

**Young Carers' Health
and Well Being: a Pilot
Study.**

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EXPLANATORY NOTES

This project has been granted a word count extension for the abstract of up to 300 words to cover the breadth of the project, and up to a maximum of 4000 words for the report.

Word count for abstract = 300

Word count for project =3980

As it is a 4 part study it has been presented with the participants, methods and results for each section displayed together to aid the reader and ensure clarity.

These changes are with the permission of my supervisor and the Examination Board through Simon Riley, SSM course organiser.

KEY TO ABBREVIATIONS

EYCP=Edinburgh Young Carers Project
DEPCAT=Deprivation Category
CFMHS=Child and Family Mental Health Services
DNA=Did not attend

ABSTRACT

Over 114,000 children in the UK provide informal care for ill or disabled family members. There is little medical research to indicate how this affects their health and well-being. This was a pilot study to investigate the health and well-being of young carers in Edinburgh.

1) Scottish Census data produced on care provision and self-rated health for 5-15 year olds was analysed. Over 11,000 Scottish children provide informal care. 266 of these have health rated as 'not good'. The proportion in 'not good' health increases with the number of hours spent caring.

2) The deprivation category of 105 young carers was compared to the general population of 5-19 year olds in Edinburgh. Young carers live in more deprived areas (mean DEPCAT=5) compared with the general population (mean DEPCAT=3, $p<0.001$).

3) 67 young carers aged 6-13 years old, were matched with controls for age, gender and deprivation category. Attendance at the children's hospital in Edinburgh, and the number of child protection referrals was computed for the cohort. From 1995-2003, significantly more young carers attended outpatient appointments (58 young carers:36 controls, $p<0.01$), casualty (53 young carers:32 controls, $p<0.01$) and were admitted to hospital (39 young carers:15 controls, $p<0.01$) than controls. 25 young carers had mental health appointments compared with 7 controls ($p<0.001$), and young carers had more mental health appointments (mean=5) than controls (mean=1, $p<0.01$). 21 young carers had child protection referrals compared with 3 of the controls ($p<0.01$).

4) 18 young carers were interviewed about their health, lifestyle and health service utilisation. A high proportion reported specific health problems(8) and recently attended their GP and casualty.

Young carers appear to be a vulnerable group of children who live in deprived areas, have high rates of health service utilisation, particularly mental health, and a high proportion have had a child protection referral. (Word count=300)

INTRODUCTION

In December 2003 Doran et al. published an analysis of the 2001 UK census data on the number of 5-15 year olds providing informal care, and on their health¹. They found of 114,000 children in the UK providing informal care (1.4% of all 5-15 year olds), almost 18,000 provided 20 hours of care or more a week, and the health of 773 of these children was rated as "not good". Doran et al. recommended further qualitative studies to provide a deeper insight into the impact of the burden of care on the lives and future wellbeing of young people.

In a seminal paper on young carers, Meredith asserted that caring can cause²:

‘adverse effects on a child’s development physically, emotionally, educationally and socially’

In the past decade there has been a large amount of research based on qualitative research methods, and considerable discussion about all of these topics. For a full literature review and discussion please see ‘Young Carers and their Families’³. Whilst many studies do pay attention to health and wellbeing with the exception of one small study, that asked project workers about young carers who they thought exhibited health problems related to their caring responsibilities⁴, to the best of my knowledge there have been no studies where health has been the primary focus.

In 1998 Dearden and Becker interviewed 22 young carers from all over the UK⁵. They found that:

‘caring can cause physical health problems as a result of lifting and carrying, particularly for children who are not fully developed, and it may also cause mental health problems due to the worry, uncertainty and anxiety associated with illness or disability in the family’

In addition to the direct influence of care-giving, it is also suggested that poverty and social exclusion related to care-giving may have indirect effects^{5 6}.

In 2002 Newman reviewed the research generated on young carers in the last decade⁷. He argued that there is limited empirical evidence to support the claims that young carers suffer, and concluded that:

‘it remains unclear to what extent, and in what way, the health and wellbeing of children is at risk from care giving activities, either in the short or long term’. ‘Given that this question is crucial as to whether a child is in need and thus how urgently health and social welfare services should respond, an assessment of this aspect of children’s welfare is of some importance’

Therefore, the main aim of this study is to investigate the health and wellbeing of a sample of young carers in Edinburgh. The project was undertaken with the help of Edinburgh Young Carers Project (EYCP), a registered charity that aims to improve the lives of young carers in Edinburgh. EYCP use the following description to define a young carer:

‘a young person aged between 5-18 whose life is affected by the illness or disability of someone in their family. They may provide physical and/or emotional support for that person. Young carers involved with EYCP may care for relatives who have a physical or learning disability, mental health problems, chronic illness or drug or alcohol misuse problems’

The World Health Organisation (1948) defines health as: ‘a state of complete physical, social and mental well-being and not merely the absence of disease or infirmity’. Due to the lack of research on the physical and mental health of young carers, it was decided to focus particularly on these aspects of health.

The study consists of four parts:

- (1) Analysis of the 2001 Census data for Scotland about the number and general health of Scottish young carers
- (2) Analysis of the Deprivation Category in which young carers in Edinburgh live, compared to the general population of 5-19 year olds in Edinburgh

- (3) Audit of the Utilisation of Tertiary Health Services and Child Protection Referrals in Edinburgh of a cohort of 67 young carers and controls matched for age, gender and deprivation category
- (4) Questionnaire based study of a group of 18 young carers on their health, lifestyle and utilisation of health services

ANALYSIS OF SCOTLAND'S CENSUS 2001 DATA ON YOUNG CARERS AND SELF-RATED HEALTH

PARTICIPANTS, METHODS AND RESULTS

For the first time in 2001, the Scottish Census asked the entire population about informal caring responsibilities and general self-rated health (see appendix A for census questions). The tabulation produced by the General Register Office for Scotland by age, sex and hours of informal care⁸ was analysed for 5-15 year olds.

Table 1. The number of 5-15 year olds providing care by sex, general self-rated health, and hours a week spent providing care, Scotland 2001:

	Good health			Fairly good health			Not good health		
	1-19	20-49	>50	1-19	20-49	>50	1-19	20-49	>50
Hours of care									
Males	3639	396	323	596	94	57	86	14	23
Female	4105	417	386	752	105	83	104	11	28

1.6% of Scottish 5-15 year olds provided informal care (5991 girls, 5228 boys). Of these, 1037 provided 20 hours of care or more a week and 900 provided at least 50 hours. The health of 266 of those providing informal care was rated as “not good”.

Table 2. Percentage of children providing care in ‘not good health’ by number of hours care provided:

Hours of care	Percentage of 5-15 year olds in 'not good health'/%
0	1.1
1-19	2.1
20-49	2.4
>50	5.7

The proportion of those in ‘not good’ health increases with the number of hours spent caring.

DEPRIVATION CATEGORIES OF YOUNG CARERS IN EDINBURGH

PARTICIPANTS AND METHODS

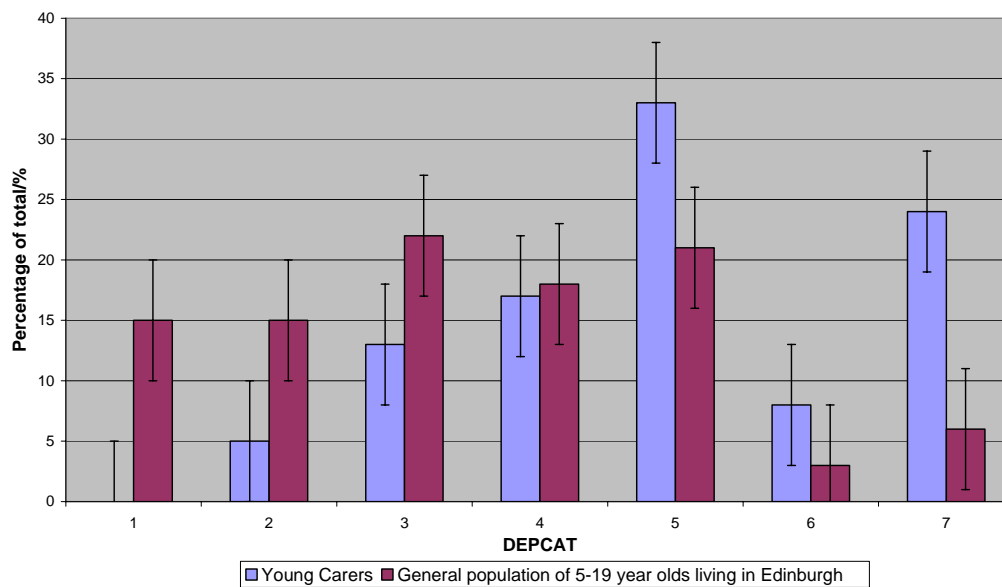
The deprivation category (DEPCAT) was calculated for all 105 young carers aged 7-18 years old that EYCP was working with, according to current postal code using the 1991 Carstairs Deprivation Score. This was compared to the DEPCATS of the general population of 5-19 year olds in Edinburgh, also based on 1991 census data⁹.

Whilst the 1991 Carstairs Score is based on data that is over 10 years old, at the time of writing it was the most up to date deprivation score linked to postcode for Edinburgh. There is good evidence that the Carstairs scores for a given area do not tend to change substantially over a period of 10 years. Comparison of 1981 and 1991 Carstairs scores found that there was a 'strong association between them ($r=0.958$), and most areas do not show a substantial change in their scores'¹⁰.

RESULTS

The Carstairs Deprivation Score ranges from DEPCAT 1, the most affluent areas, to DEPCAT 7, the most deprived areas in Edinburgh.

Figure 1. Bar chart of the DEPCATS of young carers compared to the general population of 5-19 year olds in Edinburgh:



There is a highly significant difference between the representation of young carers in the different deprivation categories and the general population of 5-19 year olds living in Edinburgh (Pearson Chi-Square=95.057, $p=0.000$).

Young carers have a mean DEPCAT of 5 compared with a mean DEPCAT of 3 for the general population of 5-19 year olds ($SD=1.522$, $SE=0.15$). Almost one quarter of the young carers live in the most deprived areas (DEPCAT 7), compared to only 6% of the general population of 5-19 year olds. No young carers live in the most affluent DEPCAT, compared to 15% of the general population of 5-19 year olds.

ATTENDANCE AT THE ROYAL HOSPITAL FOR SICK CHILDREN, EDINBURGH AND CHILD PROTECTION REFERRALS

PARTICIPANTS AND METHODS

The study population included all the young carers known to EYCP aged under 14 years old on the 07/11/2003, 69 in total. Using the hospital electronic database, a control population matched for sex, age and DEPCAT was identified. 2 of the young carers did not appear on the hospital's database so they were excluded from the study as it would not have been possible to identify a suitable control for them.

Table 3. Profile of study population:

Number of males: females	36 males: 31 females
Age/years	Range=6-13 Mean=11
DEPCAT	Range=2-7 Mean=5
Nature of parental/sibling illness	Number of young carers
Mental Health Problems	26
Physical Disability	9
Sibling	6
Physical Disability and Mental Health Problems	3
Chronic illness (including epilepsy, ME)	3
Drugs	2
Alcohol	3
Drugs and Alcohol	1
Alcohol, Mental Health and Drugs	1
Alcohol, Mental Health	1
Drugs and Hepatitis B and C	1
Multiple	2
HIV	2
Learning Difficulties	1
Blind	1
Sibling and Chronic Illness of Parent	1
Unknown	4

Using the hospital database, which starts in 1995, a full history of attendance at the hospital was obtained for the study population up to November 2003. Each child was also looked up on the Child Protection register in the department of Community Child

Health to obtain a full history of number and types of referral. The young carers' attendance at hospital was compared with the controls from 1995-2003 and over the last year, from 01/11/02-01/11/03, and the child protection referrals were compared for their whole lifetime.

The inclusion of a control population permits comparisons with children of the same age and sex who live in a similar level of deprivation. It was not possible to control for ethnicity since the hospital database did not have complete records of this. Nor was it possible to control for parental illness as the logistics of this would have been impossible in the time frame available for the study.

RESULTS

Key to statistical tests:
t=Independent Sample t-test
U=Mann-Whitney U test

Overview of hospital attendance

Table 4. Attendance at hospital outpatient appointments, casualty and admissions to hospital for young carers and controls from 1995-2003 and over a 1 year period:

		Young Carers	Controls	U	P-value
Number of young people with hospital outpatient appointments	1995-2003	58	36	1321.5	0.000
	2002-2003	27	9	1641.5	0.000
Number of young people who attended casualty	1995-2003	53	32	1541.0	0.000
	2002-2003	17	4	1809.0	0.002
Number of young people admitted	1995-2003	39	15	1440.5	0.000
	2002-2003	8	2	2043.5	0.049

Significantly more young carers have attended outpatient appointments, casualty and been admitted to hospital compared with controls, both over the last year and between 1995-2003.

Table 5. Percentage of young carers and general population of 5-15 year olds (from ONS survey, 1999¹¹) utilising hospital services over a 1 year period:

Percentage seen over 1 year period at:	Young carers	General population of 5-15 year olds in the UK ¹¹
Outpatient appointments	40%	20%
Casualty	25%	18%
Admissions	12%	5%

Over a 1 year period a high proportion of young carers attend outpatient appointments, casualty and have been admitted to hospital compared with the national figures for hospital attendance of 5-15 year olds in the UK¹¹.

Outpatient appointments

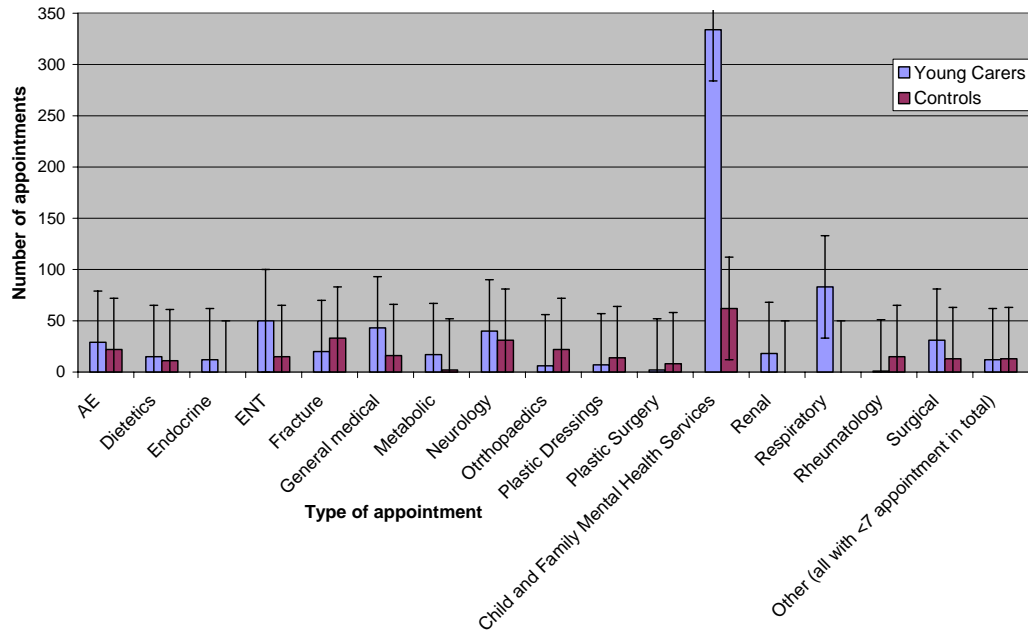
Table 6. Outpatient appointments from 1995-2003:

	Young Carers	Controls	Mean no. per young carer	Mean no. per control	t	p-value
Total number of appointments	720	277	11	4	3.842	0.010
CFMHS appointments	334	62	5	1	2.931	0.004
Total number of appointments excluding CFMHS	386	215	6	3	1.781	0.080

Young carers had significantly more outpatient appointments compared with controls. Child and Family Mental Health Services (CFMHS) appointments made up 334 of the young carers appointments and 62 of the controls appointments. Excluding CFMHS

appointments from the total number of appointments, there is no longer a significant difference between the mean number of appointments per young carer.

Figure 2. Graph illustrating the outpatient clinics attended by young carers and controls from 1995-2003:



The only type of clinic with a statistically significant difference between the attendance of the young carers and controls was the CFMHS. (Young Carers: range=0-56, mean=5, controls: range=0-25, mean=1; $t=2.931$, $p=0.004$)

Figure 3. Pie-chart of the attendance profile of young carers by clinic type:

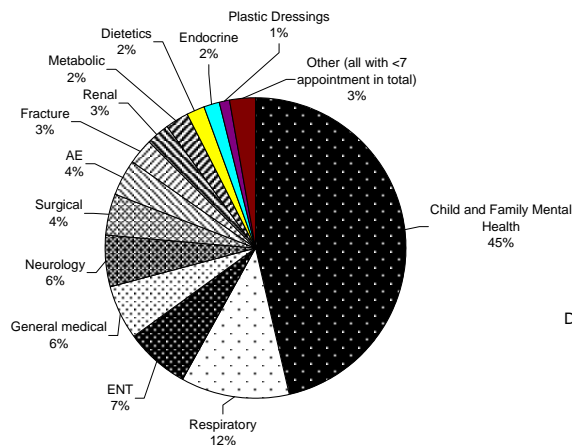
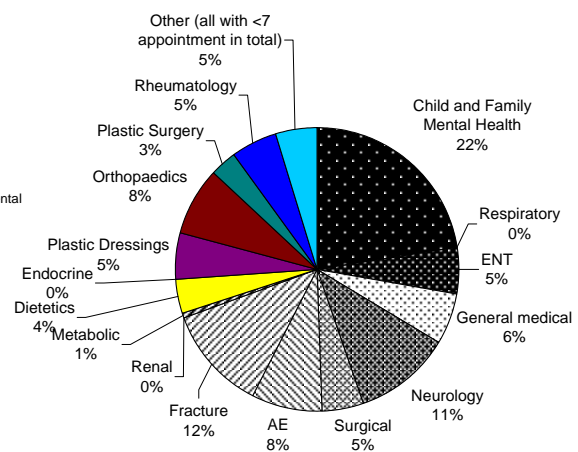


Figure 4. Pie-chart of the attendance profile of controls by clinic type:



CFMHS appointments accounted for almost half of all of the young carers appointments (45%), compared with just over one fifth of the controls appointments (22%).

25 young carers compared with 7 controls had attended CFMHS appointments (U=1641.5, p=0.000). Within the group of young carers there was no obvious correlation between the nature of parental illness and attendance at CFMHS clinics.

Attendance at hospital outpatient appointments

Table 7. Attendance of young carers and controls at their hospital outpatient appointments:

	Young Carers	Controls	General population over 1 month
Percentage of total no. of appointments attended	68%	69%	77%
Percentage of total no. of appointments cancelled	13%	12%	11%
Percentage of total no. of appointments DNA	18%	19%	12%

Young carers and controls had very similar patterns of attendance, attending about 7/10 appointments, DNA (did not attend) 2/10 and cancelling 1/10. Attendance strongly correlates with the total number of appointments (Pearson correlation, appendix B). Compared to the attendance of the general population of children with outpatient appointments at the hospital calculated over a 1 month period, the study cohort turned up for a lower proportion of their appointments appointments, and didn't turn up for a higher proportion of them (DNA).

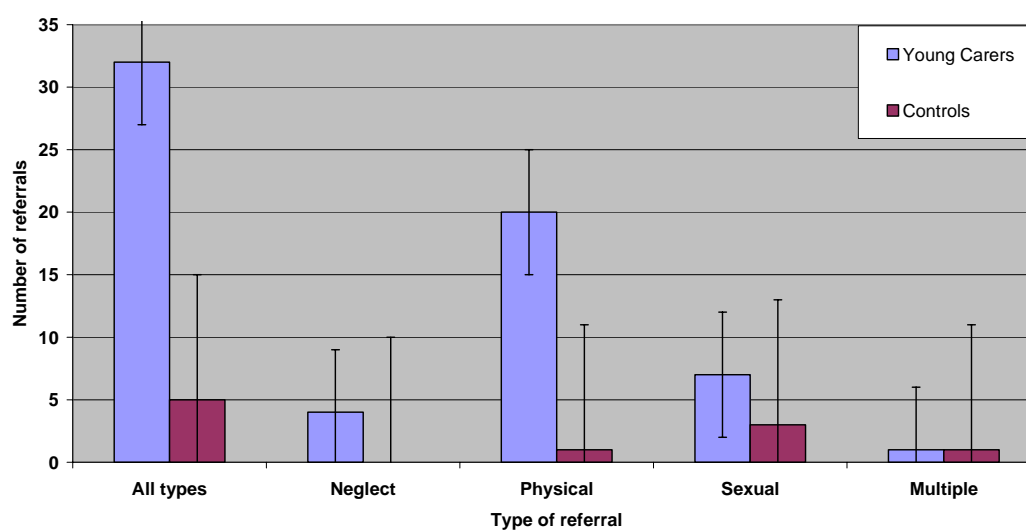
RESULTS:CHILD PROTECTION

Table 8. Child Protection referrals of young carers and controls:

	Young Carers	Controls
Total no. with a child protection referral	21	3
No. with 1 referral	13	1
No. with 2 referrals	3	2
No. with 3 referrals	4	0

Almost one third of the young carers had had a child protection referral, compared to less than one in twenty of the controls. This difference is highly significant ($U=1641.5$, $p=0.000$). One third of the young carers with referrals had multiple referrals.

Figure 5. Bar chart of child protection referrals by type for young carers and controls:



Young carers had significantly more referrals for physical abuse ($U=1840.0$, $p=0.01$). Referrals were not significantly associated with age, gender or CFMHS appointments. Nature of parental illness was not obviously associated with referrals, with the exception of caring for a parent with a drugs problem. There was a suggestion that this may be associated with neglect: 5 children cared for a parent with a drugs problem, 3 had child protection referrals, 2 of which were for neglect ($U=98.0$, $p=0.001$).

INTERVIEWS OF YOUNG CARERS

METHOD

Professionals involved in young carers work and health were consulted to identify health issues important to young carers. It was decided to focus on perceptions of health, perceived health needs, utilisation of health services and lifestyle issues related to health. The questionnaire used was adapted from the questionnaire used in 'The Health of Young People in Care and Leaving Care in Glasgow'¹²(see appendix C). It included the Kandel and Davies depression scale¹³, and an adapted version of Rosenberg's self-esteem measure¹⁴.

EYCP invited all 11-18 year old young carers currently in contact with their service to participate in this study (85). They were offered a £5 voucher as an incentive. 18 young carers volunteered to participate.

With informed consent, interviews were performed on the telephone. It had originally been planned to conduct face-to-face interviews but due to time limitations it was elected to perform telephone interviews, which have successfully been used in previous research on young carers⁵. The interviews took 10-20 minutes to complete, and were fully transcribed.

PARTICIPANTS

Table 9. Profile of interview respondents:

	Respondents	All 11-18 year old young carers
Gender	11 females, 7 males	42 females, 43 males
Mean age/years	12.6	14
Participation in EYCP activities	11/18 = 61%	35/85 = 39%
Reason for caring:		
Mental health	12	20
Physical disability	3	14
Drugs	1	4
Alcohol	0	7
Chronic illness	1	8
Sibling	1	1
Learning disability	1	5
Other	1	13
Not specified	0	4

The respondents were a self-selected group. Both genders were represented but there were some differences in the general profile of the respondents compared with the whole group. Most were relatively young, aged between 11-14 years old (17/18). Two thirds had parents with mental health problems (12/18), compared with less than one quarter (20/85) of all invited to participate. None of the participants had parents with alcohol problems, 1 had a parent with a drugs problem. A high proportion participate in EYCP activities.

RESULTS OF INTERVIEWS

(All names quoted are pseudonyms)

Physical activity

15/18 exercised regularly. The most popular activities were: football/rugby, swimming, basketball and running/jogging. 8/18 of the young carers would have liked to participate in more activities, which included: White water rafting, ice hockey, tennis, dancing, diving, swimming and kick boxing.

Reasons for not taking part in sports:

Lack of a companion (8/18)
Disinterest (6/18)
Cost (4/18)
Not liking other people watching (4/18)
Not having enough time (3/18).

Diet and weight

10/18 chose what they ate most of the time, and 6/18 some of the time. 10/18 cooked at least some of the time, and 2 most of the time. 9/18 did the shopping sometimes. They ate an average of 3 pieces of fruit and 2 portions of vegetables per day, 2 did not eat any.

The majority of respondents were happy with their weight (13/18). The other 5 (4 girls, 1 boy) felt overweight and were dieting.

Health

Perception of health

15/18 of the respondents said they were quite healthy or very healthy, 16/18 said they were quite fit or very fit. They mostly defined health as eating healthily and exercising.

Health problems

8/17 (47%) of the 11-14 year old young carers reported having specific long-term health problems. This is a higher proportion than the 20.9% of S2 pupils in the general teenage population in the 11-16 Study¹⁵ who identified long standing illnesses, disabilities or infirmities. As in the 11-16 Study¹⁶, the majority of these health problems were due to asthma (5). The others included mental health problems, migraines and a weak left hand side.

All of the young people with physical health problems said they were getting the help they needed, but several of them had ongoing problems:

Gary: *'With asthma I've felt less healthy and get knackered easily' Whenever I run or that I feel really unhealthy cos I lose my breath'.*

Perceptions of the influence of being a young carer on health

The majority of young carers thought that being a young carer did not influence their health (13/18).

Tanya, 14 years old:

'Not at all. I'm still able to do everything I want to do. Just because I help to care for someone else, and I don't really have much to do because she is so independent, I can still do everything I want to do. I feel normal. I am normal, you know what I mean'

One boy thought that it was good for his health:

Tommy, a 12 year old boy:

'It helps it (your health) if your Mum or Dad can't get up to go to the shops you go for them and it increases your lungs and all that'

The remaining 3 thought that being a young carer had negative influence on their health:

‘How do you think being a young carer affects your health?’

Sarah, 14 years old:

‘Stress. I used to look after my Mum, do the shopping, take the dogs out, put her to bed, put her in her pyjamas, I used to do everything. I used to never go to bed ’til quarter to twelve on school days’... ‘When I was at my Mum’s we mainly ate junk food. I was comfort eating because of the stress’

Dawn, 18 years old:

‘I’ve not really had any childhood. I’ve always been in to look after my Mum. I’ve hardly had any time for my social life. Half the time I’ve not had time to eat, and when I do go home I just go to bed cos it’s been a hard day’

Sleep disturbance

2/18 had to wake up during the night to help their care receiver on a regular basis. Sarah had to get up up to 3 times a night if her Mum had fallen. Dawn had recently moved out of her mother’s home, but her sleep is still regularly disturbed:

‘Sometimes I get a phone call from my Mum and she’s taken an overdose so I need to get over there. It happens about once a week’

Mental Health

When asked about general health problems, 2 of the young carers reported current mental health problems, and 1 past depression:

Dawn, 18 years old:

'Aye. Mental health problems. I'm supposed to be on anti-depressants but I dinny take them. I'd rather get better on my own.'... *'I've tried to commit suicide a few times in the last few months'*

She scored the maximum score possible on the depression scale, and the lowest score possible on the self-esteem scale

Zoe, 14 years old:

'Well, I do counselling for voices in my head about my Dad'

Malcolm: *'I have been really unhappy but not really unhealthy'*

Neither of the girls felt they were getting the help they needed:

Zoe was receiving counselling but said:

'They're no really helping it much'

Dawn: *'I've no been to the doctor for the last 6 month cos they just give me a lecture. I've tried to commit suicide a few times in the last few months, you see, and they always just lecture me'*.

Depression

Using the Kandel and Davies depression scale¹³ the majority of the respondents had a low level of depressive symptoms. The scale has a minimum score of 10 to a maximum score of 30. The mean score for the 11-14 year old young carers was 15.6 (SD=3.91) which is very similar to the mean score of 16.2 for the S2 pupils in the 11-16 study¹⁵.

Self Esteem

The Rosenberg scale¹⁴ ranges from 10-30. Using the cut-off point of >17 that was used in the 11-16 study¹⁶, most respondents had high self-esteem, with the 11-14 year olds having a mean score of 20.1 (Range=15-29, SD=3.89) was very similar to the mean score of 19.4 (SD=4.6) for the S2 pupils in the 11-16 study¹⁵.

Attendance at GP

Figure 6. Attendance of young carers at the GP

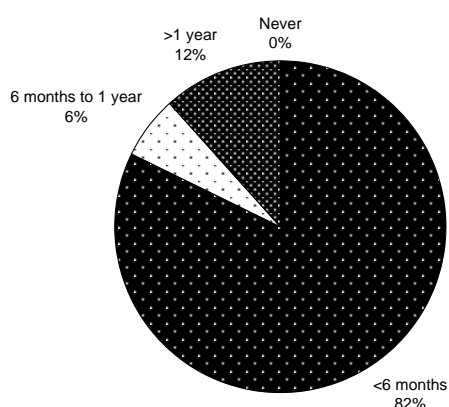
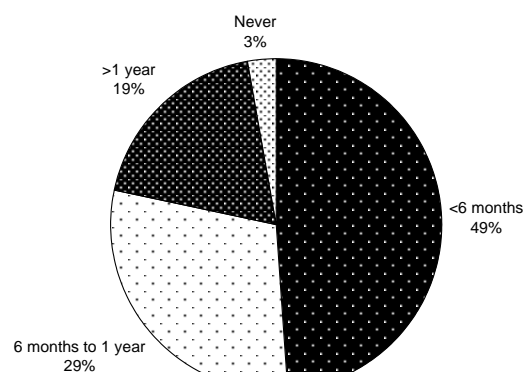


Figure 7. Attendance of the general population of S2 pupils at the GP, 11-16 study¹⁵



14/17 (82%) had been to see their GP within the last 6 months compared with 49% of S2 pupils in the 11-16 study¹⁵. A much smaller proportion had not seen their GP for over 6 months.

Casualty

A high proportion (5/17=29%) of the respondents had been to casualty in the last year, compared with 18% of the general population of 11-15 year olds (18%)¹¹.

Dental health

10/17 of the respondents had been to the dentist in the last 6 months (58.8%), compared with 76.6% of S2 pupils¹⁵. A high proportion, 6/17 (35.3%), had not seen a dentist for over a year compared to only 7.5% of S2 pupils¹⁵.

Figure 8. Pie-chart of the attendance of the young carers at the dentist

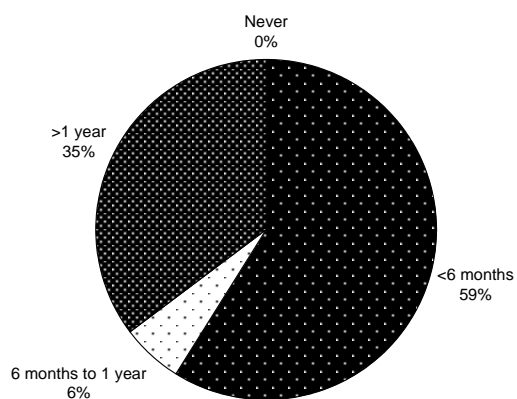
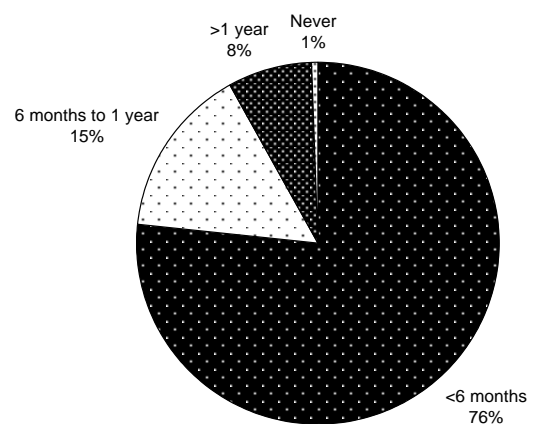


Figure 9. Pie-chart of the attendance of the general population of S2 pupils at the dentist, from the 11-16 study¹⁵



16/18 brushed their teeth everyday. 2 boys brushed their teeth less than every other day.

Views of the health services

Several young carers mentioned reasons why they didn't like going to the doctor: long waiting times, problems in relating to the medical staff and fears about what will happen at the doctors:

'I don't go to my doctor cos they just lecture me'

'I don't like going to the doctors in case they check you down below'

'You come in to the health service and you're sitting waiting there for ages and someone gets taken before you, or you ring up and say they can't see you and then they go and see someone else. It's like they're saying "Stuff you, he can and you cannae"'

'I don't like it when people just sit there and watch you, like my Mum and my brother, it's really embarrassing. It might be a wee bit better if you could go in on your own. I don't like going if it's too early in the morning, or if I'm too tired I can't be bothered'

'Sometimes it can be a pain in the neck, you go in and you can be there like 1½ hours'

How could the health services be improved?

The majority of suggestions about how the health service could be improved were based on having more doctors and nurses, shorter waiting times, and 'nicer' or 'kinder' staff.

Tommy, 12 years old:
'If they were just kinder'

Tanya, 14 years old:
'Make them nicer'

DISCUSSION

Main Findings

Young carers:

- ❖ tend to live in more deprived areas than the general population of 5-19 year olds living in Edinburgh

- ❖ have high rates of utilisation of health services, compared to a control group matched for age, gender and DEPCAT, in particular:
 - Mental health outpatient appointments
 - Casualty
 - Admissions to hospital

- ❖ have a high rate of child protection referrals

Deprivation

The finding that young carers live in more deprived circumstances is consistent with the experiences of carers of all age groups. The Carers National Association recently studied the financial circumstances of over two thousand carers in the UK, and found a large proportion of those providing substantial amounts of care live on the breadline¹⁷. Qualitative studies on young carers have found that the majority of young carers experience economic deprivation¹⁷⁻¹⁹.

Young carers may live in more deprived areas due to several factors in their family's circumstances. By definition, they live in families that experience ill-health/disability. People who are ill/disabled are more likely to experience unemployment, poverty and to live in deprived areas. Many parents of young carers are unemployed¹⁹. People who experience poverty may not have the money to pay for care. Aldridge and Becker found that many young carers are forced to undertake caring due to a lack of money for caring alternatives¹⁹. A high proportion of young

carers live in single parent families, 54%⁵, compared with the national figure of 25% of all children²⁰. Children living in single parent families are more likely to live below the poverty line compared with children living with 2 resident parents²⁰.

Utilisation of Health Services

A high proportion of those interviewed had health problems, and had recently attended the GP and/or casualty. However, most perceived themselves as quite healthy and fit, and thought that being a young carer did not affect their health. This might be explained by their concept of health which is exercising, and eating healthily.

The high attendance at casualty and their GP is supported by the database analysis which found that significantly more young carers utilised hospital health services than age, sex and DEPCAT matched controls. General deprivation cannot explain this since the controls were matched DEPCAT. Children with mental disorders utilise tertiary health services and casualty more than the general population of 5-15 year olds¹¹. The young carers had a high proportion of CFMHS appointments, reflecting a high level of mental health problems, which may contribute to a higher utilisation of general hospital services.

Another possibility, suggested by qualitative research, is that some physical health problems experienced may be attributable to their caring role^{4 5}, e.g. performing heavy moving and handling tasks may effect physical development¹⁹. However it is also possible that health problems are 'frequently related to poverty, social exclusion, and unsupported or inadequate parenting, and have no direct relationship to illness or impairment'⁷. More in depth research is needed to ascertain what health problems young carers suffer from, and what relationship these have to their caring role.

Mental Health

The interviews in this study gave some insight into the mental health of a group of young carers. 2 described current mental health problems, and a third a

history of depression. However, most respondents were not depressed and had high self-esteem as measured by well validated scores. This seems to be inconsistent with the database results showing that a high proportion of young carers had appointments with mental health services, but may be explained by the fact that this was a self-selected group and young people with depression and low self-esteem would be unlikely to volunteer to participate in this type of interview.

A high utilisation of the mental health services was common to many young carers, and not obviously associated with parental illness, suggesting that mental health problems may be related to part of the general experience of being a young carer. It was beyond the scope of this study to investigate what types of mental disorders young carers suffer from, but it is likely that these are similar to the most common types found in young people in the UK: conduct disorder, emotional disorders and hyperactivity¹¹. The prevalence of mental disorders are greater in children in lone parent families, and in families with low socio-economic status¹¹. In general, a risk factor for mental health problems is a family history of mental health illnesses²¹, both in terms of genetic loading, and due to associations with adverse family characteristics likely to create environmental risk for children²². Experience of physical or sexual abuse²³ is another risk factor, one third of young carers in this study had a child protection referral.

In terms of emotional disorders, young carers are thought to experience high levels of stress and anxiety, which may cause depression, eating disorders and parasuicide¹⁸. In this study, 3 respondents felt that being a young carer negatively affected their well-being. They described feelings of stress and anger, and also resentment towards having to do so much in terms of care-giving, and to limitations imposed on their social life. The Loughborough research group have repeatedly found that concern about parent's well-being is a central anxiety^{5 18 24}. In 2002, a study at EYCP found that 81% of young carers who took part in the study worried about their parents' health²⁵. It also found that over one third of respondents had self-harmed or thought of suicide²⁵. The experience of stress associated with living with and caring for a parent with an illness, and worrying about their well-being may contribute to the high number of CFMHS appointments.

Many young carers also experience environmental risk factors implicated in conduct disorder and ADHD: low socio-economic status, socially disorganised neighbourhood, family discord and disruption, child abuse and neglect and care-giving factors such as poor supervision^{26 27}. Since many also have parents with mental illnesses, they are also at increased risk of genetic loading for mental health problems²².

Child Protection Referrals

Almost one third of young carers had a child protection referral; this was 7 times more than the number of controls. Living in an impoverished community²⁸ and having a family with a low socioeconomic status²⁹⁻³¹ are strongly associated with child abuse. In this study, the controls were matched for DEPCAT so this cannot explain the difference between the groups.

Many young carers are exposed to a number of risk factors for child abuse and neglect including parental mental health problems^{23 32 30 33}, drug and alcohol abuse^{23 29 30 32 34}. Another risk factor is a low level of social support^{29 34 35}. The fact that children are providing care is a good indicator of a low level of social support. Aldridge and Becker found most young carers do not have a good network of informal support from immediate and extended family, friends or neighbours¹⁹. A high proportion of young carers live in single parent families⁵, and living without both biological parents is another risk factor for child abuse^{36 37}.

Social isolation and lack of a confidant are associated with child abuse^{23 32}. Dearden and Becker have found evidence that young carers are often socially isolated. They may feel that friends do not understand their situation, and having to provide care restricts their social life⁵. As Dawn commented in this study:

'I've not really had any childhood. I've always been in to look after my Mum. I've hardly had any time for my social life'.

The main reason given for not taking part in sports and leisure activities was lack of a companion.

Another risk factor is experience of stressful life events^{29 33 35}. Oates et al. found that families with children who were abused or neglected experienced more problems in areas of finance, housing, and health of family members³⁵. All young carers live in families with health problems, and many also experience financial difficulties.

The majority of young carers have several known risk factors for child abuse; they are clearly a vulnerable group at high risk of having a child protection referral.

Conclusions

This study has found important indicators that young carers are a vulnerable group, and their health and well being may be at risk, particularly in terms of mental health and child protection issues. As a result, Edinburgh City Council have agreed to prioritise young carers as a group of children in need, rather than as community carers, and Lothian NHS have provided EYCP with additional funding and promised further additional resources. Although this response is extremely encouraging, further more in-depth research is necessary to understand in what way the health and well being of these children is suffering, and why, and policy needs to be developed to support young carers and their families in order to protect these children from an unacceptable burden of care.

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Appendices

A) Questions from Scottish Census 2001 relating to provision of informal care and general health:

Carers: Do you look after, or give any help or support to family members, neighbours or others because of long term physical or mental ill health or disability, or problems related to old age? (Do not count anything you do as part of your paid employment.)

Tick time spent in a typical week:

- No
- Yes, 1-19 hours a week
- Yes, 20-49 hours a week
- Yes 50+ hours a week

General self rated health—Over the last twelve months would you say your health has on the whole been:

- Good?
- Fairly good?
- Not good?

B) Correlations between the total number of appointments and number of appointments attended, cancelled or DNA:

GROUP			CANCEL	DNA	SEEN
Young Carers	Total no. appointments	Pearson Correlation	.692(**)	.497(**)	.953(**)
		Sig. (2-tailed)	.000	.000	.000
		N	67	67	67
Controls	Total no. appointments	Pearson Correlation	.743(**)	.743(**)	.978(**)
		Sig. (2-tailed)	.000	.000	.000
		N	67	67	67

** Correlation is significant at the 0.01 level (2-tailed).

C) Questionnaire used in telephone interviews (adapted from ‘The Health of Young People in Care and Leaving Care in Glasgow’¹²)

1. Your lifestyle: exercise and diet

1. In the past week, how often did you take part in exercise or sports that made you breathe harder or sweat?
- | | | |
|-----------------|--------------------------|---|
| Never | <input type="checkbox"/> | 1 |
| Once | <input type="checkbox"/> | 2 |
| Twice | <input type="checkbox"/> | 3 |
| 3-4 times | <input type="checkbox"/> | 4 |
| 5 times or more | <input type="checkbox"/> | 5 |

2. On average, how long did you exercise for?
- | | | |
|--------------------------|--------------------------|---|
| Didn't take any exercise | <input type="checkbox"/> | 1 |
| Less than 10 minutes | <input type="checkbox"/> | 2 |
| 11-20 minutes | <input type="checkbox"/> | 3 |
| 21-30 minutes | <input type="checkbox"/> | 4 |
| More than 30 minutes | <input type="checkbox"/> | 5 |

3. What sorts of activities or sports do you take part in regularly?
- | | | |
|--|--------------------------|---|
| Basketball or volleyball | <input type="checkbox"/> | 1 |
| Swimming | <input type="checkbox"/> | 1 |
| Cycling | <input type="checkbox"/> | 1 |
| Aerobics | <input type="checkbox"/> | 1 |
| Running or jogging | <input type="checkbox"/> | 1 |
| Football or rugby | <input type="checkbox"/> | 1 |
| Netball | <input type="checkbox"/> | 1 |
| Hockey | <input type="checkbox"/> | 1 |
| Gymnastics | <input type="checkbox"/> | 1 |
| Badminton, tennis or squash | <input type="checkbox"/> | 1 |
| Ballet or dancing | <input type="checkbox"/> | 1 |
| Martial arts | <input type="checkbox"/> | 1 |
| Something else (please say what) | <input type="checkbox"/> | 1 |
| OR: Don't do any activities or sports | <input type="checkbox"/> | 1 |

4. Are there any physical activities or sports you'd like to do but can't at the moment for whatever reason?

5. Do any or all of these things stop you from taking part in physical exercise or sport?

- Not enough time to do exercise or sport 1
- Cost - too expensive to take part 1
- Not interested 1
- Afraid that I'll not be fit enough 1
- No-one to go with me 1
- No transport 1
- Don't like other people watching me 1
- Not cool to do sports 1
- Getting there safely 1
- Don't know where to get information 1
- Something else (please say what) 1

Food & Diet

6. On average, how many pieces of fruit do you eat each day?

(includes fresh, frozen or tinned fruit.

A glass of fruit juice also counts as 1 piece of fruit.)

0 1 2 3 4 5 more than 5

7. On average, how many portions of vegetables or salad (not potatoes) do you eat each day?

(includes fresh, frozen or tinned)

0 1 2 3 4 5 more than 5

Now some questions about food

8. Do you choose what you eat?

- Yes, most of the time 1
- Some of the time 2
- Hardly ever 3
- Never 4

9. Do you cook for yourself?

- Yes, quite often 1
- Sometimes 2
- Hardly ever 3
- Never 4

10. Do you do the shopping for your food?

- Yes 1
- No 2

11. Do you ever get information or advice on healthy eating?

- Yes 1
- No 2

12. Do you ever get information or advice on how to cook?

- Yes 1
- No 2

13. Do you ever get information or advice on shopping?

- Yes 1
- No 2

14. Are you happy with your weight?

Yes 1
No 2

If NO, are you:

Underweight 1
Overweight 2

15. Are you currently on a slimming diet?

Yes 1
No 2

16. How often do you brush your teeth?

Every day 1
Every other day 2
Less than every other day 3

2. Your 'health'

17. I know that 'being healthy' means different things to people. I'm interested in what it means to you. Please use the lines below to tell me what 'being healthy' means to you.

.....
.....

18. How healthy do you think you are?

Very healthy 1
Quite healthy 2
Not very healthy 3

19. And what about keeping fit, how fit do you think you are?

Very fit 1
Quite fit 2
Not very fit 3

20. Please finish these sentences:

I feel good about myself when.....

I feel bad about myself when.....

21. Do you have any medical/health problems?

Yes 1
No 2

If YES, Please say what these are in the space below:

.....
22. Are you getting the help you need with your medical/health problems?

Yes ₁
No ₂
Not sure ₃

If YES, what help or treatment are you getting?

.....
If NO or NOT SURE, what do you need help with (that you're not getting at the moment)?

.....
23. Do you think that being a 'young carer' affects your health in any way?

Yes
No
Not sure

If YES, how do you think being a 'young carer' affects your health?

.....
24. Do you ever have to wake up during the night to help look after someone in your house?

Yes ₁
No ₂

If YES, how often do you have do this?.....

25. Please tick the box next to the answer that best describes how you have felt in the last month about your health and yourself:

	Most of the time	Sometimes	Never	
I've felt too tired to do things	<input type="checkbox"/> 1	<input type="checkbox"/>	<input type="checkbox"/> 3	24
I've had trouble going to or staying asleep	<input type="checkbox"/> 1	<input type="checkbox"/>	<input type="checkbox"/> 3	
I've felt unhappy, sad or depressed	<input type="checkbox"/> 1	<input type="checkbox"/>	<input type="checkbox"/> 3	
I've felt hopeless about the future	<input type="checkbox"/> 1	<input type="checkbox"/>	<input type="checkbox"/> 3	
I've felt tense or nervous	<input type="checkbox"/> 1	<input type="checkbox"/>	<input type="checkbox"/> 3	
I've worried too much about things	<input type="checkbox"/> 1	<input type="checkbox"/>	<input type="checkbox"/> 3	29

26. How much do you agree with the following?

(Please tick one box for each line)

	Strongly agree	Agree	Disagree	Strongly disagree
I am pretty sure about myself	<input type="checkbox"/> 1	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/> 4
I often wish I was someone else	<input type="checkbox"/> 1	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/> 4
I am easy to like	<input type="checkbox"/> 1	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/> 4
I have a low opinion of myself	<input type="checkbox"/> 1	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/> 4
I am a failure	<input type="checkbox"/> 1	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/> 4
There are lots of things about myself that I would like to change	<input type="checkbox"/> 1	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/> 4
I am able to do things well	<input type="checkbox"/> 1	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/> 4
Most of the time I am satisfied with myself	<input type="checkbox"/> 1	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/> 4
I like myself	<input type="checkbox"/> 1	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/> 4
I feel I have a number of good qualities	<input type="checkbox"/> 1	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/> 4

Being Healthier

27. Think of a time, maybe it's now, when you felt healthy, and tell me in your own words what helped you to be healthy:

.....

28. Think of a time, maybe it's now, when you felt *un*healthy, and tell me in your own words what stopped you from being healthy:

.....

3. What do you think about local health services?

29. When did you last see or use any of these services, if ever?
(Please tick one box on each line)

	In the last 6 months	6 months to a year ago	Over a year ago	Never
See the doctor/GP	<input type="checkbox"/> 1	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/> 4
Get your eyes tested	<input type="checkbox"/> 1	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/> 4
Visit the dentist	<input type="checkbox"/> 1	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/> 4
Go to the hospital casualty department	<input type="checkbox"/> 1	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/> 4
Visit an information/ drop-in centre with a health problem	<input type="checkbox"/> 1	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/> 4
Rang a telephone helpline with a health problem	<input type="checkbox"/> 1	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/> 4
See the school nurse	<input type="checkbox"/> 1	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/> 4
Go to a family planning/contraceptive service	<input type="checkbox"/> 1	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/> 4

30. Is there anything that would encourage you to use health services?

.....

.....

31. Is there anything else you want to tell me about your health or how services can be improved?

.....

.....

32. Finally, please tick ONE box only to tell me which of these you would like to receive as a thank you for completing this questionnaire:

- A £5 voucher for HMV/Waterstones 1
A £5 mobile phone top-up card 2

THANK YOU, THE END!