Care Alliance Ireland

Guiding support for family carers

A Review of the National Carers' Strategy (2012): How relevant are the actions in 2021 and for the future?

July 2021

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Acknowledgements

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Care Alliance Ireland

iss21 Institute for Social Science in the 21st Century

IRISH RESEARCH COUNCIL
An Chomhairle um Thaighde in Éirinn

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Executive Summary

The National Carers' Strategy – Recognised, Supported, Empowered (2012) (NCS) sets out current government policy for those who provide care in an unpaid capacity to older people, children and adults with an illness or a disability. It includes a Roadmap for Implementation containing 42 priority actions to be achieved on a cost-neutral basis in the short to medium term (Department of Health, 2012). The Programme for Government 2020 includes a commitment to review and update the NCS to inform how best to support family carers in Ireland into the future (Department of An Taoiseach, 2020). The Department of Health is leading this update, in consultation with the wider family care sector.

In this context, as part of the CARERENGAGE project, Care Alliance Ireland (CAI) and the Institute of Social Science in the 21st Century (ISS21), University College Cork, commissioned a survey to determine the relevance of the NCS in 2021. The aim of the survey was to assess the extent to which the 42 actions in the NCS continue to be relevant from the perspectives of key stakeholders, including family carers, policymakers, relevant service providers, and researchers.

The specific objectives of the survey were to collect data on stakeholders' awareness, knowledge and use of the Strategy; their views on the relevance of the 42 actions outlined in the Strategy; and the top three priority areas they would include in the next National Carers' Strategy if they had a 'magic wand'. The online survey was administered between 14 January 2021 and 5 February 2021.

The total number of respondents was 734 (678 family carers, 37 staff working in service provider organisations, 18 researchers, 15 staff working in not-for-profit sector organisations, 9 policymakers and 10 others. Respondents could choose more than one role, as some were caring whilst also working in sector organisations, etc.)

The following are the key findings of the review:

- There were low levels of awareness of the NCS among family carers, with less than one-third (30.7%) having heard of the NCS. Nevertheless, a majority of respondents indicated that the Strategy was personally and/or professionally relevant to them.

- 55.2% (n=405) answered questions about the continued relevance of the 42 actions. The majority wanted each of the 42 actions to be retained, indicating that the actions are still relevant in 2021. However, many wanted the actions to be updated or expressed differently. A number of actions were regarded as too weak and in need of revision to strengthen them and to reflect greater commitment on the part of government to bring about change for family carers in Ireland.

- There was a strong desire among family carers and their representative organisations to be consulted and actively involved in the development of policy.

- With respect to decisions relating to the person they provide care to, family carers wanted decision-making to be based on a two-way dialogue or to take the form of shared decision-making, an approach whereby family carers, the person and professionals work together to make decisions about treatment and care.

- The top three priority action areas identified by both family carers and other stakeholders (i.e. policymakers, service providers, staff in the not-for-profit sector and researchers) were: income supports, supports and services, and respite.

- Actions in the NCS that relate specifically to income supports focus largely on providing family carers with information and advice about income supports and reducing waiting lists, and these continue to be regarded as relevant actions in 2021. However, regarding the structure of income supports paid directly to family carers in Ireland, a range of fundamental issues which pose challenging questions both for policymakers and Irish society, were highlighted.

- In relation to ‘supports and services’, family carers indicated that they would like more help and support with their caregiving role, particularly support within the home to continue caring and enable the person being cared for to remain in their own home.

- ‘Respite’ was ranked by stakeholders as the third priority area.

- Other issues highlighted by stakeholders for inclusion in the next iteration of the NCS included new and more advanced possibilities for online support of family carers, greater service integration along a number of dimensions, and greater recognition of the heterogeneity of family carers and their diverse needs for support.

Overall, this review provides a timely and valuable contribution from a range of stakeholders including family carers who are and will be directly impacted by a revised NCS. The results can be used for ongoing engagement with the Department of Health with respect to its work in reviewing the Strategy and to inform the next iteration of the NCS. This review therefore meets CARERENGAGE's aim and CAI's mandate to produce practically oriented knowledge and evidence-based research impacting family carers in Ireland.

1. Introduction

The National Carers' Strategy – Recognised, Supported, Empowered (2012) (NCS) sets out current government policy for those who provide care in an unpaid capacity to older people, children and adults with an illness or a disability. It includes a Roadmap for Implementation containing 42 priority actions to be achieved on a cost-neutral basis in the short to medium term (Department of Health, 2012). Over a decade on, it is now timely to review this Strategy in order to examine whether it remains fit for purpose in 2021. The Programme for Government 2020 includes a commitment to review and update the NCS to inform how best to support family carers in Ireland into the future (Department of An Taoiseach, 2020). The Department of Health is leading this update, in consultation with the wider family care sector. The exact timeframe for the Departmental review has not been announced.

The CARERENGAGE project, funded by the Irish Research Council (New Foundations), is a joint project between Care Alliance Ireland (CAI) and the Institute of Social Science in the 21st Century (ISS21), University College Cork.[1] The NCS was identified in one of the CARERENGAGE workshops as an issue of significant importance.

In this context, CAI and ISS21, as part of the CARERENGAGE project, commissioned a survey on the *National Carers' Strategy* (2012). The specific aim of the survey was to assess the extent to which the 42 actions in the *National Carers' Strategy* continue to be relevant from the perspectives of key stakeholders including family carers, policymakers, relevant service providers, and researchers. This survey is closely aligned with CARERENGAGE's aim and CAI's mandate to produce practically oriented knowledge and evidence-based research impacting family carers in Ireland.

This report presents the findings of the survey of 734 respondents on the *NCS* (2012), which was administered between 14 January 2021 and 5 February 2021. The results provide valuable information from the perspectives of a range of stakeholders, including family carers, and represent an early contribution by key stakeholders to the review of the *National Carers' Strategy*. The findings can be used for ongoing engagement with the Department of Health with respect to its work in reviewing the Strategy and to inform the next iteration of the *National Carers' Strategy*.

This report is available to download from the CARERENGAGE project and Care Alliance Ireland websites. All queries in relation to the report can be directed to info@carealliance.ie.

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[1] More information about the CARERENGAGE project can be found at: https://www.ucc.ie/en/iss21/researchprojects/researchprojects/carerengage/

2. Methodology

An online survey of family carers and other stakeholders was conducted to determine the relevance of the 42 priority actions in the *NCS* 2012. A copy of the survey is included in Appendix A. Data was collected anonymously using a questionnaire designed in conjunction with the CARERENGAGE partners, CAI and ISS21.
The questionnaire comprised three parts. The first part contained questions on respondents' awareness, knowledge and use of the *NCS*. In the second part, respondents were asked to indicate the relevance of each of the 42 actions outlined in the Strategy. The actions were worded in the questionnaire exactly as they appear in the Strategy. Respondents could choose from the following options:

- 'Action should be retained without change'
- 'Action should be retained but updated or expressed differently'
- 'Action should be removed'
- 'Don't know'

For each action, respondents were also given an option to add a comment. A closing question asked respondents to list the top three priorities that they would include in the next National Carers' Strategy.

The survey was piloted in December 2020 and revised according to the feedback of family carers and others who participated in the pilot. Participants who at the time of the survey were aged 18 years of age or over, were resident in the Republic of Ireland, and were a current/former family carer, service provider, policymaker, or researcher were eligible to complete the questionnaire. To recruit participants, the survey was circulated widely by email by CAI and UCC to organisations, including community and voluntary organisations, with a care remit, family carers, policy makers, care researchers in higher educational institutes via email and social media platforms – Twitter, Facebook and LinkedIn. The survey was administered between 14 January 2021 and 5 February 2021 using the SurveyMonkey platform. The responses were analysed using descriptive statistical analysis. Optional comments and priorities identified by respondents were analysed thematically. The results of this survey are presented in the following section.

As a secondary element to this project, on 23rd March 2021 Care Alliance and ISS21 co-hosted an online workshop and discussion seminar with an invited audience to begin the dissemination of these results. The event also acted as a form of 'member check' to encourage policy makers, researchers and most importantly family carers to comment on the outcomes of the survey. The presentations and summary of the workshop discussions and feedback are available in Appendix B.

3. Survey Results

This section presents the results of the survey.

- Section 3.1 profiles the respondents who participated in the survey.
- Section 3.2 outlines respondents' levels of awareness and knowledge of the NCS.
- Section 3.3 presents respondents' views on the relevance of the 42 actions and summarises the comments added by respondents.
- Section 3.4 presents the areas identified by respondents as priorities for the next iteration of the National Carers' Strategy.

3.1 Responses and current situation of respondents

A total of 744 questionnaires were submitted. Ten questionnaires were excluded because respondents, other than describing their current situation, did not respond to any questions, leaving 734 questionnaires for inclusion in analysis.

The vast majority (92.6%) of respondents were family carers. Questionnaires were also submitted by 37 staff working in service provider organisations, 18 researchers, 15 staff working in not-for-profit sector organisations, 9 policymakers and 10 others (Fig. 1).

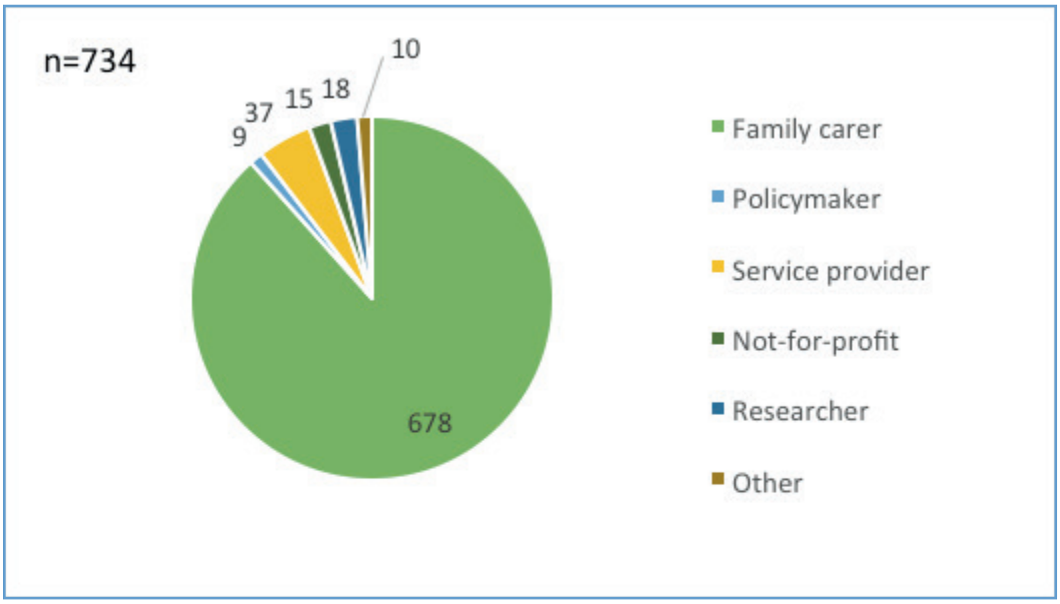

Figure 1: Current situation of survey respondents

Note: The numbers add up to more than 734, as 34 family carers had a dual role, e.g., family carer/researcher.

3.2 Awareness and knowledge of National Carers' Strategy

Respondents were asked if they had heard of the NCS 2012. More than one-third of all respondents (n=267; 36.1%) had heard of the NCS. Family carers were the least likely to have heard of the NCS; less than one-third (30.7%) had heard of the Strategy. In all other respondent groups, at least two-thirds of respondents had heard of the NCS (Fig. 2).

Figure 2: Awareness of National Carers' Strategy (n=734)

The 265 respondents who had heard of the NCS were asked three further questions. First, respondents were asked to self-rate their knowledge of the NCS on a scale of 1 to 10, with 0 reflecting the lowest level of knowledge and 10 reflecting the highest level of knowledge. A total of 239 responses were received. One-half of respondents self-rated their knowledge of the Strategy as either 1, 2 or 3, indicating no or a low level of knowledge. More than one-third (37.7%) self-rated their knowledge as between 4 and 7, indicating a moderate level of knowledge and just over one in ten indicated a relatively high level of knowledge of the NCS (Fig. 3).

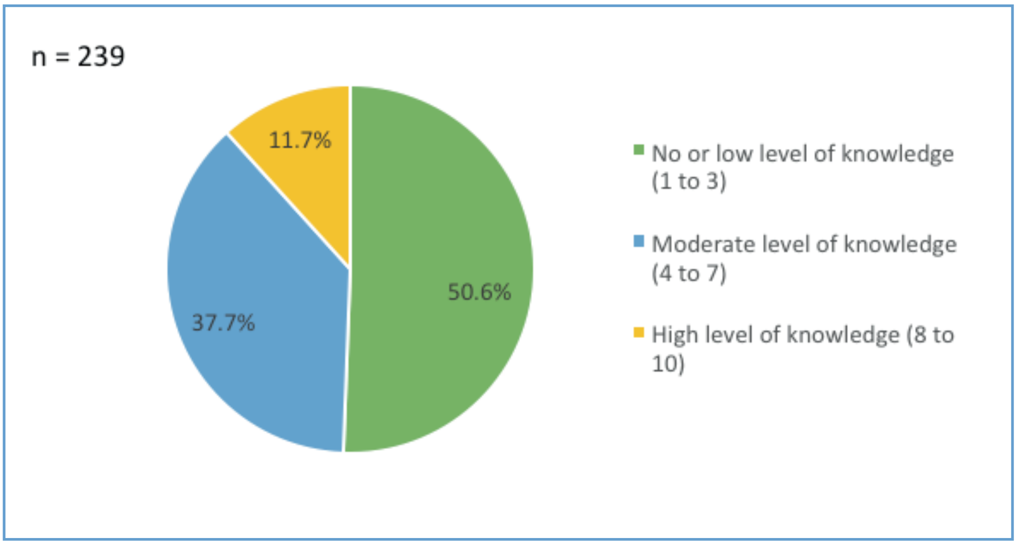

Figure 3: Self-rated knowledge of National Carers' Strategy

Family carers tended to have a lower level of knowledge of the NCS than other stakeholders (Fig. 4). Due to small sample sizes, it was not possible to determine whether there were marked differences between other stakeholder groups with respect to their self-rated knowledge of the NCS.

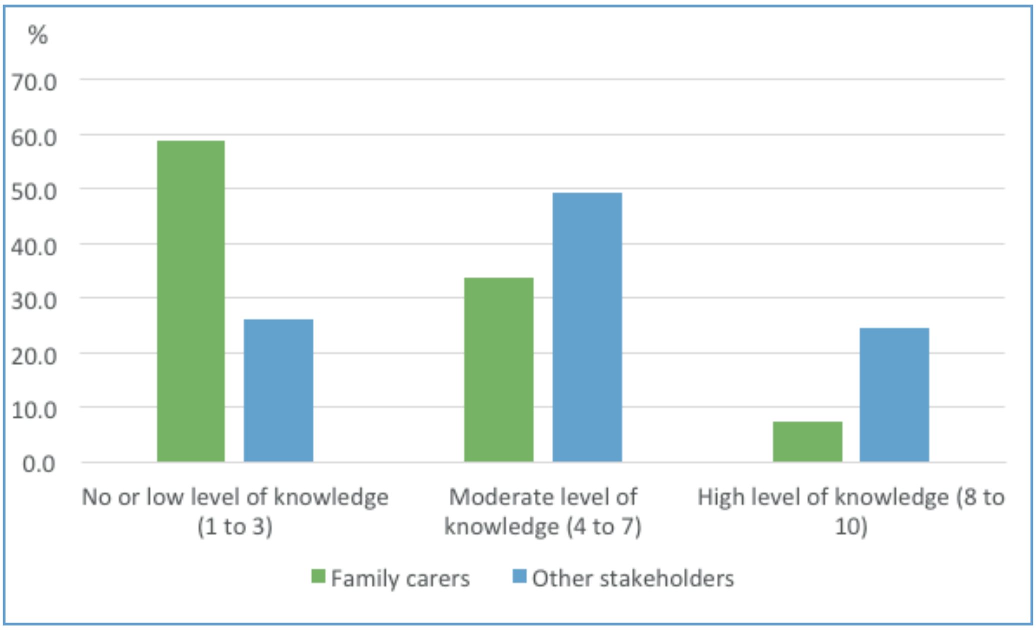

Figure 4: Self-rated knowledge of National Carers' Strategy, family carers compared to other stakeholders, % (n=239)

Second, respondents were asked if the NCS was professionally and/or personally relevant to them. A high proportion (79.4%) responded that the NCS was professionally and/or personally relevant to them. A substantial minority (14.9%) responded 'Don't know'.

Figure 5: Personal and/or professional relevance of National Carers' Strategy (n=242)

Third, respondents were asked how often, if ever, they had used the NCS to influence and/or reform service provision. Overall, 5% of respondents reported that they had used the Strategy 'often' or 'very often' to influence and/or reform service provision, 12.5% had used it 'sometimes' and more than three-quarters (77.1%) had 'rarely' or 'never' used it for this purpose.

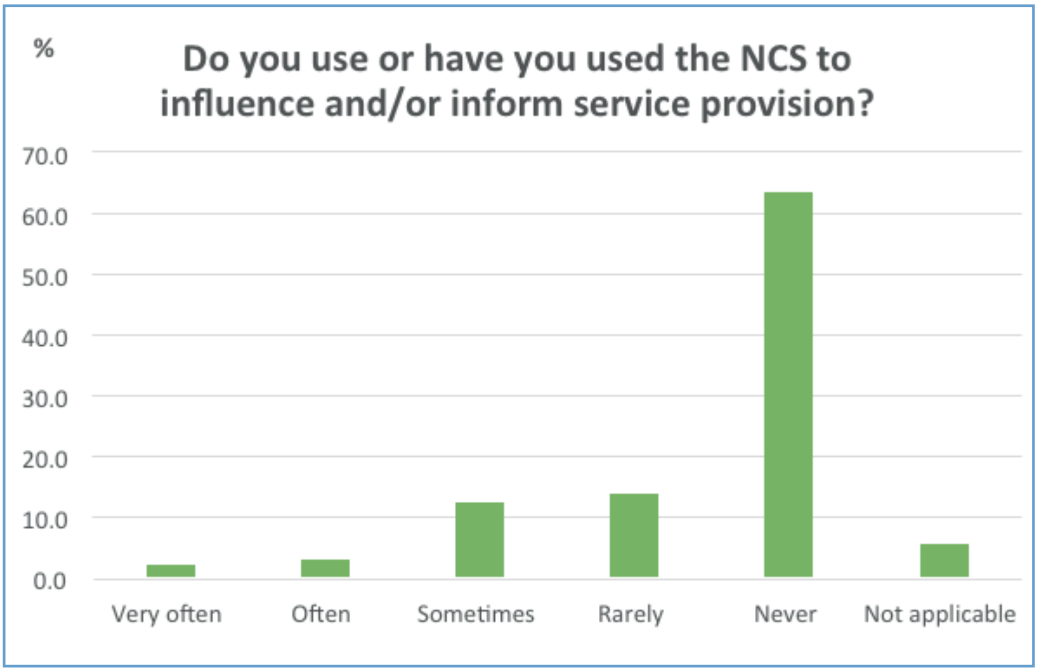

Figure 6: Use of National Carers' Strategy by respondents to influence and/or reform service provision (n=240)

Those using the NCS to influence and/or reform service provision included a mixture of policymakers, researchers, people working in a service provider organisation or not-for profit organisation, and family carers. Somewhat surprisingly, between 55% and 60% of policymakers, researchers, service providers and not-for-profit organisations had 'rarely' or 'never' used the NCS to influence and/or reform service provision. However, this rose to 83% for family carers (not shown).

3.3 Relevance of the 42 actions

The NCS includes an implementation roadmap containing 42 priority actions to be achieved on a cost-neutral basis in the short to medium term. This section outlines respondents' views on the relevance of the 42 actions and summarises respondents' additional comments. Of the 734 respondents, 405 (55.2%) answered questions about the relevance of the 42 actions.

In the NCS, each of the 42 actions relates to specific goals and objectives. This format is replicated below to present the results.

Goal 1: Recognise the value and contribution of carers and promote their inclusion in decisions relating to the person that they are caring for

Objective 1.1: Strengthen awareness and recognition of the role and contribution of carers at national, regional and local level

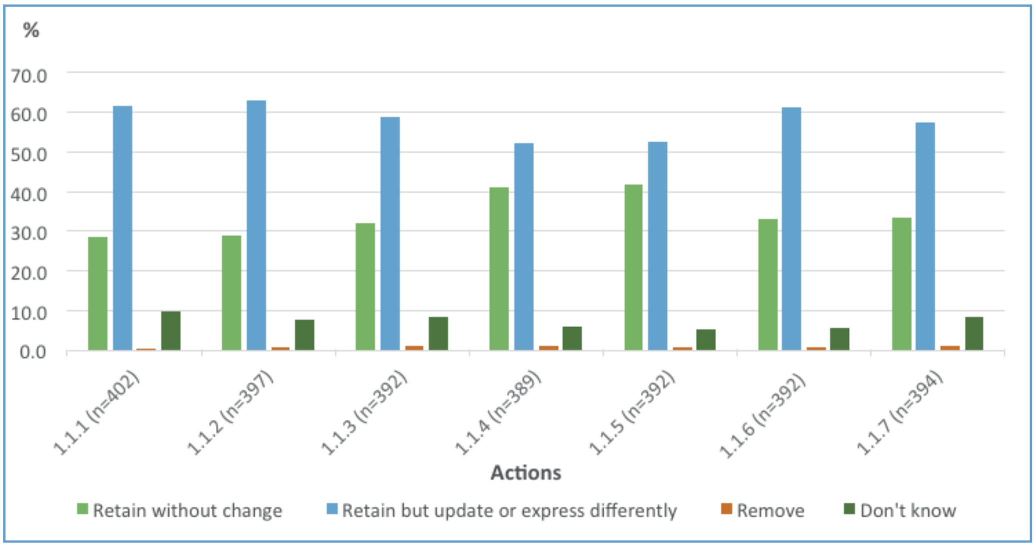

Figure 7: Relevance of Actions 1.1.1 to 1.1.7 under Objective 1.1 of NCS

Action 1.1.1: Promote a better recognition of the role and contribution of carers at a national level

More than one-quarter of respondents indicated that they wanted this action to be retained without change (28.4%). Almost two-thirds wanted it retained but updated or expressed differently (61.7%) (Fig. 7). Comments were received from 45 respondents.

Respondents highlighted that the numbers of family carers in Ireland currently providing, or who previously provided, care to family members are large. They also commented that some provide intense levels of care. Many respondents feel that family carers are usually ‘invisible and forgotten’, and the role and contribution they make goes unrecognised leaving them feeling ‘isolated’ and ‘excluded’. They want the significant role that family carers perform, and the reality of their lives, recognised, including by government and the general public. They would like the contribution that they make and its economic value acknowledged. They would like the wording of this action to include specific details about whom family carers are to be recognised by.

Recognition was described as a ‘vague’ and ‘nebulous’ term. For some, recognition means going beyond recognising family carers in speeches and celebrations of family carers. It means being recompensed for the contribution that family carers make to society. For others, it means having the needs of family carers assessed and adequate supports and resources put in place to help them provide care. For others, recognition means family carers, alongside person to whom they provide care, being involved in decisions that affect them. Some would like the action to closely mirror the phrasing in Objective 1.1 and include recognition at a regional and local level as well as at a national level.

Action 1.1.2: Ensure that carer’s needs are considered in the development of any policies (such as the Review of Disability Policy (DoH)), the National Positive Ageing Strategy (DoH, forthcoming), and the Children and Young People’s Policy Framework 2012–2017 (DCYA, forthcoming)

The vast majority of respondents indicated that they either wanted this action to be retained without change (29.0%) or retained but updated or expressed differently (63.0%) (Fig. 7). Comments were received from 31 respondents. Three main points were raised by respondents. First, several argued that the word ‘considered’ is too weak and suggested that it be replaced with a stronger word such as ‘included’, incorporated’, ‘central to’, ‘addressed’ or ‘embedded’. As one respondent pointed out: *‘if the needs of carers are not adequately met, then they cannot in turn, adequately support the person they care for’.* Other respondents wanted the diverse needs of family carers to be acknowledged. Others noted that some family carers do not have the skills or may be unable because of ill health to provide care. Sadly, some respondents felt that, despite this action, the needs of family carers are not considered in the development of policies.

Second, it was pointed out that the policies named in the action were not up to date. Two alternative suggestions were made: either (1) update the list of policies to include all relevant policies developed since 2012 (e.g. National Dementia Strategy) and those in development, or (2) remove references to specific policies. Third, several respondents stressed the importance of actively consulting with family carers regarding the development of any policies affecting them, but also on behalf of people they provide care to who may not be able to voice their views.

Action 1.1.3: Build on the work begun in 2011 to establish a comprehensive statistical profile of Family Caring in Ireland

The vast majority of respondents indicated that they either wanted this action to be retained without change (32.1%) or retained but updated or expressed differently (58.9%) (Fig. 7). Comments were included from 31 respondents.

This action was viewed as essential as a comprehensive statistical profile of family caring in Ireland would help to make family carers visible and highlight the valuable contribution that they make to society. While statistics were seen as crucial for identifying the needs of family carers and for service planning and resource allocation, the value of such statistics was questioned by one respondent.

One respondent would like to see more research on the actual costs incurred by family carers in relation to caring. Others would like statistics to highlight the number of family carers not receiving social welfare payments or to show the impact of the pandemic on family carers. Another would like the actual care work that family carers do to be better portrayed and communicated to government. Due to the reluctance of some people to self-identify as a family carer, one respondent suggested that since family carers are likely to be under-represented in the statistics, work in addressing this barrier should continue. It was pointed out that as well as the Census data, other data sources such as TILDA (The Irish Longitudinal Study on Ageing) are useful for building a statistical profile of family carers. 2012 had been set as an indicative timeframe for the completion of this action. However, several respondents commented that they did not know if this action had been completed or not.

Action 1.1.4: Continue to convene an annual carers forum to provide carers with a voice at policy level

The vast majority of respondents indicated that they either wanted this action to be retained without change (41.1%) or retained but updated or expressed differently (52.2%) (Fig. 7). Comments were included from 33 respondents. The overall consensus that the annual carers forum should continue to be convened was echoed in the comments, which showed that respondents felt it is critical that family carers are given a voice.

> *'Supporting and empowering the voice of the family carer is critical and must be sustained and facilitated.'*

However, concerns were expressed about whose voice is being heard at the forum.

There is a lack of awareness about the forum among some family carers, while others are not able to participate due to the time demands of caring. One respondent pointed out that family carers are not a homogenous group, e.g., the people they care for are different, and while some choose to take on a caring role, others fall into the role. This respondent stressed that a diversity of voices need to be heard. Several respondents suggested ways for enhancing the forum including allowing family carers to attend virtually, offering those who cannot attend alternative ways of having their voice heard, ensuring more transparency regarding the process of engagement, and ensuring that family carers receive feedback from the forum. Several respondents suggested that local fora would facilitate greater participation. Seven respondents felt that it would be valuable to have a forum more frequently than once a year.

While the forum provided a voice for family carers at policy level, several family carers in their comments asked: 'Is anybody listening?' There was a sense that unless family carers could see positive changes in their lives, the forum was providing family carers with a voice in only a 'tokenistic' way, leaving family carers feeling that they are 'shouting in the wind'.

Some felt that the forum on its own was not sufficient to provide a voice for family carers or to bring about change. One suggestion put forward was the appointment of a specific lead at Departmental level with responsibility for following up on the issues raised at the forum. Others felt the voices of family carers should be heard at all levels and stages of decision-making. For example, it was suggested that there should be family carer representation on all committees making decisions affecting family carers.

Action 1.1.5: Support national organisations representing the interests of carers

The vast majority of respondents indicated that they either wanted this action to be retained without change (41.8%) or retained but updated or expressed differently (52.6%) (Fig. 7). Comments were added by 23 respondents.

This action was seen as important because of the support that national organisations provide to family carers – ‘they keep us going’ – and the work these organisations do in promoting the interests of family carers and making their lives visible. Several respondents wanted more detail to be included on what ‘support’ means. In what ways are these national organisations supported? Does support include funding? One respondent suggested changing the word ‘support’ to ‘actively support’. Some wanted the national organisations supported to be named, while others wanted all organisations, not just national organisations, representing the interests of family carers to be supported.

One respondent suggested removing the words ‘the interests of’. Several comments related to the question of whose interests the national organisations are representing, with specific reference to the diversity of caring contexts and need. They stressed the importance of representing the interests of all family carers including those of former family carers. One respondent commented that while these national organisations are doing their best, sometimes, organisations’ interests (for example, organisations may be competing for limited funding) can overshadow the interests of family carers.

Barriers to membership of national organisations representing family carers were also raised. Such barriers include lack of awareness of these organisations and lack of time to join and become involved due to the demands of caring. Two respondents felt that national carer organisations are being ignored by policymakers. A further two respondents remarked that national organisations should not only be supported to represent the interests of family carers, but should be involved in policymaking decisions that impact family carers. Two family carers took the opportunity to express how unsupported they feel.

Action 1.1.6: Provide more proactive approaches to the identification of carers and to addressing their needs among staff and organisations (e.g. health and personal social service providers, and particularly primary care team members, community and education professionals)

Almost one-third of respondents wanted this action to be retained without change (32.9%) and close to two-thirds wanted it to be retained but updated or expressed differently (61.6%) (Fig. 7). Comments were added by 24 respondents.

Respondents stressed that this action was key for helping to maintain family carers' health and wellbeing, because of the high level of stress among family carers, and that targeted approaches are needed. Two respondents highlighted that better communication between services, both horizontally and vertically, and more collaborative working between health professionals, are needed for this action to be achieved. Another respondent suggested that involving family carers as experts by experience in the education and training of health care professionals would be beneficial. Another respondent highlighted that family carer training was also needed.

As the action mentions primary care specifically, a number of respondents commented on the nature of primary care provision in Ireland. Some commented that, although improvements have been made, primary care services remain under-resourced, are more reactive than proactive, and are more focused on responding to crises than on prevention. Two respondents felt that the term 'proactive approaches' was vague and too wide-ranging and that it would be helpful to focus on and specify those approaches that have been shown to work well.

The importance of holistic carer needs assessments was also highlighted. Respondents called for this to be specifically mentioned in this action and for the Single Assessment Tool (SAT)[2] to be implemented. Some respondents wanted more acknowledgement of family carer diversity and of those persons to whom they are provide care. A specific issue raised by some respondents was for home care workers and health professionals from minority ethnic communities to be afforded more visibility.

Action 1.1.7: Promote carer self-identification initiatives and encourage carers to formally identify themselves to service providers

One-third of respondents wanted this action to be retained without change (33.5%) and more than half wanted it to be retained but updated or expressed differently (57.4%). Almost one in ten gave 'Don't know' as a response (8.4%) (Fig. 7). Comments were added by 32 respondents.

This action was highlighted by some respondents as a high priority action that should be promoted and facilitated. Self-identification was seen as important because of the valuable role that family carers play in communicating with health professionals as the care partner who best understands the specific needs and wishes of the cared-for person. It was pointed out that not everyone wants to self-identify as a family carer. However, family carers would be more likely to self-identify if they knew what the benefits of doing so were, and this needs to be clearly communicated. Some questioned the value of self-identifying as a family carer when service providers do not have capacity to provide support to family carers. Others complained about a disconnect between policy and practice. On the one hand, people are being asked to self-identify as a family carer, while on the other hand family carers remain invisible at national level and some feel unsupported and that nobody cares. Others felt that this had to be a two-way process, with family carers encouraged to self-identify, while, at the same time, health and social care professionals should be proactively reaching out to family carers. They felt that this process could be supported through improved communication and collaboration between health professionals and services, and with clear pathways and processes for family carers to follow. One respondent suggested that any changes to this action could be informed by lessons from self-identification initiatives shown to have worked in Ireland and/or other jurisdictions.

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[2] The Single Assessment Tool is a comprehensive IT-based standardised assessment used to assess the health and social care needs of people (primarily those over the age of 65 years). https://www.hse.ie/eng/services/list/4/olderpeople/sat/

Objective 1.2 Include carers in care planning and decision-making forthose that they care for

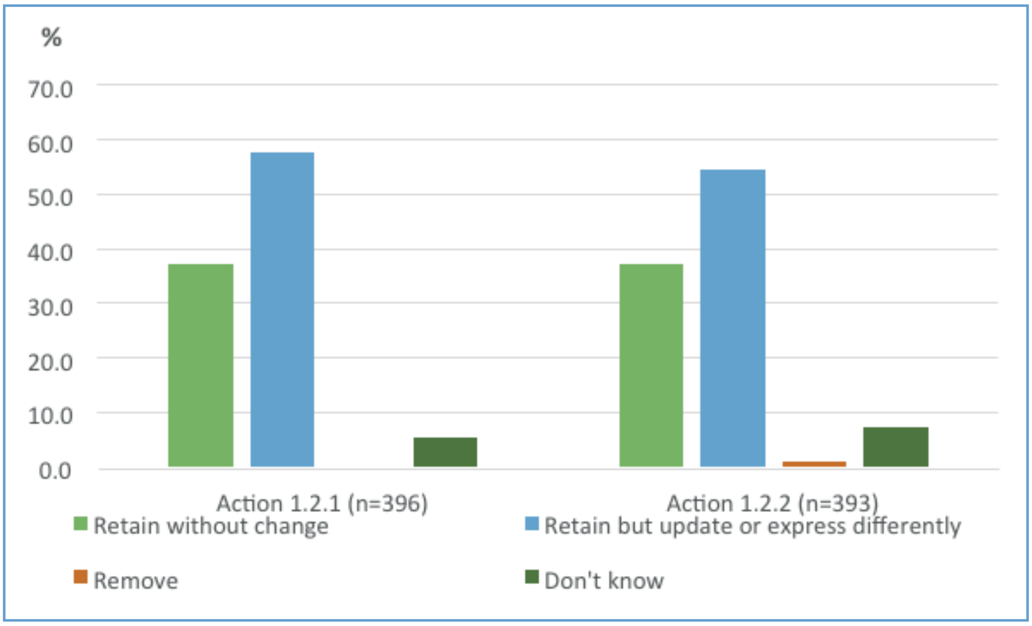

Figure 8: Relevance of Actions 1.2.1 and 1.2.2 under Objective 1.2 of NCS

Action 1.2.1: Involve carers, as appropriate, as care partners in care planning and provision by health and personal social service providers and particularly by the primary care team

More than one-third of respondents indicated that they wanted this action to be retained without change (37.1%) and more than one-half wanted it to be retained but updated or expressed differently (57.6%) (Fig. 8). Comments were received from 34 respondents.

This action was generally deemed to be necessary by respondents. The inclusion of the term ‘care partner’ was seen to be ‘integral’ and it was agreed that ‘carers should be treated as a care partner and be more central in planning and care provision’. The main reason given by respondents for involving family carers as care partners in care planning and provision by health and social services providers was that care is primarily provided by family carers and it is family carers (together with the person themselves) who tend to have detailed knowledge of the person, what is best for them and what their needs and wishes are.

Family carers reported different experiences of being involved as care partners at service level. One respondent reported that the family is involved in an annual review of their daughter's care, while another's experience was that communication with health professionals could be difficult. There were differing views on the extent to which family carers' voices are heard at the policy level as well. For example, one respondent commented that family carers are increasingly heard in relation to acute hospital care and home care. The potential of the End-Of-Life Survey,[3] currently in development by the Health Information and Quality Authority (HIQA), to facilitate the voices of bereaved family carers to be heard further was also highlighted. However, another respondent felt that family carers are ignored, as illustrated by their invisibility during the Covid-19 pandemic. Given the responsibilities that family carers have, two respondents questioned the leading role given to health and personal social services providers for care planning and decisions in this action. They would like to see family carers and health and social service professionals 'working together' or more 'co-production' of care planning and decisions. It was believed that training for staff and family carers is needed with respect to what this involved.

Action 1.2.2: Identify carers and their involvement in discharge planning, including their details provided in discharge letters to GPs

This action was also seen as necessary, especially since family carers are often the main provider of care when a person is discharged home. Two respondents suggested that the action could be slightly reworded to read 'Identify and involve carers in discharge planning …'. It was advised that staff and family carer training about what the discharge process involves was necessary. One respondent asked that family carers be identified and involved not only for the purposes of discharge planning but for the duration of care within acute hospitals, especially in cases where the person admitted has a cognitive impairment. Respondents reported differing experiences of discharge planning. One family carer remarked that in their experience 'discharge always negotiated/agreed after case made/discussed with carer by hospital staff'. However, others highlighted that family carers can experience the discharge process in busy hospital settings as challenging. According to these respondents, discharge can be especially challenging when hospital staff are inexperienced or communicate poorly, where families feel under pressure from hospital staff for the person to be discharged home prematurely (in their view), or when adequate in-home or community-based supports are not in place.

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[3] https://yourexperience.ie/end-of-life/about-the-survey/

Respondents wanted it noted that there may be more than one family member involved in the person's care, which can present its own challenges. Respondents asked that discharge planning be informed by a holistic assessment of a person's needs and that the needs of family carers be considered as well. Before discharge takes place, family carers wanted more time with health professionals, more information and better communication about changes to the person's care, e.g. use of catheter, medication changes. Family carers would also like to see more integration of hospital and community services, with follow-through after discharge. Some respondents wanted the action to specify that family carers' details are provided to the GP only with their consent. In addition to the provision of their details to GPs, family carers would like GPs to follow up on addressing their needs and to be signposted to family carer supports.

Objective 1.3: Recognise the needs of carers by the provision of income supports

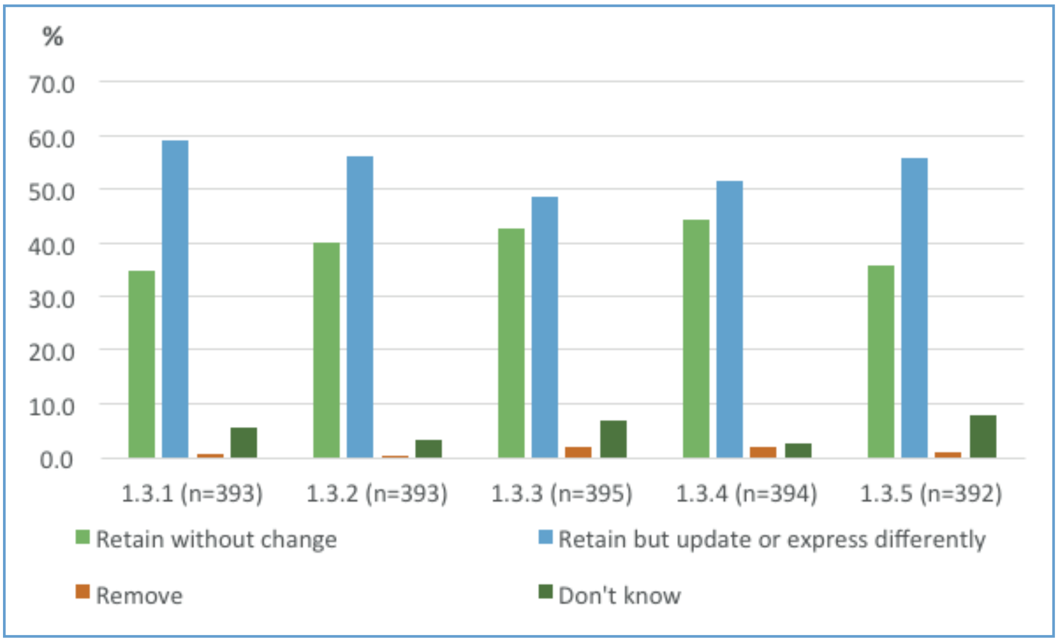

Figure 9: Relevance of Actions 1.3.1 to 1.3.5 under Objective 1.3 of NCS

With respect to Actions 1.3.1 to 1.3.5, a relatively large number of respondent comments related to Carer's Allowance as a model of income support for family carers and there were many calls for its reform. Key among the issues raised was the large number of family carers who do not qualify for Carer's Allowance because of the means test, and the assessment of household rather than individual income.

Action 1.3.1: Provide regular benefits advice sessions and information through the application process

The vast majority of respondents indicated that they either wanted this action to be retained without change (34.9%) or retained but updated or expressed differently (59.0%) (Fig. 9). Comments were received from 43 respondents.

Most comments provided under this action related to Carer's Allowance as a model of income support for family carers, as referred to above. However, some comments related specifically to Action 1.3.1. These comments highlighted the value of advice sessions and information. One respondent found the application process for family carer income supports to be 'daunting', and another suggested that the application process could be simplified to make it less stressful. Respondents argued that advice sessions and information provision should continue after the application process is complete, as family carers' circumstances can change over time and information and advice on income supports for family carers are needed at different junctures of caring. One respondent felt that advice sessions and information on income supports could be linked in with information and advice on other supports for family carers. This respondent also highlighted the important role that health and social care professionals can play in disseminating such information and providing advice. Other respondents highlighted that finding the time to attend advice sessions can be extremely difficult due to caring demands. They stressed that different modes of communicating information and advice would be useful. One respondent suggested that the action could be strengthened by replacing 'provide …' with 'ensure that carers have access to …'

Action 1.3.2: Ensure that carers can access benefits advice as early as possible when their caring role begins

The vast majority of respondents indicated that they either wanted this action to be retained without change (40.2%) or retained but updated or expressed differently (56.2%) (Fig. 9). Comments were received from 27 respondents. Respondents considered this action to be necessary and that it could be enhanced, for example, by ensuring that benefits advice was easy to understand. They recommended that key differences between Carer's Allowance and Carer's Benefits are communicated clearly. Accessing advice as early as possible was seen to be especially important for family carers of people who develop a cognitive impairment. For these family carers, there should be a greater emphasis placed on communicating the benefits of getting advice early on. Respondents felt that access to benefits advice should be available throughout the caring role. Some respondents pointed out that, while benefits advice is an important aspect, this has limited benefit when the application process itself is complicated and onerous. Respondents suggested that more concrete information on how this action is be achieved would be helpful. The important role that carers organisations such as Family Carers Ireland play in this regard could be acknowledged and there could be more encouragement for health and social care professionals to take a more proactive role in providing such advice to family carers. Some respondents commented on waiting times, and the points they raised are included under Action 1.3.4.

Action 1.3.3: Publicise more widely that Carer's Allowance can be shared by two carers providing care on a part-time basis

Close to 90% of respondents wanted this action to be retained without change (42.8%) or retained but updated or expressed differently (48.6%) (Fig. 9). Comments were added by 30 respondents. Some respondents felt that this action was 'absolutely necessary' and some pointed to the need for this information to be publicised more widely. Incidentally, five respondents remarked that they did not know that Carer's Allowance could be shared between two carers providing care on a part-time basis. One respondent suggested replacing 'publicise more widely that …' with 'ensure that all carers know that …' One respondent would like the action to include more information about how this information would be publicised and to whom. Citizens Information[4] was highlighted as a useful vehicle for publicising this type of information.

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[4] https://www.citizensinformation.ie/en/

Action 1.3.4: Continue to work to reduce waiting periods for processing of Carer's Allowance applications and appeals

The vast majority of respondents indicated that they either wanted this action to be retained without change (44.2%) or retained but updated or expressed differently (51.5%) (Fig. 9). Comments were received from 27 respondents. The issue most frequently raised in comments was that the waiting time for processing Carers' Allowance continues to be 'too long'. In the experience of one respondent, it had taken nine months for Carer's Allowance to be approved, while another questioned whether the issue of long waiting times still persists. Respondents highlighted that when waiting times are protracted, family carers and their families are impacted financially, and delays are experienced as stressful and frustrating. Several respondents suggested that a maximum waiting time for applications to be processed should be specified, and performance against this measured. Some wanted this action to be stronger such as by including a commitment to resolving issues relating to lengthy waiting times. One respondent commented on the process itself and suggested that it should be simplified and streamlined. Another reported that their experience of the process had been extremely negative. Only one respondent commented on the appeals process, noting that there is often a reluctance among applicants to appeal and that guidance on the appeals process is needed. Three respondents highlighted that, because of means testing, many family carers are ineligible for the Carer's Allowance.

Action 1.3.5: Review existing transition arrangements for carers at the end of their caring role

The vast majority of respondents indicated that they either wanted this action to be retained without change (35.7%) or retained but updated or expressed differently (55.9%) (Fig. 9). Comments were received from 26 respondents.

Respondents stressed that family carers face a range of issues when caring comes to an end, and that, in addition to income supports, other supports are needed. Such supports include training or retraining for workforce re-entry, and support with job seeking, personal development, and emotional and psychological issues, and these supports should be available to access at a local level. Some respondents wanted support with planning for when caring comes to an end, including for older family carers who are planning for the future care of a child when they die. One respondent expressed worry about the impact of caring on pensionable income in later life. It was pointed out that family carers do not always choose when transition out of caring takes place. Some family carers will continue to care even when demands and stresses of caring are huge or because alternative caring arrangements are not available. Respondents wanted family carers to be treated compassionately and, since experiences and circumstances are different for every individual, the transition should be assessed and arrangements made on a case-by-case basis. Some respondents wanted to know what the review of existing transition arrangements for family carers at the end of their caring role had found, and if new transition arrangements had been put in place. It was suggested that findings from the review inform this action in the next iteration of the National Carers' Strategy.

Goal 2: Support carers to manage their physical, mental and emotional health and wellbeing

Objective 2.1 Promote the development of supports and services to protect the physical, mental health and wellbeing of carers

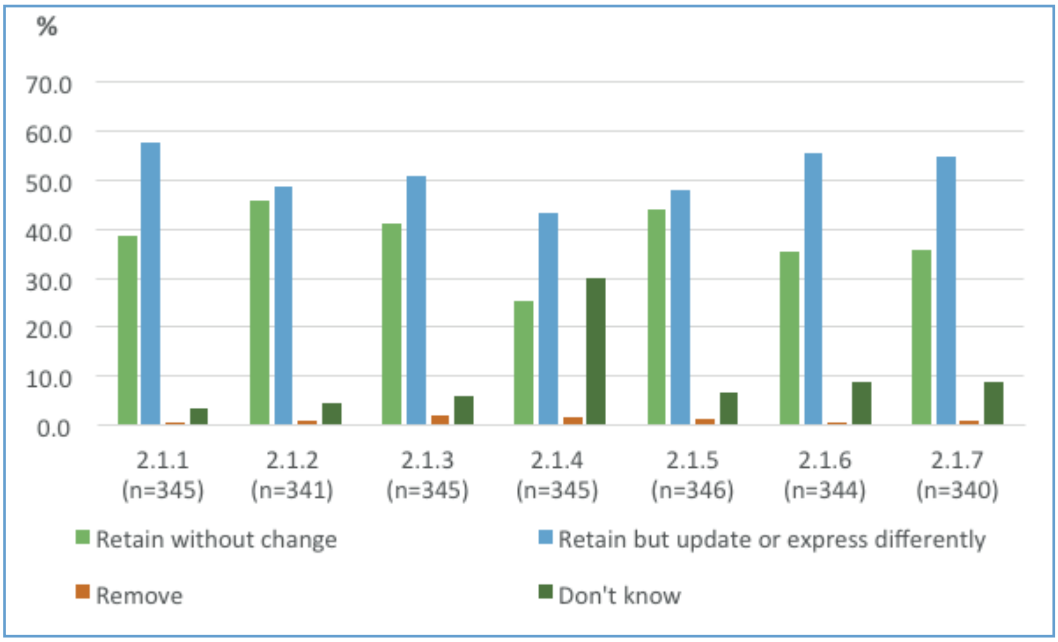

Figure 10: Relevance of Actions 2.1.1 to 2.1.7 under Objective 2.1 of NCS

Action 2.1.1: Raise awareness among health and personal social service providers of the physical and emotional health issues that family carers may experience

More than one-third of respondents indicated that they wanted this action to be retained without change (38.1%) and more than one-half wanted it retained but updated or expressed differently (57.7%) (Fig. 10). Comments were received from 36 respondents. Respondents described this action as ‘paramount’, but wanted it broadened and strengthened. In addition to physical and emotional issues, they wanted it broadened to include psychological or mental health, and social and financial issues. Some respondents expressed how lonely and isolating family caring can be:

> *‘Having been a carer for my parents I am aware of how forgotten a carer can become in the health care system and in the family also. This can be a very lonely and relentless place to be’*
>
> *‘Caring is an extremely isolating journey’*

It was suggested that this action could be linked to the action on carer needs assessment (Action 2.1.3). Respondents stressed that many family carers experience physical and emotional health issues on an ongoing and sometimes daily basis, and that this needs to be recognised, especially since these issues have been exacerbated during the Covid-19 pandemic. Respondents pointed out that such issues can be experienced by former family carers as well as current family carers, and that family circumstances can be very different, a factor that needs to be taken into account. Respondents wanted this action to be broadened to include raising awareness among the public and education providers as well as health and personal social service providers.

A key sentiment expressed was that this action was not strong enough, that ‘raising awareness’ is not sufficient. This action also needs to focus on the requirement for service providers to take action and put services and supports in place and proactively promote and implement interventions to address issues family carers are experiencing, and to make these supports available to everyone on the basis of need, irrespective of income.

Action 2.1.2: Encourage carers to attend their GP for an annual health check

Close to one-half of respondents indicated that they wanted this action to be retained without change (46.0%) and almost another half wanted it retained but updated or expressed differently (48.7%) (Fig. 10). Comments were received from 40 respondents.

This action was seen as important because the care a person receives is impacted by the health of the family carer. However, while caring place high demands on and often impacts health, family carers often neglect their own health. Respondents suggested that general practitioners (GPs) could be encouraged to identify patients who are family carers from their records and send out an invitation reminding family carers to attend for an annual health check. While some family carers said that they personally would not want this, one respondent felt that it would be better if the health check took place bi-annually. Some wanted the health check to be more than a medical check. They wanted it to include an assessment of the family carer's physical, psychological and emotional wellbeing. They would like the GP to make recommendations for self-care to stay well and connected, and to refer onwards to other health professionals or supports if necessary.

Some respondents took issue with the word 'encourage', as it failed to acknowledge barriers preventing family carers attending their GP for an annual health check. Respondents highlighted two main barriers. The first, raised by 15 respondents, concerned the fees incurred by family carers who do not qualify for a medical card or a GP visit card. Even with encouragement, some family carers would not be able to attend because of these charges. The second issue related to time, with six respondents saying that it is 'difficult to find the time' or similar. Related to this issue was the lack of support or a replacement carer to take over from the family carer and enable them to attend an annual health check.

> *'This is only possible if there is someone on hand to look after the care recipient while the family carer goes to the doctor. This is not always the case in my experience.'*

House calls by GPs was suggested by one respondent as a way to overcome this barrier.

Action 2.1.3: Develop and roll out a single assessment tool for older people and ensure that the views of carers as well as the people they care for are taken into consideration

The vast majority of respondents indicated that they either wanted this action to be retained without change (41.2%) or retained but updated or expressed differently (51.0%) (Fig. 10). Comments were received from 27 respondents. A comment from one respondent was that it would be 'wonderful' to see the Single Assessment Tool (SAT) for older people developed and rolled out. It was pointed out that the Common Summary Assessment Report (CSAR),[5] currently being used to assess a person's care needs, does not include an assessment of their family carer's needs. Other respondents would like this action updated to reflect the current status of the

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[5] A Common Summary Assessment Report (CSAR) is a form that records assessment information from various sources, creating a single, permanent and transferable report of the information relevant to a decision on an individual's care needs at a given point in time. This report is being replaced by the Single Assessment Tool (SAT) (HSE, 2018).

SAT and the carer needs assessment component, with a clear timeframe for its implementation and evaluation. Respondents also highlighted that training of staff in the use of SAT as an assessment tool is an issue. It was requested that family carers be involved in the development and rollout of SAT. Some respondents wanted the limitations of SAT (e.g. limited information collected on family carers) acknowledged. Importantly, the assessment must be followed up with action. Respondents questioned why this action was limited to older people and their family carers and asked that the action be revised to include all groups of people in receipt of care, including children with disabilities and adults aged under 65 years with disabilities, and their family carers.

Action 2.1.4: Continue to implement the recommendations of the Home Solutions Report (13) on telecare

One-quarter of respondents indicated that they wanted this action to be retained without change (25.1%) and 43.2% wanted it or retained but updated or expressed differently (Fig. 10). More than one-quarter of respondents indicated that were unable to assess the relevance of this action. Comments were received from 18 respondents. Several respondents had never heard of the Home Solutions Report referred to in this action, but several others remarked on the importance of telehealth. Given the experience of the Covid-19 pandemic, which has demonstrated the value and potential of telehealth, respondents felt that it would be important to develop this further in the next NCS. While one respondent said that telehealth was non-existent, others gave examples of new assistive technology or telehealth initiatives that had been developed across the country such as the Memory Technology Resources Rooms or by organisations such as Alone to illustrate how far this area has advanced. It was suggested that the word ‘continue’ should be removed or the action be revised to ‘promote the use of assistive technology and telecare to assist both service users and carers’.

Action 2.1.5: Promote awareness of adult and child protection services that are in place

The vast majority of respondents indicated that they either wanted this action to be retained without change (44.2%) or retained but updated or expressed differently

(48.0%) (Fig. 10). Comments were received from 14 respondents. A key point raised by respondents was that, while there is awareness of adult and child protection services among health professionals and in services, awareness among family members is low and needs to be improved. To reflect this, it was suggested the action could be reworded to read: ‘Ensure that all carers are aware of …’ and be more specific about who is responsible for promoting awareness. It was pointed out that awareness on its own is not sufficient; education and training on adult and child protection services is also needed. There also needs to be a commitment to putting adequate adult and child protection services in place. It was felt that this action would need to be updated regularly to reflect changes in legislation and practice.

Action 2.1.6: Review the Fair Deal system of financing nursing home care with a view to developing a secure and equitable system of financing for community and long-term care which supports older people to stay in their homes

More than one-third of respondents indicated that they wanted this action to be retained without change (35.5%) and slightly over one-half wanted it retained but updated or expressed differently (55.5%) (Fig. 10). Comments were received from 26 respondents. This action was described as the ‘single, most urgent need’, ‘this should be number 1’. There was a sense from the responses that home is often the best place for older people (e.g. ‘I think it’s best older people remain in their own homes’). However, respondents felt that the current system of financing long-term care is biased towards nursing home care and ‘unfair’.

The development of a Statutory Home Support Scheme (Institute of Public Health in Ireland, 2018) was seen as essential for enabling older people to remain at home, for preventing premature admission into nursing homes, and for reducing family caregiver stress and burnout. However, respondents expressed frustration at the delays and slow progress made with respect to a scheme that ‘was to be piloted in 2020’. It was stressed that in the new scheme, home supports must be person-centred, tailored to the needs of the person and available at night if required. Respondents expect that home care will be cheaper than nursing home care, but want care allocated at a level that meets all of the person’s needs. For example, people with high levels of dependency living at home requiring 24/7 care need to be allocated a high level of formal home care. It was also stressed that the needs of family carers, as well as those requiring care, must be assessed. Issues such as whether or not private providers should be involved in delivering home care, and the need for training of and good working conditions for home care workers, were also raised.

Action 2.1.7: Progress the development and implementation of national standards for home support services, which will be subject to inspection by the Health Information and Quality Authority (HIQA)

The vast majority of respondents indicated that they either wanted this action to be retained without change (35.6%) or retained but updated or expressed differently (54.7%). Comments were received from 25 respondents. Respondents felt that national standards for home support services are necessary and expressed concern that home support services are often unmonitored. While one respondent appeared satisfied that this action is currently being progressed, others felt that this action needs to be progressed with more urgency and that an end date and resources be attached. Respondents believed that this action needs to happen as part of a wider reform of home support services. They hoped that the standards and inspections, when introduced, would be ‘realistic’ and lead to greater standardisation of home support services across the country. Two respondents, however, expressed concern that the introduction of standards and inspections would not address the current under-provision of home support services and felt it would be better to properly resource home supports instead. Several questions were raised concerning the introduction of national standards for home support services, with inspections by HIQA, namely:

- How would this link in with reviews of homes supports that PHNs are currently undertaking?

- Would it lead to more bureaucracy?

- Would HIQA have responsibility for investigating individual cases brought to their attention?

Concerns were also raised regarding the model of regulation that would be introduced. Three respondents worried that there would be inspections of people's homes which would put additional pressure on family carers.

> *'Home life needs to be home life. I wouldn't like the home to become too clinical with inspections putting pressure on carers who already are carrying so much responsibility'*

> *'While caring situations do need monitoring, introducing HIQA to a private home situation is additional pressure on a family carer'.*

Objective 2.2 Support children and young people with caring responsibilities and protect from adverse impacts of caring

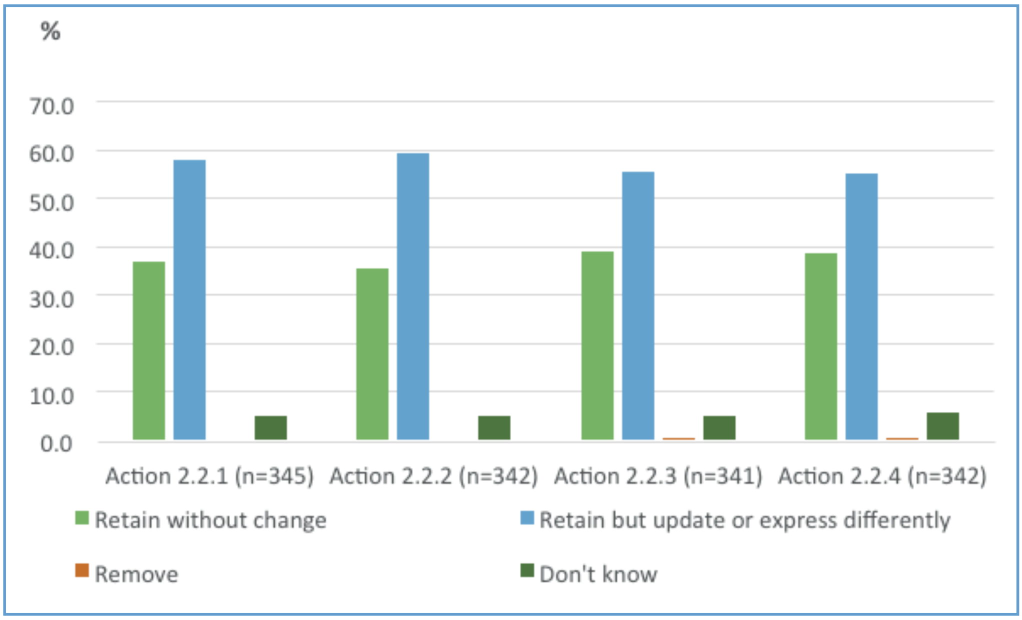

Figure 11: Relevance of Actions 2.2.1 to 2.2.4 under Objective 2.2 of NCS

Throughout the feedback on the actions under Objective 2.2, respondents frequently commented that children should not be caring.

Action 2.2.1: Raise awareness and understanding among education providers of the signs that children and young people have caring responsibilities and the impact of caring on them

The vast majority of respondents indicated that they either wanted this action to be retained without change (37.1%) or retained but updated or expressed differently (58%) (Fig. 11). Comments were received from 25 respondents.

This action was highlighted as ‘very important’. The challenges for, and impacts on, children and young people with caring responsibilities was acknowledged by respondents. Respondents highlighted that the caring responsibilities that children and young people have are varied and that many children and young people with caring responsibilities do not self-identify as family carers. A key point raised by respondents was that raising awareness and understanding among education providers is just a first step. This needs to be augmented with training and guidance for education providers on what the signs are, on what impact caring is having and how to respond, with concrete steps that can be taken outlined. However, one respondent felt that the meaning of words ‘of the signs of’ was unclear. Another could not see how education providers could make a difference. In addition to training and guidance, it was stressed that supports and resources need to be in place, and that investment is needed for this to happen.

Some respondents thought that children and young people under 16 years of age should not have to provide care, and that children and young people would not have to be full-time family carers if the right supports were in place. One suggestion was to make a special liaison person available to work with children and young people with caring responsibilities. This person could help with practical issues and/or address psychological or emotional problems that they may be having, and support personal growth and development, confidence building and inclusion. Some respondents felt that this action should be extended to those providing education to adult learners with caring responsibilities, as well as to youth workers and the public generally. Another suggestion was that a system of rewarding children and young people with caring responsibilities could be put in place as a recognition of the care they provide.

Action 2.2.2: Encourage statutory agencies to review the way that they respond to children and young people with caring responsibilities

The vast majority of respondents indicated that they either wanted this action to be retained without change (35.7%) or retained but updated or expressed differently (59.4%) (Fig. 11). Comments were received from 14 respondents.

Respondents commented that the word ‘encourage’ in this action was far too weak and should be replaced with a stronger word such as ‘require’ or ‘commit’ or ‘mandate’. They also suggested that statutory agencies should work according to a model of continuous improvement. Such agencies may require education with regard to how they respond to children and young people with caring responsibilities, and about the harsh realities of their lives. Respondents argued that statutory agencies should respond in a compassionate and understanding way and that it would be useful to have guidance to underpin how they respond. One respondent would like the statutory agencies and the contexts in which they respond to be specified.

Action 2.2.3: Identify support services needed by children and young people with caring responsibilities and create mechanisms for young carers tocontact service providers

The vast majority of respondents indicated that they either wanted this action to be retained without change (39.0%) or retained but updated or expressed differently (55.7%) (Fig. 11). Comments were received from 13 respondents.

In their previous comments on Action 2.2.1, respondents had already raised the issue of supports for children and young people with caring responsibilities. One respondent said that it was a ‘travesty’ if this action had not been implemented and if supports had not been put in place. The main issue raised by respondents was that children and young people with caring responsibilities lack awareness of what supports are available and the know-how to make contact with service providers. The onus should be on service providers to reach out to and actively engage with children and young people with caring responsibilities and inform them of support services. This could be done virtually or in person. First and foremost, it was felt that supports should be put in place to relieve children and young people of their caring responsibilities. The importance of consulting with children and young people with caring responsibilities about actions relevant to them in the NCS was stressed by one respondent.

Action 2.2.4: Investigate and analyse the situation of younger people undertaking caring roles

The vast majority of respondents indicated that they either wanted this action to be retained without change (38.6%) or retained but updated or expressed differently (55.3%) (Fig. 11). Comments were received from 18 respondents. Respondents commented that this was an important action and would like to know that the findings from any investigation and analysis of younger people in caring situations was used to inform the design and development of appropriate support services. It was also felt that this action should include a focus on finding out why children are in caring roles and whether there is stigma attached. Action should be taken to investigate and analyse the supports available to children and young people with caring responsibilities. Respondents felt that such studies should include both quantitative and qualitative approaches and that children and young people with caring responsibilities should be involved.

Goal 3: Support carers to care with confidence through the provision of adequate information, training, services and supports

Objective 3.1 Promote the availability of user-friendly and timely information and advice

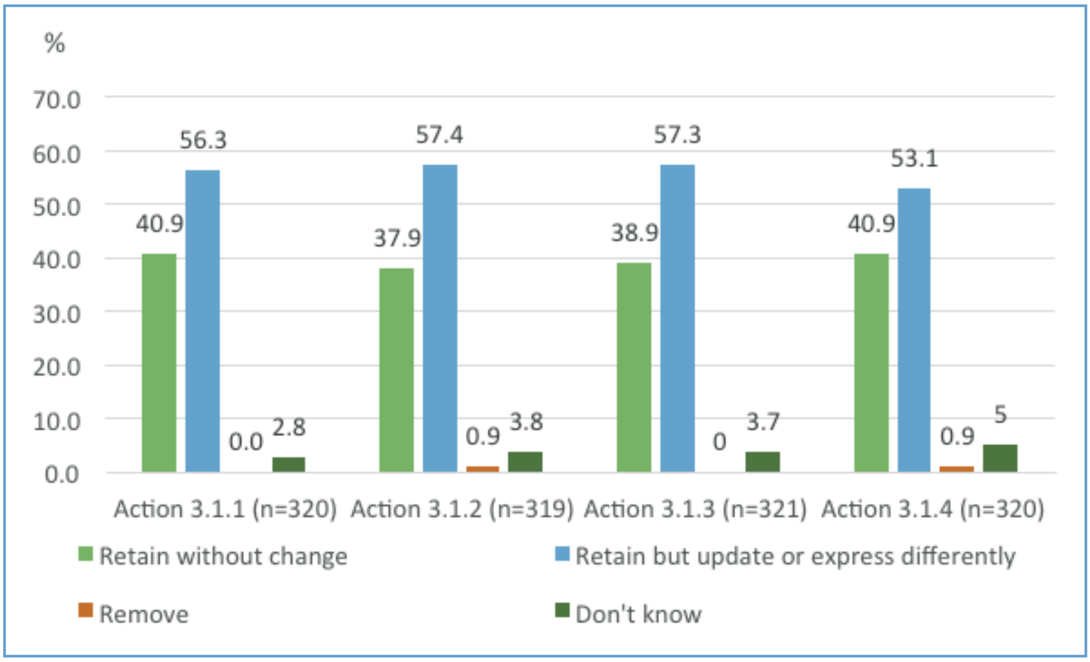

Figure 12: Relevance of Actions 3.1.1 to 3.1.4 under Objective 3.1 of NCS

Action 3.1.1: Ensure frontline staff in key 'first contact' agencies such aslocal authorities, local health offices and health and personal social service providers have the correct information to be able to sign-post carers to other services as appropriate

The vast majority of respondents indicated that they either wanted this action to be retained without change (40.9%) or retained but updated or expressed differently (56.3%) (Fig. 12). Comments were received from 23 respondents.

This action was regarded as a 'great idea' or an 'excellent suggestion' and information as 'power'. Respondents felt that services are still too fragmented and that some staff lacked information on services available for family carers. However, they acknowledged that there had been significant improvements with increased availability of information online. The importance of staff training in relation to family carers and their needs was highlighted as a prerequisite, with one respondent suggesting that this action could be incorporated into an action on staff training about family carers.

Equipping family carers to ask the right questions was also seen as important. The value of having a key contact as soon as possible after a diagnosis is made was also highlighted. One respondent recounted her positive experience when living in Scotland of being provided with a Dementia Advisor as the key contact after her mother was diagnosed with dementia, and would like to see a similar initiative in Ireland. The experience of another was that high turnover of staff means that family carers are continually having to get to know the new person appointed as key contact.

Respondents stressed the importance of information providers following up information-giving with action. They also highlighted how critical it is to have links between different health professionals and service providers, especially links between GPs and other supports, as well as the signposting role of information providers. Two respondents wanted to know how it would be ensured that frontline staff have the correct information and how would it be shown that this action had been achieved.

Action 3.1.2: Review material (paper and Internet based) available to carers and investigate (in conjunction with carer's representative organisations) how more comprehensive information materials dedicated to carers' needs can be developed and distributed to service providers likely to be a carer's first point of contact

The vast majority of respondents indicated that they either wanted this action to be retained without change (37.9%) or retained but updated or expressed differently (57.4%) (Fig.12). Comments were received from 24 respondents.

While one respondent remarked that there had been significant improvements with respect to this action, another felt that improvements were still needed. Respondents commented on how much there is to know as a family carer and how hard it is to keep up to date with all the information. The importance of having easy-to-understand, up-to-date information was stressed. Such information should also be easily understood by people with literacy difficulties and be available in different languages. GPs were identified by one respondent as most suitable for distributing material, as they are likely to be the first point of contact for many family carers. Contact with family carers was regarded as equally important as information. Several respondents would like it stated that material reviewed or developed would be carried out 'with' family carers as well as organisations representing family carers. Some respondents would like to know what the outcomes of this action were.

Action 3.1.3: Ensure that the information needs of sub-groups of carers, such as older carers, children and young people with caring responsibilities, carers in rural areas are addressed

The vast majority of respondents indicated that they either wanted this action to be retained without change (38.9%) or retained but updated or expressed differently (57.3%) (Fig. 12). Comments were received from 13 respondents.

Respondents felt that this action was definitely needed, but were of the view that additional sub-groups of family carers also need to be named. Sub-groups named should include, for example, family carers from the Traveller community, Black and Ethnic Minority communities, migrant communities, family carers who have a disability, LGBT family carers and family carers of people with rare or less common diseases. It was stressed that addressing information needs requires dialogue with family carers, regular contact and review of information needs, and needs to be backed up with supports. One respondent identified the public health nurse (PHN) as a health professional with a key role in ensuring the information needs of sub-groups of family carers are addressed.

Action 3.1.4: Proactively collate and disseminate information about services and supports available at a local level for carers

The vast majority of respondents indicated that they either wanted this action to be retained without change (40.9%) or retained but updated or expressed differently (53.1%) (Fig. 12). Comments were received from 20 respondents.

This action was seen by respondents as vital and urgently needed. They would like the information collated on services and supports at a local level kept up to date. Family Carers Ireland was identified as excellent for disseminating such information.

However, many family carers continue to struggle to get information, especially about entitlements to services and supports. According to one respondent:

> *‘This is the key and most important element. There is little point in having lots of information unless carers know about it and have easy access to it. We have usually received this type of information through word of mouth rather than from some official source.’*

Respondents would like service providers to proactively reach out and contact family carers with information on services and supports available at local level. However, one of the difficulties is that services and supports needed by family carers are not always available in every area.

Objective 3.2 Provide relevant and accessible carer training opportunities for carers

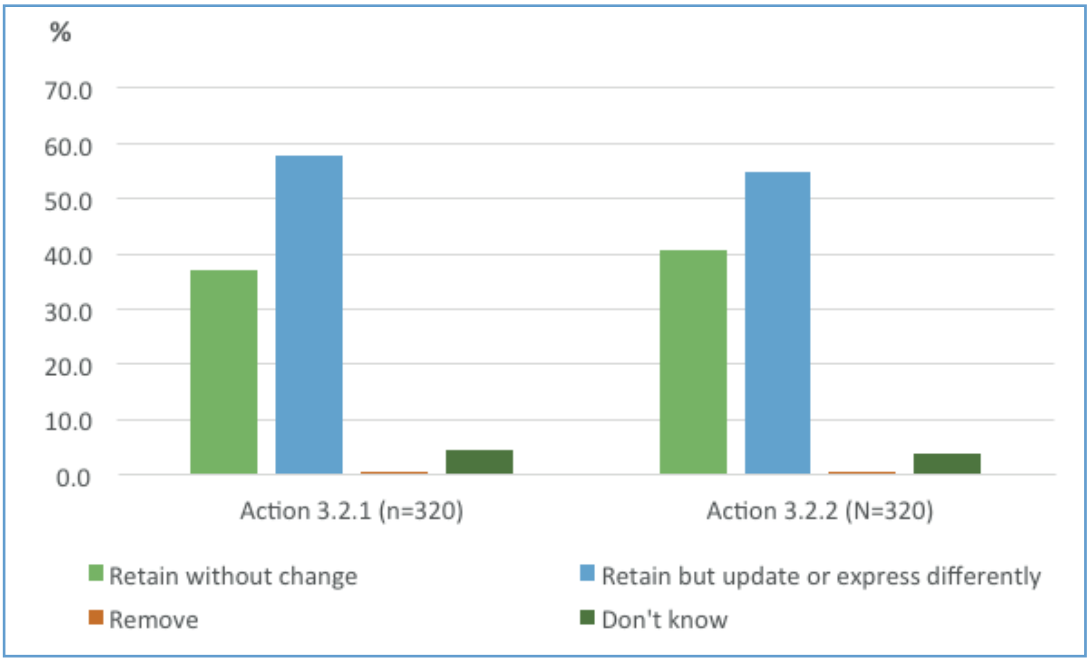

Figure 13: Relevance of Actions 3.2.1 and 3.2.2 under Objective 3.2 of NCS

Action 3.2.1: Identify gaps in the content of current training programmes for carers (in conjunction with carers' representative organisations)

The vast majority of respondents indicated that they either wanted this action to be retained without change (37.2%) or retained but updated or expressed differently (57.8%) (Fig. 13). Comments were received from 19 respondents.

Some respondents requested that the action be amended to include the participation of family carers, as follows:

Identify gaps in the content of current training programmes for carers (in conjunction with carers and carers' representative organisations).

The need for better promotion of training programmes for family carers was highlighted, especially by health professionals in all healthcare settings. Indeed, three family carers commented that they had never been offered any training. It was suggested that the development of a training plan for family carers would be useful. Manual handling training for family carers was mentioned specifically by two respondents.

Others would like to know if gaps had been identified and what training programmes had been developed to address these gaps. Some respondents highlighted that family carers can often find it difficult to attend training programmes due to caring demands and/or timing of the training. Respondents would like access to online training programmes, distance learning options, the provision of training on a more flexible basis, and supports to allow them to attend training.

It was pointed out that family carers are not just recipients of training, but many have a role to play in providing training, e.g., training home care workers to provide care. It was also pointed out that training on its own is not sufficient and family carers need hands-on practical support to assist them in their caring role.

Action 3.2.2: Enhance the accessibility of education and training courses through the use of face-to-face, online and distance learning options

The vast majority of respondents indicated that they either wanted this action to be retained without change (40.6%) or retained but updated or expressed differently (55.0%) (Fig. 13). Comments were received from 17 respondents.

Respondents welcomed this action aimed at enhancing greater accessibility to training programmes through the adoption of a blended approach, distance learning or online options. The benefits, especially for family carers with limited time or limited support and for rural family carers, were highlighted. Issues relating to internet access also need to be taken into account. Enhancing accessibility included ensuring that family carers are informed about training programmes that exist. The importance of tailoring programmes to enhance accessibility of family carers with literacy difficulties or those who do not speak English was raised. One respondent thought that incentives would encourage greater take-up of training by family carers. One respondent commented on the valuable role that carer organisations play in providing training programmes.

Objective 3.3 Promote the development of accessible living environments for all

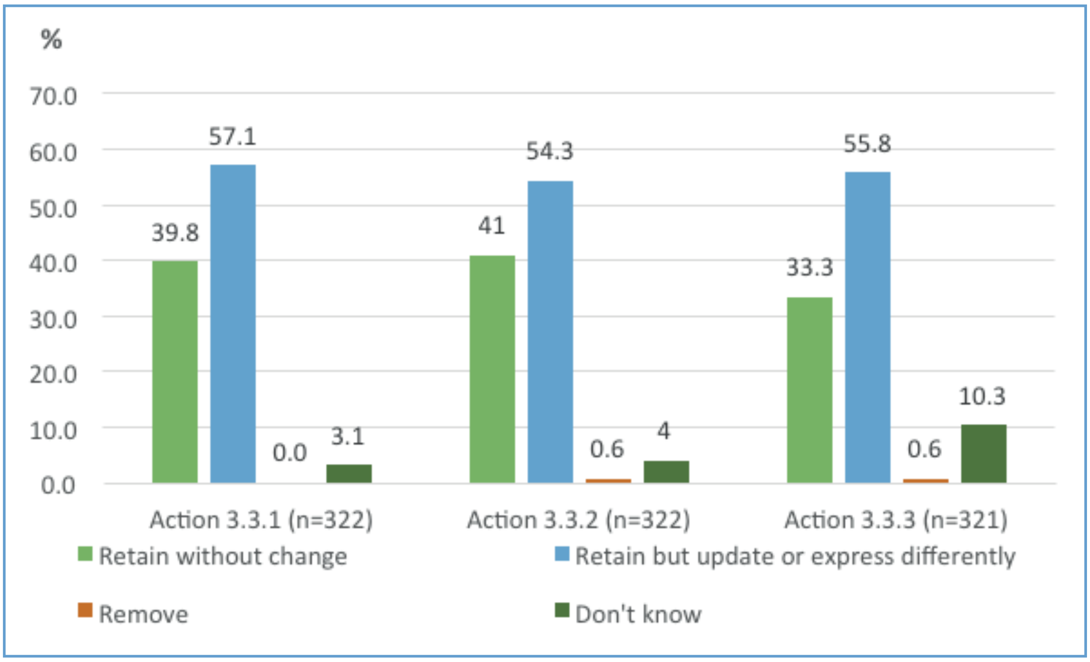

Figure 14: Relevance of Actions 3.3.1 to 3.3.3 under Objective 3.3 of NCS

Action 3.3.1: Prioritise funding for the operation of the suite of housing grants for older people and people with a disability and ensure that they can be accessed by families in a timely way

The vast majority of respondents indicated that they either wanted this action to be retained without change (39.8%) or retained but updated or expressed differently (47.1%) (Fig. 14). Comments were received from 33 respondents.

Respondents felt that the operation of housing grants was extremely important. Grants were important for adapting homes to enable older people and people with disabilities remain safe in their own homes and for preventing premature admission to long-stay residential care facilities. This issue has become even more important since the onset of the Covid-19 pandemic and the separation of people living in residential care facilities from their families. According to the comments, many families are not accessing housing grants for older people and people with disabilities in a timely manner. The application process for housing grants was described as an onerous, time-consuming and lengthy process with lots of unnecessary 'red tape' resulting in delays. It posed problems for family carers who were already feeling overwhelmed with their caring role. Staff in local authorities were not always helpful or accommodating of the needs of people who need housing adaptations. It was suggested that the maximum level of funding allowed should be reviewed regularly and linked to inflation. Two respondents explained that adult children were living in the house because they could not afford to rent or buy accommodation and their income was taken into account for the purposes of the financial assessment. This was regarded as unfair. Respondents pointed out that housing may need to be adapted for people with mental health problems or behavioural or cognitive difficulties. However, respondents' experience was that housing grants tend to be prioritised for people with physical disabilities. The difficulty of finding housing already suitably adapted was highlighted and getting adaptations for people with a disability living in private rented accommodation was described as 'almost impossible'. The importance of building new homes that were accessible was stressed.

Action 3.3.2: Identify good practice in implementing assistive technology and ambient assisted living technology to support independent living and telehealth opportunities

The vast majority of respondents indicated that they either wanted this action to be retained without change (41.0%) or retained but updated or expressed differently (54.3%) (Fig. 14). Comments were received from 18 respondents.

Respondents suggested that the wording of this action should be changed to read: ‘identify and promote …’ or ‘identify and ensure …’ and that the focus should move from identifying good practice to implementing good practice. Respondents felt that assistive technology can be great but, to avail of it, family carers often have to pay out of pocket. They felt that it can be costly and that not everyone is able to afford it. It would be useful therefore to have a reference to funding included in the action. In addition, it is not always easy to source and it would be good to have help with this. Respondents reported that access to assistive technology seems to vary according to where people live, and addressing geographical inequities was, therefore, seen as important. Furthermore, respondents felt that it was important to be sure that the assistive technology was fit for purpose. Good practice developed during the Covid-19 pandemic in the use of telehealth could be retained and built upon. One respondent remarked that they were ‘not a fan of telehealth’ and had a preference for personal support.

Action 3.3.3: Review and update Transport Sectoral Plan under Disability Act 2005

One-third of respondents indicated that they wanted this action to be retained without change (33.3%) and more than one-half want it retained but updated or expressed differently (55.8%) (Fig. 14). Comments were received from 17 respondents. Transport was described as ‘definitely an area that needs attention’ and the action as needing to be continued, enhanced and more specific. Inaccessibility and lack of public transport in rural areas were raised as key issues facing people with disabilities and their family carers living in those areas. This meant that people with disabilities had to rely on family carers to drive them to and from their destination. It was pointed out that the free travel pass is of little use in areas with poor public transport links or inaccessible transport or for people with disability for whom public transport is unsuitable, e.g. because of responsive behaviours. One respondent suggested fuel allowance as an alternative option in these situations. The cost of transport to get to services such as day care services or for those who do not qualify for a free travel pass was raised by two respondents. It was suggested that family carers and the people to whom they provide care should be involved in any review and update of actions on transport.

Goal 4: Empower carers to participate as fully as possible in economic and social life

Objective 4.1 Enable carers to have access to respite

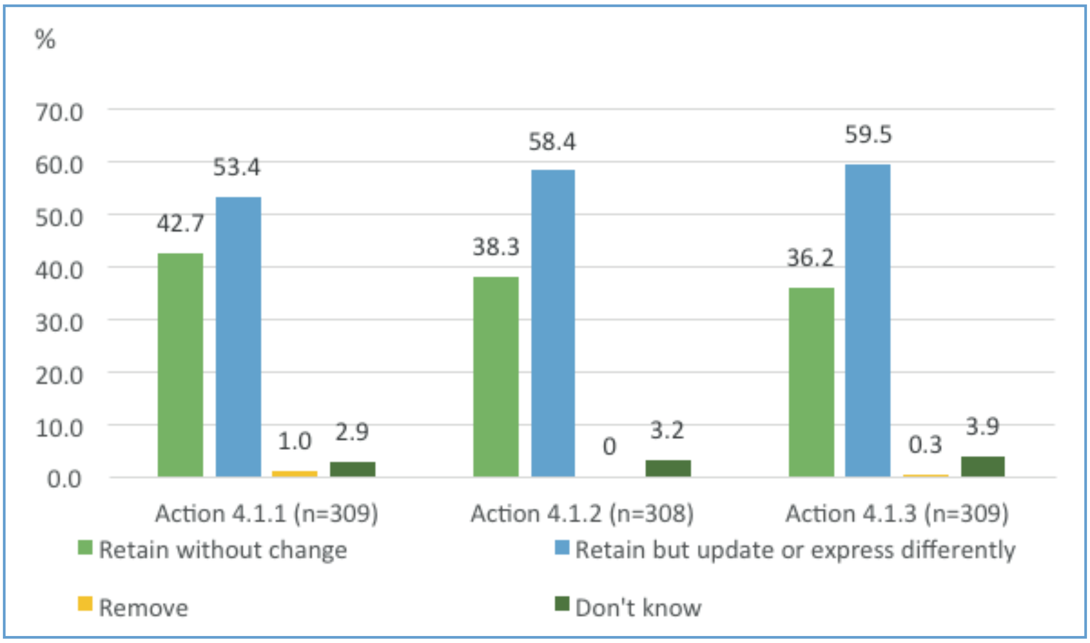

Figure 15: Relevance of Actions 4.1.1 to 4.1.3 under Objective 4.1 of NCS

Action 4.1.1: Promote better awareness of the existence of the Respite Care Grant

The vast majority of respondents indicated that they either wanted this action to be retained without change (42.7%) or retained but updated or expressed differently (53.4%) (Fig. 15). Comments were received from 34 respondents.

As alluded to by respondents, the Respite Care Grant was renamed the Carer's Support Grant[6] in 2016 to better reflect how it can be used. As well as updating this action to reflect the name change, it was felt that the action would be better placed under Objective 1.3 as use of the grant is not restricted to paying for respite services and is more akin to an income support. It was suggested that the wording of this

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[6] The Carer's Support Grant (formerly called the Respite Care Grant) is an annual payment for carers who look after certain people in need of full-time care and attention. https://www.gov.ie/en/publication/461f37-operational-guidelines-carers-support-grant/#description-of-scheme

action be changed by replacing ‘promote better awareness of …’ with ‘ensure all carers are aware of …’.

Respondents felt that promoting awareness of the grant was important as not all family carers knew about it, and some only got to hear about it through word of mouth. One respondent was aware of the grant, but had chosen not to avail of it so that it could be used by others instead.

Some felt the action should be expanded to not only promote awareness of the grant but also to improve access to it through a revision of the rules of qualification and use. There were different views on the eligibility criteria for the grant. Some felt that the requirement that family carers cannot be engaged in employment or self-employment outside the home for more than 18.5 hours per week was unfair, as it meant that care provided by those who combine work with caring goes unrecognised:

> *‘Not all carers are eligible for the grant. It should be available to all regardless of employment status. Some carers have to work to keep a roof over their heads and look after the needs of the person they care for. Working full-time does not lessen the impact of caring.*
>
> *Personally, I work from home to ensure I can still care ... but that is never recognised and I never get any respite as financially it is out of reach.’*

Respondents regarded the grant as crucial for supporting family carers with their mental health, because of the societal benefits that accrue. It enables people to remain living at home longer thereby reducing the costs on the state. One respondent felt the level of payment could be increased and another that it could be paid more regularly. While appreciation for the grant was expressed, some respondents felt that its value was lowered because the availability of respite services was inadequate and the range of respite options limited. Some expressed their poor experience of respite. One respondent suggested increasing the rate of payment temporarily to compensate for the lack of access to respite and many other services since March 2020

Action 4.1.2: Promote a range of person-centred and flexible respite options

The vast majority of respondents indicated that they either wanted this action to be retained without change (38.3%) or retained but updated or expressed differently (58.4%) (Fig. 15). Comments were received from 34 respondents.

Respondents believe that promoting a range of person-centred and flexible respite options is essential, but that this action could be stronger. Respondents suggested that it should be a commitment to ‘provide …’, ‘ensure access to …’ or ‘ensure existence of …’ rather than ‘promote …’ and that this needed to be backed up with funding. Respondents felt that the concept of respite promoted by this action was broad, which was welcomed. Respondents also welcomed the reference to ‘person-centred’ in this action, as it focused attention on the person, and the value of respite for them, as well as the benefit of providing a break for the family carer. The promotion of a range of options was also welcomed.

Respondents would like to see the provision of more in-home respite, especially for groups such as people with dementia, and greater promotion of awareness of different options. However, it was felt that in reality, respite is a neglected area and that the availability of respite in many areas is often inadequate and not individualised to the person’s needs. Two respondents recounted their positive experience of innovative models of respite, but considered themselves to be ‘lucky’ or ‘fortunate’, and would like to see such models funded and spread throughout the country. It was suggested that the carer needs assessment as part of SAT (see Action 2.1.3) would be a useful way of identifying the need for respite. Respondents made particular reference to residential or overnight respite for those providing intense levels of care; this kind of respite was reported to be limited, and often crisis driven rather than planned. The absence of respite during the Covid-19 pandemic was raised by two respondents, who called for it to be restored.

Action 4.1.3: Identify gaps in existing services and establish performance indicators for the provision of respite services

More than one-third of respondents indicated that they wanted this action to be retained without change (36.2%) and more than one-half wanted it retained but updated or expressed differently (59.5%) (Fig. 15). Comments were received from 27 respondents.

Some respondents commented that this action is fundamental to enabling people being cared for to remain living at home for longer, and the importance of consulting family carers about this was reiterated. Respondents felt that there were many gaps in respite services, described by one respondent as more of a ‘gaping abyss’. Gaps identified by respondents included in-home respite, peer support, information about respite, and respite for particular groups such as people with mental health difficulties or people with dementia. For the identified gaps to be addressed, however, respondents pointed to the need for political will and funding to be made available. Some had given up hope of gaps ever being addressed, especially because family carers did not have the time to protest at the slow pace of change. While some respondents stressed the importance of using performance indicators for the provision of respite services, one wanted more clarity about what this entailed and another expressed uncertainty about the value of using indicators, which were seen as potentially a waste of resources.

Objective 4.2: Enable carers to stay in touch with the labour market to the greatest possible extent

Figure 16: Relevance of Actions 4.2.1 to 4.2.5 under Objective 4.2 of NCS

Action 4.2.1: Promote existing carer-friendly HR policies within Government Departments and Agencies

The vast majority of respondents indicated that they either wanted this action to be retained without change (39.7%) or retained but updated or expressed differently (53.5%) (Fig. 16). Comments were received from 29 respondents.

Respondents suggested that, in addition to promoting existing family carer-friendly HR policies within Government Departments and Agencies, policies need to be updated to facilitate family carers to combine work and caring, and that the emphasis should be on implementation rather than promotion. It was felt that employees who are caring are rarely acknowledged by employers and that it would be useful to identify how many people employed in Government Departments and Agencies are family carers, for example, through a care audit. Some respondents wanted to know how Government Departments and Agencies promote existing family carer-friendly HR policies.

One suggestion was to extend this action beyond public sector employers. Issues raised by respondents included the perceived absence of financial support for those who combine working with caring, the application of family carer-friendly HR policies for employees in low-paid jobs, the challenges of negotiating working hours with employers, and the challenges of finding suitable part-time jobs or jobs that facilitated flexible working. Some respondents pointed out that the reality for many family carers is that the intense levels of caring they provide or the unpredictable nature of caring means that caring is incompatible with working, but this is not always recognised.

> *'The reality is that on any given day, any minute of any day, or at any time, a carer will have to drop everything to care for their dependent'*

Exiting the labour market to care can have huge financial implications and family carers are faced with many challenges when trying to return to work after years of absence. Options such as working from home could facilitate people to combine work with caring.

Action 4.2.2: Promote awareness of the Carer's Leave Act 2001

The vast majority of respondents indicated that they either wanted this action to be retained without change (41.4%) or retained but updated or expressed differently (52.1%) (Fig. 16). Comments were received from 29 respondents.

The comment most frequently made by respondents was that there is currently very low awareness of the Carer's Leave Act 2001. This point was made by seven respondents, including five who had never heard of Carer's Leave. It was suggested that awareness needs to be promoted among employers as well as employees. This should include awareness about how Carer's Leave can be used, e.g. it can be spread over time, which may be more useful for family carers of people with lifelong illnesses. Since it is unpaid leave, one respondent suggested including information on financial supports available for family carers when awareness of this Act is being promoted. Another respondent pointed out that there are overlaps between this action and Actions 1.3.1 and 1.3.2 and linking these actions together could help promote awareness of the Carer's Leave Act 2001.

Action 4.2.3: Encourage work–life balance provisions that are needed to ensure working arrangements are carer friendly

The vast majority of respondents indicated that they either wanted this action to be retained without change (40.7%) or retained but updated or expressed differently (55.4%) (Fig. 16). Comments were received from 20 respondents.

Respondents felt that this action needs to be stated in stronger terms and needs to be brought in line with the EU Directive on Work–Life Balance. Some respondents felt that to make this happen, more work is needed with employers including making them more aware of the employment rules attached to social welfare payments for family carers. Others believed that this action should be underpinned by legislation. Some respondents would like work to be understood as including both paid work and unpaid caring work, and a recognition that those family carers providing full-time care on an unpaid basis need to be supported and enabled to balance caring work with time out for themselves.

Action 4.2.4: Explore how back-to-work and education training courses can be tailored to the needs of carers who wish to return to the workplace

The vast majority of respondents indicated that they either wanted this action to be retained without change (40.6%) or retained but updated or expressed differently (55.2%) (Fig. 16). Comments were received from 24 respondents.

Instead of using the words ‘explore how’, respondents suggested that this action could be reworded as ‘develop’, ‘provide’ or ‘encourage’ back-to-work and education training courses tailored to the needs of family carers who wish to return to the workplace. Alternatively, it could be reworded to state: ‘tailor back-to-work and education training courses to the needs of family carers who wish to return to the workplace’. This action was regarded as ‘especially important as caring role comes to an end’ and definitely an area that needs attention. The importance of tailoring actions to the needs of specific groups of family carers such as family carers living in rural areas or older family carers, those who are still caring and those whose caring role has come to an end, was highlighted. It was suggested that back-to-work and education training programmes should be tailored based on findings from exploratory work carried out under this action, and that it was important to consult with family carers. Remote learning, flexible learning options and flexible timetables were identified as ways of tailoring such programmes. Some respondents expressed the desire to return to work but explained that this is not currently an option because of their full-time caring role. Linked to this was that suggestion that this action includes training for reasons other than return to work such as training to support family carers in their caring role.

Action 4.2.5: Review access by family carers to labour market activation measures

The vast majority of respondents indicated that they either wanted this action to be retained without change (38.2%) or retained but updated or expressed differently (52.6%) (Fig. 16). Comments were received from ten respondents, which was the least number of comments of all of the actions. It was suggested that this action should be reworded to read:

> *Increase access by family carers to labour market activation measures and measure performance.*

This action was seen as important because entitlements to social insurance benefits are linked to pay-related social insurance contributions, and family carers not in the labour market may find that they are not entitled to social insurance payments when the person they care for dies or when they reach pensionable age.

Some respondents recommended that labour market activation measures be designed to meet the needs of both family carers and the economy. However, for these measures to work, caring supports need to be in place. Respondents suggested that the employment rules for those availing of social welfare payments such as Carer's Allowance also need to be taken into account. Concern was expressed by some respondents that this action does not recognise the situation of those family carers who have no option but to care full-time and are not in a position to join the labour market.

3.4 Priority areas for the next National Carers' Strategy

Respondents were asked to list the top three priorities for the next NCS if they had a 'magic wand' and everything was possible. This section presents the findings with respect to this question. The priority areas identified by family carers are presented separately from those of other stakeholders.

3.4.1 Top three priority areas identified by family carers

When asked to list their top three priorities, family carers identified a wide range of areas. The priority areas they are identified are listed in Table 1. When ranked according to the frequency with which they were mentioned, the top three priorities areas are income support, supports and services, and respite (Table 1).

Priority area	Priority 1 (n=228)	Priority 2 (n=223)	Priority 3 (n=207)	Total	Rank order
Income support / financial assistance	78	55	40	173	1
Supports and services (including home support)	40	26	39	105	2
Respite	22	38	22	82	3
Recognition	22	10	19	51	4
Carer Needs Assessment / family carer supports / family carer training	11	21	11	43	5
Health services	5	22	14	41	6
Housing, long-term care options, etc.	8	8	12	28	7
Engagement and involvement in decision-making	4	11	10	25	8
Mental health of family carers	8	8	8	24	9
Information	9	6	4	19	10
Labour market participation	5	5	3	13	11
Rights and equality	3	3	2	8	12
Action on the *Strategy*	4	2	2	8	13
Specific categories of family carers	1	0	6	7	14
Transport	2	1	3	6	15
Other	5	7	12	24	
Priority area	Priority 1 (n=228)	Priority 2 (n=223)	Priority 3 (n=207)	Total	Rank order
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Engagement and involvement in decision-making	4	11	10	25	8
Mental health of family carers	8	8	8	24	9
Information	9	6	4	19	10
Labour market participation	5	5	3	13	11
Rights and equality	3	3	2	8	12
Action on the *Strategy*	4	2	2	8	13
Specific categories of family carers	1	0	6	7	14
Transport	2	1	3	6	15
Other	5	7	12	24	

Table 1: Priority areas identified by family carers

Priority area 1: Income supports

‘Income supports’ was in the top three of priorities identified by 173 family carers. Family carers want renumeration for the care work that they do, which is often provided round the clock, 24/7. This is to give family carers financial stability and an independent income, and to recognise the contribution family carers make to society and the savings made by the state. Two main requests were made. The first was to give all family carers, especially full-time family carers, access to Carer’s Allowance by removing the means test. The second was for an increase in social welfare payments for family carers, especially the Carer’s Allowance, to reflect the amount of work involved in caring. A number of family carers would like the hours of work allowed outside the home increased and the waiting time for assessment of eligibility for Carer’s Allowance reduced.

Priority area 2: Supports and services

‘Supports and services’ is ranked as the second priority area; 105 family carers identified this in their top three priorities. Some family carers simply stated ‘help’ or ‘support’. Others identified ‘more support and services’ or ‘better support and services’ as the priority. Others were a little more specific and looked for ‘supports in a practical way’ to be prioritised, easy access to support when it is required, access to ‘relevant’ or ‘expert’ support, or ‘individualised’ or ‘person-centred’ support. Many specified the type of supports they wanted prioritised. Key among these were home supports. These were often identified as a priority area with reference to enabling the person being cared for to remain in their own homes. One respondent would like consumer-directed care[7] prioritised.

Priority area 3: Respite

‘Respite’ is ranked as the third priority area for family carers and was identified in their top three priorities by 82 family carers. Like the second priority area identified, some family carers simply stated ‘respite’, while others wanted greater access to or availability of respite and for it to be available in all areas. Some already availing of respite want to be able to access it on a more frequent basis. The reason why they

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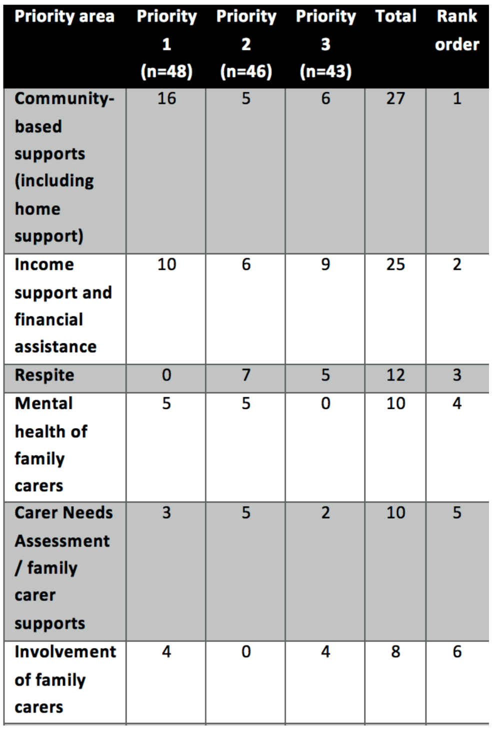
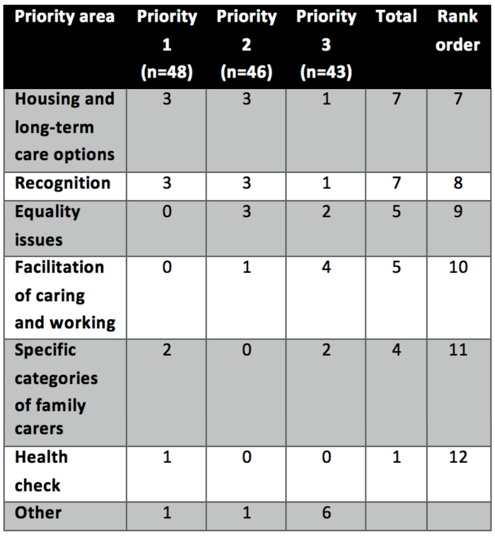
[7] A client approved by the HSE for a home support service can apply to be considered for Consumer Directed Home Support (CDHS). CDHS programmes give clients more control over who provides the services and how and when these services are delivered. CDHS empowers the consumer to make informed choices about the types of services they access and the delivery of such services. The approval of CDHS is dependent on the capability of the client to have control of their own service delivery, or their wish to do so, and is relative to their assessed level of need (HSE, 2018).

wanted respite prioritised was added by some and included: to support the mental wellbeing and physical health of family carers – *'Respite or lack of has caused my health to suffer and deteriorate'; to give family carers a much-needed break – 'I need a break, so any respite would help'*; to free up time to spend with their own family; or to enable working family carers to achieve a better balance between working, caring and home life. The type of respite, for example, 'emergency', in-home' or 'night-time', was specified by some. Issues to be prioritised with respect to respite included: greater transparency regarding allocation, more respite options, and individualised respite.

3.4.2 Top three priority areas identified by other stakeholders

Other stakeholders include policymakers, service providers, staff in the not-for-profit sector and researchers. Similar to family carers, a range of areas were identified by stakeholders when asked to list their top three priorities. The priority areas they identified are listed in Table 2. When ranked according to the frequency with which they were mentioned, the top three priorities areas matched those of family carers. However, community-based supports were ranked higher than income support. Like family carers, respite was ranked third by other stakeholders (Table 2).





Priority area	Priority 1 (n=48)	Priority 2 (n=46)	Priority 3 (n=43)	Total	Rank order
Community-based supports (including home support)	16	5	6	27	1
Income support and financial assistance	10	6	9	25	2
Respite	0	7	5	12	3
Mental health of family carers	5	5	0	10	4
Carer Needs Assessment / family carer supports	3	5	2	10	5
Involvement of family carers	4	0	4	8	6
Housing and long-term care options	3	3	1	7	7
Recognition	3	3	1	7	8
Equality issues	0	3	2	5	9
Facilitation of caring and working	0	1	4	5	10
Specific categories of family carers	2	0	2	4	11
Health check	1	0	0	1	12
Other	1	1	6		

Table 2: Priority areas identified by other stakeholders

Priority area 1: Community-based supports

‘Community-based supports’ was identified as the top priority area by other stakeholders. They wanted adequate financing and provision of good quality home care, day care and other community-based services as well as other supports such as therapeutic interventions. They wanted these services and supports to be appropriate to the needs of the people being cared for at home and those of family carers. They wanted services to sufficiently support family carers, reduce family caregiver strain and enable family carers to continue to care and prevent admission to long-stay residential care. Among these respondents, the introduction of a Statutory Home Support Scheme was specifically identified by three respondents.

Priority area 2: Income supports

‘Income supports’ was identified as the second priority area by policymakers, service providers and researchers. Respondents wanted family carers to be paid for the care work that they do, and the financial disadvantage experienced by family carers to be addressed. They suggested different ways of doing this including increasing the level of payment for those in receipt of Carer’s Allowance or the Carer’s Support Grant, making it easier to access these income supports, removing or increasing the means test for Carer’s Allowance for full-time family carers, or through the introduction of Universal Basic Income.

Priority area 3: Respite

‘Respite’ was identified as the third priority area by stakeholders. Providing respite was seen as a way of recognising family carers, to reduce family caregiver burden and to enable family carers to continue in their caring role. Respondents wanted adequate resourcing and provision of respite, flexible respite options to be made available, and equitable provision of and access to respite across the country.

4. Implications for the Next National Carers' Strategy

This survey was undertaken as part of CARERENGAGE, a joint project between CAI and ISS21. Its purpose was to assess the extent to which the 42 actions in the National Carers' Strategy's Implementation Roadmap continue to be relevant in 2021 from the perspectives of key stakeholders including family carers, policymakers, relevant service providers and researchers. This survey is timely, as it coincides with the Department of Health's review of the *NCS*, following a commitment to update the Strategy in the Programme for Government.

A total of 743 individuals responded to the survey. The vast majority (92.6%) of respondents were family carers, including both current and former family carers, and this can be taken as an indication of the high level of interest in policy development and implementation among family carers. Staff working in service provider and not-for-profit sector organisations, researchers and policymakers also participated.

Awareness and knowledge of National Carers' Strategy low

Increasingly, it is argued that family carers and the people to whom they provide care must have a stronger voice, aptly captured by the slogan 'Nothing About Us Without Us' borrowed from the disability movement. Organisations representing family carers can and do act to facilitate the participation of family carers in policy design and development. In addition, patient and public involvement (PPI) in research is increasingly in evidence (Murphy et al., 2020) and the results of research involving family carers can be used to advocate for policy change (CAI, 2021). Despite the great efforts that are being made to involve family carers in influencing policy, it is striking that most family carers participating in this survey had never heard of the National Carers' Strategy. Yet, this is a policy which, according to respondents in this survey, has much relevance to them. Among those who were aware of the existence of the National Carers' Strategy, knowledge about it was low.

All 42 actions are relevant, but many need to be strengthened

The main purpose of the survey was to obtain the views of stakeholders on how relevant the 42 actions in the NCS are in 2021, and for that reason, the actions were worded in the questionnaire exactly as they appear in the Strategy. Of the 734 respondents, 405 answered questions about the relevance of the 42 actions in the Strategy. For each and every one of the 42 actions in the NCS, the majority of respondents wanted the actions to be retained, indicating that the actions are still relevant in 2021. However, many wanted the actions to be updated or expressed differently. A number of actions – Actions 1.1.2, 2.1.5, 2.2.2, 3.3.2, 4.1.2, 4.2.4, 4.4.1 – were regarded as too weak, and it was suggested that the wording be revised. **In the next iteration of the National Carers' Strategy, the wording of actions need to be stronger and reflect greater commitment on the part of government to bringing about change in these areas**. It was beyond the scope of the survey to provide information to respondents on progress that has been made over the past decade on each action. Given the low levels of awareness and knowledge of the NCS, it is not surprising that many respondents lacked information on progress that has been made, but it was clear that they would like to hear more about this.

A greater focus on implementation is needed

More than one-quarter of actions commenced with the word 'review', 'identify', 'investigate' or 'explore' (i.e. Actions, 1.3.5, 2.1.6, 2.2.3, 2.2.4, 3.1.2, 3.2.1, 3.3.2. 3.3.3, 4.1.3, 4.2.4 and 4.2.4). For example, Action 1.3.5 is to review existing transition arrangements for family carers at the end of their caring role. Respondents were particularly keen to know what the outcomes of these actions were, and if and how the findings of a review, investigation or exploration had been used to bring about change in practice. There was a very strong sense from the comments that respondents would like to see change happening and a greater focus on implementation. **Implementation must be a key focus of the next iteration of the NCS.**

Recognise, listen to and involve family carers in making change happen

Ensuring that the needs of family carers are considered in the development of policy is an action in the NCS. However, stakeholders want this action to go further and for family carers and their representative organisations to be consulted and actively involved in the development of policy. With respect to being included in decisions relating to the person they provide care to, stakeholders wanted decision-making to be a two-way dialogue and seemed to embrace the notion of shared decision-making, an approach in which family carers, the person and professionals work together to make decisions about treatment and care.

Recognising the value and contribution of family carers is a central theme of the NCS. The word ‘recognised’ is included in the Strategy’s title. The vision statement affirms that ‘carers will be recognised …’ (p. 2) and it was acknowledged in the Strategy that ‘… many [carers] can feel invisible or undervalued and that their needs and contributions are unrecognised’ (p. 12). A decade on, there is still a strong sense among many family carers of being invisible or undervalued, a viewed echoed by other stakeholders. Recognition ranked highly in the top priorities of family carers. Family carers are struggling for recognition. They want recognition of family carer needs, recognition of what caregiving and their daily lives are actually like, and recognition that they too are ‘real’ workers. They want recognition at an interpersonal as well as at a societal level. They want caring to be visible and valued, and this to be reflected in the provision of social services and income supports.

Income supports – the top priority for family carers

Based on responses from family carers, ‘income supports’ was identified as the top priority area; it was the second priority area for other stakeholders. The actions in the NCS that relate specifically to income supports focus largely in providing family carers with information and advice about income supports and reducing waiting lists for them. While these are still regarded as relevant actions in 2021, respondents raised a range of fundamental issues regarding the structure of income supports paid directly to family carers in Ireland, which pose challenging questions both for policymakers and for us as a society. Many respondents suggested that the rate of payment to family carers in receipt of income supports such as Carer’s Allowance, Carer’s Benefit and the Carer’s Support Grant be increased, raising the question of how generous these income supports for family carers should be? Should income support for family carers be means-tested, as Carer’s Allowance is, or universally paid to family carers as several respondents suggested? Typically means-tested income supports involve a number of eligibility criteria, but a downside of directing income supports such as Carer’s Allowance to those with greatest need is that they can be viewed as unfair to those who do not meet the means test but cannot earn an income through participation in the labour market due to caring responsibilities, a view held by some respondents in this survey. Some family carers wanted the eligibility criteria widened, highlighting the difficult eligibility decisions attached to means-tested income supports for policymakers. The hidden costs of caregiving were also highlighted, particularly financial insecurity for family carers, generally women, over the longer term, but also the physical and mental health consequences.

Community-based supports are critical for the wellbeing of both carer and cared for

Community-based supports was the top priority area identified by other stakeholders, and 'services and supports' the second priority area identified by family carers. In this context, it is striking that Action 2.1.6, concerned with developing a secure and equitable system of financing for community and long-term care which supports older people to stay in their homes, is still outstanding.

The Covid-19 pandemic has profoundly impacted family carers and the people to whom they provide care and there is still a way to go to get services such as day services, schools, respite, etc. back up and running. Given the widespread suspension of respite services since March 2020, it is not surprising that respite figures so high as a priority for family carers and other stakeholders. However, it must be acknowledged that before the pandemic, access to respite was problematic. The pandemic has served to reinforce the significant role played by respite services in supporting family carers and the people to whom they provide care.

Recognise the heterogeneity of carer needs and contexts

Respondents want all family carers to be included in the NCS. However, family carers are not a homogenous group and the diversity of family carers was a recurring theme in comments. We know that family carers are a highly heterogeneous group. The people they provide care to are different, relationships with the people they provide care to are different, the type and intensity of care that they provide is different, and family and care networks upon which they can rely vary greatly. In almost every age cohort there are family carers, and family carers live in different areas of the country, come from different socio-economic and ethnic backgrounds, and include people from the LGBT+ community. Some are still affected by a former caring role. Apart from Action 3.1.3, which mentions 'sub-groups of carers', diversity and difference are missing from the current NCS. Stakeholders want diversity of family carers not only referred to, but also that diverse voices of family carers are heard and inform policy. The issue of person-centred care is linked to this. It is not possible to provide person-centred supports and services without first acknowledging the unique circumstances and distinct needs of individual family carers. The importance of tailoring supports and services, including community-based supports, family carer supports, family carer training programmes and back-to-work education and training programmes, to respond to the assessed needs of family carers and those receiving care was a recurring theme identified in the comments of stakeholders. **Understanding the diverse needs of family carers is also essential for the effective targeting of integrated care.**

Joined-up integrated services and supports

Integration was an issue raised by stakeholders. In the current NCS, the only reference to integration is in relation to information. Stakeholders argued that more integration is needed if services are to better respond to the needs of family carers. Integration has been described as a 'nested' concept (Kodner, 2009) and stakeholders referred to many different dimensions of integration in their comments. They referred to the breadth of integration, that is, the ways in which services and supports link up horizontally (between services at primary and community care level) and vertically (between primary/community and acute services). They referred to professional integration, that is, professional and provider relationships and collaborative working within and between organisations (e.g. GPs, nurses and social workers, occupational therapists, physiotherapists, geriatricians). They referred to service integration, the coordination of services and integration in a single process across time, place and discipline. Integration is a very strong theme in Sláintecare (Oireachtas Committee on the Future of Healthcare, 2017) and there is good work currently ongoing to bring about integration of care. ***Family carers need to be a focus of integration and integration needs to be strong theme in the next iteration of the NCS.***

Need for online supports to extend beyond the Covid-19 pandemic

The Covid-19 pandemic has opened up new possibilities. Key among these has been the shift to online supports. There was a strong desire among stakeholders for more online supports that enable family carers to be supported and stay connected and that facilitate them to participate in economic and social life. Virtual attendance at the annual carer forum, virtual engagement between family carers and professionals and service providers, online family carer training, and remote working were examples suggested. Though not referred to by respondents, the online Family Carer Support Group established by CAI in March 2020 in response to the pandemic is a concrete example of how online supports can be offered to family carers. **The value and potential of online support as amply demonstrated during the pandemic means that this is an important area for development in the next iteration of the NCS.**

The survey results provide valuable information from the perspectives of a range of stakeholders, including family carers, and can be used for ongoing engagement with the Department of Health with respect to its work in reviewing the Strategy and to inform the next iteration of the National Carers' Strategy.

References

Care Alliance Ireland (2021) *Public and Patient Involvement: A Guide for Not-for-Profit and Community Groups New to Research*. Dublin: Care Alliance Ireland.

Department of An Taoiseach (2020) *Programme for Government: Our Shared Future.* https://www.gov.ie/en/publication/7e05d-programme-for-government-our-shared-future/

Department of Health (2012) *National Carers' Strategy – Recognised, Supported, Empowered.*
https://www.gov.ie/en/publication/a1e44e-national-carers-strategy/

HSE (2018) National Guidelines & Procedures for the Standardised Implementation of the Home Support Service (HSS Guidelines).
https://www.hse.ie/eng/services/list/4/olderpeople/national-guidelines-and-procedures-for-the-standardised-implementation-of-the-home-support-service-hss-guidelines.pdf

Institute of Public Health in Ireland (2018) *Improving Home Care Services in Ireland: An Overview of the Findings of the Department of Health's Public Consultation.* Dublin: Institute of Public Health in Ireland.
https://assets.gov.ie/9990/1e6ec3b04d8a4c1480c6637cce471c88.pdf

Kodner, D. (2009) 'All together now: a conceptual exploration of integrated care', *Healthcare Quarterly*, Special Edition, 13: 6–15.

Murphy, E., Tierney, E., Ní Shé, É. *et al*. (2020) 'COVID-19: Public and patient involvement, now more than ever' [version 1; peer review: 2 approved]. *HRB Open Res*, 3:35 (https://doi.org/10.12688/hrbopenres.13067.1).

Oireachtas Committee on the Future of Healthcare (2017) *Houses of the Oireachtas Committee on the Future of Healthcare Sláintecare Report*. Dublin: Houses of the Oireachtas.

Appendix A: Survey

About the survey

Background to the survey: The National Carers' Strategy 2012 describes government policy for those who care (in an unpaid capacity) for older people, children and adults with an illness or a disability. A commitment to review and update this strategy was included in the Programme for Government 2020. The update is being led by the Department of Health, in consultation with the wider family carer sector.

Purpose of the survey: There are 42 actions in the National Carers' Strategy. This survey is being conducted to assess whether these actions continue to be relevant from the perspectives of key stakeholders including family carers, policymakers, relevant service providers, and researchers. It is hoped the survey findings will help inform the next National Carers' Strategy.

Who is conducting the survey: The survey is being conducted by Dr Maria Pierce (Independent Researcher) on behalf of Care Alliance Ireland (CAI) and the Institute of Social Science in the 21st Century (ISS21), University College Cork. This is part of the joint CARERENGAGE project, funded by the Irish Research Council (New Foundations). You can read more about the CARERENGAGE project here if you wish.

Who can take part? You can take part if you are aged 18 years or over, are resident in the Republic of Ireland and are a current/former family carer, a service provider, a policymaker, or a researcher.

What does the survey involve? Completing this short survey will take approx. 10 minutes.

Do you have to take part? No, completion of the survey is entirely voluntary.

Confidentiality: This is an anonymous survey. All responses you provide will remain anonymous. Responses will be stored securely, accessed only by Dr Maria Pierce and used only for research purposes. Staff in Care Alliance Ireland and University College Cork will not have access to survey data. The data will be retained by Dr Maria Pierce for one year, after which it will be destroyed by her. The results will be presented at a key stakeholder consultation workshop on 23 March 2021 organised as part of CARERENGAGE. The findings will be presented in a short report, which will be published on the CARERENGAGE project and Care Alliance Ireland websites.

Advantages / disadvantages of taking part: The main advantage is ensuring the views of key stakeholders are taken into account in the next National Carers' Strategy. It is not envisaged that there will be any negative consequences for you in taking part.

Funding: The study is grant-funded by the Irish Research Council (New Foundations) CARERENGAGE project.

GDPR: This study complies with the EU's General Data Protection Regulation (GDPR). If you have any concerns about this survey and your data protection rights under GDPR, contact piercemaria@hotmail.com or the Data Protection Officer in Care Alliance Ireland at ndo@carealliance.ie. You can also contact the Data Protection Commissioner here

Overview

This survey will take approximately 10 mins to complete. There are three parts to the survey.

Part 1 explores your level of awareness of the National Carers' Strategy 2012.

Part 2 explores your views on the current relevance of each of the 42 actions in the National Carers' Strategy 2012. In particlar, we wish to find out your views on whether they should be retained without change; retained but updated or expressed differently; or removed. Please note: the actions listed in this survey are exactly as they appear in the National Carers Strategy 2012.

Part 3 provides you with an opportunity to list the three top priorities that you would like to see in the next National Carers' Strategy.

By completing this survey, you are confirming that you:

- **Understand the purpose of the study and are participating voluntarily.**
- **Are aware that you can withdraw at any time, even after starting the survey.**
- **Understand that your anonymity will be assured.**
- **Are aged 18 years or over.**
- **Are resident in the Republic of Ireland.**

Your current stituation

Please indicate which of the following best describes your current situation (Please tick all that apply)

☐ I am a family carer

☐ I am a policymaker

☐ I work for a service provider

☐ I work for a not-for-profit organisation (non-service provider)

☐ I am a researcher

Other (please specify)

☐

I have heard of the National Carers' Strategy 2012

○ Yes

○ No

On a scale from 1 to 10, how would you rate your knowledge of the National Carers' Strategy (where 1 reflects lowest level of knowlege and 10 the highest level of knowledge)

1 = No or little knowledge	2	3	4	5	6	7	8	9	10 = Detailed or specific knowledge
○	○	○	○	○	○	○	○	○	○

Is the National Carers' Strategy personally and/or professionally relevant to you?

- ○ Personally relevant
- ○ Professionally relevant
- ○ Both
- ○ Not relevant
- ○ Don't know

Do you use or have you used the National Carers' Strategy to influence and/or reform service provision?

Never	Rarely	Sometimes	Often	Very Often	Not applicable
○	○	○	○	○	○

Relevance of actions under Goal 1 of the National Carers' Strategy 2012

Goal 1: Recognise the value and contribution of carers and promote their inclusion in decisions relating to the person that they are caring for.

For each action listed below, please select the response that best represents your assessment of the relevance of the action. Please select one box only for each action. You can add optional comments for each action, if you wish.

Objective 1.1: Strengthen awareness and recognition of the role and contribution of carers at national, regional and local level.

Action

	Action should be retained without change	Action should be retained but updated or expressed differently	Action should be removed	Don't know
Promote a better recognition of the role and contribution of carers at a national level	○	○	○	○

Optional comments

Ensure that carer's needs are considered in the development of any policies (such as the Review of Disability Policy (DOH), the National Positive Ageing Strategy (DOH, forthcoming) and the Children and Young People's Policy Framework 2012-2017 (DCYA, forthcoming)	○	○	○	○

Optional comments

Build on the work begun in 2011 to establish a comprehensive statistical profile of Family Caring in Ireland	○	○	○	○

Optional comments

Continue to convene an annual carers forum to provide carers with a voice at policy level	○	○	○	○

Objective 1.2: Include carers in care planning and decision making for those that they care for.

Action

	Action should be retained without change	Action should be retained but updated or expressed differently	Action should be removed	Don't know
Involve carers, as appropriate, as care partners in care planning and provision by health and personal social service providers and particularly by the primary care team	○	○	○	○

Optional comments

Identify carers and their involvement in discharge planning, including their details provided in discharge letters to GPs	○	○	○	○

Optional comments

Objective 1.3: Recognise the needs of carers by the provision of income supports

Action

	Action should be retained without change	Action should be retained but updated or expressed differently	Action should be removed	Don't know
Provide regular benefits advice sessions and information through the application process	○	○	○	○
Optional comments				
Ensure that carers can access benefits advice as early as possible when their caring role begins	○	○	○	○
Optional comments				
Publicise more widely that Carer’s Allowance can be shared by two carers providing care on a part-time basis	○	○	○	○
Optional comments				
Continue to work to reduce waiting periods for processing of Carer’s Allowance applications and appeals	○	○	○	○
Optional comments				
Review existing transition arrangements for carers at the end of their caring role	○	○	○	○
Optional comments				

Relevance of actions under Goal 2 of the National Carers' Strategy 2012

Goal 2: Support carers to manage their physical, mental and emotional health and well-being

For each action listed below, please select the response that best represents your assessment of the relevance of the action. Please select one box only for each action. You can add optional comments for each action, if you wish.

Objective 2.1 Promote the development of supports and services to protect the physical, mental health and wellbeing of carers

Action

	Action should be retained without change	Action should be retained but updated or expressed differently	Action should be removed	Don't know
Raise awareness among health and personal social service providers of the physical and emotional health issues that family carers may experience	○	○	○	○
Optional comments				
Encourage carers to attend their GP for an annual health check	○	○	○	○
Optional comments				
Develop and roll out a single assessment tool for older people and ensure that the views of carers as well as the people they care for are taken into consideration	○	○	○	○
Optional comments				
Continue to implement the recommendations of the Home Solutions Report (13) on telecare	○	○	○	○
Optional comments				
Promote awareness of adult and child protection services that are in place	○	○	○	○

Objective 2.2: Support children and young people with caring responsibilities and protect from adverse impacts of caring

Action

	Action should be retained without change	Action should be retained but updated or expressed differently	Action should be removed	Don't know
Raise awareness and understanding among education providers of the signs that children and young people have caring responsibilities and the impact of caring on them	○	○	○	○
Optional comments				
Encourage statutory agencies to review the way that they respond to children and young people with caring responsibilities	○	○	○	○
Optional comments				
Identify support services needed by children and young people with caring responsibilities and create mechanisms for young carers to contact service providers	○	○	○	○
Optional comments				
Investigate and analyse the situation of younger people undertaking caring roles	○	○	○	○
Optional comments				

Relevance of actions under Goal 3 of the National Carers' Strategy

Goal 3: Support carers to care with confidence through the provision of adequate information, trainining, services and supports

For each action listed below, please select the response that best represents your assessment of the relevance of the action. Please select one box only for each action. You can add optional comments for each action, if you wish.

Objective 3.1: Promote the availability of user friendly and timely information and advice

Action

	Action should be retained without change	Action should be retained but updated or expressed differently	Action should be removed	Don't know
Ensure frontline staff in key 'first contact' agencies such as local authorities, local health offices and health and personal social service providers have the correct information to be able to sign-post carers to other services as appropriate	○	○	○	○
Optional comment ☐				
Review material (paper and Internet based) available to carers and investigate (in conjunction with carer's representative organisations) how more comprehensive information materials dedicated to carers' needs can be developed and distributed to service providers likely to be a carer's first point of contact	○	○	○	○
Optional comment ☐				
Ensure that the information needs of sub-groups of carers, such as older carers, children and young people with caring responsibilities, carers in rural areas are addressed	○	○	○	○
Optional comment ☐				

	Action should be retained without change	Action should be retained but updated or expressed differently	Action should be removed	Don’t know
Proactively collate and disseminate information about services and supports available at a local level for carers	○	○	○	○

Optional comment

Objective 3.2: Provide relevant and accessible carer training opportunities for carers

Action

	Action should be retained without change	Action should be retained but updated or expressed differently	Action should be removed	Don't know
Identify gaps in the content of current training programmes for carers (in conjunction with carer’s representative organisations)	○	○	○	○

Optional comments

Enhance the accessibility of education and training courses through the use of face-to-face, on-line and distance learning options	○	○	○	○

Optional comments

Objective 3.3: Promote the development of accessible living environments for all

Action

	Action should be retained without change	Action should be retained but updated or expressed differently	Action should be removed	Don't know
Prioritise funding for the operation of the suite of housing grants for older people and people with a disability and ensure that they can be accessed by families in a timely way	○	○	○	○

Optional comments

Identify good practice in implementing assistive technology and ambient assisted living technology to support independent living and telehealth opportunities	○	○	○	○

Optional comments

Review and update Transport Sectoral Plan under Disability Act 2005	○	○	○	○

Optional comments

Relevance of actions under Goal 4 of the National Carers' Strategy 2012

Goal 4: Empower carers to participate as fully as possible in economic and social life

For each action listed below, please select the response that best represents your assessment of the relevance of the action. Please tick one box only for each action. You can add optional comments for each action, if you wish.

Objective 4.1: Enable carers to have access to respite

Action

	Action should be retained without change	Action should be retained but updated or expressed differently	Action should be removed	Don't know
Promote better awareness of the existence of the Respite Carer Grant	○	○	○	○

Optional comment

Promote a range of person-centred and flexible respite options	○	○	○	○

Optional comment

Identify gaps in existing services and establish performance indicators for the provision of respite services	○	○	○	○

Optional comment

Objective 4.2: Enable carers to stay in touch with the labour market to the greatest extent possible

Action

	Action should be retained without change	Action should be retained but updated or expressed differently	Action should be removed	Don't know
Promote existing carer friendly HR policies within Government Departments and Agencies	○	○	○	○
Optional comments				
Promote awareness of the Carer's Leave Act 2001	○	○	○	○
Optional comments				
Encourage work-life balance provisions that are needed to ensure working arrangements are carer friendly	○	○	○	○
Optional comments				
Explore how back-to-work and education training courses can be tailored to the needs of carers who wish to return to the workplace	○	○	○	○
Optional comments				
Review access by family carers to labour market activation measures	○	○	○	○
Optional comments				

Part 3 - Your priorities

If you had a magic wand, and everything was possible, please list, in order of importance, the top three priorities that you would include in the next National Carers' Strategy. Please be as precise about these three priorities as you can.

Priority 1

Priority 2

Priority 3

€50 survey participant voucher / Further contact?

Please click on this google link if you wish to provide Care Alliance Ireland with your email address for one or more of the four reasons outlined below. (Please note: to protect your privacy, clicking this link will bring you to a new page. If you choose to provide an email address at this page, your email address will not be linked in any way to responses that you have given to the survey questions, ensuring your anonymity.)

- **If you would like to be entered in the draw for the €50 survey participant voucher**
- **If you would like to participate in future consultations in relation to the development of the next National Carers' Strategy**
- **If you would like to receive a copy by email of the report arising from this survey when it is complete**
- **If you would like to be kept informed of the CARERENGAGE Project**

Appendix B: Roundtable workshop and discussion of the NCS survey results

The roundtable workshop and discussion took place via zoom on 23rd March 2021.

The workshop comprised four components, namely:

1. **Presentation of the NCS survey results by Dr. Maria Pierce**
2. **Responses to the report from an expert panel**
3. **Panel Q&A**
4. **Breakout discussion groups with attendees (family carers, researchers, CVOs and policy makers)**

1. Presentation of the NCS survey results

The presentation of the results by Dr. Pierce is available to watch on the Care Alliance Ireland YouTube channel (https://youtu.be/I4ZJWSM-Gcc).

2. Responses to the report from an expert panel

Following the presentation of the survey findings, responses were heard from Susan Scally (Principal Officer, Social Care Performance & Integration, Department of Health); Emily Holzhausen OBE (Director of Public & Policy Affairs, Carers UK); and Clare Duffy (Policy & Public Affairs Manager, Family Carers Ireland). Some brief notes from each speakers' response to the survey are detailed below.

2.1 Ms Susan Scally, Department of Health (DoH) response

- Ms. Scally acknowledged the support of Minister Stephen Donnelly and Minister Mary Butler for the National Carers Strategy (NCS), and that the Department would use the report in their review of the NCS.
- The DoH's remit covers the diverse circumstance of family carers in Ireland.
- In terms of the report findings, Susan found that the findings that carers feel invisible and forgotten was very important. This also came across during Covid, where many Carers suffered increased social isolation.
- The DoH actively engages to support carers. In September 2020 last, Minister Butler organised a roundtable for family carers. The DoH also liaises with organisations such as the Alzheimer's Society of Ireland, Family Carers Ireland and other organisations. They also work closely with the HSE to support family carers

- The finding that there were low levels of awareness of the NCS was interesting. Susan wondered whether it was because carers are so engaged with their day-to-day work that they do not have time to engage with the strategy or if it is due to some other reason.
- A key issue going forward will be how the DoH might refocus increased supports for family carers with a particular focus for example on well-being.
- Susan was interested in the findings that more needs to be done in relation to the priorities and was interested in hearing more about that.
- She also found it interesting to hear that some actions remain relevant, as opposed to requiring the DoH to come up with a totally new strategy. This poses questions about for example:
    - What are the findings saying about implementation of the NCS?
    - What are/were the barriers to implementation?
    - Does cross departmental remit pose challenges or prevents implementation and how can these be overcome?
- Overall, Susan sees this work as part of a key part of the evidence-based review of the NCS.
- **A key question is how we might use the review to involve cares in strategy in a more meaningful way and remove the barriers to implementation?**

2.2. Emily Holzhausen, OBE, Carers UK response

- This survey is an important piece of work and a timely one.
- Interested in the difference between carers and professional opinions in the survey.
- The methodology was excellent, including questioning whether the vision is right.
- The principles are there in the Strategy, but they need to be strengthened and improved.
- There is a need for increased awareness with regard to accessing carer supports. Sometimes this is due to the lack of identification as carers. It would be interesting to examine the take up of existing provisions and supports.
- It is evident that there are opportunities for cross departmental cooperation. For example, in the UK, there is quite a bit of data sharing between departments.

- To support carers, there is a need to be flexible and also to address diversity. For example, through online training in the UK, they have increased their digital engagement for carers and this can offer some carers greater flexibility, which is what they want.
- In relation to any revised NCS, it would be good to put in a time scale for implementation.
- It would be also worthwhile considering rehabilitation and rebuilding carer supports in the short term, in particular as carers emerge from lockdown and the Covid19 experience. Carers UK are anticipating that there will be a greater need for support at that stage.

2.3. Ms. Clare Duffy, Family Carers Ireland response

- Family Carers Ireland (FCI) has been involved in the NCS since 2012 and they also convened a monitoring group for the Strategy actions (which included Care Alliance Ireland and family carers).
- FCI's position differs slightly from that presented. FCI believes that the infrastructure still stands so, for example, the vision and the goals etc. in the current NCS should be brought forward in any revised strategy. However, FCI feels that the actions need to be refreshed. Since 2012, many government departments have changed. The policy environment in 2021 is also very different than in 2012. There are now over 500,000 family carers in Ireland. More than 1 million of the population indicate that they had caring responsibilities during the Covid19 pandemic.
- FCI has had several meetings with various Departments and they feel that the actions are now exhausted.
- Clare is less concerned that carers are not aware of the NCS than she is about the impact of the NCS on carers. Having a NCS gave a mandate to FCI to meet various government departments and to encourage dialogue.
- Clare noted that in the current Program for Government, while there are four specific actions relating to family carers, there are probably 20 actions overall that will support family carers.

3. Panel Q&A

Key points from the panel Q&A included:

Diversity and equality:

- We have to ensure that we listen to carers and in particular minority groups and include them around the table also.
- Covid has highlighted existing inequalities between different carers. It is important to connect with different carer groups; the Travelling Community etc.
- There is also a need to rethink our supports for young carers. For example, developing more dialogues with schools to enable the first person voice. Scotland is quite far ahead of the rest of the UK in this regard, and may be worth looking at for examples.
- Northern Ireland has done some interesting work around carers in employment, working carers. Emily would like to hear more working carers' voices going forward.
- What's also particularly interesting is the international nature of caring, so caring from a distance and the digital supports required. The voices of this group would be quite interesting because their journeys through the system are quite different.

Engagement with government departments and policy makers:

- Within the UK, they have noticed that care has tended to drop off the health agenda, so there is still a job to do in relation to awareness about caring in general.
- It is a challenge to get the attention of different Government departments. It has been helpful that FCI set out some new actions.
- There are a lot of different policies and strategies in place across various populations and Government departments in Ireland; for example in relation to older people and mental health. We need to look at them collectively to ensure that the family carers are represented in these policies and in their agendas going forward.
- We also need to look at how the NCS references these policies; where are the matches? Are there specific actions that can be included? This will involve bringing all players around the table and involve them in the consultation.

- The right language is critical; so for example Carers UK administer the State of Caring annual survey - a lot of demographic questions are included. What we are missing are those carers at the lower end i.e. carers with just a few hours care an week or a day it's hard to get hold of these.

Outcomes Vs impact:

- How can we measure it? This is the challenge, but it will be important to understand and measure progress for family carers.
- One carer asked: why do we have a National Carers Strategy if it does not lead to anything? Susan replied if we don't have an updated strategy, we will not be able to continue to raise awareness of the issues impacting carers and to support them.

4. Breakout discussion groups with attendees (family carers, researchers, CVOs and policy makers)

In addition to the above comments during the panel discussion, participants were invited to discuss 3 questions:

1. How can the knowledge of the national carrier strategy be improved across family carers, health and social professionals, and others?

2. What was the most surprising finding from the research that you heard from Maria's presentation? Why did it surprise you?

3. Please draft at least two high level objectives for the next Carer's Strategy

Participation across the breakout rooms was highly engaged, and below are some of the key points made under each question.

***Please note; the points made below reflect the opinions of different voices invited to the discussion. They do not necessarily reflect the opinions of the research team.*

1. How can the knowledge of the national carrier strategy be improved across family carers, health and social professionals, and others?

Awareness raising:

- Carers believe there needs to be a governmental department responsible for care, which is informed by family carers.
- It is hard to get people interested until it affects them – see the example of the Assisted Decision-Making legislation, people were disinterested but now, when it will start to affect practice, people are concerned

Register of carers:

- One carer mentioned that it is a hard question for carers, particularly those who are not involved in carer organisations as there is no National Register for carers for example.
- Need a national database/ one dedicated place to post texts/ messages/ notifications for all support groups to spread these messages. Only have one port of call for all social media.

Accessible, clear communication:

- As family carers are engaged in caring and their daily work, they are not necessarily aware of the NCS. Therefore, any communication should use accessible, simple language which is easy to understand and also remove numbers from the actions.
- Not all carers have online access or are computer literate. A printed leaflet or paper letter signposting to the strategy, giving a brief overview/summary, could be disseminated by healthcare professionals online and in print for consistency and reach a large number of carers.
- A general postal campaign could access carers that we are missing, or who are caring but don’t identify themselves as carers. Think, for example, in terms of the Supervalu vouchers that come through the post and everyone reads, at least for a few minutes.
- Digital only campaigns can’t work as not everyone is online – useful to have leaflets at GP surgeries, pharmacies, etc.
- A researcher mentioned that for researchers the NCS 2012 strategy is rather obsolete. However, she made the point that it is it is really important that the key messages of the NCS be presented in a much more accessible way. For example, using diverse methods such as infographics, short films etc.

- Not all elements of the NCS are relevant to all groups. It might be useful to edit the relevant information/messages to stakeholders who have scope to engage, and promote specific sections, rather than promoting the whole document.
- Multiple languages should be used to reach as many minority groups as needed.

Dissemination of NCS Scorecards:

- Opportunity to raise public awareness of and interest in the strategy by disseminating/reissuing the scoring mechanism cards conducted by FCI via media channels. The public would react strongly to information on government reaching or failing its targets.

2. What was the most surprising finding from the research that you heard from the research presentation? Why did it surprise you?

- One researcher was disappointed that the same issues are arising as those that came up over a decade ago. This indicates that a number of carer needs are not being met.
- The importance of true recognition to carers and the way they specify what recognition means for them (much more than being appreciated and recognised).
- One carer felt that there was a disconnect between the research and respondents and the responses from Family Carers Ireland and the Department of Health. This person felt that, while the carers in the survey wanted the actions retained, the Department of Health and FCI seemed to be advocating for a new strategy.
- That there are 42 actions in the first Strategy. It is impossible to reasonably prioritise that many actions. Succinct targets would be more likely to succeed as they are more representative of the greater carer cohort.
- What wasn’t asked in the survey, but what would be interesting to find out about, would be the differences between urban and rural carers and the diversity nationally in relation to the standard of services and the levels of service available to carers.

3. Please draft at least 2 high level objectives for the next Carers Strategy

Rights-based assessment:

- FCI advocated a **rights-based assessment** that would **recognise the needs for the carer and the cared for and that there should be a right to adequate holistic community care and for the resourcing of home care supports in the community.**
- Enshrine the right to statutory provision of respite and care rights and the right of access for all. 'At the moment we have to seek out and request care; care is never offered'.
- The Carers' Strategy (and the Disability Strategy) needs to be underpinned by rights to services, including assessment of needs and right to assistance. 'I don't want to be clapped on the back; I want rights.'

Integrated and universal care:

- One carer commented that **communication between health professionals and family carers needs to be improved.**
- There needs to be much better signposting to services. 'I want to be asked about the services I need, rather than having to go searching for what is available'.
- 'Equitable services that remove current post code lotteries'.
- There needs to be an upskilling of professionals to provide the wrap-around service that is needed. This requires integration of services and supports for carers and recognition of the multiple roles carers play.

Mental health supports:

- There should be **mental health supports for carers,** as many carers have struggled with their mental health throughout Covid.

Income supports:

- Income disregards and thresholds need to be updated and made more equitable.

Educational supports:

- There should be more of an emphasis on the training and education of carers.

Community-based supports:

- Another carer who cares for an adult daughter would like community supports to **address care needs after elderly parents pass away, so knowing what will happen after somebody dies.**

Respite:

- Dementia specific respite care policy for the dementia cohort is vital. Reintegration on transfer home can be traumatic for both the person living with dementia and for the (family) carer(s)

Care
Alliance
Ireland

Guiding support for family carers

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