

Carers Consultation Survey

Results Summary

KCC Analytics Team

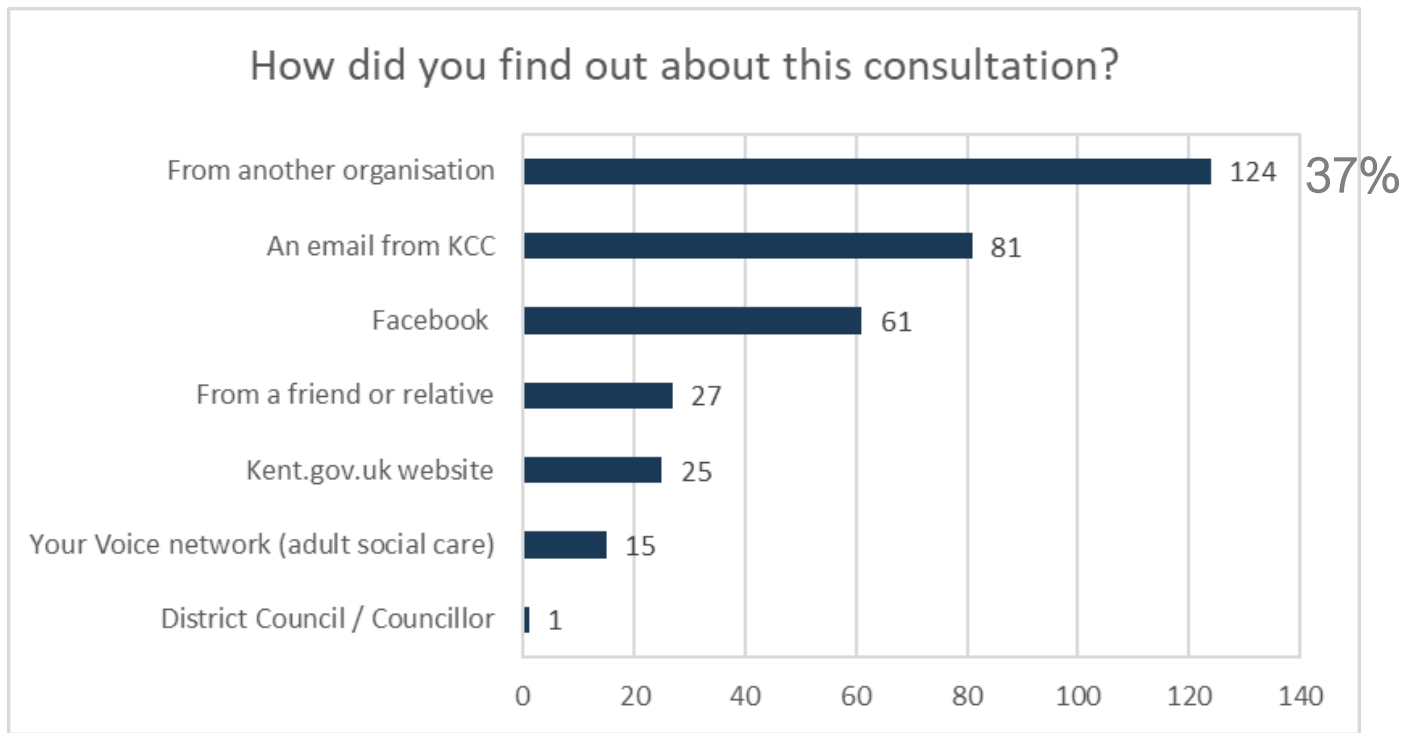
March 2022

Summary of Main Findings (387 responses)

- 78% of survey participants ‘mostly agreed’ or ‘strongly agreed’ with the draft vision.
 - 72% thought the wording was easy to understand.
 - 72% thought it was easy to understand the diagrams and pictures.
- 88% agreed the ‘Supporting you to be you’ list will support carers to live a full and health life.
- 88% agreed the ‘Providing the best support possible’ list will create a better experience for carers.
- 90% agreed the ‘Positive outcomes’ list will create a better future for carers.
- Regular and reliable support was considered the most important service aspect by 60% of 385 survey participants.
 - Respite care / breaks are seen as intrinsically linked to regular and reliable support.
 - Respite care / breaks is particularly important to carers with disabilities / is mentioned frequently in their feedback comments.

How did you find out about the consultation?

37% of respondents heard about the consultation 'from another organisation' and 24% from an email from KCC and 18% via Facebook



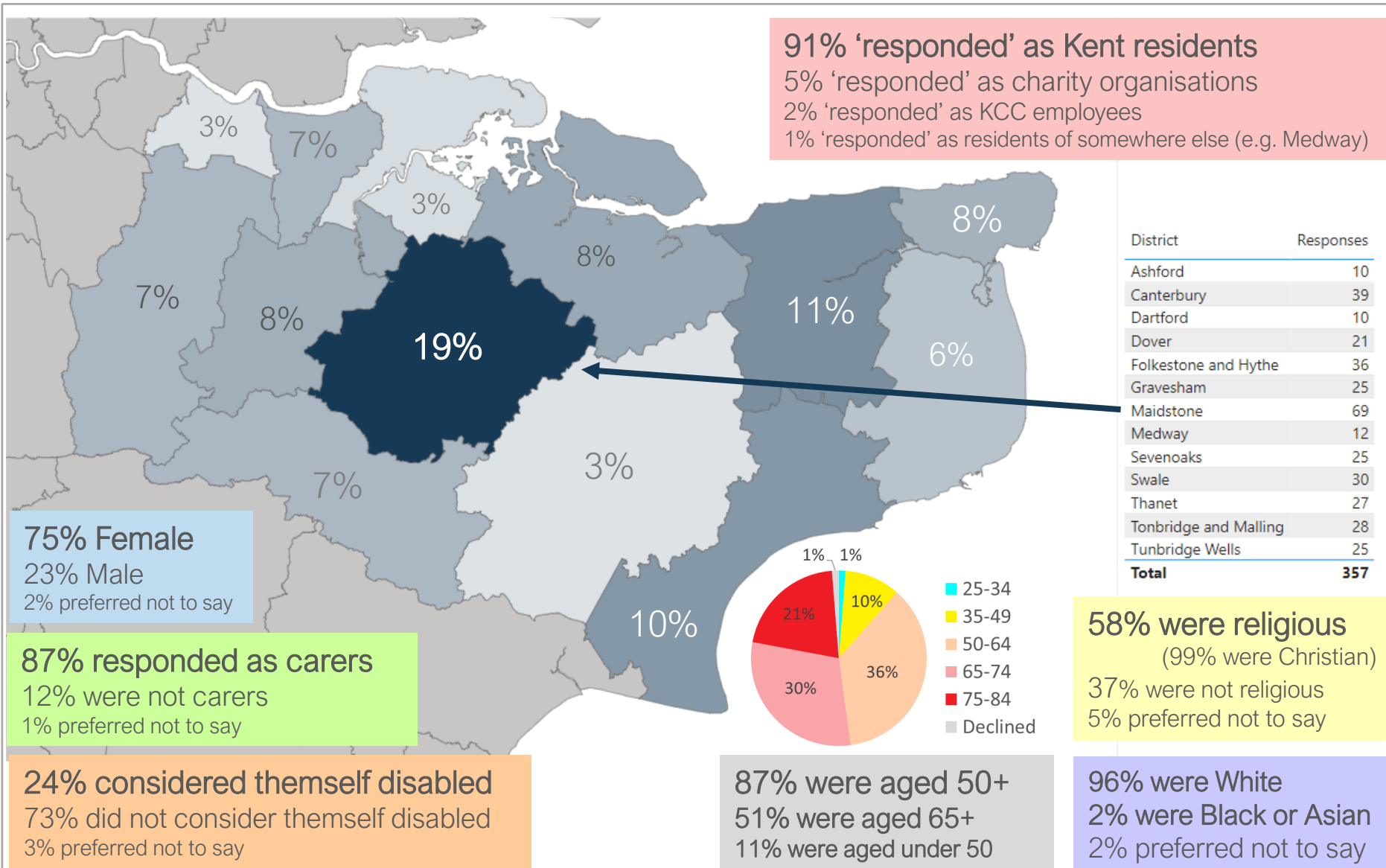
387 participants answered this question

Survey Respondent Profiles

Sub-Title / Notes / Key Insights

Survey participant map and profiles

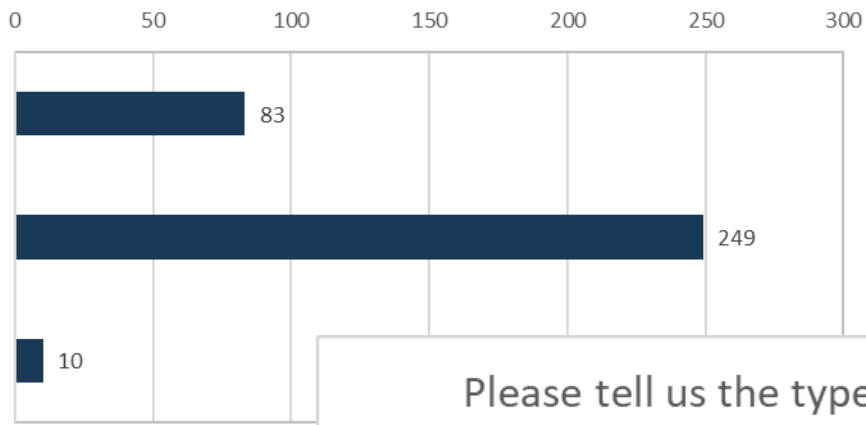
Note: 29 postcodes weren't complete / were ambiguous in location and may belong to more than one district.



Incidence of disability and impairment amongst survey participants



Do you consider yourself to be disabled as set out in the Equality Act 2010?



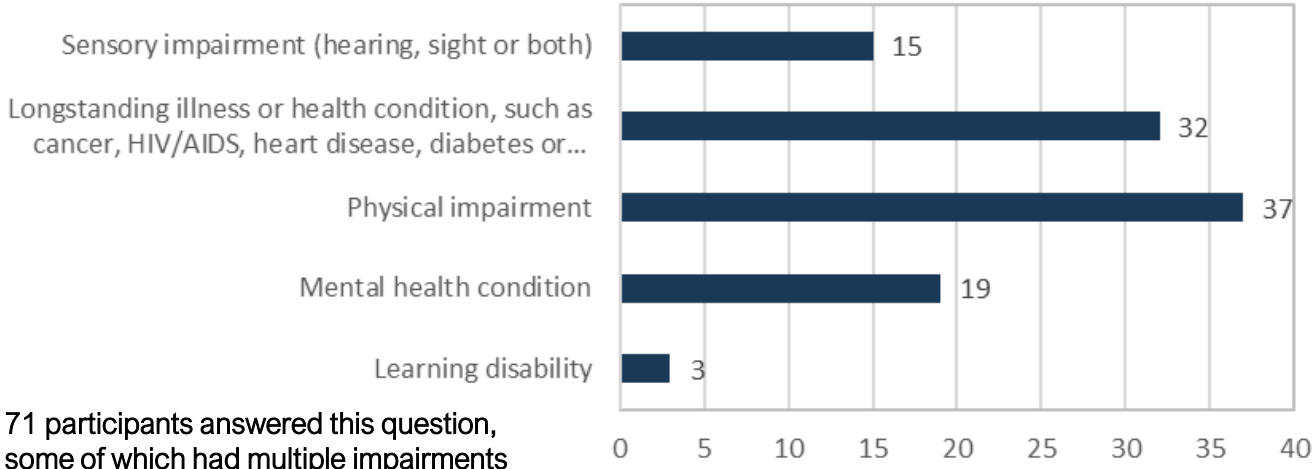
342 participants answered this question

83 (24%) participants considered themselves disabled.

73% did not consider themselves disabled
3% preferred not to say

The impairments with the highest incidence amongst participants was physical impairment (37 respondents) followed by long standing illness (32) sensory impairment (15) mental health condition (19) and learning disability (3)

Please tell us the type of impairment that applies to you:
You may have more than one type of impairment, so please select all that apply.?

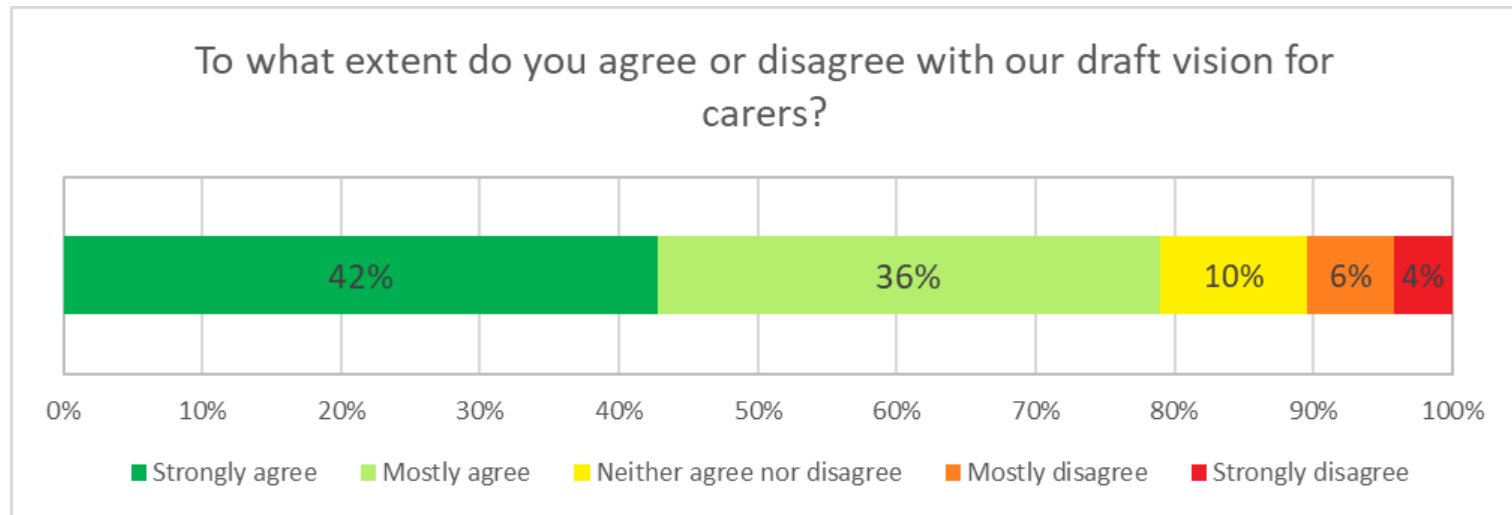


71 participants answered this question, some of which had multiple impairments

78% of survey participants 'mostly agreed' or 'strongly agreed' with the draft vision (300/385)

Our draft vision for carers is:

'Making a difference every day by supporting and empowering you to live a fulfilling life whilst being a carer, as long as you are willing and able'



385 participants answered this question

It is perfectly laudable provided the caring organisations are properly funded.

in theory it sounds good, reality is different

High on aspiration but it remains to be seen whether the will and funding materialises.

6% of survey participants **'mostly disagreed'** with the draft vision, below are some of their comments and suggestions. (23/385)

Note: Additional response comments received in answer to this question are included in the appendix

Too long and wordy

I agree with the general intention of the strategy but there is very little direct information of what this means in practice as regards support for carers, how much, when, who will do it etc.

There is no mention on young carers below aged 16, who do exist, no mention of carers who work & potential work with employers for carer friendly policies etc.

Omit "as long as you are willing and able"

As long as you are willing and able? - so how does this draft vision support Carers who are supporting 24/7. They are not able & they are probably too tired or drained to be willing. Surely these words on the draft vision should be removed.

There shouldn't be UNPAID carers and whilst I agree there must be a process to avoid claims being approved whereby the applicant is not a "true" carer(s) the process is too robust

In theory it sounds good, reality is different

I am extremely happy with your care support from crossroads care. It is invaluable for me to have regular breaks (short). This does not mean I want to go to clubs etc. I just want to be able to go somewhere of my own choice. Not what you think I want.

You need continuity when you ring a number and not going to be passed to countless departments pillar to post

4% of survey participants **'strongly disagreed'** with the draft vision, below are some of their comments and suggestions. (15/385)

Note: Additional response comments received in answer to this question are included in the appendix

Not enough concentration on the carers. Lack of actual physical contact on a regular or even irregular basis!!!

Respite provided by Crossroads is a crucial lifeline for me and any cutting back of this service would be lifestyle threatening. This is the ONLY time I can get out and do "normal" things without having to worry.

Why is a "vision" required? It's a collection of meaningless words to an exhausted carer?

They don't help carers get breaks. Carers need help and have a person that can give proper advice to you

I don't feel it is aimed at older carers, it is more to do with supporting those still in employment which is great but the older generation have not been included.

I didn't know of its existence. It doesn't have a relevance to my situation.

It doesn't clarify at all what the "journey" means. It's full of well-meaning phrases but doesn't show how on earth it will work. Who will implement it etc.

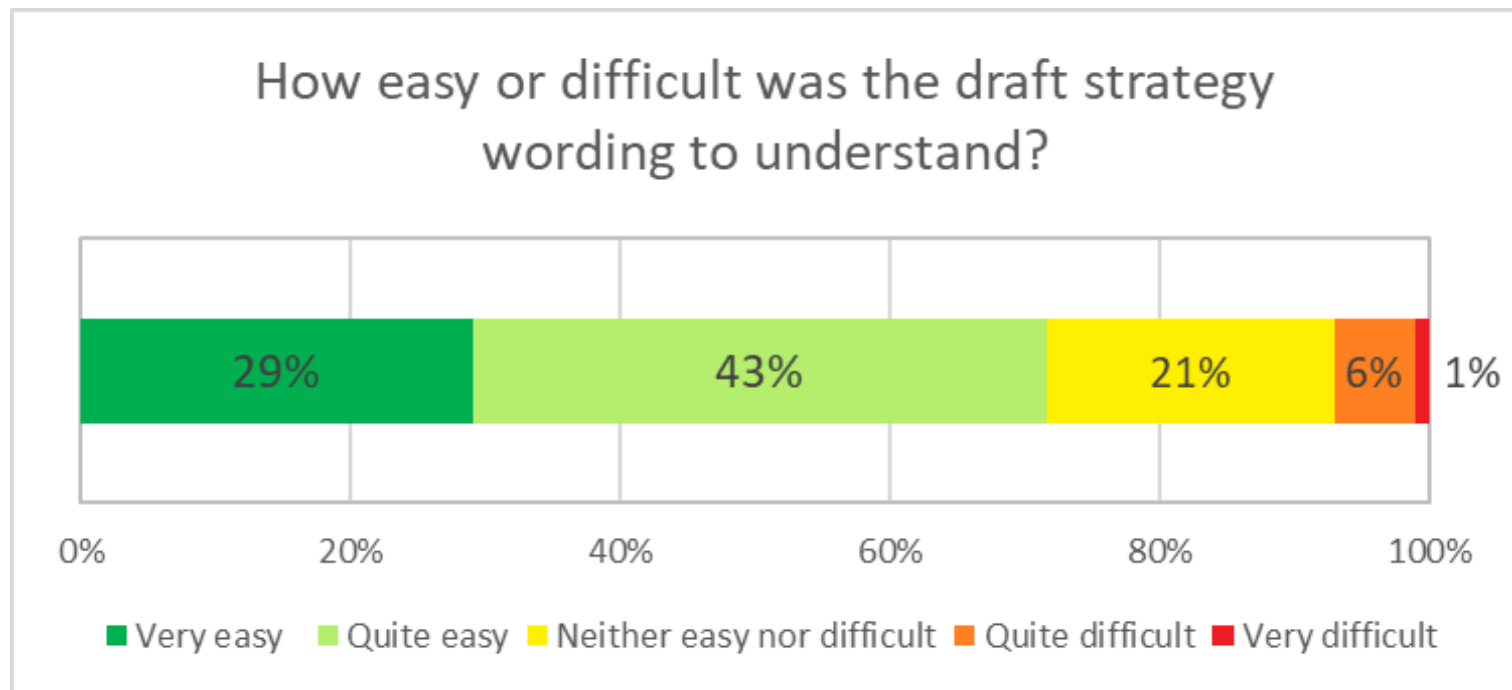
This is going as far from the arrangement that is in place at the moment as possible. I don't need courses in how to look after my wife or to be a better carer. I need to have my wife sat with a trusted person whilst I do my shopping etc... to enable me to carry on caring.

It's just a load of words that never transpire into any help for those who need it.

72% thought the wording was easy to understand (275/383)

Our draft vision for carers is:

'Making a difference every day by supporting and empowering you to live a fulfilling life whilst being a carer, as long as you are willing and able'

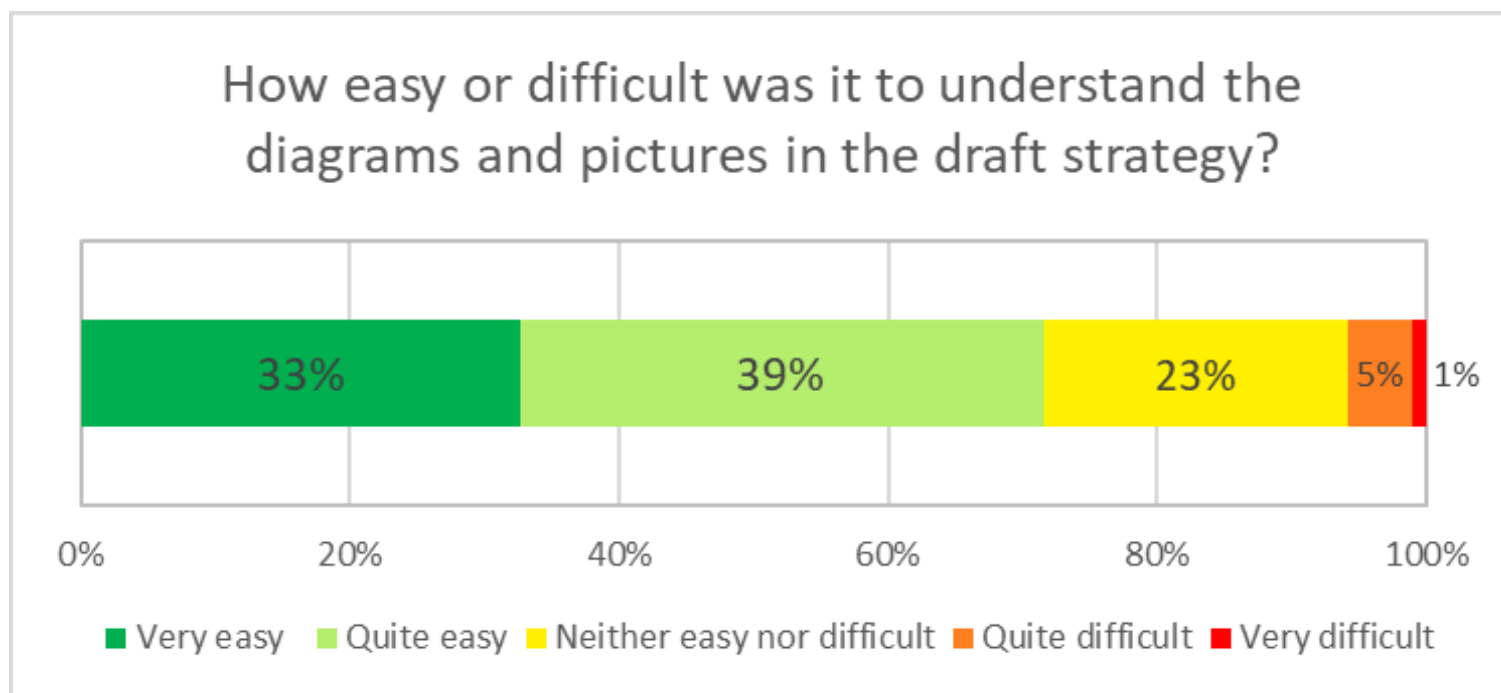


383 participants answered this question

72% thought it was easy to understand the diagrams and pictures in the draft strategy (277/385)

Our draft vision for carers is:

'Making a difference every day by supporting and empowering you to live a fulfilling life whilst being a carer, as long as you are willing and able'



385 participants answered this question

Supporting you to be you



The next question in the survey had multiple elements and was asked as follows:

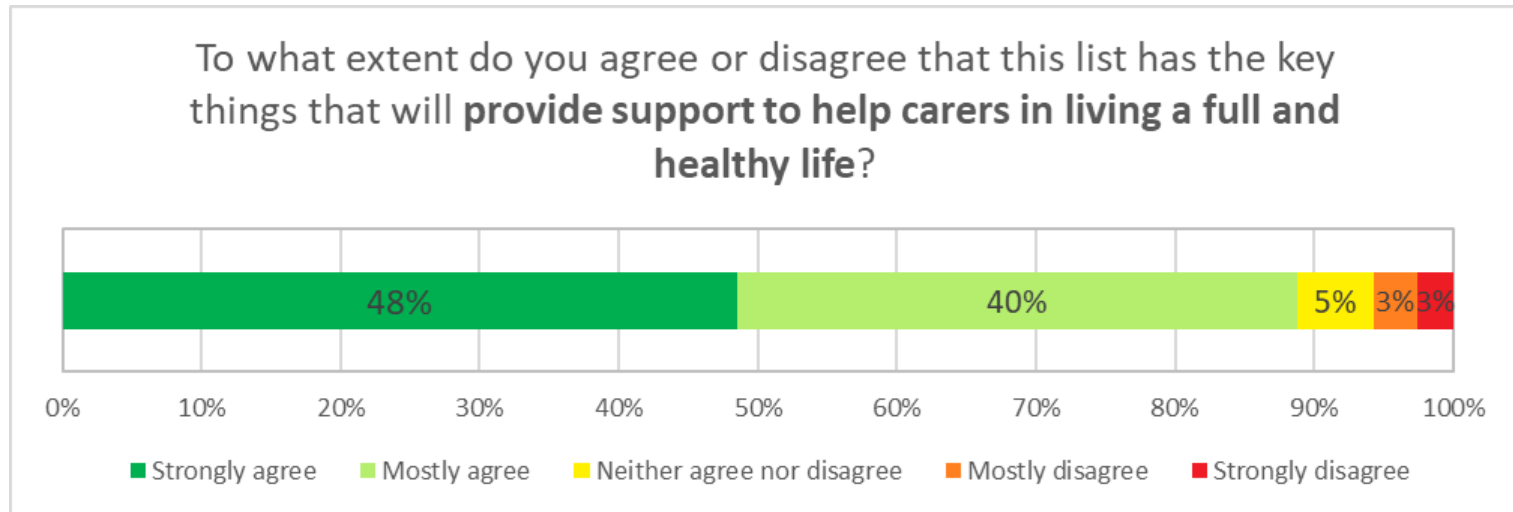
Supporting you to be you - what carers have told us is important for living a full, healthy life:

- ★ *Health and emotional wellbeing*
- ★ *Advice and information*
- ★ *Support to work*
- ★ *Funding information*
- ★ *Breaks*
- ★ *Support to study*

To what extent do you agree or disagree that this list has the key things that will provide support to help carers in living a full and healthy life?

88% agreed the 'Supporting you to be you' list will provide support to help carers live a full and health life (338/385)

'Supporting you to be you - what carers have told us is important for living a full, healthy life: Health and emotional wellbeing; Advice and information; Support to work; Funding information; Breaks; Support to study'



385 participants answered this question

Ambition is good, funding could be a barrier to reach the principles

Being there to help in a crisis is most important, crossroads deliver this. Short breaks are my best support.

It's a brilliant principal.

Supporting you to be you – Feedback comments

Supporting you to be you - what carers have told us is important for living a full, healthy life:

Please tell us if you have any comments on the core principle “Supporting you to be you” and if you think anything is particularly important on the list or missing from it?

Description of comment	Count	Theme
★ Respite / breaks for carers are important / "Time to do my own thing"	8	9
Help in a crisis / emergency	1	
★ Better financial support for carers	5	7
Funding concerns / a Salary for carers	2	
★ Make available support easy to find / Accessible advice and information	7	8
Help to first access services	1	
★ Health and Wellbeing support / "Carers don't have time to think about their own needs"	3	3
Unpaid carers feel "invisible"	0	
Unsure that plans will be implemented / mistrust of the system	1	13
Specifically assigned named support workers	0	2
Dedicated contacts for frequently used services (GP, benefits etc)	2	
★ Support carers in work / access to work / maintain work	2	7
I agree with / support the principle (generally)	0	7
Conjoined approach from services needed	2	6
Facilitation of Peer support groups	1	3
Clarity regarding timeframes	1	2
Understand carer motivations / people don't always want to be carers ("landed" with it)	2	2
Other	6	27

The breaks are most important

emotional support would be helpful for me at this time.

There's nothing about financial support, signposting to benefits. Whilst these are welcome, it doesn't support those who are the heavy-duty carers. Those that can't work, find time for self care etc.

★ 'Support to study' not mentioned in feedback comments

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"Supporting you to be you" is the most difficult principle to maintain when weighed down by day-to-day caring. Health and emotional wellbeing are the most important issues.

Supporting you to be you – Feedback comments from participants that consider themselves disabled

Supporting you to be you - what carers have told us is important for living a full, healthy life:

Please tell us if you have any comments on the core principle “Supporting you to be you” and if you think anything is particularly important on the list or missing from it?

Description of comment	Count	Theme
Respite / breaks for carers are important / "Time to do my own thing"	28	28
Help in a crisis/emergency	0	
Make available support easy to find / Accessible advice and information	9	10
Help to first access services	1	
Better financial support for carers	8	9
Funding concerns / a Salary for carers	1	
Health and Wellbeing / "Carers don't have time to think about their own needs"	7	7
Unsure that plans will be implemented / mistrust of the system	3	3
Support to access/maintain work	2	2
Conjoined approach from services needed	2	2
Dedicated contacts for frequently used services (GP, benefits etc)	1	1
Clarity regarding timeframes	1	1
Understand carer motivations / people don't always want to be carers ("landed" with it)	1	1
Specifically assigned named support workers	1	1
Other	8	8

★ 'Support to study' not mentioned in feedback comments

65

Support needed to have a break from the 24hr caring

breaks have a bearing on health and emotional wellbeing

I feel I need more breaks as my time at home is demanding. Having to look after someone with 3 conditions - blindness, deafness + schizophrenia which is very demanding.

The support gives me (full-time carer) some 'me' time where I don't have to think about the needs of the person being cared for. The support gives me some welcome freedom from what would be being a prisoner in my home.

Providing the best support possible



The next question in the survey had multiple elements and was asked as follows:

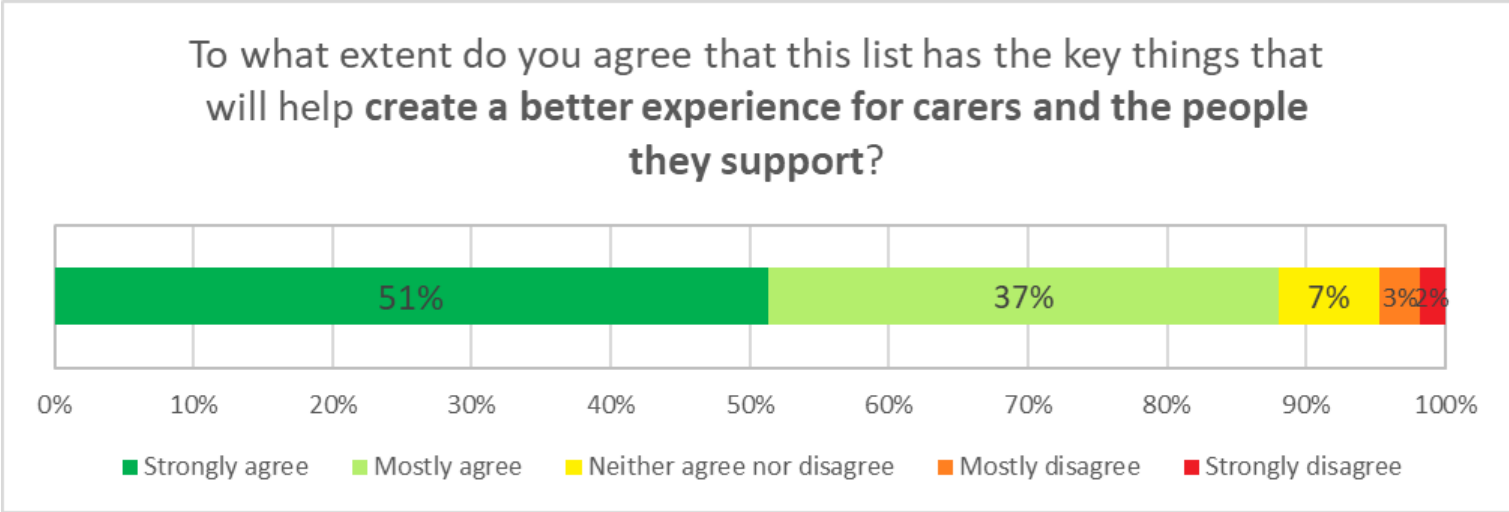
Providing the best support possible – how carers have told us they want us to work with them:

- ★ *Listening and learning from you;*
- ★ *Respect and trust;*
- ★ *Working with you at every step;*
- ★ *There to help in a crisis.*

To what extent do you agree that this list has the key things that will help create a better experience for carers and the people they support?

88% agreed the 'Providing the best support possible' list will create a better experience for carers (338/385)

'Providing the best support possible – how carers have told us they want us to work with them: Listening and learning from you; Respect and trust; Working with you at every step; There to help in a crisis'



385 participants answered this question

Support available in a crisis is so very important

'Working at every step' is particularly important, the current situation of support sometimes often only becoming available in crisis needs to change.

'I think it is all covered'

Providing the best support possible – Feedback comments

Providing the best support possible – how carers have told us they want us to work with them:

Please tell us if you have any comments on the core principle “Providing the best support possible” and if you think anything is particularly important on the list or missing from it?

Description of comment	Count	Theme
Crisis support is important / There to help in a crisis most important	27	52
Respite / breaks for carers are important / better life balance	25	
Lack of detailed information about available support	13	40
Could be a challenge to implement / an ambitious step-change to present transactional support	12	
Very topline / not believable without detail / very different to reality	10	
Unsure that plans will be implemented / mistrust of the system	5	
Listen more / Understand individual needs better / More bespoke tailored support	16	34
Listen and learning from you is important / most important	10	
Working with you at every step is important / most important	6	
Understand carers motivations / people don't always want to be carers ("landed" with it)	2	
Provide a quicker reponse / support when you need it / better communication	17	30
Provide more regular, preventative support, not just crisis support	13	
Dedicated contacts for frequently used services (GP, benefits etc) / Single point of contact	15	24
Conjoined approach from services needed / no mention of joined-up approach	9	
More support for carers / better financial support for carers	9	20
Funding concerns / More financial support / Pay staff more	8	
Support to access / maintain work / support unpaid carers to remain in work	3	
Help to first access services / easier / simpler to access / make available support easy to find	10	19
Accessibility of relevant advice (or lack of)	6	
Unpaid carers feel "invisible"	3	
Provide more emotional support for lone carers	7	10
Health and Wellbeing/MH support/"Carers don't have time to think about their own needs"	3	
Respect and trust in most important	3	3
Other	32	32

There to help at all times not just in a crisis would be better

Working with you at every step - very important - simply knowing there IS someone to turn to who can support and give help.

Listen but then act on what carers say. No point in listening but doing nothing.

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*Some carers reach crisis point - with no friends or family to rely on. Carers need a short break also help with doctors/hospitals appointments that need to be attended by the carer. **To respect and trust a care support worker is important to the carer and cared for.***

Positive Outcomes



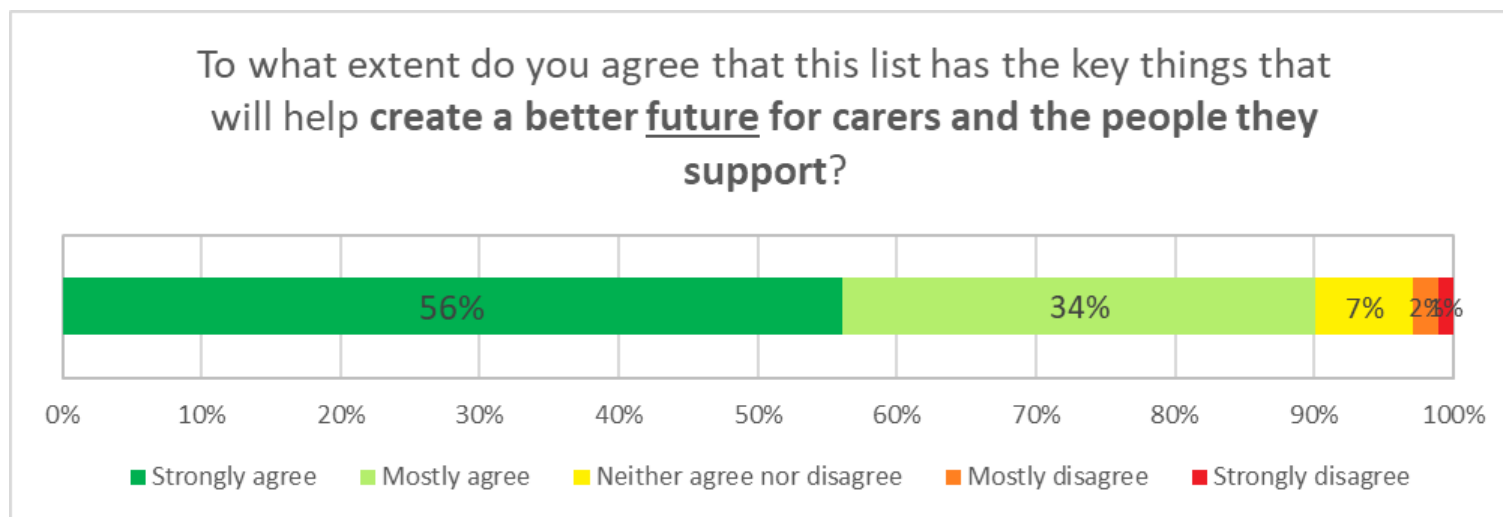
Positive outcomes – creating a better future for carers and the people they support by aiming for what they have told us is important:

- ★ Organisations working together;
- ★ Support workers building good relationships with carers;
- ★ Organisations reaching more carers;
- ★ Support for younger and older adults;
- ★ Telling your story once;
- ★ Access to high quality carers support;
- ★ Regular and reliable help;
- ★ Personalised support;
- ★ Trusted points of contact;
- ★ Carer education and training;

To what extent do you agree that this list has the key things that will help create a better future for carers and the people they support?

90% agreed the 'Positive outcomes' list will create a better future for carers (346/385)

'Positive outcomes – creating a better future for carers and the people they support by aiming for what they have told us is important: Organisations working together; Support workers building good relationships with carers; Organisations reaching more carers; Support for younger and older adults; Telling your story once; Access to high quality carers support; Regular and reliable help; Personalised support; Trusted points of contact; Carer education and training'



385 participants answered this question

That's all good but what's needed is a more personalised strategy rather than forms, signposts, web pages at the end of the day.

We need support from people face to face to help us. Not all email or webpage to talk to you just don't have that time but if someone is there it makes all the difference.

Again, good ideas but won't work unless there are support staff who are well paid, well qualified and good at their jobs.

Positive Outcomes – Feedback comments

Positive outcomes – creating a better future for carers and the people they support by aiming for what they have told us is important:....

Please tell us if you have any comments on the core principle “Positive outcomes” and if you think anything is particularly important on the list or missing from it?

Description of comment	Count	Theme
Very topline / not believable without detail / very different to reality	18	38
Desire for more detail about available support	13	
Could be a challenge to implement / an ambitious step-change to present transactional support	7	
★ Tell story once. Greater continuity of social workers is important	15	33
Consistency of support / support staff is important	7	
Listen more / Understand individual needs better / More bespoke tailored support	5	
Dedicated contacts for frequently used services (GP, benefits etc) / Single point of contact	6	
★ Regular and reliable help is important	12	27
Respite / breaks for carers are important / better life balance	12	
Health and Wellbeing support / "Carers don't have time to think about their own needs"	3	
★ Organisations working together is important	17	20
Conjoined approach from services needed / no mention of joined-up approach	3	
Funding concerns / Pay staff more	12	21
More support for carers / better financial support for carers (generic)	9	
I agree with / support the principle (generic)	16	16
★ Access to high quality carers support is important	9	9
★ Support workers building good relationships with carers	8	8
Help to find / first access services / easier / simpler to access	7	7
Provide a quicker reponse / support when you need it / better communication	4	4
★ Carer education and training is important	3	3
★ Supporting young and older adults are two separate things	2	2
★ Trusted points of contact is important	2	2
★ Support for younger and older adults is important	2	2
Put people first, not organisations working together	1	1
Organisations reaching more carers is important	3	3
Support to access to work / maintain work / support unpaid carers to remain in work	2	2
Other	16	16

Telling your story once is very important. Often things that have already been proven once will end up need to be proven over and over again to new staff.

Regular and reliable support (my weekly respite time) has been crucial in helping me to continue in my caring role.

Would like to see included: The right expert at the right time. I want expert help when it's appropriate (rather than e.g. signposting).

Which actions are more important to you?

- Regular and reliable support mentioned by 60% of 385 survey respondents

Please tell us which actions are the most important to you, by choosing up to three from the list below:



"As a carer, I worry about how my wife would be looked after in my absence in a crises (eg if I was suddenly taken to hospital with serious Covid) Our son lives and works 300 miles away and my wife needs 24/7 support. Having a single point of contact in an emergency would be a great relief. A 'red button' system could be the answer in many cases, but the call handler would need to know who to contact if there was an event that could not be resolved in the short term. (My wife would not be able to operate this a system herself, and her speech is very poor following a stroke).I have been putting together some notes, including contact information for various agencies, relatives and friends, but a County system would be better"

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 - 72% thought the wording was easy to understand.
 - 72% thought it was easy to understand the diagrams and pictures.
- 88% agreed the ‘Supporting you to be you’ list will support carers to live a full and health life.
- 88% agreed the ‘Providing the best support possible’ list will create a better experience for carers.
- 90% agreed the ‘Positive outcomes’ list will create a better future for carers.
- Regular and reliable support was considered the most important service aspect by 60% of 385 survey participants.
 - Respite care / breaks are seen as intrinsically linked to regular and reliable support.
 - Respite care / breaks is particularly important to carers with disabilities / is mentioned frequently in their feedback comments.

Appendix

If you mostly disagree with our draft vision, please tell us your comments and suggestions below. (23/385)

What does support for carers look like? Who is involved in identifying carers & how? What respite entitlement is possible & how can it be accessed? Who is coordinating the response/support from health and social care for example do GPs have a carers register and how do people know about it?

Not enough substance in the strategy of things that will actually help individual carers. Intent is fine but with no strategic direction it is not enough.

I 'mostly disagree', only in the sense that while this 'vision' is unexceptionable as far as it goes, as stated it does not discern the difference between the desirable and the essential. A 'fulfilling' life is highly desirable, but what many Carers, especially older Carers, even with support can scarcely achieve is just a basically tolerable, or possible, life. Support for them is essential, just to enable them to keep their cared-for one at home and to avoid – or postpone – their transfer to more intensive, and resource-hungry, forms of care.

My husband has alzheimers he needs 24 hour care 7 days a week he gets £89 a week it costs me £112 for 4hours free time per week .

I am finding it quite difficult to get support as a carer. I work and have my own family yet the only respite I get that I don't pay for is from crossroads who are invaluable as they are with my mum in her own house and the Ellenor. Both charities I have to take my mum to the Ellenor and pick her up which can be difficult but again the support they offer me and my mum we find invaluable.

Apologies I misread teh question but you will see from my comments below how valuable local charities are in achieving your vision.

I am a full time carer for my daughter and have been for the last 38 years right from her birth. I could not be without my support worker who comes in 3 hours a week to give me time to do the things I cannot do i.e. shopping, wshing my hair and other general chores.

it depends what you intend to do. I do not want to lose my support from Crossroads. I can go out for three hours enabling me to be me for that time.

working with the carers know what a difference time off makes. Breaks very important so they don't want to spend that time being pointed in different directions. Plus filling in forms to see what time they can get off. This just stresses them out more when they are already stressed in their caring role

I think its impossible to live a fulfilling life as a full time carer. It is too tiring and very difficult to get respite care. I think you as a carer can give your loved one a fulfilling life but it comes with a great cost.

Need more help but can not afford to pay for care! So have to do it myself and care for my wife.

Not enough hours in the day for my hobbies. What time I have from Crossroads Care Kent enables me to visit my friends or shopping or walking.

As a carer I do not have a fulfilling life and although some support is appreciated, caring 24/7 is tiring and very demanding and negates any life I might choose for myself.

If you strongly disagree with our draft vision, please tell us your comments and suggestions below. (15/385)

There is nothing that tells me how you are going to Make a difference to the lives of carers every day. You state that there are 38k carers in Kent who do over 50 hours of caring a week and get you aren't saying you will be prioritising them or saying what you will do to find them. Currently only a very small proportion of these receive a carers assessment. This needs to be addressed. Whilst the principle is fine there is no information about what it means to an individual carer.

"Please note that the carer doesn't always know that they are a carer most of the time they feel that they are having to look after them due to their needs and know one knows how to look after their loved one as well as them. Many of the older generations feel that in sickness and in health means that they just DO what they need to and wouldn't expect husband/wife/child to be able to do it many people feel that they can't give up caring and toileting their parent or child even though it is something that they do not wish to do. ""Having my mum with her feet in the air cleaning up her mess after she has had a bowel movement is not the position I should be put in"" is something I hear in the community far too much!"

I have tried to access services as an autistic father with cancer and with two autistic children. I receive no support whatsoever. I just get flagged to an ever increasing amount of services who all flag me on and on one occasion I have been flagged back to my wife's training company, it's a joke. No support and absolutely no MH support or any other kind within a reasonable time scale

Not suitable for older carers, no consistency. Whoever produced it has no practical experienced of caring 24/7 x 52 or being in prison. Not every loved one wants clubs / groups, where they will be among those who are their future. I.E you will die one day, do you want to attend a club in the morgue mixing with those who are your future?

money could be spent elsewhere to help our needs. Too many chiefs and not enough indians comes to mind - being an old timer said many in my life

Bottom line is the Govt does not want to pay and just use praise as a way to fool us

I disagree with how kcc are spending tax payers money