

Annex A -Carer Breaks Consultation Outcome (May 23 to Aug'23)

Background of Engagement

This report summary of the engagement work undertaken as part of the actions from the York Carer's Strategy (CSG). A subgroup of CSG was set up to research and provide solutions to the limited supply of and access to carers breaks across the city with feed-in from York Carers Centre, Age UK York, York Mind and Carer representatives as part of co-production

Why the survey was conducted

Under the Care Act 2014, Local Authorities must promote carers' wellbeing and prevent their needs from escalating. Breaks have a potentially crucial role in helping local authorities meet their Care Act Duties. The survey was conducted to enable co-production by ensuring carers have a voice and are involved in planning the specific services, enable them to make informed choices about access to care support, health, and wellbeing, ensure that both young and adult carers have opportunities to be heard and review other opportunities that are there for carers to take a break

The survey was to gauge the demand and current state of access and provision of carers breaks. This ran for 12 weeks from May 2023 to August 2023 through paper copies online through websites and shared through a communications and engagement plan to all stakeholders that come across unpaid carers including YCC newsletters and carer hubs across the city. A total of 170 response have responded with 51% adult carers and 39% child carers.

Below are the results of the consultation:

Figure 1; Carer of adult, child, or Both

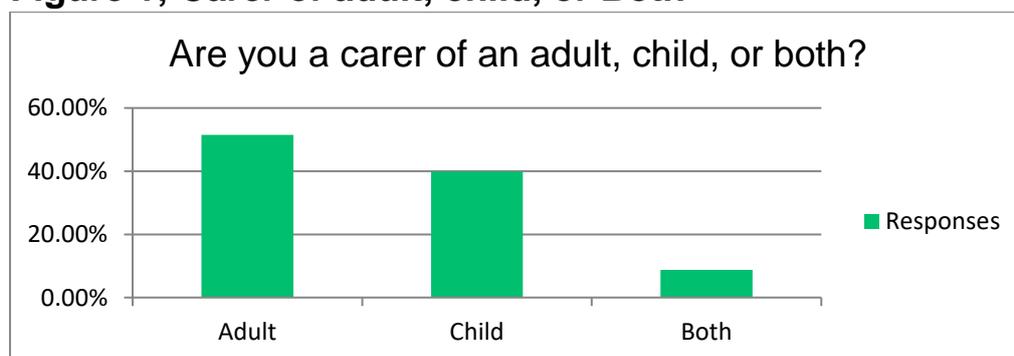


Figure 2: If you care for both, please complete a survey for one and indicate which of the above your answers relate to.

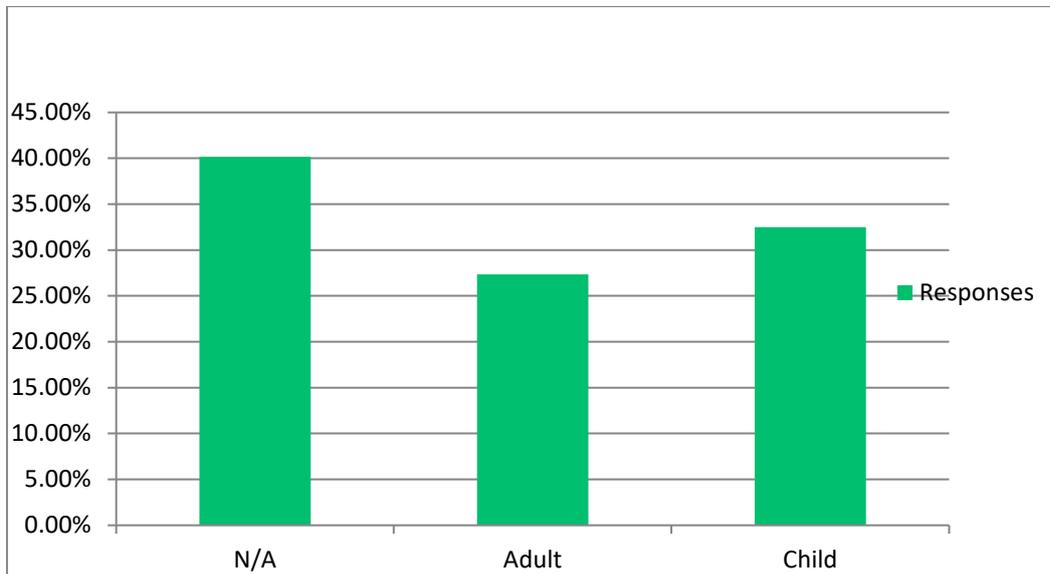
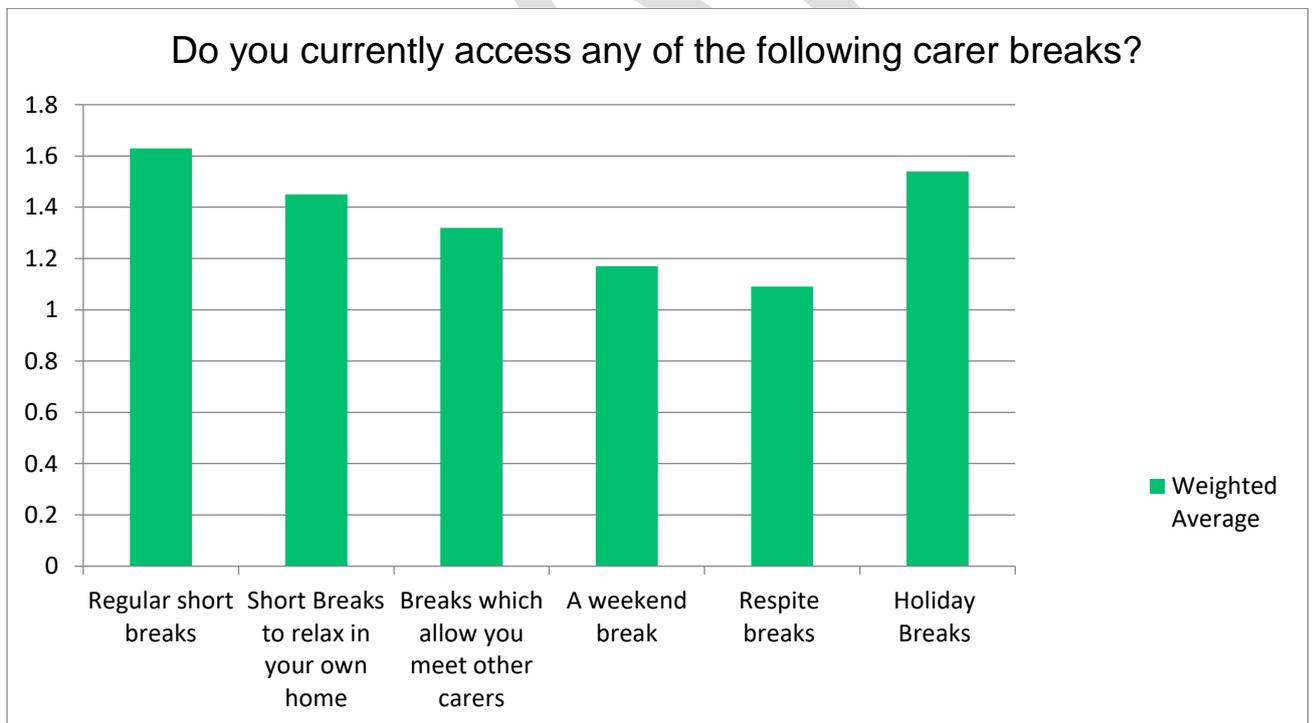


Figure 3: Types of Carer Breaks Accessed



Comments on the type of breaks.

- we get 100 hours only for short breaks, but this is not a break for the carer, the money has to be used for my son.
- We use short breaks to give our son a break away from his sibling but we never get a break. We are desperate for both children to be looked after so we could have a night or weekend away. Or help and come with us on a holiday!
- mum and I go to 2 singing groups each week, with other carers and people with dementia. Is this classed as a break?? Both sessions are 1.5 hours long.

Figure 4: Would you like to have breaks from your caring role?

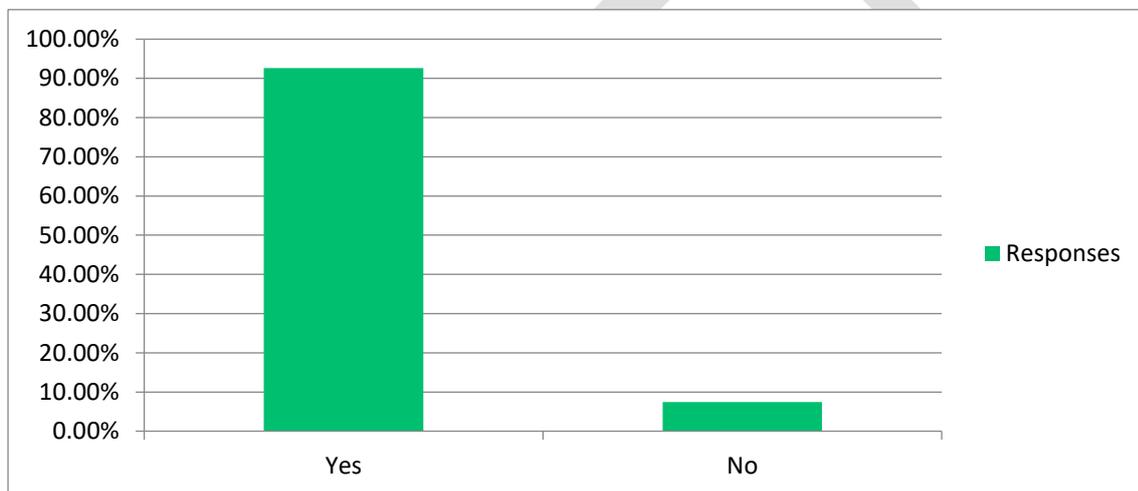
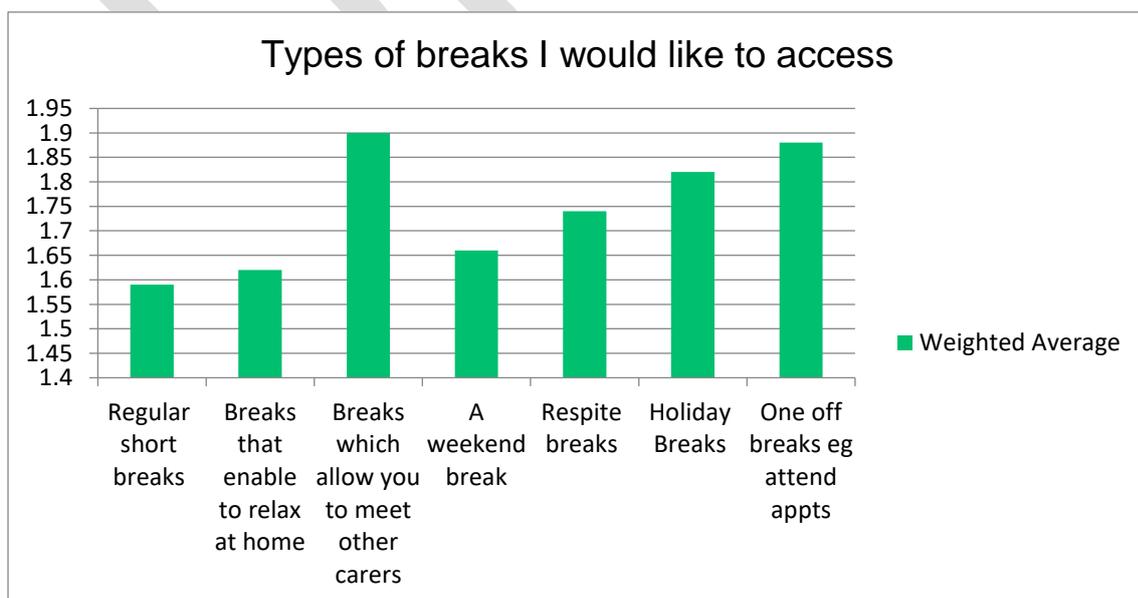


Figure 5: Which breaks would you like to be able to access?

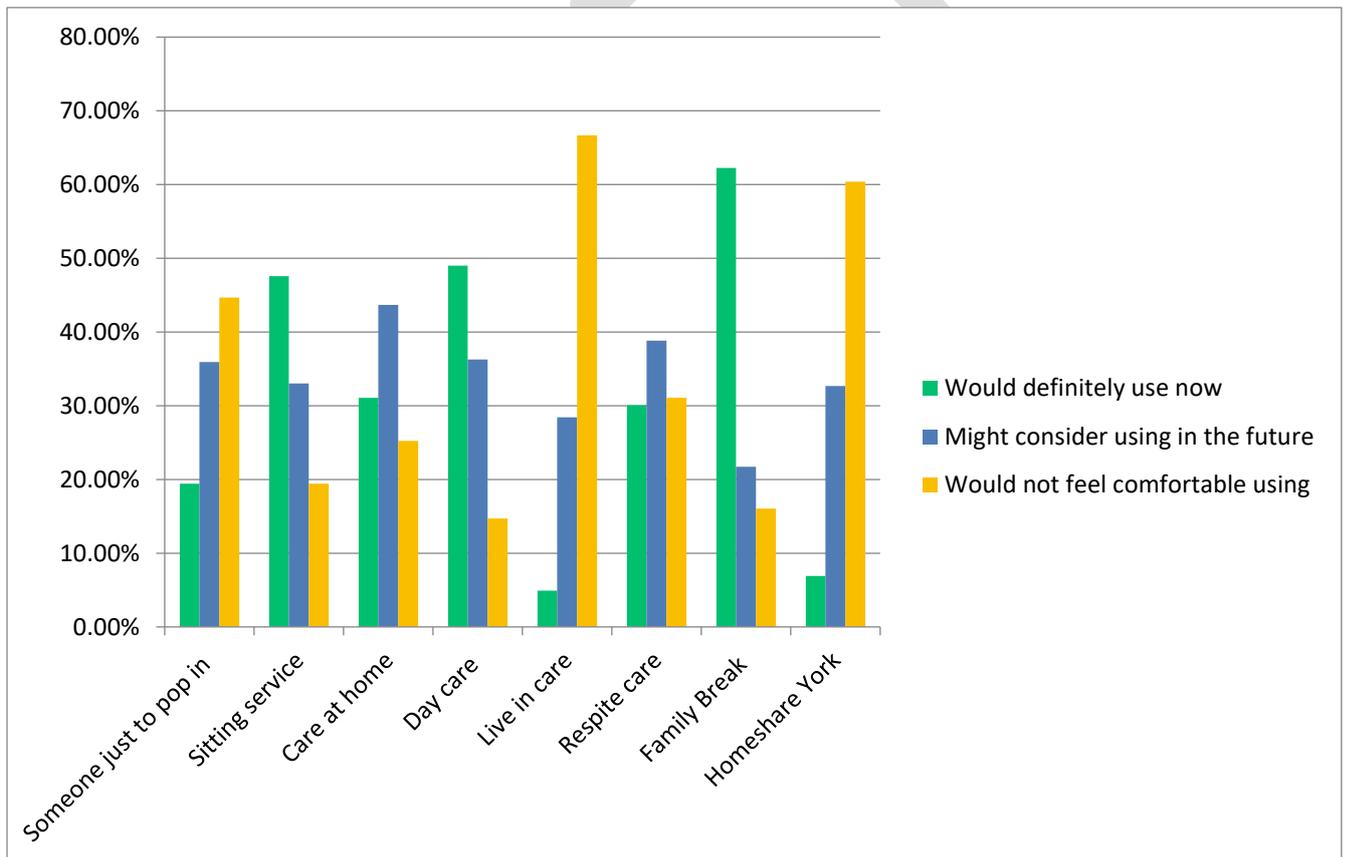


Other Suggestions on the type of Breaks:

- Want Vida Jenkins carers support back.
- The short breaks of 2 hours per week is too short for a child with autism (its too shorter timeframe in order to settle). So, we need to use it more like a fortnightly or every 3-week option and use 4 or 5 hours at one time
- Instant help with an unforeseen impromptu appointment, like sudden hospital or dentist work. An ability to get someone to sit for 30 minutes or an hour while the above is achieved.
- My husband passed away April 2023 I used carers group for support.
- In my carer role I can leave my husband for a short time. But I believe his health will get worse so I guess the access will get harder.
- Some of these I have answered yes to but I already have them so I'm not sure if I am answering correctly? The main thing I would like that I don't currently have access to is an **occasional weekend break**. I would also like support for my son to be supported to go out for short breaks away from the home to aid independence.
- I long for a night away with my wife and no children.
- I have no idea how this could work but I need my daughter to go somewhere away from the house. Planned and when she has a meltdown *she asks to go somewhere away from me but I have nowhere).
- We currently receive **Direct Payments**, but we are not allowed to use this to pay for any breaks away, **only the cost of the PAs**. Therefore, this severely restricts the number of breaks away from caring we are able to have, as we are not able to afford the cost of going away somewhere.
- No point having a one off and it take too long for children to get used to the carer.
- All of the above should be available both regular and ad hoc depending on the needs.
- **My employer doesn't understand** that sometimes medical appointments are on a working day and time off is required. I hate the feeling of dread asking for time off.

- Day care, to enable me to do larger cleaning jobs, without being disrupted or worrying what Mum is up to.
- Just **having a break from caring overnight** would make an enormous difference. I can cope so much better if I've had a night's sleep.
- Providing transportation for child to access activities without parents.
- I would have liked to be able to access flexible, appropriately paid part time employment that utilises by significant healthcare and management skills whilst maintaining a home environment that supports my 3 neurodivergent teenagers.
- Care home trial.

Figure 6: What type of break would you feel comfortable using?

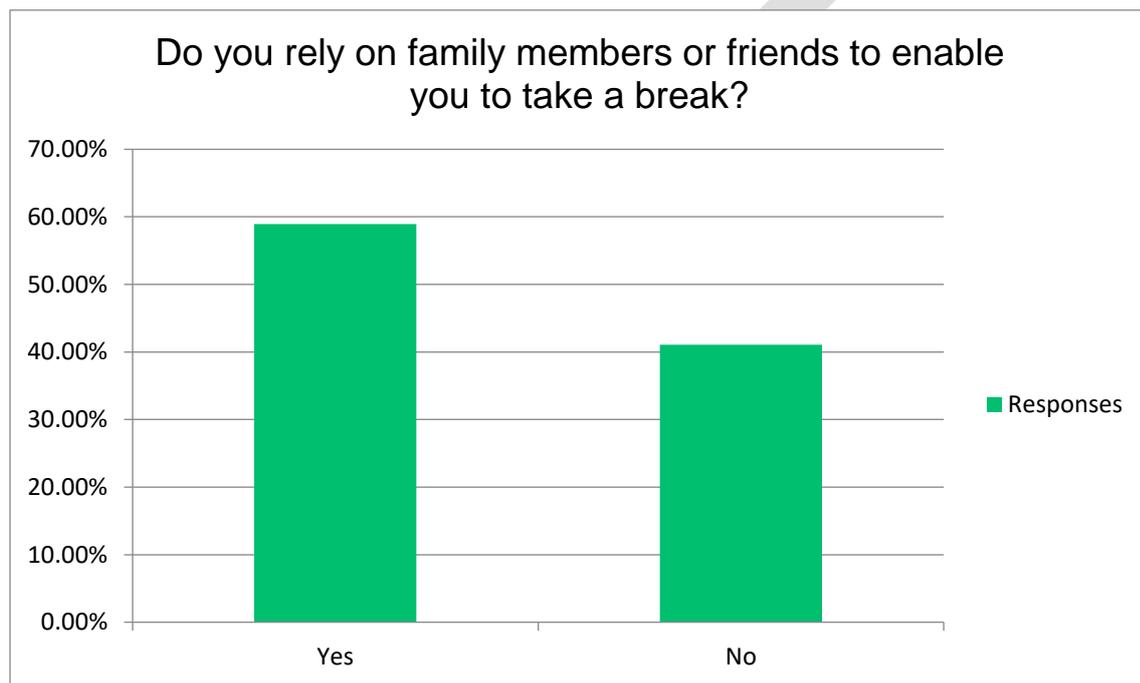


If you have any other suggestions, please specify below:

- would like help from Vida Jenkins
- Husband passed away April 23 I would have liked these services
- Love to get away maybe with other carers

- Anyone caring for a severely disabled person needs to be known and trusted by the disabled person.
- Some of the above are not appropriate for my situation. I get sick of my house having so many people coming round. Every day its, tutors or nurses. Then when friends ask to come, i just think please not someone else coming round. It's hard for my other children too.

Figure 7: Reliance on Family members to take a break.



If yes, why is this?

- No one else
- We cannot leave him with just anyone and only close family are able to meet his needs. However, as he gets bigger and stronger there is only a limited time family members will be able to help look after him. Our parents are getting older and there is no one else to care for him. I don't know what we will do when he is older and stronger, and our parents can no longer help out.
- As my child has potential ASD
- We have to pay our sons key worker to baby sit as she is the only person who can handle him
- Being a single mum, I don't get a break otherwise

- No other access
- They live overseas
- Did not know about any help
- Difficulty in finding right person outside family
- have no one at all my family are all deceased
- Cos of child
- My mum looks after my daughter when I am working one day a week
- Its not an option as parents are elderly
- social care not available as person in education
- Not aware of other options
- I rely on my husband and Father to care whilst I shop, meet friends.
- No family available
- Family enjoyed time with father
- That is family
- Because we have lovely family and friends who offer.
- My sister shared carer duties so she takes on more when I'm unable to sue to a break and vice-versa
- Only myself or my partner (the children's dad) can take care of our kids. So we take it in turns to have a break.
- Because we have never been offered any other option.
- My children ages 21 to 16
- This is the only kind of break we have access to
- No family nearby, my dad would not be comfortable having friends look after him.
- Because there is no one else
- No alternative except for Island mentoring for a couple of hours a week in term time
- There are no services my daughter can access
- Because it is difficult to find ad hoc carers
- Choice - my son is nonverbal so very vulnerable; it is hard to trust even DBS/trained paid staff.
- Husband
- So hard to get PA
- I have
- Yes, but it is very rare they can help

- Because who else is there? Also, they know and understand their needs and are a familiar person.
- Because York has failed to adequately assess or support carers and their needs.
- They are not able or have the capacity to support the needs
- No one available or capable
- I belong to a choir (for my mental health) Sometimes we have all day rehearsals. I rely on friends and family to call in or phone in that 6 hour period, so Mum has someone to talk to.
- I do not have other options
- Difficult to find a PA
- my husband - he is the only other person my son will stay with if I'm not there.
- The person i care for will only stay with family
- Can call on them at short notice
- Our daughter has very complex health needs and have limited hours of care with her personal health care budget.
- No support has been offered at EHCP reviews and not aware we are eligible
- Only support I have
- Paid-for care at weekends has not been available
- No family locally and my daughter would not be comfortable with friends
- support if needed

Figure 8: Does the Cared for Person have any cognitive issues / or identify any risks of safety to them if they were left alone?

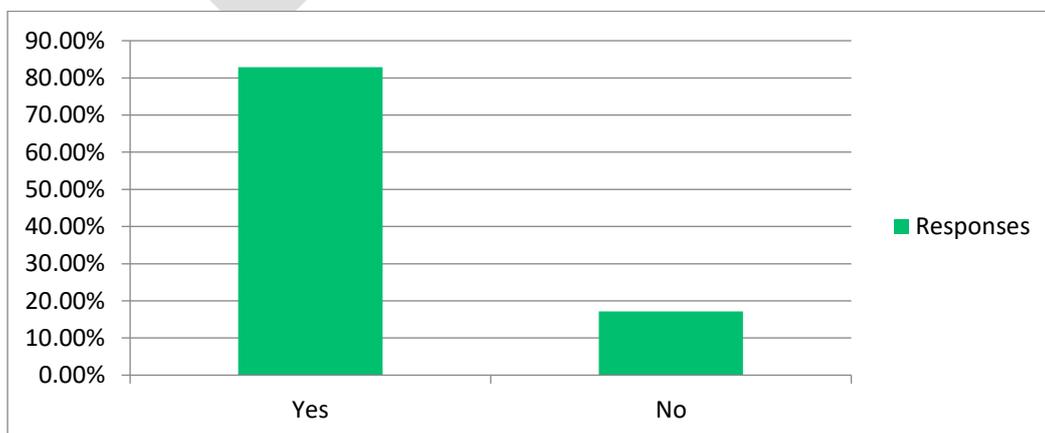
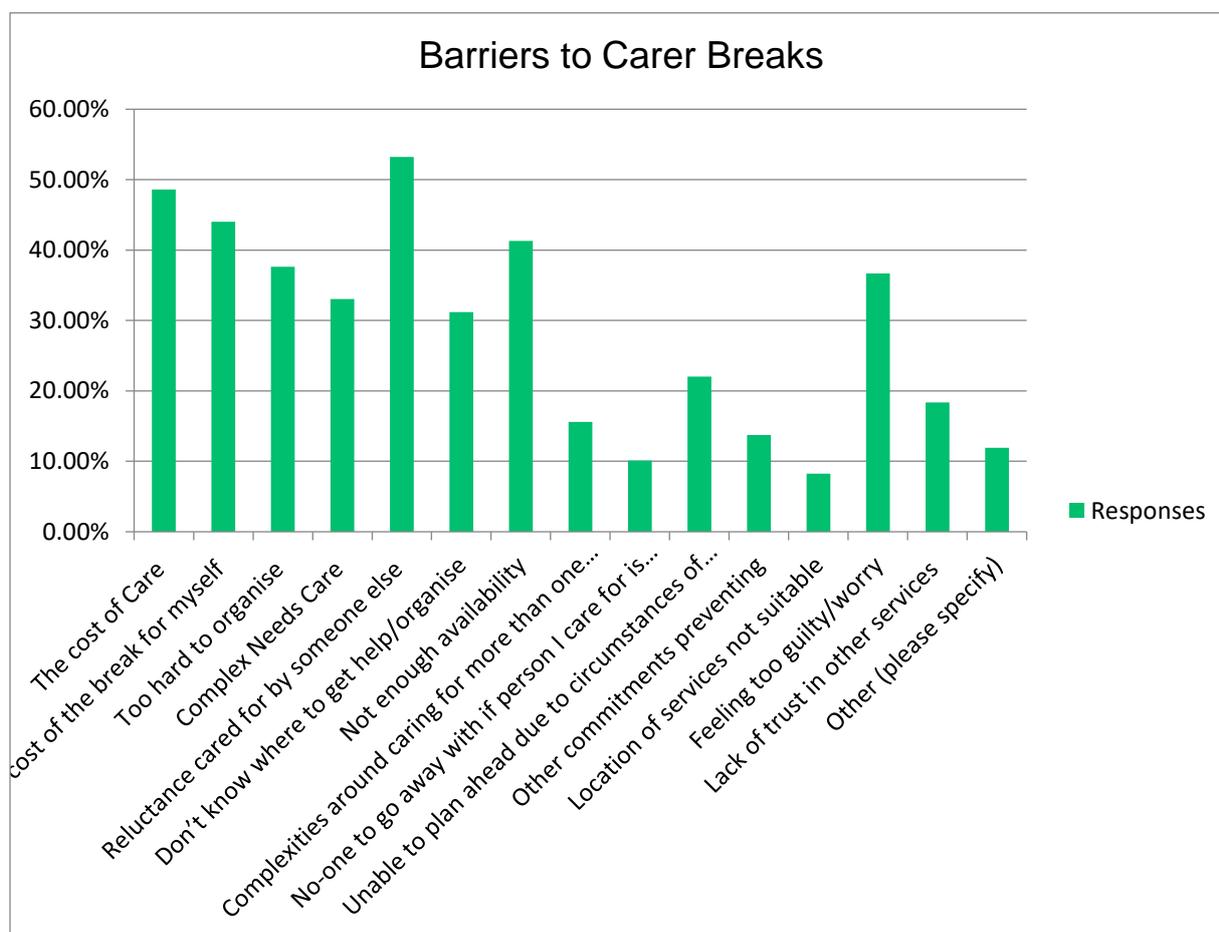


Figure 9: What are the barriers for you to using breaks (if any)?

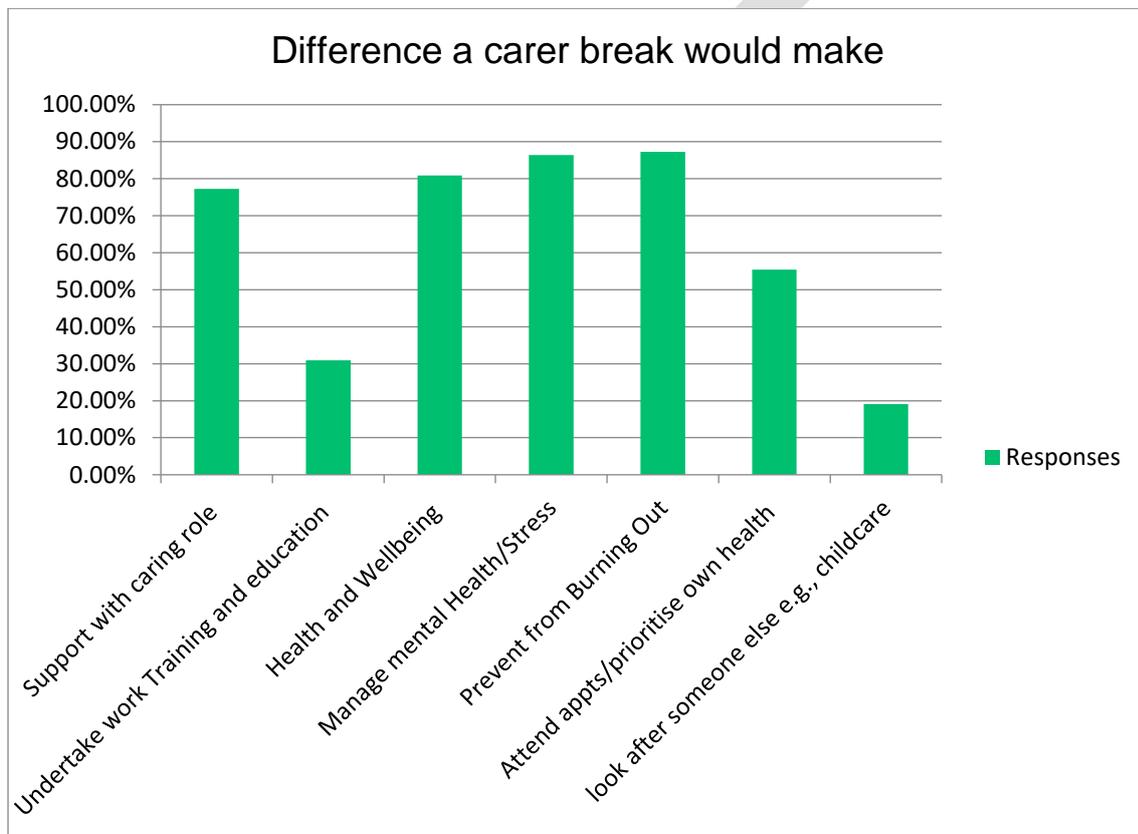


Other Barriers to Carer Breaks

- No money no support it was removed and our family was on the at risk list my son is suicidal I have been struggling to manage alone he's 6ft 4 ins and 18 and a half stone .. I am exhausted its not living
- The person I care for is not yet at the stage, where I need a break.
- There do not seem to be any opportunities for assistance/support.
- Lack of availability of PAs and having to 'pick up the pieces' when returning from a break if things have not gone well.
- My son is only seven.
- Would jump at the chance of help but couldn't afford to fund myself
- Dependent on mental health of the person I care for.
- My wife panics when i am out of her sight.

- Night-time incontinence. Taking essential equipment i.e., commode, frame, and wheelchair
- The rate of pay provided by personal budget for short breaks
- We go together the person I care for needs a break a change of scenery and a holiday is a break for us both
- not sure if eligible
- I also work full time

Figure 10: What difference would a break mean to you?

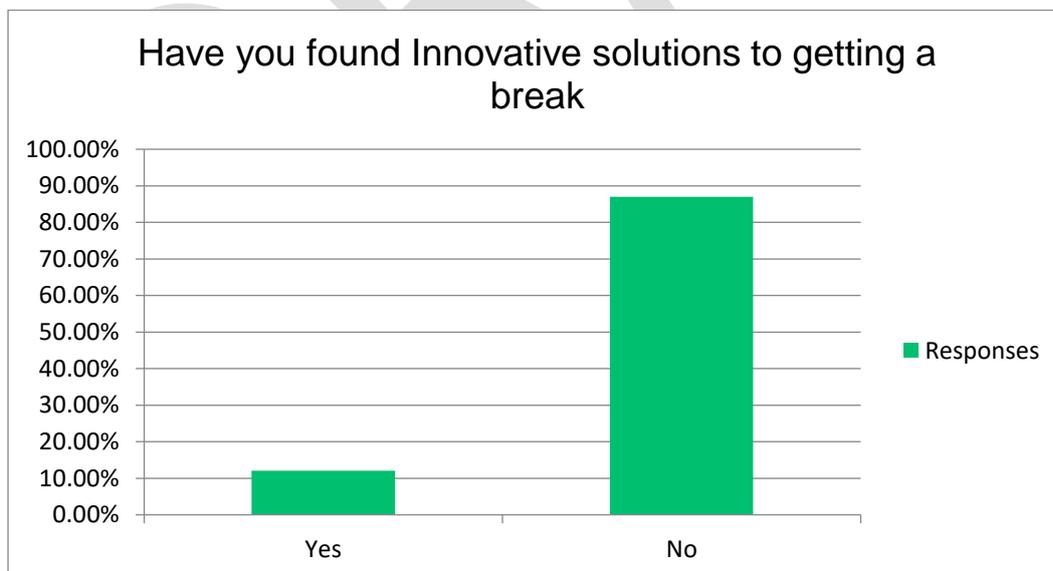


Other comments:

- It is very difficult to look after our 18-month-old NT child at the same time, sometimes we could do with doing separate activities with then and giving him a break as he gets upset when his sister is noisy, which is a lot of the time.
- Support for after school clubs. I have had to reduce my working hours to fit around school times as there is no suitable provision for my autistic son.
- Just get life back I don't have one.

- Would help me and my partner have a break together and feel more normal like our life matters too.
- Have some focussed time with another family member I care for.
- I can cope with the day to day caring but struggle with lack of sleep. My mother has dementia and wanders at night and can be incontinent. If I don't get enough sleep at night, I can be irritable and need to nap during the day. I feel shattered all the time. My father who is 86 also does a lot of the caring during the daytime.
- My physical and mental health took a back seat. Had to get my daughter to do a 150mile round trip to enable me to attend a hospital appointment.
- Currently I can only work during term time, I am self-employed and would like to be able to work more hours than this.
- Avoid isolation and improve physical and mental health.
- Would give me something to look forward to.
- It would be good for my daughter to know other people can care for her and it will be ok.

Figure 11: Some carers have told us about innovative solutions to get a break, or to manage their caring roles where they otherwise would have not been able to continue. Have you found any solutions to getting a break that are not listed or mentioned in this survey?



If yes, please tell us more about these Innovative solutions:

- The only current way is that me and my partner allow the other to go out. But it means we do not get to go out together and it can be very stressful for the person at home caring for both our sons (4-year-old autistic, high need and 1 year old).
- Short breaks CYC.
- I have no help at all.
- I have two children (1 adult 1 child) with needs. It's so hard to match up activities/ clubs etc for both at the same time so I can get a break. If I can it's generally at high cost so hard to then justify spending more money on something for me.
- "Unfortunately, long-term care needs as the person being cared for becomes an adult become very complex. As an adult carer you find your health fails and relatives who may have once been invaluable pass away and your network for care support become smaller and smaller. The situation you dealt with when your child was 10 years old is not what you have to deal with when they are thirteen.
- You can find yourself in a place where you are trying to constantly firefight and stave off the inevitable passing away of yourself, leaving your child in a position that will be a huge crisis for them."
- "My daughter looks after the family so I can have a short weekend away with my friends once a year."
- We use Amazon Alexa screen so we can see and talk to them and remind them of things they need to do even when we are not there. We also use a ring doorbell in the kitchen so we can check they are not at risk of accidents and can speak to them to remind them what to do when we are not there
- Now my son is in residential college weekdays in term time, but this will end soon
- Where someone has identified an activity from a defined approved list of provisions this should be a simple evidence-based access to funding. E.g., Ofsted registered facility for non-school additional provision (like after school club).
- Have a very supporting friend.
- We both go to Singing for the Brain, Singing for All and Dementia Forward sessions where i can meet other people who are usually carers.

- Facilitating an online mentor weekly session so that he has half an hour gaming with someone, and I have half an hour for myself elsewhere in the house.
- Going away without partner so we can each get a break from caring, but not ideal for our relationship.
- Financial we could not afford to get away for a week the careers break gives a a chance to get a way and recharge our battery s it is very helpful to both of us for mental health
- Caring for wife with Alzheimer’s means afraid of incontinence issues so have bought bed pads which make going away again a possibility.
- Occasionally I have asked a good friend to help out.

Demographics

There were 95 respondents filled out this section.

Figure 12: Age Range

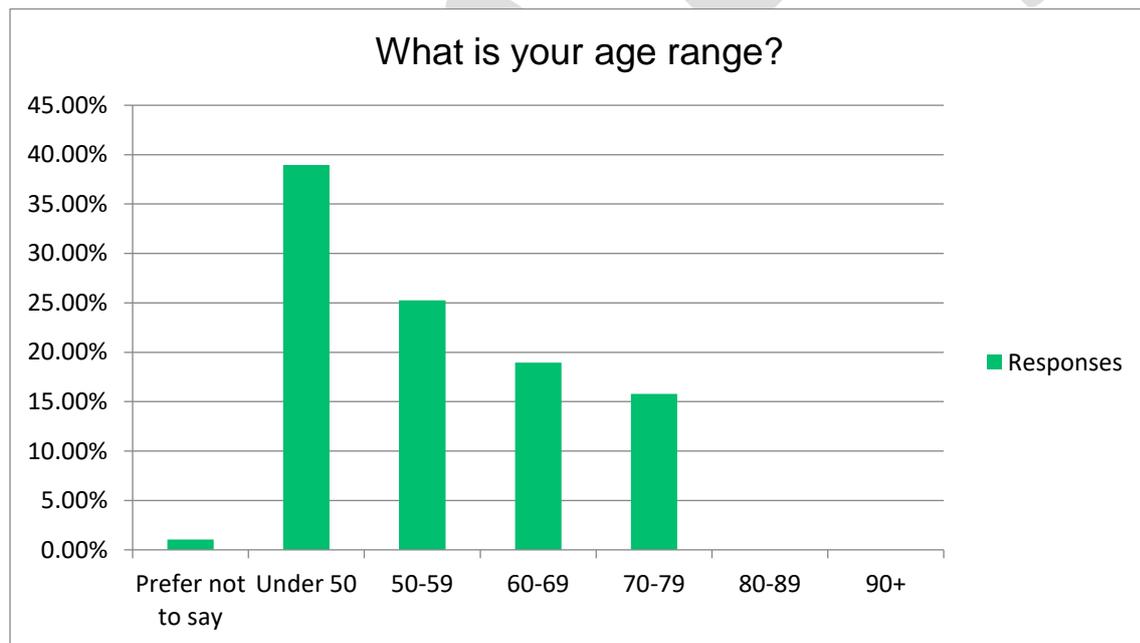


Figure 13: Gender

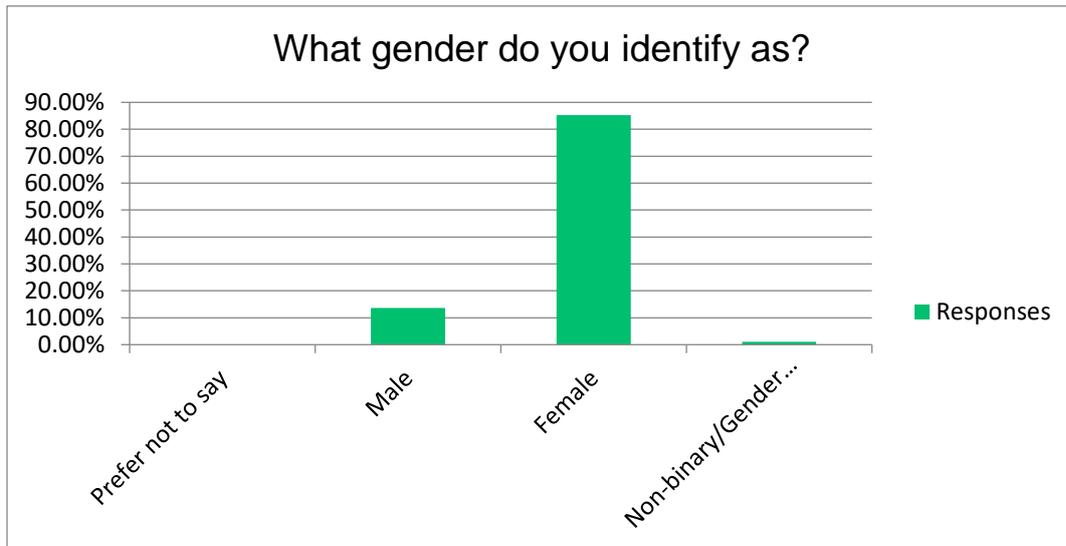


Figure 14: Gender Identity

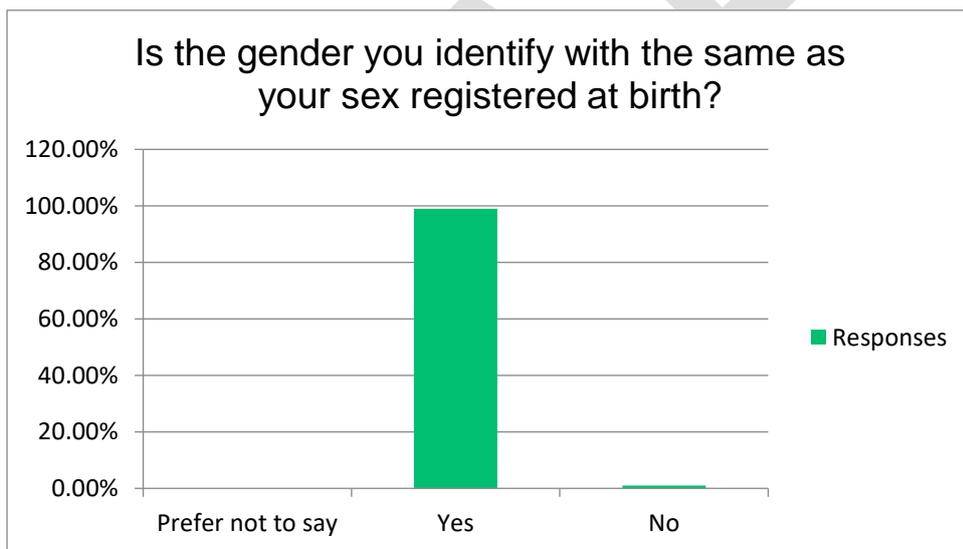


Figure 15: Sexual Orientation

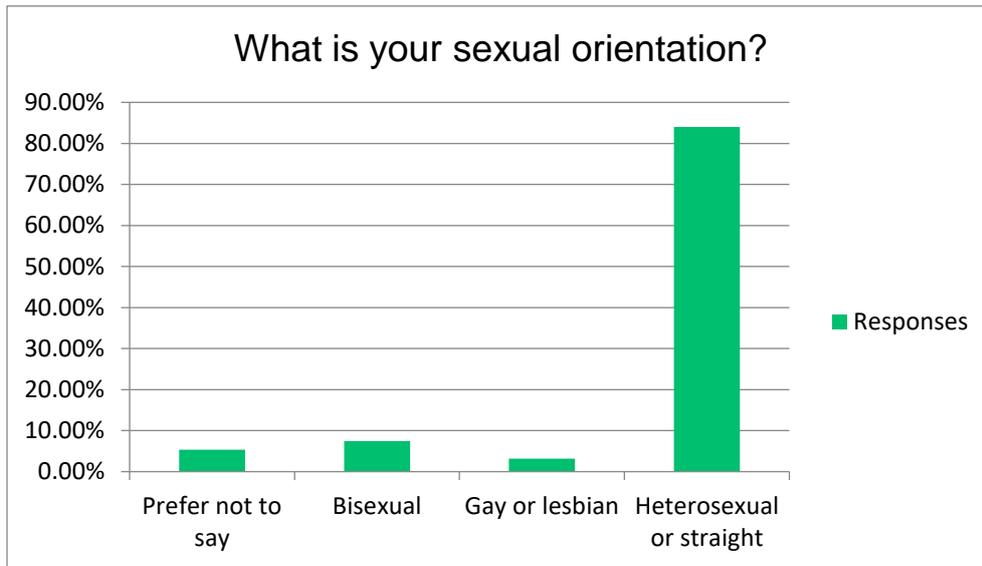


Figure 16: What is your ethnic group?

