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## article

# The first cross-national study of adolescent young carers aged 15–17 in six European countries

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For the first time, this article will provide a cross-national profile of adolescents who provide unpaid care to their ill or disabled family members in six European countries with varied levels of awareness, policy and service provision regarding adolescent young carers. Utilising an online survey, 2,099 adolescent young carers were identified in Italy, the Netherlands, Slovenia, Sweden, Switzerland and the UK. This article focuses on the impact of unpaid care on their mental health, well-being, physical health and education. Their preferences for informal and formal support were also examined. These groundbreaking findings help promote a 'rights' approach to adolescent young carers, which can serve as a critical driver for supportive policy creation on both a country-specific and pan-European level.

**Key words** adolescent young carers • mental health • well-being • Europe

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## Introduction

Children and young people with caring responsibilities in families, often referred to as 'young carers', have been historically marginalised in research, scholarship and policy developments in many European states and generally across the globe. Over the last decade, however, there has been some recognition of this group of children among a small number of researchers, non-governmental organisations (NGOs), policymakers and professionals in some European and other countries. While the UK has 30 years of research on young carers and a 'patchwork quilt' of legislation (Aldridge, 2018), other countries are beginning to move forward, albeit very slowly (Leu and Becker, 2017).

The commonly accepted definition establishes that young carers are: '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 which would usually be associated with an adult' (Becker, 2000: 378). The term 'adolescent young carer' (AYC) will be used here to refer to young people with caring responsibilities between the ages of 15 and 17 years old – the transitional phase between 'childhood' and 'adulthood' (Gilmore and Meersand, 2014). Becker and Becker (2008) also coined the phrase 'young adult carers' to identify carers aged between 18 and 24 years old, as well as their specific experiences, needs and rights as young adults and as carers (see also Rose and Cohen, 2010; Sempik and Becker, 2013a; 2013b). AYC's are therefore a subgroup within the young carer population, sandwiched between 'young carers' and 'young adult carers'. They are recognised as having their own particular experiences and needs, as they transition to being considered, labelled and treated as adults, with their corresponding move to adult legal status and adult health and social care services and interventions.

In this article, for the first time, we systematise knowledge on AYC's by identifying their profiles, caring characteristics, needs and preferences across six European countries: Italy, the Netherlands, Slovenia, Sweden, Switzerland and the UK. The European Union (EU) Horizon 2020-funded 2018–21 research project 'Psychosocial support for promoting mental health and well-being among adolescent young carers in Europe' (ME-WE for short) sought to further understanding of the mental health and well-being of European adolescents with caring roles as they navigate both this phase in their lives and their changing relationship with 'adulthood', while maintaining their contribution of unpaid care. This research also recognises that the experience and needs of AYC's may be associated with the specific setting in which they reside due to societal and cultural factors, law, policy, and national/local population demographic characteristics. This is explored later in the article.

These six countries were brought together in the ME-WE research project because they each represented a specific phase or 'level' on the cross-national and comparative classification of awareness and policy responses to young carers devised by Becker (2007) and developed by Becker and Leu (2019), Leu and Becker (2017) and Leu et al (2019). Each country also has a research organisation/unit that was interested in commencing or developing research in this field. Leu and Becker's (2017) classification illustrates the levels of awareness and response to young caring within and between those (few) countries that had a discernible and verifiable engagement with young carers in 2017 and 2021. The classification takes account of, for example, whether a country has specific legal rights for young carers, whether there is an established body of rigorous and reliable research, and whether there are codes of guidance for professional practice (Leu and Becker, 2017).

At the time of Leu and Becker's (2017) classification scale and the start of the ME-WE research project (in 2018), the UK was classified as 'advanced' and was the only country to receive an advanced classification. The UK is generally considered the 'global leader' in young carer research, awareness and policy responses due to its development of dedicated legislation to give young carers legal rights and access to formal supportive services, as well as the hundreds of dedicated support services for young carers, called 'young carers projects', across the UK. All these advances have been based on a foundation of research (Leu and Becker, 2017).

Sweden was classified as 'intermediate' (Level 3) in view of its medium-sized research base, specific legislation within the Swedish Health Care Act and localised formal supportive services. Italy, Switzerland and the Netherlands were classified as

Figure 1: Classification of in-country awareness and policy responses to 'young carers' (Leu and Becker, 2017)

Levels 1-7	Characteristics	Country Example
1 <b>Incorporated / Sustainable</b>	<ul style="list-style-type: none"> <li>• Extensive awareness at all levels of government and society of the experiences and needs of young carers</li> <li>• Sustained and sustainable policies and interventions aimed at meeting young carers' needs and promoting their health, well-being and development</li> <li>• Responses and law built on a foundation of reliable research evidence and clear legal rights</li> </ul>	None
2 <b>Advanced</b>	<ul style="list-style-type: none"> <li>• Widespread awareness and recognition of young carers amongst public, policy makers and professionals</li> <li>• Extensive and reliable research base, and growing</li> <li>• Specific legal rights (national)</li> <li>• Extensive codes and guidance for welfare professionals and national and local strategies</li> <li>• Multiple dedicated services and interventions nationwide</li> </ul>	United Kingdom
3 <b>Intermediate</b>	<ul style="list-style-type: none"> <li>• Some awareness and recognition of young carers among public, policy makers and professionals</li> <li>• Medium-sized research base, and growing</li> <li>• Partial rights in some regions</li> <li>• Small but developing body of professional guidance</li> <li>• Some dedicated services and interventions, mostly local but a few nationwide</li> </ul>	Australia Norway Sweden
4 <b>Preliminary</b>	<ul style="list-style-type: none"> <li>• Little public or specialist awareness and recognition of young carers</li> <li>• Limited research base, but growing</li> <li>• No specific legal rights but other laws may be applicable or relevant</li> <li>• Few, if any, dedicated services or interventions at national or local levels</li> </ul>	Austria Germany New Zealand
5 <b>Emerging</b>	<ul style="list-style-type: none"> <li>• Growing public or specialist awareness and recognition of young carers</li> <li>• Small but growing research base</li> <li>• No specific legal rights but other laws may be applicable or relevant</li> <li>• No specific services or interventions for young carers, but other services might be applicable</li> </ul>	Belgium Ireland Italy Sub-Saharan Africa Switzerland The Netherlands United States
6 <b>Awakening</b>	<ul style="list-style-type: none"> <li>• Embryonic awareness of young carers as a distinct social group within the «vulnerable children» population</li> </ul>	Greece Finland United Arab Emirates France
7 <b>No response</b>	<ul style="list-style-type: none"> <li>• No apparent awareness or policy response to young carers as a distinct social group</li> </ul>	All other countries

‘emerging’ (Level 5) countries, highlighting that there is a lack of services for young carers, as well as a lack of an established body of scholarly research and legal rights. In Switzerland, to date, there have been a small number of research studies focused on young carers (Leu et al, 2022). The first national research programme on young carers was launched there in 2014 (Leu and Becker, 2017). There has also been very little scholarly research in Italy, despite recent figures in 2015 indicating that there are at least 391,000 carers aged 15–24 years old in Italy (Italian Institute of Statistics, 2015). In the Netherlands, estimates on the probable number of adolescents who have a family member with a chronic illness or disability range between 11 and 37 per cent, but the actual prevalence of these young people with caring roles has hitherto been unknown (De Roos et al, 2017; 2020). In 2020, a national study of schoolchildren (12–16 years old) growing up with a long-term ill family member was conducted (De Roos et al, 2020). An estimated one in five schoolchildren aged 12–16 grow up with an ill family member in the Netherlands. Between 6 and 8 per cent of the 12- to 16-year-olds provide care tasks for these ill family members, and 3 per cent provide intensive care tasks (four or more hours per week). Furthermore, research involving Dutch AYCs only commenced in 2018 (Van Loon et al, 2017; Boumans and Dorant, 2018). The Netherlands was thus classified as ‘emerging’ (Level 5). Finally, Slovenia was classified as ‘awakening’ (Level 6) due to its lack of research (there is only one study published) and only the most rudimentary awareness (Hlebec, 2019; Leu et al, 2022).

For some time now, it has been recognised that there is a need for large-scale survey research to identify the size and scope of the problems faced by young people who care (Joseph et al, 2020). The cross-national profile of AYCs presented here for the first time was collected through an online survey in these six countries, utilising quantitative and qualitative methods, and it is the quantitative and statistical results of that survey that are the focus of this article. The qualitative, open-ended question on informal and formal support preferences was designed with the aim of giving AYCs the opportunity to disclose their desires for support, including original ideas for formal support that may not have already been identified by the research team in the online survey’s multiple-choice format. This present article has three objectives: (1) to describe the demographic information of participants in each of the six countries; (2) to assess the extent of caring and its outcomes for AYCs in each of the countries; and (3) to compare results across each of the countries.

While the definition of young carers (see earlier) can be understood and applied conceptually and in policymaking by all six countries, the terms used to denote (and label) young carers can and do vary between these and other countries. In Sweden, the term ‘children as next of kin’ is more commonly used in discourse, policy and law to reflect those children who are affected by parental illness, disability, substance abuse or death (Hjern et al, 2017). In Italy, the Netherlands, Sweden and Slovenia, there lacks a commonly accepted term and, instead, ‘young carer’ is simply translated into their respective national languages (Nap et al, 2020). In Switzerland, the term ‘young carer’ is used, usually with a brief definition in German and Italian; in the French region, the term is translated into French: ‘jeune aidant’. Our study agreed on the term ‘adolescent young carers’ to draw attention to the specific physical, psychosocial and emotional circumstances of young carers in this transition phase, and to highlight the implications for social policy, services and intervention (Dearden and Becker, 1998; Lewis, 2018; Becker and Sempik, 2018; Rolling et al, 2020).

Previous research has acknowledged that AYCs are at risk of a variety of negative impacts to their mental health and well-being (Carers Trust, 2016; Becker and Sempik, 2018). A total of 50 per cent of AYCs sampled in research with the Carers Trust (2016) in the UK experienced stress related to their caring activities, and 40 per cent experienced mental health problems. AYCs are typically at risk of a host of other health inequalities, such as physical health problems because of caring (for example, back strain), exhaustion, lack of sleep and disrupted sleep, and emotional difficulties, such as anxiety and depression (Aldridge and Becker, 1993; 2003; Cree, 2003). Furthermore, AYCs often experience severe impacts to their educational and work experiences, with many young carers facing chronic problems of lateness, absenteeism and inability to maintain paid employment due to caring responsibilities (Aldridge and Becker, 1993; Hamilton and Adamson, 2013; Becker and Sempik, 2018). Migrant AYCs are at particular risk of ill health and social disadvantages, as their increasing family responsibilities for ill or disabled family members coexist within their experience of trauma, displacement and instability (Children's Society, 2013). Confounding the issues facing AYCs, they are considered to be a vulnerable group of young people 'hidden' from the view of educators, health and social care professionals, and policymakers (Nap et al, 2020). The terms 'hidden' or 'hard to reach' have been used by academics to describe the position of young carers who are not in contact with formal support services. Conversely, their caring role is 'unknown' to others in their daily life, especially those who might be gatekeepers to support services, such as teachers and health and social care providers (Aldridge et al, 2016). However, caring can be fulfilling and has positive aspects, such as love and strengthened attachment bonds between the AYC and the care recipient (Santini et al, 2020).

## Methods

The study featured an online survey in six countries, made available in two data collection periods: April 2018–December 2018 (all six countries) and January 2019–July 2019 (Switzerland, Sweden, the Netherlands and the UK only). The survey included: a demographic section; two specific psychometric instruments that have been designed for use with young carers – the Multidimensional Assessment of Caring Activities (MACA) and the Positive and Negative Outcomes of Caring (PANOC) (Joseph et al, 2009); a section on education, employment, health and support; and an open-ended qualitative question on support preferences. In Italy and Slovenia, the survey included an additional open-ended qualitative question on the difficulties experienced when caring for an older family member. In Italy and Slovenia, the ageing population and lack of long-term formal care provision provided a rationale for asking a more specific question on care for older family members. In addition, the survey included the KIDSCREEN-10 Measure of Health-Related Quality of Life, an instrument used in the context of childhood well-being (Ravens-Sieberer, 2006; Ravens-Sieberer et al, 2010). The demographic section featured questions on age, gender (including gender identity), place of residence, nationality/citizenship, family composition and caring role (for example, who they care for and the condition of the person cared for).

AYCs were identified by their answers to a series of questions in the demographic section. The questions were designed in recognition that the survey would be taken

in some countries with a low awareness of young caring and therefore that direct questions on young caring (such as ‘Are you a young carer?’) might not fully capture AYC’s who had never been identified (or self-identified) as a young carer. Thus, the following series of questions were designed with the aim of capturing responses from AYC’s who might not have previously considered or thought of themselves to be an AYC:

- Q1. Do you have someone in your family with a health-related condition?
- Q2. What type of health-related condition does these persons have?
- Q3. Who are these persons (for example, parent[s], sibling[s], grandparent[s] and so on)?
- Q4. Do you live with the family members who have a health-related condition?
- Q5. Do you look after, help or support any of these family members with a health-related condition?

Affirmative answers to Q5, ‘look after, help or support’, were used to classify a respondent as a *carer of a family member*. Respondents were then asked the same series of questions regarding friends or other close individuals in their life. Affirmative answers to the ‘look after, help or support’ question in the ‘close friends’ section were used to classify a respondent as a *carer of a close friend*. This research study was concerned with the mental health and well-being of 15- to 17-year-old carers; thus, once a respondent was classified as a carer, their age was used to determine whether they were an AYC. Only respondents aged 15–17 years old who provided affirmative answers to the ‘look after, help or support’ questions – either for a family member or close friend, or both – were classified as AYC’s for the purpose of this study.

The MACA is an 18-item self-report questionnaire that asks young people about the frequency of their caring activities (Joseph et al, 2012). Each item is rated on a three-point scale: ‘never’ = 0; ‘some of the time’ = 1; and ‘a lot of time’ = 2. As such, scores on the total MACA have a possible range of 0 to 36, with 0 indicating that no care activities take place and 36 indicating the highest amount of caring. Scores of 10–13 indicate a moderate amount of care activity, scores of 14–17 indicate a high amount and a score of 18 and above demonstrates a very high amount of caring (Joseph et al, 2012). The MACA can also be scored to produce six three-item subscale scores for domestic tasks, household management, personal care, emotional care, sibling care and financial/practice care. Each subscale score has a possible range of 0 to 6, with higher scores indicating greater activity on that domain of caring.

The PANOC is a 20-item self-report measure that can be used to obtain an index of the positive and negative outcomes of care provision (Joseph et al, 2012). This measure recognises that young caring can feature both positive and negative effects in a young person’s life. The PANOC is typically used to determine whether the receipt of formal support has resulted in a reduction of the negative effects of caring and an increase in the positive effects of caring. Each item is rated on a three-point scale: ‘never’ = 0; ‘some of the time’ = 1; and ‘a lot of the time’ = 2. The PANOC contains two ten-item subscales for positive responses and negative responses, with a potential range of 0 to 20 on both subscales. Higher scores indicate a greater positive and negative score, respectively. Scores less than 12 on the PANOC positive scale and/or greater than 8 on the PANOC negative scale indicate potential concern (Joseph et al, 2012).

Both the MACA and the PANOC are validated psychometric instruments that are now being used in 15 countries. The New Zealand government's 2019 National Carers Action Plan, for example, calls for the MACA to be used to identify young carers in that country ([New Zealand Carers Alliance, 2019](#)). The MACA has also been used in the UK by the British Broadcasting Corporation (BBC) in two national surveys (in 2010 and 2018) to identify the proportion of young carers in schools and the population of young carers in the UK ([BBC News, 2010](#); [Joseph et al, 2019](#)).

The recruitment strategy of all partner countries involved the targeting of schools, in which AYC's would be in classrooms with children who are not AYC's. The survey was designed in such a manner that children who are not AYC's could also take the full length of the survey. The answer choices for the MACA and PANOC were revised to allow non-young carers to select 'not applicable'. This approach ensured that non-young carers and young carers would take the same reasonably expected time to complete the survey (and therefore that AYC's would not be exposed in the classroom for taking longer). An outcome of this approach means that we have a large database on AYC's in the six countries and a larger database on other young people who do *not* have a caring role. Thus, we are able to make meaningful (and statistically reliable) comparisons between the two groups (see the 'Results' section later).

The KIDSCREEN-10 questionnaire is a widely used and respected ten-item measure used by children and young people to report on the health-related quality of life standard. The instrument was designed to provide an overview of the subjective quality of health of a young person and has been validated in over 13 European countries. The Kidscreen-10 instrument has been used in another school survey involving young carers ([Schlarmann et al, 2008](#); [Kuhne et al, 2012](#); [Ravens-Sieberer et al, 2010](#)). The Kidscreen-10 is a shortened version of a larger, 27-item questionnaire. A total sum score (range 10–50) is indicated, and higher scores indicate greater well-being. The next section of the survey included questions on education (for example, institution attended, educational achievements, employment and vocational training status), impacts from caring on education, paid employment and mental and physical health, and support received (for example, formal services provided by government and voluntary agencies [if any], and informal support by friends or school staff).

The online survey was first designed in English by the UK research leaders and hosted on the 1ka online platform (a survey development tool similar to SurveyMonkey). The English version of the online survey was then translated by each country partner into the languages necessitated by their specific country context: Italian, Dutch, Slovene, Swedish, Swiss German, Arabic and Dari. The online survey was designed to be taken on a personal computer, laptop, tablet or mobile phone. Paper-and-pencil versions of the survey were utilised in a very few instances in all six European countries; however, the unavailability of electronic devices within the sampled schools in Italy required a greater use of paper-and-pencil questionnaires. The answers to the paper-and-pencil surveys were then entered electronically by country partner teams during the data-collection period and checked for data-entry accuracy.

To reduce the risk of sampling bias as much as possible, all partners agreed to adopt a multistage facility sample: (1) using regional differentiation within the countries, ensuring participants from urbanised, somewhat less urbanised and rural areas; and (2) using various recruitment channels for AYC's through schools, care organisations, interest groups of care recipients and municipalities. Due to challenges in recruitment,



this strategy was not always adhered to in low-AYC-awareness countries, that is, for example, rural areas were particularly difficult to reach, and in Slovenia and Italy, recruitment occurred only in schools. Information about the survey was disseminated through formal support services for carers and health service users. Social media and traditional media were also used to promote the survey. The project had a target sample size of 200 AYC's per country to enable meaningful statistical analysis.

In Italy, recruitment only took place in high schools of two Italian regions: Marche and Emilia-Romagna. The gatekeeper was the head or a teacher who was contacted by the research team for an introductory meeting. At the meeting, the research team provided the participant information sheet and consent form to be distributed to the students and their parents/guardians. On the day of data collection, the researchers had paper-and-pencil versions of the survey, as well as the online version.

In the Netherlands, the recruitment strategy included social care and support centres for carers, schools, and a social media campaign that especially targeted sibling carers. A total of 95 AYC's were recruited through schools (48 per cent) and the other 104 AYC's were recruited through care organisations, support centres or patient organisations (using direct invitations or social media channels). In the Netherlands, schools are registered in a database, and using this information, schools were approached to participate in the study by the researchers, explaining the objective and method of the study using telephone calls or site visits. Schools that agreed to participate were offered promotional material to be distributed in school or in class. All pupils in a class were invited to fill in the online survey, or, alternatively, pupils received an invitation to fill in the survey using their online school communication channels.

In Slovenia, the recruitment strategy targeted vocational schools that train health and educational professions; all AYC's were recruited from schools. In Slovenia, parents express consent for their children to participate in survey research at the discretion of school administrations. This consent is collected every year prior to the start of classes. Discussion as to whether or not a particular school considers it appropriate to allow survey research is held with the representative of the school administration, usually the school directors.

In Switzerland, recruitment primarily took place through vocational training schools and high schools in the German-speaking part of Switzerland. For the first data-collection period, three schools with three departments (Health and Social Science, Industrial Science, and Commercial Science) took part. In order to reach the target sample size of AYC's, a second data-collection period (January – July 2019) took place, reaching more vocational and high schools and four training hospitals. In total, over the two recruitment periods, 11 schools and two hospitals were engaged in the study. Schools were contacted via email and phone calls. In some schools, the research team delivered a presentation to give greater detail about the project. Informational materials were also provided to teachers and parents. The teachers were invited to forward the online survey link to their students and, where possible, to conduct the survey during one lesson (lasting 40 minutes).

In Sweden, 647 AYC's were recruited via schools. A survey was sent to the schools and a total of 3,015 young people aged 15–17 years old answered the questionnaire, both carers and non-carers. A total of 19 AYC's were recruited via other channels (NGOs, brochures, general practitioners, pharmacies or municipalities' websites). The Swedish research team contacted the education administration in 11 municipalities in the south of Sweden to get their approval to carry out the study in schools.

After approval, the research team informed the schools' principals, both orally and in writing, about the research project and the survey. The principals forwarded the oral and written information to the teachers in each class and instructed them to set aside lesson time (40 minutes) for the students to complete the questionnaire online on the schools' electronic devices or on paper. Two classes in one school pilot-tested the questionnaire on paper. In classes where the questionnaire was completed on paper, one member of the research team was present in the classroom, collected the completed paper questionnaires and added the answers online.

In the UK, recruitment of participants took place mainly through formal support organisations for young carers across England and Wales. The research team emailed the online survey weblink to formal support organisations for young carers and made phone calls to organisations across the country. Calls for participants were posted on Twitter, Facebook and Instagram by the lead UK researcher. Phone calls were made to over 50 secondary schools across the UK, requesting to send paper versions of the survey or to email the online survey weblink; however, uptake from schools was extremely low. Heads of schools expressed that their students were over-surveyed and that they would therefore not allow any further survey research to take place in their schools. The majority of the research participants accessed the online survey via a weblink sent through social media or distributed through the online newsletters of formal organisations for young carers. The lead UK researcher also attended festivals for young carers in England and Scotland and distributed the paper version of the survey. A research assistant entered the answers on the paper surveys into the online survey. Only a small number of participants were recruited from schools: the UK research team attended a sixth-form college in Brighton and Hove, England, and distributed the online survey on tablets to four classes of fewer than ten students; the paper version was also mailed to a secondary school in Northern Ireland.

### *Ethics*

Institutional ethical approval or detailed ethics opinions (Switzerland) were secured by all country partners in their respective countries in April 2018. The practice of ongoing informed consent held utmost priority in the study. The process of informed consent was utilised to ensure that AYC's were involved in the study on a voluntary basis, without coercing their participation, either directly or indirectly, in any way. In keeping with the Oviedo Convention on Human Rights and Biomedicine, all participants involved in the research were fully informed about the study appropriately to their age. The participant information sheet and consent form were written in clear, easy-to-understand language and described all relevant aspects of the research protocol in full. Informed consent also necessitated that the information sheet and consent form included the foreseen benefits and possible risks of participation, while drawing attention to their ability to withdraw participation at any time without consequence. Country partners translated the English version of the participant information sheet and consent form into their relevant national languages. In addition to the language translation, country partners added their country-specific referral mechanisms to external education, care and support professionals in case of need. Where necessary and applicable due to national legislation, informed consent was also secured by the participants' parents/legal guardians. Each country partner followed the General Data Protection Regulations

(GDPR) in addition to their respective national laws and EU laws governing data protection. No data were collected that would identify a specific participant, thus keeping the identity of all participants anonymous.

### Data analysis

Data were analysed using IBM SPSS Statistics (version 25.0). In order to address the first research objective of describing the demographic information of participants across the six countries, descriptive data, including frequency, mean and standard deviation, were reported. To address the remaining two objectives, which looked at the extent of caring and its effects, both within each country and across them, descriptive data were again presented, along with inferential tests, including independent-samples *t*-tests, paired-samples *t*-tests and Pearson’s correlation coefficient.

## Results

### General demographics

The figures presented in this section are from the final data set in the ME-WE research project; figures in earlier project publications and reports may have slight differences due to data-collection waves and subsequent data cleaning. A total of 9,437 participants across six countries responded to the online survey. Of these, 7,146 were aged 15–17 years old. A total of 2,746 participants (all ages) were identified as carers. Using the survey’s filtering questions, the total number of identified AYC’s aged 15–17 was 2,099. In terms of individual countries, Sweden had the largest sample of AYC’s (with 702), followed by the UK (402), Slovenia (342), Switzerland (240), Italy (214) and finally the Netherlands (199).

The majority of the AYC’s identified as female (1,476). A further 558 AYC’s identified as male, 15 identified as transgender and 25 identified as ‘other’. Table 1 shows the gender breakdown for AYC’s in each country.

Of the 2,099 AYC’s in all partner countries, 1,444 indicated that they care for a *family member*, with 77 per cent stating that they live with this person. A total of 1,121 AYC’s care for a *close friend*, with 7 per cent living with that person. Some AYC’s provide care to family members and close friends.

**Table 1: Gender identified among AYC’s across each country**

	Female	Male	Transgender	Other
Italy	141 (67.1%)	67 (31.9%)	1 (0.5%)	1 (0.5%)
Netherlands	141 (72.3%)	48 (24.6%)	3 (1.5%)	3 (1.5%)
Slovenia	298 (88.7%)	34 (10.1%)	1 (0.3%)	3 (0.9%)
Sweden	447 (64.3%)	238 (34.2%)	2 (0.3%)	8 (1.2%)
Switzerland	193 (80.8%)	45 (18.8%)	0 (0%)	1 (0.4%)
UK	256 (64.2%)	126 (31.6%)	8 (2%)	9 (2.3%)
<b>Total</b>	<b>1,476 (71.2%)</b>	<b>558 (26.9%)</b>	<b>15 (0.7%)</b>	<b>25 (1.2%)</b>

Note: Valid percentages are reported, which do not take account of missing data (that is, those who selected ‘prefer not to say’ in response to gender).

Of those caring for a *family member*, two fifths (42 per cent) of AYC's reported that they provide care for their mother. Fewer AYC's provide care for their father (25 per cent), followed by their brother (19 per cent), grandmother (17 per cent), sister (16 per cent) and grandfather (11 per cent). All remaining categories, such as aunt or uncle, were selected by less than 10 per cent.

The research was also concerned to observe any country-specific patterns and themes. In regards to the identity of the cared-for family member, there is a preponderance of care provided for grandparents in the Italian sample (59.3 per cent). However, a significant amount of care provided to grandparents is also indicated in the Swiss (34.2 per cent) and Slovenian (37.8 per cent) samples. In contrast to grandparent care, the Italian sample indicated much lower levels of parental care (12.9 per cent for mother; 10.7 per cent for father) than other countries. For example, 54.3 per cent and 23.4 per cent of the UK sample indicated that they care for their mother and father, respectively. In terms of sibling care, Sweden (20.6 per cent for sister; 18.8 per cent for brother), the UK (22.3 per cent for sister; 25.2 per cent for brother) and the Netherlands (15.3 per cent for sister; 29.3 per cent for brother) showed much higher rates in comparison to the other countries in the sample, such as the Italian carers, who had the lowest figures (5.0 per cent for sister; 9.3 per cent for brother).

In terms of the health-related conditions that these family members required care for, more AYC's indicated that they provide care for family members with physical disabilities (46 per cent) and mental illness (40 per cent) than cognitive impairments (26 per cent) or substance addiction (10 per cent). It should be noted that totals exceed 100 per cent because many family members who receive care have a number of conditions ('co-morbidity').

Examining the six countries for potential cross-cultural differences, we observe some between-sample patterns. Swedish AYC's caring for family members selected physical disabilities less frequently (28.7 per cent) than the other countries (ranging from 49.8 per cent among the Slovenia AYC's to 57.0 per cent among the Dutch AYC's). There is a divide in terms of the number of participants selecting mental illness, with higher rates observed in the UK (56.5 per cent), Switzerland (48.1 per cent) and Sweden (45.7 per cent) than in Italy (17.7 per cent), the Netherlands (30.4 per cent) and Slovenia (21.9 per cent). Cognitive impairment was fairly consistently selected across the six countries, however, with participants in the Netherlands selecting it most frequently (34.2 per cent) and participants in Slovenia the least likely to select it (17.4 per cent). Finally, addiction was also fairly consistently selected, though noticeably less so in the Netherlands (4.4 per cent) than in the other countries (ranging from 7.7 per cent in Slovenia to 15.0 per cent in Sweden).

In addition to the care provided to family members, the survey also investigated the AYC's' caring responsibilities for their *close friends*. Of the 2,099 AYC's, 1,121 indicated that they have a close friend for whom they provide care. The majority of these AYC's reported that they provide care for their friend (80 per cent), with fewer AYC's providing care for their partner (10 per cent), colleague (7 per cent), neighbour (4 per cent) and ex-partner (7 per cent). Only 7 per cent of the AYC's stated that they live with the friend they care for.

Looking at the health-related conditions that these friends have, mental illness (69 per cent) was the most frequently reported condition requiring care. A smaller number of AYC's provide care for their friends with physical disabilities (20 per cent), cognitive impairment (18 per cent) and addiction (20 per cent).

There are, however, some interesting differences between the countries. For example, while the majority of the samples reported a high frequency of mental illness, such as the UK (82.2 per cent), Sweden (77.5 per cent) and the Netherlands (70.3 per cent), the Italian sample is markedly lower (30.1 per cent). In contrast, the Italian participants, compared to those in the other countries, more frequently reported that the friend they care for has cognitive impairments (25.2 per cent) or substance abuse issues (32.0 per cent).

Looking at the number of participants who care for multiple people, across all six countries, 332 AYC's indicated that they care for more than one family member (28.4 per cent). Swiss AYC's most frequently reported this (40.0 per cent), closely followed by the Dutch (31 per cent) and UK (29.4 per cent) AYC's, while the Swedish AYC's reported the lowest levels of multiple caring roles within their family (22.7 per cent). Additionally, 466 AYC's indicated that they care for at least one family member and one close friend (22.2 per cent). In this instance, the UK sample shows the most frequent rates (28.4 per cent), followed by the Swedish (23.9 per cent) and Slovenian (21.6 per cent) samples, with the Italian AYC's reporting the lowest frequency (14.0 per cent).

In consideration of family structure, most of the AYC's in this sample reported that they live in two-parent households, including step-parents (80.2 per cent). A total of 19.8 per cent indicated that they were from one-parent households, selecting only their mother (16 per cent) or only their father (3 per cent). Two thirds (67 per cent) of AYC's stated that they live with at least one sibling, while only 10 per cent stated that they live with at least one grandparent.

Adolescent young caring also exists in migrant families. A total of 174 (8.3 per cent) AYC's disclosed that they were born in a different country than their current residence. This was most prevalent among the Italian AYC's (12.2 per cent), closely followed by the Swiss (11.3 per cent) and the Swedish AYC's (10.5 per cent). It was less frequently shown among the UK (7.4 per cent), Dutch (4.0 per cent) and Slovenian (3.2 per cent) AYC's. Additionally, 527 (25.2 per cent) AYC's disclosed that at least one of their parents was born in a foreign country. This was indicated by 44.6 per cent of the Swiss AYC sample. The other countries showed fairly similar lower levels, ranging from 15.6 per cent among the Dutch AYC's to 21.4 per cent in the Swedish sample.

### *The MACA*

The MACA questionnaire indicates the number of caring activities an individual carries out in the home, with higher scores indicating that they perform more caring activities. In order to investigate whether those participants who identified as AYC's via the survey's filtering questions did complete more caring activities than the 15- to 17-year-old participants who did not identify as AYC's, a series of independent-samples *t*-tests were conducted.

When examining the data overall, the scores on the MACA demonstrate that when compared to their non-caring peers ( $M = 8.81; SD = 4.57$ ), AYC's perform a greater number of caring activities in the home ( $M = 12.57; SD = 5.64$ ) ( $t[3210.93] = 26.73; p < .001; d = 0.73$ ). As can be seen in [Table 2](#), this finding is consistent across each of the six countries.

In addition to investigating differences in MACA scores between carers and non-carers, we also investigated gender differences between AYC's. Overall, it is shown

**Table 2: Independent-samples *t*-tests on mean MACA score (SD) for both AYC and 15- to 17-year-old non-carers, separately for each country**

	AYCs	Non-AYCs	<i>t</i>	<i>df</i>	<i>p</i>	<i>d</i>
Italy	11.42 (5.38)	8.33 (4.51)	7.54 <sup>a</sup>	307.83	< .001	0.62
Netherlands	12.24 (5.37)	7.48 (3.58)	11.35 <sup>a</sup>	280.98	< .001	1.04
Slovenia	14.22 (5.81)	10.81 (4.62)	9.35 <sup>a</sup>	555.99	< .001	0.65
Sweden	10.92 (4.97)	8.50 (4.12)	11.46 <sup>a</sup>	964.42	< .001	0.53
Switzerland	13.15 (5.84)	9.66 (5.96)	7.65	846	< .001	0.59
UK	14.44 (5.72)	7.95 (4.12)	17.41 <sup>a</sup>	692.39	< .001	1.30
Total	<b>12.57 (5.64)</b>	<b>8.81 (4.57)</b>	<b>26.73<sup>a</sup></b>	<b>3210.93</b>	<b>&lt; .001</b>	<b>0.73</b>

Note: <sup>a</sup> Equal variances not assumed.

**Table 3: Number of AYC scoring below 12 on the PANOC positive scale and number scoring above 8 on the PANOC negative scale, separately for each country**

	PANOC positive score below 12		PANOC negative score above 8	
	<i>N</i>	%	<i>N</i>	%
Italy	42	23.0%	20	11.8%
Netherlands	64	43.8%	19	12.7%
Slovenia	57	23.3%	31	12.7%
Sweden	230	45.5%	166	34.2%
Switzerland	52	29.5%	37	22.4%
UK	157	44.4%	143	39.6%
Total	602	37.4%	416	26.4%

that female AYC (M = 13.07; SD = 5.70) scored significantly higher on the MACA than male AYC (M = 11.24; SD = 5.16) ( $t [1051.11] = 6.80; p < .001; d = 0.34$ ). For the Dutch AYC, female participants scored significantly higher (M = 12.86; SD = 5.22) than male participants (M = 10.15; SD = 4.16) ( $t [101.42] = 3.65; p < .001; d = 0.57$ ). Likewise, the female AYC in the UK sample scored significantly higher (M = 15.64; SD = 6.14) than the male AYC (M = 11.98; SD = 3.99) ( $t [341.20] = 6.91; p < .001; d = 0.71$ ). In each country, female AYC, on average, scored higher than male AYC. However, this difference is only significant in the Netherlands and the UK.

### The PANOC

The PANOC questionnaire is split into two scales: the PANOC positive, which assesses the level of positive adaptation associated with the participant's caring responsibilities; and the PANOC negative, which assesses the negative effects. Scores below 12 on the positive scale and/or scores above 8 on the negative scale may indicate that the AYC is suffering from emotional distress. Table 3 shows the proportion of AYC whose scores indicate potential concern for each country.

Inspection of Table 3 reveals some between-country differences. The UK and Sweden both had a high proportion of AYC scoring below 12 on the positive scale

(44 per cent and 46 per cent, respectively), as well as a high proportion of those scoring above 8 on the negative scale (40 per cent and 34 per cent, respectively). Italian AYCs had the lowest proportions on average, with only 23 per cent scoring below 12 on the positive scale and 12 per cent scoring above 8 on the negative scale. There was a relatively high proportion of Dutch AYCs scoring below 12 on the positive scale (44 per cent); however, the proportion scoring above 8 on the negative scale was relatively low (13 per cent).

Additionally, the study examined whether there was a gender difference in both PANOC positive and negative scores. In order to investigate this, a series of independent-samples *t*-tests were conducted. With all countries combined, the results show that there is no significant difference in PANOC positive scores between male AYCs ( $M = 12.48$ ;  $SD = 4.66$ ) and female AYCs ( $M = 12.98$ ;  $SD = 4.45$ ) ( $t [1559] = 1.92$ ;  $p = .06$ ,  $d = 0.11$ ). However, there is a significant difference in PANOC negative scores, with male AYCs ( $M = 4.44$ ;  $SD = 4.55$ ) scoring significantly lower than female AYCs ( $M = 5.64$ ;  $SD = 5.10$ ) ( $t [793.71] = 4.40$ ;  $p < .001$ ;  $d = 0.25$ ). This suggests that while male and female AYCs have similar positive experiences of caring, female AYCs report more negative effects than their male counterparts.

When looking at individual countries, the same is true in each for the PANOC positive scores, with no significant difference between male and female AYCs in any of the six countries. The PANOC negative did produce some gender differences. In the Swedish sample, the female AYCs ( $M = 6.66$ ;  $SD = 4.94$ ) scored significantly higher on the PANOC negative than the male AYCs ( $M = 5.45$ ;  $SD = 4.47$ ) ( $t [473] = 2.61$ ;  $p = .01$ ;  $d = 0.26$ ). The same was true in the UK, with females ( $M = 8.56$ ;  $SD = 5.61$ ) scoring significantly higher than the males ( $M = 4.34$ ;  $SD = 4.97$ ) ( $t [235.73] = 7.03$ ;  $p < .001$ ;  $d = 0.80$  [equal variances not assumed]). However, in the remaining countries, no such significant difference arises.

Finally, in order to examine whether there is a relationship between the level of caring activities and negative effects of caring, a Pearson's correlation coefficient was conducted to test for the association between scores on AYCs' MACA and PANOC negative score. The results indicate that there is a significant positive correlation between the two variables ( $r [1545] = .29$ ;  $p \leq .001$ ;  $R^2 = .08$ ). This suggests that the more caring responsibilities an AYC has, the more negative effects of caring they perceive. However, while the relationship between these variables is significant, it is nevertheless a weak correlation, explaining only 8 per cent of the variance shared by both variables. This suggests that there are other, as yet unknown, factors impacting the level of negative effects associated with caring.

### KIDSCREEN-10

The reported scores on the KIDSCREEN-10 help to indicate a comprehensive state of well-being in young people. A total score of 50 indicates extremely high well-being. In order to examine whether there is a difference in well-being between 15- to 17-year-old carers and non-carers, a series of independent-samples *t*-tests were conducted (see Table 4). The analyses reveal that with all countries included, the AYCs score significantly lower on the KIDSCREEN-10 ( $M = 33.04$ ;  $SD = 7.38$ ) than the 15- to 17-year-old participants who were not identified as AYCs ( $M = 36.72$ ;  $SD = 6.53$ ) ( $t [3346.25] = 19.27$ ;  $p < .001$ ;  $d = 0.53$ ). This indicates that the AYCs, on average, consider themselves to have a lower state of well-being than non-AYCs.

**Table 4: Independent-samples *t*-tests on mean KIDSCREEN-10 score (SD) for both AYC and 15- to 17-year-old non-carers, separately for each country**

	AYCs	Non-AYCs	<i>t</i>	<i>df</i>	<i>p</i>	<i>d</i>
Italy	33.46 (6.45)	34.63 (5.68)	2.36 <sup>a</sup>	319.63	.02	0.19
Netherlands	36.08 (7.06)	38.50 (6.07)	3.94 <sup>a</sup>	310.66	< .001	0.37
Slovenia	30.58 (7.14)	33.09 (6.96)	5.16	926	< .001	0.36
Sweden	34.40 (7.17)	38.27 (6.09)	12.78 <sup>a</sup>	1003.47	< .001	0.58
Switzerland	33.29 (7.12)	36.29 (6.33)	5.52 <sup>a</sup>	369.87	< .001	0.45
UK	30.74 (7.57)	35.78 (6.94)	8.94	673	< .001	0.69
Total	33.04 (7.38)	36.72 (6.53)	19.28 <sup>a</sup>	3346.25	< .001	0.53

Note: <sup>a</sup> Equal variances not assumed.

**Table 5: Independent-samples *t*-tests on mean KIDSCREEN-10 score (SD) for female and male AYC, separately for each country**

	Female	Male	<i>t</i>	<i>df</i>	<i>p</i>	<i>d</i>
Italy	32.65 (6.58)	35.53 (5.69)	3.05	203	.003	0.47
Netherlands	35.39 (6.81)	39.31 (6.35)	3.29	169	< .001	0.60
Slovenia	30.24 (7.09)	33.57 (6.12)	2.47	305	.01	0.50
Sweden	33.33 (7.10)	36.65 (6.74)	5.87	664	< .001	0.48
Switzerland	33.05 (7.09)	34.33 (7.19)	1.06	220	.29	0.18
UK	29.26 (6.76)	34.73 (7.43)	6.86	350	< .001	0.77
Total	32.11 (7.21)	35.95 (6.87)	10.55	1921	< .001	0.55

Inspection of [Table 4](#) reveals that this finding is consistent across all six countries, with AYC reporting significant lower KIDSCREEN-10 scores than non-AYC in each country. Looking at scores between the countries, the data show that the Slovenian AYC report the lowest state of well-being, closely followed by the AYC in the UK. The AYC in the Netherlands report the highest average levels of well-being, followed by the Swedish AYC. The Italian and Swiss AYC fall in the middle, with similar average KIDSCREEN-10 scores.

In order to investigate whether there is any gender difference in well-being among the AYC, another series of independent-samples *t*-tests were conducted (see [Table 5](#)). The findings reveal that there is a significant gender difference in the KIDSCREEN-10 scores overall, with female AYC scoring significantly lower ( $M = 32.11$ ;  $SD = 7.21$ ) than male AYC ( $M = 35.95$ ;  $SD = 6.87$ ) ( $t[1921] = 10.55$ ;  $p < .001$ ;  $d = 0.55$ ). Looking at the findings from individual countries, this pattern appears to be consistent, with female AYC rating their own well-being significantly lower than their male counterparts in all six partner countries.

Closer inspection of [Table 5](#) shows that the female AYC based in the UK have the lowest KIDSCREEN-10 score, followed by those in Slovenia. The female AYC in the Netherlands recorded the highest average score, followed by the Swedish and Swiss AYC. Taken together, the results from the KIDSCREEN-10 survey indicate that the UK and Slovenia both have a potential issue with AYC experiencing poor well-being in their sample of AYC, with female AYC appearing to experience this more strongly.



**Table 6: Number (valid percentage) of AYC's who indicated that they had experienced issues and difficulties due to their caring responsibilities**

	Negative effect on school performance	Experience of bullying	Physical health problems	Mental health problems	Considered hurting self	Considered hurting others	Harmed care recipient
Italy	19 (9.0%)	17 (8.1%)	52 (29.1%)	34 (19.0%)	18 (8.5%)	14 (6.6%)	8 (57.1%)
Netherlands	22 (12.3%)	24 (13.3%)	23 (18.9%)	15 (12.3%)	20 (11.2%)	6 (3.4%)	2 (33.3%)
Slovenia	32 (10.1%)	14 (4.4%)	62 (23.7%)	38 (14.5%)	23 (7.3%)	15 (4.8%)	11 (78.6%)
Switzerland	36 (16.1%)	36 (16.1%)	68 (36.0%)	64 (33.9%)	41 (18.3%)	11 (4.9%)	3 (27.3%)
Sweden	90 (13.1%)	68 (10.0%)	73 (12.2%)	157 (26.2%)	77 (11.3%)	31 (4.6%)	8 (26.7%)
UK	139 (37.3%)	136 (36.2%)	81 (29.6%)	157 (57.3%)	105 (27.9%)	43 (11.5%)	20 (48.8%)
Total	338 (17.0%)	295 (14.8%)	359 (22.1%)	465 (28.6%)	284 (14.3%)	120 (6.1%)	52 (44.8%)

Note: The valid percentage is presented, ignoring missing values. For the 'harmed care recipient' column, the percentage reflects the valid percentage of the participants who indicated that they had considered hurting others.

### *Difficulties in school, health and risk of 'harm'*

In order to examine the potential issues and difficulties that arise due to caring, the survey asked a number of questions (see Table 6). First, the participants were asked whether they believed their school performance had been negatively affected because of providing care to someone. Overall, 17 per cent of AYC's indicated that their school performance has been negatively affected. AYC's from the UK are most likely to report this, with 37 per cent stating this to be the case. Second, they were asked whether they had been bullied, teased or made fun of at school because of their caring. Overall, 15 per cent reported that this is the case, with bullying again being substantially more prevalent in the UK sample (36 per cent) than the samples of other countries.

The AYC's were also asked whether, in their opinion, their own physical health had been affected because of caring. Overall, 22 per cent of AYC's indicated that their physical health had been impacted. On this occasion, Switzerland exhibits the highest rate (36 per cent) (see Table 6). Next, they were asked if their caring is related to them experiencing any mental health problems. This is more common, with 29 per cent of AYC's overall reporting it to be the case. Again, the UK-based AYC's are the most frequent to report mental health problems associated with caring (57 per cent), followed by Sweden (34 per cent).

The survey additionally investigated the risk of 'harm' linked to caring responsibilities. Initially, the AYC's were asked if they had thought about hurting themselves due to caring. Overall, 14 per cent confirmed that they had. The UK-based AYC's are again the most frequent to report this finding (28 per cent). Second, they were asked if they had considered hurting others due to caring. This is less commonly reported, with 6 per cent of AYC's overall indicating that they had. Again, it is the UK-based AYC's who most frequently reported this (12 per cent). Finally, the participants who had indicated that they had considered hurting others were asked whether the person they considered hurting was the person they care for or someone else. Overall, 45 per cent of the AYC's who said that they had considered hurting others indicated that this person is the family member or friend that they care for.

In order to determine whether the level of caring responsibility is associated with increased health and other problems among the AYC's, a series of independent-groups

**Table 7: Independent-groups *t*-tests on average MACA score (SD) between AYC's who answered 'yes' and 'no' to questions regarding care-related issues and difficulties**

	Answered 'yes'	Answered 'no'	<i>t</i>	<i>df</i>	<i>p</i>	<i>d</i>
Negative effect on school performance	15.81 (6.05)	12.33 (5.36)	9.61 <sup>a</sup>	462.13	< .001	0.61
Experience of bullying	16.27 (6.23)	12.30 (5.23)	10.04 <sup>a</sup>	367.92	< .001	0.69
Physical health problems	15.08 (6.03)	11.92 (5.42)	8.84 <sup>a</sup>	520.12	< .001	0.55
Mental health problems	14.28 (5.91)	11.96 (5.49)	7.21 <sup>a</sup>	779.63	< .001	0.41
Considered hurting self	14.73 (6.27)	12.62 (5.39)	5.24 <sup>a</sup>	361.02	< .001	0.36

Note: <sup>a</sup> Equal variances not assumed.

**Table 8: Formal and informal support received in connection to caring role**

	Familial adult working and in receipt of wage	Family receipt of government assistance	AYC receipt of support	Family receipt of support	School awareness of caring	Employer awareness of caring	Friend awareness of caring
Italy	205 (97.6%)	50 (23.8%)	46 (22.1%)	58 (27.6%)	23 (10.8%)	10 (4.8%)	93 (44.1%)
Netherlands	169 (94.9%)	79 (45.9%)	39 (22.4%)	62 (35.8%)	52 (30.8%)	22 (13.1%)	107 (62.2%)
Slovenia	301 (97.1%)	67 (22.0%)	42 (13.8%)	91 (30.1%)	43 (14.2%)	13 (4.3%)	134 (44.5%)
Sweden	661 (96.1%)	186 (27.2%)	279 (41.8%)	77 (11.4%)	213 (31.8%)	31 (4.7%)	342 (51.3%)
Switzerland	210 (94.6%)	52 (24.0%)	37 (16.8%)	41 (18.8%)	20 (9.1%)	29 (13.5%)	140 (63.6%)
UK	267 (72.8%)	236 (64.5%)	168 (45.8%)	165 (46.2%)	215 (58.6%)	36 (10.1%)	247 (67.1%)
Total	1,813 (91.8%)	670 (34.3%)	611 (31.5%)	494 (25.5%)	566 (29.2%)	141 (7.4%)	1,063 (54.8%)

Note: The valid percentage is presented, ignoring missing values.

*t*-tests were performed between the MACA scores of those who answered a selection of the questions reported earlier (see Table 7). The results show that there is a significant difference between those who had answered 'yes' and 'no' to questions about caring-related difficulties. In each case, those who answered 'yes' had a significantly higher average MACA score. This indicates that higher levels of caring responsibility are indeed associated with a greater incidence of caring-related difficulties and issues, including experiences of bullying, poorer self-perceived mental health and difficulties in school.

### Support received

The survey also assessed the AYC's access to formal and informal support structures. Table 8 shows the number of AYC's across each country who indicated that they receive these forms of support. Looking at each, most AYC's have an adult family member who is employed and receives wages. Overall, 92 per cent indicated this to be the case. The outlier in this question is the UK, where 73 per cent of AYC's reported that they have an employed family member. Moreover, the UK-based AYC's are the most frequent to report that they have a family member who receives government assistance, for example, social security benefits (65 per cent).

UK-based AYC's are also the most frequent to state that both they themselves (46 per cent) and their family (46 per cent) receive support in connection to their caring

responsibilities. Both are considerably higher than the overall average frequencies of 32 per cent and 26 per cent, respectively. This pattern continues with the remaining questions. Overall, 29 per cent of the AYC's across all countries reported that their school is aware of their caring responsibilities, while 55 per cent indicated that they have a close friend who is aware. Although, again, the UK-based AYC's demonstrated the highest frequencies for these methods of support, with 59 per cent indicating that their school is aware and 67 per cent reporting they have friends who are aware, this finding can be explained by the recruitment strategy of outreach to young carers projects. Therefore, relatively many of the AYC's that filled in the survey have received support – or their family did – given that they were identified as AYC's by social services.

### Strengths and limitations of the study

For the first time, this research provides findings of a large sample of AYC's in six European countries. However, there are limitations to the study. Country partners made concerted efforts to create harmonious sampling through dedicated discussions and the drafting of an agreed-upon, multistage, facility-based sampling strategy, highlighting, first, the regional differences within the partner countries (urban, semi-urban or rural) and, second, the various recruitment channels of AYC's, such as schools, municipalities and carer organisations. Previous research with young carers in European countries has utilised schools as a way to gain access to spaces inhabited by large numbers of young people (Metzing-Blau and Schnepf, 2008; Leu et al, 2018). However, the realities of conducting research with vulnerable young people who are hidden from the view of wider society means that difficulties in recruiting AYC's are to be expected. In the UK, difficulties in gaining access to schools required a focus on the recruitment of AYC's through young carers projects. Historically, research with young carers and AYC's in the UK has typically utilised young carers projects (Earley et al, 2007; Aldridge et al, 2016). Thus, while the sample in the UK includes only two high schools, the origin of the sample (for example, young carers projects) reflects other established research with AYC's in the UK. It is important to stress that relatively many 'identified' AYC's are included, who may also have higher care responsibilities or care needs than those (unidentified) AYC's recruited through surveys in schools in other countries. Furthermore, recruitment efforts in all six European countries focused primarily on schools that would grant access to classrooms to host the online survey. In Switzerland and the Netherlands, vocational schools were targeted; however, the process of data cleaning and analysis revealed that the classrooms sampled included students older than the target age range of this study, who then had to be excluded through data cleaning. Due to the variance between the six countries' sampling strategies and the lack of a known representative sample in all six countries, this research study is limited in its scope to make extrapolations to the wider (AYC) population; hence, the reader should keep this in mind when country differences are highlighted in this study.

Despite limitations, this research study, the first of its kind, contributes substantial new knowledge about AYC's, especially those in EU countries, where there was (mostly) little research in this field. The statistical profile of 2,099 AYC's presented here provides a clear picture of the characteristics of these carers and the impact of caring on their (self-perceived) health, well-being and school life. Moreover, it is the

first time that the PANOC and other instruments have been used for a sample of this scale, involving AYC's across Europe. Thus, this study presents the first opportunity to use validated tools to assess the positive and negative outcomes of young caring on a substantial sample. The study's originality and significance rests on this being the first-ever cross-national survey of adolescent young caring, with analysis within and across six European countries.

## Discussion

This is the first-ever study at the European level providing demographic information on AYC's, investigating their self-reported health and well-being, and focusing on their needs and support received. A generalised profile of adolescent young caring in Europe emerges from the data presented here, suggesting that an AYC is most typically a girl who provides care for her mother who has a physical disability. However, this is a gross oversimplification of the complete data set and between-country differences, and the findings presented here show a complex and varied cross-national profile of the characteristics of AYC's within and between the six nations. In each of these countries, AYC's are found to carry out high or very high amounts of caring activities in the home, though there are cross-national differences in the types of roles performed by AYC's. It is also clear that AYC's perform greater amounts of caring-related activities in the home than non-caring peers in all six European countries, as would be expected. The AYC's sampled in Slovenia and the UK do more caring on the whole than AYC's in the other European countries, which could be due to the recruitment strategies inviting more AYC's in caring situations with (probable) higher care needs. The total MACA scores indicate that girls perform a greater amount of care activities than boys; however, the differences are only statistically significant in the Netherlands and the UK.

In consideration of overall well-being, this research finds that AYC's in the six countries experience both positive and negative outcomes related to caring. It is of note that there are between-country differences, as some AYC's report positive effects from caring, for example, only 23 per cent of Italian AYC's scored below 12 on the positive scale of the PANOC. This finding serves as a signal that the act of caregiving during adolescence is not a wholly negative or detrimental experience for all AYC's, but can also be a role from which young people learn and grow personally. However, and perhaps more predictably, the more caring an AYC performs, the more negative effects they feel, though this is a weak correlation. In relation to the KIDSCREEN-10, the AYC's in this research were found to more likely self-report a lower state of well-being in comparison to their non-caring peers. AYC's in the UK and Slovenia were shown to have the worst self-reported well-being. AYC's in the UK and Slovenia were also found to have a greater number of caring tasks than AYC's in the other countries, and recent research also supports such a relationship (Kallander et al, 2020; Santini et al, 2020). Further research should continue to examine the relationship between higher amounts of caring and poor well-being in AYC's. Furthermore, girls are demonstrated to have poorer self-reported well-being than boys, and considering that girls generally perform more caring tasks than boys, these findings suggest that the amount of caregiving that an adolescent engages in can have negative ramifications for their own health and well-being. This may be especially true for adolescent girls.

Generally, the UK AYC's report more significant negative mental health impacts in comparison to the other European countries in this study. Perhaps surprisingly,

while the AYC's sampled in the UK report the greatest number of formal support services received in connection to their caring role, they also have the highest negative mental health and negative school impacts, as well as the second-highest poor physical health scores, reported across all nations. Cross-country differences in mental health and well-being may be influenced by the sampling strategy in the UK in particular, as there was a focus on recruiting AYC's from young carers projects, and the AYC's found within those projects have likely been providing care activities at a higher intensity and caring for longer periods of time. Indeed, these higher levels of caring may be a precondition ('eligibility criteria') for being able to access young carers projects in the UK. Moreover, a recruitment strategy utilising patient organisations (in addition to schools) in Slovenia may also help explain why the AYC's in Slovenia self-reported poorer well-being. We should also consider the state of the mental health and well-being of adolescents in the UK generally, including those children who do not encounter a caring role. Previous research has suggested that UK adolescents have the highest prevalence of mental health problems across Europe (Polanczyk et al, 2015; Kovess-Masfety et al, 2016). It may be that UK adolescents already experience poorer mental health compared to their European counterparts and UK AYC's further reflect this cross-national difference.

An additional finding includes the relatively high percentage of AYC's across the six European nations who have reported thoughts of self-harm or harm towards others due to their caring role. This finding indicates that many AYC's are at significant risk of mental distress and likely points to a lack of dedicated, appropriate psychosocial and other support designed to reduce feelings of harm to self or others. These are the first-ever data concerning the thoughts of AYC's of hurting themselves and others, especially the care recipient, due to caring activity. This study therefore contributes to shedding light on the severe mental health condition of some AYC's and a need for timely and adequate support to reduce the risk of violence and harm to people with care needs or others, as well as self-harm to AYC's themselves.

This research also provides new understanding about the family demographics of European AYC's. An unexpected result concerns the identity of the cared-for family members across the six countries. In Italy, there is a higher number of adolescents caring for older family members (that is, grandmothers and grandfathers). It may be that Italian AYC's are being pushed or nudged into caring roles through the lack of a formal, long-term eldercare system, a cultural reliance on intergenerational familial care, and ageing demographic trends of a large number of older people (Tosi and Oncini, 2018; Martani et al, 2020; Santini et al, 2020). Nevertheless, these findings signal that the care of an ageing European population is sometimes the responsibility of children and young people aged 15–17, rather than a role that might be assumed to fall to much older family carers.

The research also finds that AYC's providing care for siblings are a strong feature of young caring in Sweden, the Netherlands and the UK. While the significance of AYC's caring for siblings in the UK sample is not readily explained, the differences observed in the Swedish and Dutch samples likely reflect their community-care practices, in which ill or disabled family members are often cared for in the home, thus increasing the numbers of siblings needing to take on caring roles in their families. In the Netherlands, the recruitment strategy can partly account for the significance of caring provided by sibling AYC's: utilising social media platforms for sibling carers meant that many more sibling carers received an invitation to participate in the

study. In addition, due to the recruitment strategy, more sibling carers may have been included in the Swedish sample. The care that siblings provide is underdeveloped in young carers research and requires more attention.

Regarding formal and informal support, the AYCs generally reported relatively low amounts of formal dedicated support in connection with their caring role. The exceptions include Sweden and the UK. In Sweden, the welfare state model of formal support may help to explain why there is a greater receipt of formal support services within this specific country context. In the UK, the sampling strategy relied predominately on dedicated young carers services and is thus reflected in the comparatively high numbers of AYCs receiving formal support in this research. Overall, AYCs indicate that they have informal support through a close friend who is aware of their caring role and offers some support. This is an important finding in considering the resilience of some AYCs and their ability to resource peer support without the intervention of formal dedicated services through governmental, charitable or other health and social care agencies.

This research shows that adolescent young caring is present in all six European countries, irrespective of their economic circumstances or welfare model (Nordic, Continental, Anglo-Saxon or Mediterranean) (Bambra and Eikemo, 2009; Hay and Wincott, 2012; Casu et al, 2021). Italy, the Netherlands, the UK, Slovenia, Switzerland and Sweden are European countries that traditionally uphold the values of social protections for all citizens, with varying approaches to welfare programmes and delivery. Yet, as this research shows, AYCs remain at risk of a range of negative outcomes (poor self-reported physical health, mental health and well-being, educational disadvantage, bullying, self-harm, and potential danger to others), albeit with important variations between countries. In the UK particularly, dedicated formal support services provided or funded by the state or charitable organisations (or a combination of both) have been regarded internationally as 'best practice' to addressing the needs, experiences, circumstances and negative outcomes experienced by young carers. Hundreds of young carers projects exist across the UK, and previous research has found that such projects deliver positive experiences, and outcomes, for young carers (Becker and Becker, 2008). However, receipt of a formal support service should not be relied on (by the state or families) as the sole intervention in the lives of AYCs, as our research findings indicate that AYCs can identify sources of informal and formal support yet still experience detrimental effects in school, employment and on their own mental and physical well-being, including risk of harm to self or others. Thus, young carers projects are only a 'partial solution' to the needs of AYCs, and more systemic interventions within schools, families and communities, and from health and social care, will need to be developed and delivered in all six countries (and beyond) to reduce the amount of caring performed by adolescents and the negative outcomes that some AYCs experience, as well as to help maximise the positive impacts of caring. Progress will also require a shift in thinking and discourse about the 'rights' of adolescents who are carers, in keeping with current European policy emphasising the rights of the child in general (European Commission, 2021a) and vulnerable children in particular (European Commission, 2021b).

The push for policy and legislation to give explicit rights and protections to young carers has emerged in recent years as a possible panacea to the adverse childhood experiences facing AYCs. This approach is especially argued for by young carers advocates and researchers in the six EU countries sampled in this research, and

this view is also promulgated by the premier cross-national European network for informal, unpaid carers, Eurocarers. Indeed, the pursuit of a ‘rights’ discourse and policy approach by countries in [Leu and Becker’s \(2017\)](#) classification has been one of the key factors that has led to progress within those countries.

Continued engagement of advocates on young carers issues has proven fruitful, as named policy in England giving young carers a legal right to a carer’s assessment and to have their needs met was established in 2014 (under the Children and Families Act 2014 and the Care Act 2014). However, the [Children’s Commissioner for England \(2016\)](#) estimated that approximately four out of five young carers may not be receiving any support from their local authority. In Italy, Sweden, Switzerland, Slovenia and the Netherlands, no specific policy or legislation on young carers exists. Swedish laws to protect children from parental harm or neglect in situations of parental illness, substance abuse or disability may be applicable to AYC’s but do not recognise young caring as a concept or terminology ([Häls ooch sjukvårdslag, 2017:30](#)). Similarly, Dutch law recognises that children have a right to education (Leerplichtwet [Compulsory Education Act], 1969) and that they should be protected from child labour (Jeugwet [Child and Youth Act], 2015), but there is an absence of any legislation that refers to young carers specifically. In Italy, family carers are recognised not by national law, but by regional laws. Similar to the Netherlands, there are laws to protect children, but those laws do not specifically mention young carers. In Switzerland, the Swiss Federal Council has endeavoured to collect information about children who care for family members in a three-year project that ended in 2020 ([Leu et al, 2022](#)). Slovenia, deemed an ‘awakening’ country ([Leu and Becker, 2017; Leu et al, 2022](#)) is in a notably worse position on dedicated policy for young carers, as Slovenia has only recently instituted specific policy targeting youth generally.

As the basis of the development of policy and practice across countries, a ‘rights’ approach or paradigm to furthering the recognition and identification of young carers offers young carers hope and opportunity that their experiences and needs will be more greatly recognised and supported. Noticeably, in the discussion on the need to have a right-based approach, experts also point to whether AYC’s should be responsible for caring tasks ([Nap et al, 2020](#)). However, as the UK shows, even with legal rights, many young carers are still left behind and have no access to (or are excluded from) formal health and social care support, whether provided by state, market or the charitable sector. Thus, many young carers are hidden and unsupported, relying on their own informal family and friendship networks to provide them with some support or respite. The research presented here casts a light, for the first time, on the experiences and needs of a large sample of AYC’s in six European countries, and offers a platform on which future policy can be developed.

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### Author contributions

Feylyn Mercedes Lewis and Saul Becker conceived of the study, participated in its design and coordination, drafted the manuscript, helped perform the statistical analysis, and participated in the design and interpretation of the data. Thomas Parkhouse participated in the study's design and coordination, drafted the manuscript, performed the statistical analysis, and participated in the design and interpretation of the data. Stephen Joseph, Valentina Hlebec and Rosita Brolin participated in the study's design and coordination, drafted the manuscript, helped perform the statistical analysis, and participated in the design and interpretation of the data. Maja Mrzel participated in the study's design and coordination, participated in the design and interpretation of the data, and helped perform the statistical analysis. Giulia Casu, Licia Boccaletti, Sara Santini, Barbara D'Amen, Marco Socci, Renske Hoefman, Agnes Leu and Elena Guggiari participated in the study's design and coordination, drafted the manuscript, and participated in the design and interpretation of the data. Nynke de Jong and Daniel Phelps participated in the study's design and coordination, and participated in the design and interpretation of the data. Lennart Magnusson and Elizabeth Hanson conceived of the study, participated in its design and coordination, drafted the manuscript, and participated in the design and interpretation of the data. All authors read and approved the final manuscript.

### Conflict of interest

The authors declare that there is no conflict of interest.

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