to identify any changes that have occurred. Go to pages 6-9 for further details.

We also include the MACA-YC42 which is a 42-item checklist of caring activities. It can be used to obtain a detailed picture of the caring activities undertaken by an individual (see Additional Resources section of the Manual for the MACA-YC42). This may be of particular use to practitioners conducting assessments of young carers. Go to pages 13-15 for further details.

The **Positive and Negative Outcomes of Caring (PANOC-YC20)** is a questionnaire (20-item self-report measure) that can be used to provide an index of positive and negative outcomes of caring. The PANOC-YC20 can be used before, during and after receiving support in order to identify any changes that have occurred. Go to pages 10-12 for further details.

Both measures are useful in research into caring and its effects, to practitioners in health and social care, youth work, psychology, and social work, and also to young carers organisations interested in evaluating their intervention strategies. The measures provide the resources with which to evaluate whether interventions are associated with changes in levels of caring activity, as well as understanding the psychological effects of caring. The PANOC-YC20 is particularly useful with its focus on negative and positive outcomes of caring and whether support has resulted in a reduction of negative outcomes and an increase in positive ones.

Research has shown that although caring can have many negative effects, like other stressful situations it can also lead to the development of resilience and considerable personal benefits such as increased self-knowledge and maturity (Joseph, Knibbs and Hobbs, 2007; Evans and Becker, 2009). While we recognise this may sometimes be the case and we argue that it is appropriate to assess both negative and positive outcomes of caring, we do not suggest that recognising the positive aspects of caring is justification for leaving young carers unsupported.



2.2 Development of the measures

In the original study, Joseph, Becker, Becker and Regel (2009) reported data from 410 young carers ranging in age from 7 to 22 years of age who were recruited via Carers Trust database of UK projects and asked to complete two questionnaires to assess caring activities and caring outcomes, respectively. Following statistical analysis we reduced the length of the two questionnaires and piloted them with another 124 young carers.

The statistical procedure allowed us to select a small set of items which are representative of a particular domain of activity. For example, although we might only ask whether the young person washes dishes, if they say yes to this our statistical analysis indicates that it can be safely assumed that they are likely to do other related activities such as washing clothes. For this reason, we are able to pick only a small number of items to measure various domains of activity, so the overall scores reflect much more than simply what questions are asked.

Thus, 18 items were chosen to compose the Multidimensional Assessment of Caring Activities (MACA-YC18) and 20-items were chosen to compose the Positive and Negative Outcomes of Caring Scales (PANOC-YC20).



2.3 Multidimensional Assessment of Caring Activities (MACA-YC18)

The Multidimensional Assessment of Caring Activities (MACA-YC18) is a questionnaire to be completed by young carers (an 18-item self-report measure) that can be used to provide an index (or score) of the total amount of caring activity undertaken by a child or young person, as well as six subscale scores for:

- (1) domestic tasks,
- (2) household management,
- (3) personal care,
- (4) emotional care,
- (5) sibling care, and
- (6) financial/practical care.

The MACA-YC18 was designed as a very short, easy to use, psychometric instrument able to provide an index of the extent of caring activities that the young person is currently engaged in (Joseph, Becker, Becker and Regel, 2009). The MACA-YC18 is recommended for:

- Use in surveys of the amount of caring activity undertaken by children and young people.
- To compare different groups of children and young people on the amount of caring activity.
- To use before and after interventions to examine what sort of interventions are helpful in reducing caring burden.
- To examine the association between caring activity and other factors – such as age and gender.
- To use in a one-to-one context by professionals who want to understand the types of caring tasks undertaken, but where time is short.

How to use the MACA-YC18

Care has been taken to ensure that the wording is appropriate for most children and young people so that they will be able to complete the MACA-YC18 by themselves. Although it may be appropriate sometimes to help with explanations, we recommend that children and young people are given the opportunity to complete the MACA-YC18 by themselves whenever possible.

When it is necessary to provide explanations this should be carried out by the professional involved. We do not recommend that the MACA-YC18 be completed in the presence of the person who is being supported. Young carers' responses on the MACA-YC18 should always be treated in confidence and used in line with an appropriate professional Code of Ethics and within an organisation's child protection and confidentiality policies.



Scoring for the MACA-YC18

For the MACA-YC18 each of the items are rated on a 3-point scale, 'Never', 'Some of the time', and 'A lot of the time'.

For scoring purposes:

- 'Never' = 0
- 'Some of the time' = 1
- 'A lot of the time' = 2

Overall Score of Caring Activity

The MACA-YC18 can be used to provide an overall summary score (index) of caring activity by totalling all 18 items. The lowest the young person can score is 0 and the highest the young person can score is 36. For example, if the young person ticks 'never' for each of the 18 items, they would get a total score of 0 but if they ticked 'a lot of the time' for each of the items, they would get a score of 36. Of course, most children and young people will score somewhere in between these two extremes. The average score is around 14.

Interpretation of scores on the MACA-YC18

Higher scores indicate greater levels of caring activity. The following categories are useful:

0	No caring activity recorded
1-9	Low amount of caring activity
10-13	Moderate amount
14-17	High amount
18 and above	Very high amount of caring activity



Subscale scores

For more sophisticated research and assessment purposes where an individual profile for the young person is required, it is also possible to use the MACA-YC18 to identify the pattern of caring activity in six domains (subscales):

- (1) **Domestic Activity** – the extent to which the young person engages in activities such as cleaning, cooking, washing dishes or clothes etc.
- (2) **Household Management** – the extent to which the young person engages in activities to keep the household running such as shopping, household repairs and lifting heavy objects etc.
- (3) **Financial and Practical Management** – the extent to which the young person helps financially (for example with bills, benefits and banking), and takes practical adult responsibilities (such as working part-time, interpreting) etc.
- (4) **Personal Care** – the extent to which the young person engages in caring activities such as helping the person dress and undress, wash and use the bathroom, helping with mobility and giving health care (such as administering medicine or changing dressings) etc.
- (5) **Emotional Care** – the extent to which the young person provides company and emotional support to the person, keeping an eye on them, providing supervision and taking them out.
- (6) **Sibling Care** – the extent to which the young person is responsible for looking after siblings either alone or with a parent present. This excludes any young person caring for his/her own child.

To calculate subscale scores:

Subscales	Add the scores from the following questions:
Domestic Activity	Questions 1,2 and 3
Household Management	Questions 4, 5, and 6
Financial and Practical Management	Questions 7, 8, and 9
Personal Care	Questions 10, 11, and 12
Emotional Care	Questions 13, 14, and 15
Sibling Care	Questions 16, 17, and 18



The caring jobs I do

Please complete this first

YC initials

YC date of birth

Today's date

Name of young carers' service

.....

Below are some jobs that young carers do to help.

Think about the help you have provided over the last month.

Please read each one and put a tick in the box to show how

often you have done each of the jobs in the last month. **Thankyou.**

	Never	Some of the time	A lot of the time
1 Clean your own bedroom	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2 Clean other rooms	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3 Wash up dishes or put dishes in a dishwasher	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4 Decorate rooms	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5 Take responsibility for shopping for food	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6 Help with lifting or carrying heavy things	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7 Help with financial matters such as dealing with bills, banking money, collecting benefits	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8 Work part time to bring money in	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9 Interpret, sign or use another communication system for the person you care for	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10 Help the person you care for to dress or undress	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11 Help the person you care for to have a wash	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12 Help the person you care for to have a bath or shower	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13 Keep the person you care for company e.g. sitting with them, reading to them, talking to them	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14 Keep an eye on the person you care for to make sure they are alright	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15 Take the person you care for out e.g. for a walk or to see friends or relatives	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16 Take brothers or sisters to school	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
17 Look after brothers or sisters whilst another adult is near by	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
18 Look after brothers or sisters on your own	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

MACA-YC18

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School of Sociology and Social Policy, University of Nottingham, University Park, Nottingham NG7 2RD.

We care what YOU think.



2.4 Positive and Negative Outcomes of Caring (PANOC-YC20)

The Positive and Negative Outcomes of Caring (PANOC-YC20) is a questionnaire to be completed by young carers (a 20-item self-report measure) that can be used to provide an index (or score) of the subjective cognitive and emotional impact of caring in young people. Research and practice have identified that many young carers are significantly affected by their caring responsibilities both negatively and positively. For this reason, the PANOC-YC20 was designed to provide two scores. One score showing how much caring is experienced negatively and one showing how much caring is experienced positively.

Scoring

The PANOC-YC20 is a 20-item psychometric instrument designed to assess the positive and negative effects of caring activity. Each item is rated on a 3-point scale, 'Never', 'Some of the time', and 'A lot of the time'.

For scoring purposes:

'Never'	= 0
'Some of the time'	= 1
'A lot of the time'	= 2

The PANOC-YC20 consists of two 10-item subscales: (1) positive responses, and (2) negative responses. Scores on both the subscales have a potential range of 0 to 20, with higher scores indicating greater positive and negative responses, respectively.

To calculate the positive response score: sum items 1, 2, 3, 4, 7, 8, 15, 18, 19, and 20.

To calculate the negative response score: sum items 5, 6, 9, 10, 11, 12, 13, 14, 16, and 17.

Interpretation of scores

Statistical analysis indicates that scores of less than 12 on the PANOC-YC20 positive scale and/or greater than 8 on the PANOC-YC20 negative scale may be indicative of concern (see Table 1). For example, this may indicate that the young person is suffering from emotional distress. In such circumstances practitioners will need to follow their usual working practices and procedures in terms of exploring the young person's feelings with them and their family and responding appropriately, perhaps in partnership with appropriate health or children's social care services.



Table 1: Interpreting scores on the PANOC-YC20

	Scores	Interpretation
Positive	0	No positive outcomes reported – potential for concern
	1-12	Relatively few positive outcomes, potential for concern
	13-20	Relatively high positive outcomes reported
Negative	0	No negative outcomes reported
	1-8	Relatively few negative outcomes reported
	9-20	Relatively high negative outcomes reported, potential for concern

Of most concern will be those young carers who score less than 12 on the positive scale AND greater than 8 on the negative scale. However, where there are serious concerns we recommend that the PANOC-YC20 be used as part of a fuller assessment process by qualified health and social care professionals.



How caring affects me

Please complete this first

YC initials

YC date of birth

Today's date

Name of young carers' service

Below are some things young carers like you have said about what it feels like to look after someone. Please read each statement and tick the box to show how often this is true for you. There are no right or wrong answers. We are just interested in what life is like for you because of caring. **Thank you.**

	Never	Some of the time	A lot of the time
1 Because of caring I feel I am doing something good	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2 Because of caring I feel that I am helping	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3 Because of caring I feel closer to my family	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4 Because of caring I feel good about myself	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5 Because of caring I have to do things that make me upset	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6 Because of caring I feel stressed	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7 Because of caring I feel that I am learning useful things	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8 Because of caring my parents are proud of the kind of person I am	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9 Because of caring I feel like running away	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10 Because of caring I feel very lonely	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11 Because of caring I feel like I can't cope	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12 Because of caring I can't stop thinking about what I have to do	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13 Because of caring I feel so sad I can hardly stand it	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14 Because of caring I don't think I matter	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15 Because of caring I like who I am	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16 Because of caring life doesn't seem worth living	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
17 Because of caring I have trouble staying awake	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
18 Because of caring I feel I am better able to cope with problems	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
19 I feel good about helping	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
20 Because of caring I feel I am useful	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>



3. Additional Resources

3.1 Introduction

Additional resources are included in this section as professionals may find these complimentary to the outcome measurement tools (MACA-YC18 and PANOC-YC20). They are potentially useful questionnaires that can inform individual assessments of need or evaluation of interventions. They include some areas not already covered by the MACA-YC18 and PANOC-YC20, for example, the young carer's views on the support they have been provided with and their participation in, amongst other things, education. Three additional resources are included in this section:

- **Multidimensional Assessment of Caring Activities-Young Carers (MACA-YC42)**
- **What I Like and Dislike About Caring**
- **Post-Intervention Self Assessment (PISA-CT2012)**

3.2 Multidimensional Assessment of Caring Activities-Young Carers (MACA-YC42)

While we would recommend the use of the MACA-YC18 in most research and professional contexts because it is shorter and has been carefully refined to produce six subscale scores, there are occasions when professionals may wish to use the MACA-YC42. The MACA-YC42 might be useful in one-to-one contexts when professionals want to explore with young carers the nature and extent of their caring tasks.

Scoring

For the MACA-YC42, each of the items are rated on a 3-point scale, 'Never', 'Some of the time', and 'A lot of the time'.

For scoring purposes:

'Never'	= 0
'Some of the time'	= 1
'A lot of the time'	= 2

Overall Index of Caring Activity

The MACA-YC42 can be used to provide an overall summary index of caring activity by totalling all 42 items. The lowest the young person can score is 0 and the highest the young person can score is 84. For example, if the young person ticks 'never' for each of the 42 items, they would get a total score of 0 but if they ticked 'a lot of the time' for each of the items, they would get a score of 84. Of course, most people will score somewhere in between these two extremes. Higher scores indicate greater levels of caring activity.



The caring jobs I do

Below are some jobs that young carers do to help. Think about the help you have provided **over the last month.** Please read each one and put a tick in the box to show how often you have done each of the jobs in the last month.

Thank you.

Please complete this first

YC initials

YC date of birth

Today's date

Name of young carers' service

.....

	Never	Some of the time	A lot of the time
1. Tidy / dust your own bedroom	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Hoover your own bedroom	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Hoover other rooms	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Tidy / dust other rooms	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Lay the table	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Make snacks	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. Make main meals	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. Wash up dishes or put dishes in a dishwasher	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. Wash your own clothes	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. Wash clothes for other people you live with	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. Iron your own clothes	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12. Iron clothes for other people you live with	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13. Mow the grass	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14. Weed or look after the garden	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15. Do repairs to the home	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16. Decorate rooms	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
17. Take responsibility for shopping for food	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
18. Help with lifting or carrying heavy things	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
19. Help with paperwork e.g. writing letters for someone, filling in forms	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
20. Help with financial matters such as dealing with bills, banking money, collecting benefits	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
21. Work part time to bring money in	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Continued on the next page



The caring jobs I do

...Continued

	Never	Some of the time	A lot of the time
22. Interpret for someone you live with because English is not their first language	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
23. Signing for someone you live with because they are hearing impaired	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
24. Give medicines to someone you live with e.g. making sure s/he takes their pills, giving injections, changing dressings	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
25. Prepare special food or diet because of medical needs of the person you care for	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
26. Take someone you live with to the doctors or hospital	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
27. Help someone you live with to walk, get up the stairs, get into and out bed	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
28. Help someone you live with to dress or undress	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
29. Help someone you live with to have a wash	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
30. Help someone you live with to have a bath or shower	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
31. Help someone you live with to shave	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
32. Help someone you live with to cut their nails	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
33. Help someone you live with to use the toilet	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
34. Help someone you live with to eat and drink	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
35. Keep someone you live with company e.g. sitting with them, reading to them, talking to them, playing cards with them	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
36. Keep an eye on someone you live with to make sure they are alright	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
37. Take someone you live with out e.g. for a walk or to see friends or relatives	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
38. Taking brothers or sisters to school	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
39. Look after brothers or sisters whilst another adult is near by	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
40. Look after brothers or sisters on your own	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
41. Talking with officials (eg doctor or benefits office) about the person you care for	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
42. Miss out on sleep eg have to get up in the night or stay up late in order to look after someone	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

MACA-YC42

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Developed for Carers Trust by Young Carers International Research and Evaluation,

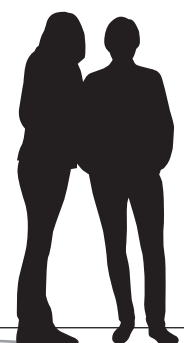
School of Sociology and Social Policy, University of Nottingham, University Park, Nottingham NG7 2RD.



3.3 What I Like and Dislike About Caring

The purpose of this short questionnaire is to enable professionals to gain an understanding of the nature and extent of caring undertaken and the young carer's feelings about the caring tasks they do. The questions are designed to elicit children and young people's positive perceptions as well as what they dislike doing or find upsetting. This information can inform assessments and intervention plans for the young carer and their family. Information about what children and young people dislike and find upsetting (in terms of their caring roles) can also be used to develop a better understanding of what might be 'inappropriate' caring tasks with regards to individual young carers. Protection from inappropriate caring tasks is identified as a key aim of the government's strategy for interventions with young carers and their families (HM Government, 2008).

This questionnaire is different from the MACA-YC18 in that it allows young people to describe, in their own words, what they like, dislike and find upsetting about caring. There is no 'scoring' associated with these responses. This questionnaire can be used with young carers before, during and after receiving support in order to see if there have been any change in perceptions.



What I like and dislike about caring

We want to ask you some questions about the hours you spend caring and what caring tasks you like and dislike the most. There are no right or wrong answers to any of the questions, we are just keen to hear what you think. **Thank you.**

Please complete this first

YC initials

YC date of birth

Today's date

Name of young carers' service

.....

Thinking about all the jobs you do in the home, including keeping an eye on people, please tell us how many hours of caring you do on a *typical day* in the week (Monday to Friday)?

..... hours per weekday

How many hours of caring do you do on a *typical day* at the weekend (Saturday or Sunday)?

..... hours per day at weekend

At what age did you first start to do caring jobs? age

Which one of your caring jobs do you like the most? Please tell us a little bit about it.

.....
.....
.....
.....

Please say why you like this caring job.

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Which one of your caring jobs do you dislike the most? Please tell us a little bit about it.

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Please say why you dislike this caring job.

.....

.....

.....

Which one of your caring jobs upsets you the most? Please tell us a little bit about it.

.....

.....

.....

.....

Please say why this caring job upsets you .

.....

.....

.....

In the last 2 weeks of term time, how many days have you missed at school, college or university because of caring?

..... days missed

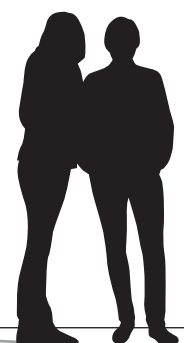
In the last 2 weeks of term time, how many days were you late for school, college or university because of caring?

..... days late



3.4 Post Intervention Self Assessment (PISA-CT2012)

This questionnaire 'Me and My Young Carers Project' has been designed to elicit young carers' views of the interventions they have received and the impact these have made in certain areas of their lives. It asks young carers to explain what type of support they have received, their views about the support and any resultant changes in terms of their experiences of school or college and the amount of caring activity undertaken. Some of the information gained can be usefully compared with the information collected from the 'What I Like and Dislike About Caring' questionnaire completed at the pre-intervention stage. The PISA-CT2012 has been designed specifically to examine areas of importance to a specific grants programme and can be amended to collect other types of information or to self-assess other outcomes.



Me and my young carers project

PISA-CT2012

Please complete this first

YC initials

YC date of birth

Today's date

Name of young carers' service

.....

**What kind of help and support have you been getting from your Young Carers Project?
Please tell us a little bit about it.**

.....

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.....

.....

Here are some ways that the project might have helped you.

Please read the list and tick the box to show whether this is true for you.
There are no right or wrong answers. We just want to know what you think.

	Yes	No
1 I enjoyed most of the activities	<input type="checkbox"/>	<input type="checkbox"/>
2 The project helped me make new friends	<input type="checkbox"/>	<input type="checkbox"/>
3 The project taught me useful things	<input type="checkbox"/>	<input type="checkbox"/>
4 The project was worth going to	<input type="checkbox"/>	<input type="checkbox"/>
5 The project made me feel good about myself	<input type="checkbox"/>	<input type="checkbox"/>
6 The project made me feel good about my family	<input type="checkbox"/>	<input type="checkbox"/>
7 The project helped the person I care for	<input type="checkbox"/>	<input type="checkbox"/>



Here are some things that might have changed for you since going to the project.

Please read the list and tick the box to show whether this is true for you. There are no right or wrong answers. We just want to know what you think.

Because of the project...	Yes	No
1 I now feel more able to choose the level of care I provide	<input type="checkbox"/>	<input type="checkbox"/>
2 I now do less caring	<input type="checkbox"/>	<input type="checkbox"/>
3 I now do less of the caring jobs that I dislike	<input type="checkbox"/>	<input type="checkbox"/>
4 I now do less of the caring jobs that upset me	<input type="checkbox"/>	<input type="checkbox"/>
5 I now do less of the caring jobs that worry me the most	<input type="checkbox"/>	<input type="checkbox"/>
6 Other organisations are providing more help for the person I care for	<input type="checkbox"/>	<input type="checkbox"/>
7 Other people are providing more help for the person I care for	<input type="checkbox"/>	<input type="checkbox"/>
8 People are more understanding of the caring jobs that I do	<input type="checkbox"/>	<input type="checkbox"/>
9 I now attend school or college more often	<input type="checkbox"/>	<input type="checkbox"/>
10 I now do better at school or college	<input type="checkbox"/>	<input type="checkbox"/>

Please tell us one thing, if anything, which has changed for you because of attending this project.

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Please tell us one thing, if anything, which has changed about your caring jobs because of attending this project.

.....

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.....



Please tell us one thing, if anything, that you didn't like about attending the project.

.....

.....

.....

.....

Thinking about all the jobs you do in the home, including keeping an eye on people, please tell us how many hours of caring you now do on a *typical day* in the week (Monday to Friday).

..... hours per weekday

How many hours of caring do you now do on a *typical day* at the weekend (Saturday or Sunday)?

..... hours per day at weekend

Is there anything else you would like to tell us?

.....

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4. References

- Aldridge, J. and Becker, S. (1993) *Children Who Care: Inside the World of Young Carers*. Loughborough University: Young Carers Research Group.
- Aldridge, J. and Becker, S. (2003) *Children Caring for Parents with Mental Illness*. Bristol: The Policy Press.
- Becker, S. (2000) 'Young carers', in M. Davies, (ed) *The Blackwell Encyclopaedia of Social Work*. Oxford: Blackwells, p.378.
- Becker, S. (2007) 'Global perspectives on children's unpaid caregiving in the family: Research and policy on "young carers" in the UK, Australia, the USA and Sub-Saharan Africa'. *Global Social Policy*, Vol. 7, No. 1, pp. 23-50.
- Becker, S. (2008) 'Informal family carers', in K. Wilson, G. Ruch, M. Lymbery and A. Cooper (eds) *Social Work: An Introduction to Contemporary Practice*: Pearson Education, pp 431-460.
- Becker, S. and Becker, F. (2008a) *Service Need and Delivery Following the Onset of Caring Amongst Children and Young Adults: Evidence Based Review*. Cheltenham: Commission for Rural Communities. [Available on 8/1/09 at <http://www.ruralcommunities.gov.uk/files/CRC%20web36%20YCIRE.pdf>]
- Becker, F. and Becker, S. (2008b) *Young Adult Carers in the UK: Experiences, Needs and Services for Carers aged 16-24*. London: The Princess Royal Trust for Carers.
- Dearden, C. and Becker, S. (2000) *Growing up Caring: Vulnerability and Transition to Adulthood - Young Carers' Experiences*. Leicester: Youth Work Press for the Joseph Rowntree Foundation.
- Dearden, C. and Becker, S. (2004) *Young Carers in the UK: The 2004 Report*. London: Carers UK.
- Department of Health (1999) *Caring About Carers: A National Strategy for Carers*. London: Department of Health.
- Evans, R. and Becker, S. (2009) *Children Caring for Parents with HIV and AIDS: Global Issues and Policy Responses*. Bristol: The Policy Press.
- Frank, J. and McLarnon, J. (2008) *Young Carers, Parents and their Families: Key Principles of Practice*. London: The Children's Society.
- HM Government (2008) *Carers at the Heart of 21st-Century Families and Communities*. London: Department of Health.
- 'HM Government (2010) *Recognised, valued and supported: next steps for the Carers Strategy*. London: Cross-Government'
- Joseph, S., Knibbs, J. and Hobbs, J. (2007) 'Trauma, resilience and growth in children and adolescents' in A. A. Hosin (ed.) *Responses to Traumatized Children*. Houndmills: Palgrave Macmillan, pp. 148-161.
- Joseph, S., Becker, S., Becker, F., and Regel, S. (2009). 'Assessment of caring and its effects in young people: Development of the Multidimensional Assessment of Caring Activities Checklist (MACA-YC18) and the Positive and Negative Outcomes of Caring Questionnaire (PANOC-YC20) for young carers'. *Child: Care, Health and Development*, 35, 4, pp 510-520.
- Office for National Statistics (ONS) (2003) *Census 2001 data* [Table SO25]. London: ONS.

Manual for Measures of Caring Activities and Outcomes for Children and Young People

2nd Edition

Stephen Joseph, Fiona Becker, Saul Becker

This practical 'hands-on' Manual is intended to provide researchers and practitioners in the field of caring with relevant and accessible instruments (or tools) for the assessment of caring activities and caring outcomes in children and young people ('young carers'). The instruments can be used on a one-off basis for the purpose of assessment, or pre- and post-intervention to measure change and the impact of support. The instruments in this Manual were initially developed and tested with over 500 young carers and have been in use by a number of young carers' services since 2010 so can be used with confidence.

The **Multidimensional Assessment of Caring Activities (MACA-YC18)** is a questionnaire (an 18-item self-report measure) that can be used to provide an index of the total amount of caring activity undertaken by the young person, as well as six subscale scores for domestic tasks, household management, personal care, emotional care, sibling care, and financial/practical care. The **Positive and Negative Outcomes of Caring (PANOC-YC20)** is a questionnaire (20-item self-report measure) that can be used to provide an index of positive and negative outcomes of caring. **Additional resources** include an extended version of the MACA-YC18 (**the MACA-YC42**), and two short questionnaires: **'What I like and dislike about caring'**, and **'Me and my young carers project'**.

The Manual will be of interest to professionals in the fields of health and social care (including young carers workers, social workers, nurses, psychologists, psychiatrists, youth workers) as well as those researching care-giving, and caring organisations themselves.

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