Improving Home Care Services in Ireland: An Overview of the Findings of the Department of Health’s Public Consultation

A report by the Institute of Public Health in Ireland for the Department of Health
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Executive summary

This commissioned report, produced by the Institute of Public Health in Ireland (IPH), sets out an analysis of the responses to the Department of Health (DoH) consultation into the future of home care policy in Ireland. This public consultation, which opened on the 6th July 2017 and closed on the 2nd October 2017, was carried out by the Department to help develop plans for a new statutory scheme for home care services.

Consultation process

The Department published a consultation paper that set out the reasons for the new policy and the range of issues important to the development of a new system in Ireland. This included issues about the regulation of home care; how the system will be financed; how services work with other health and social care organisations and policy areas; and the need to standardise quality in the delivery of care.

The consultation set out to understand what people think about current home care services, including what is working well; what needs to be improved; as well as the public’s views on what the future scheme should look like.

The Department provided a long and easy-read version of the consultation questions (set out in Annex I and Annex II).

The total number of responses was 2,629 of which 104 were authorised responses from named organisations. A list of the organisations from which authorised submissions were received is set out in Annex III.

Respondents’ profile and experiences

The majority of responses were from individuals, most were female; the largest groups were people aged 40-59, and people who identified themselves as a relative or friend of a home care recipient. As well as individuals, responses were received from public sector agencies, private home care providers, community groups, advocacy bodies, patient interest groups and voluntary organisations delivering care.
Attitudes to home care services

What is good about home care?

Positive respondents indicated that there were important strengths in the system, especially the professionalism of staff, the range of services offered, emphasis on the person, home and family, innovative attempts to introduce better assessment processes, service integration and personal control over decisions about care plans.

Service integration and working together

Similar proportions of respondents thought that home care worked well in comparison to those who thought it had not worked well, alongside primary care and other community services, as well as with informal carers. More people felt that the service did not work well with hospitals, and in general, service integration was a priority for respondents across sectors, organisations and professionals. A number of respondents, who addressed this issue, felt that integrated care programmes and a case management approach would ensure that services were built around the needs of the user, and bring informal carers and families into decisions about the best care pathways.

Access to information and advice

Respondents broadly felt the quality, variety and usability of information on home care needed to be strengthened. This in turn raised the need for information and signposting on the range of services available; eligibility criteria; and the financial implications (and support) for the client and their families.

Tax relief

Most people who answered this question were aware, rather than unaware, that tax relief was available to people who pay for home care. A number of respondents felt that a simpler tax relief scheme would help users, although it was pointed out that a large number of clients and their informal carers were not eligible, as they do not earn sufficient income for tax relief.

Shaping the future of home care

How it can be improved?

Respondents overwhelmingly felt that there should be a statutory right to home care. They also felt that there should be a comprehensive policy framework, which integrates care with health, disability, older people, carers, housing and transport policies, all of which were considered vital for wraparound support for people living at home for longer. They also felt that the policy should set out an effective monitoring and evaluation system focused on better health, care and wellbeing outcomes for the user.
A common message was the need for a clear definition of home care, and the specific services delivered and funded under the scope of the new policy. Respondents felt that this should reflect the social, psychological, health and care needs of the user. The roll-out of a Single Assessment Tool (SAT) was considered by many of the organisational respondents, as helping to design services, improve quality and standardise the delivery of home care across various functions, professional areas, organisations and regions. Again, it was stressed that the needs of the user should be used to decide the appropriate time, service mix and health support they receive.

A reoccurring theme of organisational submissions was that a new regulatory environment is needed, which would involve the registration of providers, setting standards of service, compliance and enforcement processes, as well as monitoring outcomes for the user.

Participation and choice

The overwhelming view of respondents was that people who receive home care should have more of a say in the range of services that are provided, as well as choice about who provides them. Respondents felt that more information was needed regarding the services available; that common standards need to be applied, and that monitoring reports should be made available to the public to enable them to select the best provider.

National quality standards

Most respondents thought that a home care policy should offer standard programmes, processes and eligibility criteria across the country and service areas. It was also acknowledged that the system needs to reflect local circumstances, the spatial distribution of older people likely to need care and the particular needs of people with physical and cognitive disabilities.

Training for care workers

Respondents indicated that there needs to be a programme of training and skills development to improve standards, health outcomes and to promote caring as a good pathway for workers and service providers. It was felt that formal and informal carers also need recognition, proper financial reward and support to deliver the best care possible for the people they look after.

Paying for care

There were variations in views about the future of funding, from those who favoured a universal national health and care system delivered by the State, to a social insurance model, to others who thought co-financing based on need, plus ability to pay, was the fairest system. Some felt that the Nursing Homes Support Scheme (NHSS) should be extended to home care, and again there were differences in views on the extent to which services should be means tested, with some respondents suggesting that family resources, including the family home, should be taken into account. Most respondents felt that the home care system needed significant investment to deliver a high quality and effective service.
Buying extra hours

Most respondents to this question stated that they would be prepared to purchase additional hours of care support, using their own money. However, the issue highlighted a debate between respondents who felt that a means tested scheme was reasonable in contrast to those who felt that a state delivered system, with support through taxation and/or social insurance was the best approach.

Other issues

One of the overarching key themes emphasised under ‘other issues’, concerned putting people who use the services at the heart of service planning, delivery, monitoring and funding decisions. Furthermore some respondents felt that more research was needed to help inform the implementation and development of the home care policy in the future.

Key themes from the consultation

The following are the overarching and common messages from the consultation responses:

1. Most respondents agreed with the Government’s proposal that home care needs to be placed on a statutory basis. They also felt that this should set out clear eligibility criteria for applicants and guarantee equality of access, irrespective of age or the medical and care needs of the individual. Most respondents also felt that access to services should be standardised across the country.

2. Home care services need to be defined, with a number of respondents emphasising the need to deal with socio-psychological, as well as the care needs of the user.

3. A significant number of respondents felt that a person-centred model of care would put the user at the heart of service planning. Some suggested that this might be supported by the roll-out of personalised budgets, which would give the user greater control over the type, quantity and supplier of the services they required.

4. The Single Assessment Tool was viewed by professional bodies and organisations as integral to the home care system.

5. Respondents felt that a more integrated approach to service design and delivery, centred on the needs of the user, carers and families should be a priority when implementing a fair, efficient and effective service. Some respondents drew attention to the value of applying new models, including case management and integrated care programmes that are currently being tested across the health and social care system in Ireland.

6. A number of advocacy bodies and not-for-profit providers felt that care services need to work in a coordinated manner with the voluntary sector, local community networks and social enterprises, in delivering a broad range of local support.
7. The respondents highlighted that there also needs to be closer integration between home care and housing policy, by especially strengthening the supply and diversity of supported accommodation for older people and people with a range of disabilities.

8. A number of respondents, across professions, organisations and sectors, felt there is a need to develop a broad ranging training programme for home care workers.

9. There was broad support for the Government’s proposal to create a new regulatory environment for home care. This would include: licensing/registration providers; developing agreed standards as the basis for service contracts; and a comprehensive monitoring and complaints system. A new regulatory system, it was felt, should be easily understood by carers and families, especially when making a complaint about the service.

10. The consultation process highlighted the need for greater investment in home care and for the development of a long-term approach to how it is financed, for example between the State and service-users, or through tax-relief and social insurance.
Part 1 Introduction

This report sets out the results of the Department of Health (DoH) consultation on the future of home care in Ireland. Home care aims to enable people to continue living in their own homes throughout their lives, and the Government stated aim is to improve community-based services so that people can live with confidence, security and dignity in their own homes for as long as possible. The Department’s consultation paper (see the Annex I consultation proforma long survey) sets out the elements of a new scheme to improve access to home care services. The consultation paper highlights the need to introduce a new statutory based system to improve the consistency and coverage of services; the need to examine a range of funding options, as demand will increase in the future; and the need to better regulate services and providers. It also suggests that home care needs to work in a more integrated way with other care services, primary and community services and hospitals.

1.1 Defining home care

The DoH consultation paper points out that the meaning of home care can differ significantly between countries, and as such, there is no standardised definition. A recent evidence-review by the Health Research Board titled ‘Approaches to the Regulation and Financing of Home care Services in Four European Countries’ states that:

Home care in Ireland is typically understood as home help services, which include cleaning, cooking and other light household tasks that a person is unable to do themselves due to old age or disability. The scope of home help has subsequently developed to include more personal care assistance such as support with personal hygiene, washing, and dressing also.

While the home care service in Ireland is mainly used by older people, it is also available, in a limited way, to some people with disabilities and other identified care needs. This includes services for people leaving hospital who need support. The consultation paper indicated that the key home care services provided by, or funded by, the HSE are: Home Help, Home Care Packages and Intensive Home Care Packages. These services are explained below.

The HSE Home Help service visits people to help with: personal care (washing, changing, oral hygiene, help at mealtimes), and essential domestic duties related only to the individual client (lighting a fire/bringing in fuel, essential cleaning of the person’s personal living space).

HSE Home Care Packages aim to help people with medium-to-high support needs to continue to live at home independently. Home Care Packages consist of community services and supports which may be provided to assist a person, depending on their individual

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1 Section 1.1 is extracted from the DoH consultation long survey
2 http://www.hrb.ie/publications/hrb-publication/publications//731/
3 Since the publication of the consultation paper in 2017, the HSE has updated its home care services for older people, as detailed in the HSE’s National Service Plan 2018
assessed care needs, to return home from hospital or residential care, or to remain at home where mainstream or normal levels of services are insufficient.

The services provided in a Home Care Package include more home help hours in addition to the average level available locally. Packages may also include nursing and therapies (for example: physiotherapy, speech and language therapy, occupational therapy), respite care and aids or appliances. The services delivered are based upon the assessed client’s needs and the level of other supports already provided, such as home help services or informal care by family, friends or neighbours.

**Intensive Home Care Packages** allow people, who require a very high level of assistance, to be discharged from hospital or avoid admission. It is a limited service that includes support over and above those provided as part of a standard Home Care Package or current community services.

The consultation paper also points out that in addition to home care, it is recognised that many other services may be necessary to support people in their own homes. These include primary and community care services (GP; public health nursing; physiotherapy; speech and language therapy; occupational therapy; day centres and respite care) and specialist services, including geriatrician-led teams. Personal assistants also play an important role in helping some people with disabilities to live independent lives. Home support provides personal and/or essential domestic care and support for some people with disabilities to facilitate participation in social and leisure activities. Aids and appliances, or house adaptation grants, also help individuals make changes to their homes that are required to meet their particular needs. In addition, family members and others who provide unpaid care ‘informally’ make an important contribution to the provision of home care.

The DoH consultation paper makes it clear that the public consultation is focused primarily on home care services.

### 1.2 Policy context

Home care services play a vital role in enabling people of all ages with care needs to continue to live independently in their own homes and communities for as long as possible. However, as set out in this consultation report, there are a number of limitations to the existing system of service-provision, with there being potential to make it more responsive to the needs of service users.

While home care services can be required by people of all ages due to, for instance, care needs associated with a chronic condition or disability, or following a stay in hospital, older people represent a large proportion of service users; this is reflected in the allocation of resources for home care service-provision. In 2018, approximately €408 million of the Health Service Executive (HSE) Older Persons’ Services budget will provide over 17 million home

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4 Informal care refers to unpaid care provided by family members and others.
support hours to approximately 50,000 people\textsuperscript{5}. The Disability Services budget will support the delivery of approximately 4 million personal assistants and home support hours to people with disabilities, and the Primary Care Services budget will support 38,180 referrals to Community Intervention Teams (CITs)\textsuperscript{6}, as well as the delivery of 584 paediatric home care packages\textsuperscript{7}. Furthermore, the health trends associated with population-ageing are expected to result in an increase in demand for home care. With the Economic and Social Research Institute (ESRI) predicting that the share of the population aged 65 and over will increase from one in eight in 2015 to one in six in 2030, and that the number of people aged 80 and over will almost double during this period\textsuperscript{8}, the Department of Health’s Health Service Capacity Review 2018 forecasts that a 120% increase in home care services will be required by 2031\textsuperscript{9}.

Against this background, the Programme for a Partnership Government (2016) commits to ‘a timely review of the management, operation and funding of national home-help services’ and to the introduction of ‘a uniform home care service so all recipients can receive a quality support, 7 days per week, where possible’\textsuperscript{10}. These commitments are linked to the broader reform of healthcare provision in Ireland envisioned in the Report of the Oireachtas Committee on the Future of Healthcare, with an emphasis on ‘re-orientating the system so that the vast majority of care is delivered and accessible in primary and social care settings’, and on the provision of ‘integrated care’ which ‘puts the person at the centre of system design and delivery’\textsuperscript{11}.

It is within this policy-context that, in 2017, the DoH conducted a public consultation on home care services in Ireland, the findings of which are detailed in this report. This consultation was undertaken to inform the development of a statutory scheme for the financing and regulation of home care with which the DoH has been tasked. Further stakeholder-engagement will be undertaken throughout the process of developing the new scheme.

\section*{1.3 Methodology}

The primary purpose of the consultation was to obtain the views of service users of home care, their families and the general public on current home care provision and the development of the future scheme, as well as to obtain input from stakeholder-organisations and representative bodies. A consultation paper and surveys were launched on 6th July 2017, with advertisements placed in The Irish Times, The Irish Independent and The Irish Examiner. The consultation closed on 2nd October 2017.

\begin{footnotesize}
\begin{enumerate}
\item Health Service Executive, National Service Plan 2018 (2017), 46.
\item A Community Intervention Team (CIT) is a specialist, nurse-led health professional team which provides a rapid and integrated response to a patient with an acute episode of illness who requires enhanced services/acute intervention for a defined short period of time.
\item HSE, National Service Plan 2018, 40, 107, 109.
\item Department of the Taoiseach, A Programme for a Partnership Government (2016), 83, 58.
\end{enumerate}
\end{footnotesize}
The consultation surveys are set out in Annex I and Annex II respectively. They followed a common structure that looked at: what is good about home care services in Ireland; integration with health and care services; choice and decision-making; how to improve home care; information; standardisation of services; quality; training and skills; and funding and tax.

The total number of responses was 2,629 of which 104 were authorised responses\(^{12}\) from named organisations. A list of the organisations from which authorised submissions were received is set out in Annex III.

IPH were provided with anonymised consultation data from the DoH. The easy-read and long versions of the survey were joined to enable one dataset. Any ‘blank responses’ (where no questions were answered) were removed and the dataset was integrated and analysed.

There were three stages to the methodology:

- **Step one:** the survey data (qualitative and quantitative) was reviewed and analysed. The data was transferred into qualitative and quantitative software packages to assist with the analysis.
- **Step two:** the non-survey responses were reviewed and analysed. Issues were grouped in line with the survey questions and other themes.
- **Step three:** using the different data sources a combined descriptive analysis was structured and presented question by question. Other themes/issues identified from the data were subsequently grouped together and presented.

Parts 2, 3 and 4 of this report set out the results of the questions that invited a quantitative response in a range of diagrams and a table. When these responses are turned into percentages they do not always add up to 100%. This is known as a rounding error, which is the difference between a rounded off value as a percentage and the actual numeric value. We have reported the data to one decimal point to try and minimise the impact of rounding errors.

IPH in this report do not comment on, or evaluate, the design of the DoH consultation process; the methodology used; the scope or content of the specific survey questions; or representativeness of the results or the views expressed by respondents.

\(^{12}\) In order to be classified as an authorised organisational submission, respondents were required to indicate that they were the authorised representative of an organisation and to identify the organisation from which the response was being made.
1.4 Structure of the report

The structure of the report and the presentation format of the data and responses were set by the DoH.

- Part 2 of the report sets out a profile of respondents to the easy-read and long surveys, in terms of demographic characteristics and regional distribution, but also their experience using key home care services.
- Part 3 looks at the current system, and in particular, what is good about home care, service integration, access to information and attitudes to tax relief.
- Part 4 examines attitudes to the future of home care. This describes responses to questions on: how the system can be improved; user participation and choice; the standardisation of services; and the need for national quality standards. It then looks at: training for care workers; paying for home care and attitudes to buying extra hours from the users own resources.
- Part 5 sets out the overarching themes, as expressed by the people who responded to the consultation.
Part 2: Respondents’ profiles and experiences

This section provides an overview of the profile of respondents to both the long and easy-read surveys. It shows the mix of demographic and regional respondents, including people who had experience of services, or looked after people who were, or are, using home care. The data also includes responses from people who deliver care, professionals working in the sector and members of the public.

2.1 Individual and organisational responses

Figure 2.1 shows that the majority of respondents to the survey (86.4% of the 2,597 respondents) were individuals, with 294 responses (11.3%) received from organisations or representative bodies, while 2.3% (60) made no response.

Figure 2.1 Responses received from organisations/representative bodies and individuals

<table>
<thead>
<tr>
<th>Q. Are you making a submission on behalf of an organisation or representative body?</th>
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<tr>
<td>Yes</td>
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<tr>
<td>11.3% (294)</td>
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</table>

Responses 2,597
Of the 294 responses received from organisations and representative bodies, 113 (38.4%) supplied a category of organisation. Figure 2.2 indicates that, of the categories provided, the greatest proportion of responses (apart from the ‘other’ category) came from representative bodies (15.0%, n=17), followed by those from voluntary/not-for-profit home care providers (14.2%, n=16) and then from advocacy bodies (8.9%, n=10).

**Figure 2.2 Category of organisational affiliation of respondents**

<table>
<thead>
<tr>
<th>Category of Organisation</th>
<th>Responses</th>
</tr>
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<tbody>
<tr>
<td>Academic Institution</td>
<td>0.9% (1)</td>
</tr>
<tr>
<td>Voluntary/Not for Profit Home Care Provider</td>
<td>14.2% (16)</td>
</tr>
<tr>
<td>Union/ Staff Representative Body</td>
<td>5.3% (6)</td>
</tr>
<tr>
<td>Representative Body</td>
<td>15% (17)</td>
</tr>
<tr>
<td>Public Interest Group</td>
<td>5.3% (6)</td>
</tr>
<tr>
<td>Private Home Care Provider</td>
<td>7.1% (8)</td>
</tr>
<tr>
<td>Patient Interest Group</td>
<td>3.5% (4)</td>
</tr>
<tr>
<td>Other, please specify</td>
<td>36.3% (41)</td>
</tr>
<tr>
<td>No response</td>
<td>3.5% (4)</td>
</tr>
<tr>
<td>Advocacy Body</td>
<td>8.9% (10)</td>
</tr>
</tbody>
</table>

2.2 Respondents’ personal details

As illustrated in Figure 2.3, of the 71.4% of respondents (n=1,853) who answered the question, 81.7% were female (n=1,513), 16.9% were male (n=314) and 1.4% (n=26) declined to indicate their gender.
Of the 71.4% of respondents (n=1,853) who answered the question on age, the greatest proportion (54.4%, n=1,008) fell within the 40–59 age-bracket, with those aged 60-69 making up 16.4% (n=303), and those aged between 70-79 comprising 8.5% (n=158) of respondents. Those aged over 80 made up 3.9% (n=71) of respondents, as illustrated by Figure 2.4 (below).
Table 2.1 (below) shows that while responses were received from all counties in Ireland: North and South (apart from Tyrone); Dublin-based respondents accounted for the greatest proportion. Of the 1,853 respondents to the question asking what county they lived in (71.4% of the total responses), 29.5% (n=547) were from Dublin, followed by 10.7% (n=199) from Cork and 5.7% (n=106) from Galway.

Table 2.1 Respondents’ county of residence

<table>
<thead>
<tr>
<th>County</th>
<th>Percentage</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Antrim</td>
<td>0.2</td>
<td>3</td>
</tr>
<tr>
<td>Armagh</td>
<td>0.2</td>
<td>3</td>
</tr>
<tr>
<td>Carlow</td>
<td>1.5</td>
<td>27</td>
</tr>
<tr>
<td>Cavan</td>
<td>1.7</td>
<td>31</td>
</tr>
<tr>
<td>Clare</td>
<td>2.4</td>
<td>45</td>
</tr>
<tr>
<td>Cork</td>
<td>10.7</td>
<td>199</td>
</tr>
<tr>
<td>Derry</td>
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<td>2</td>
</tr>
<tr>
<td>Donegal</td>
<td>2.1</td>
<td>39</td>
</tr>
<tr>
<td>Down</td>
<td>0.1</td>
<td>2</td>
</tr>
<tr>
<td>Dublin</td>
<td>29.5</td>
<td>547</td>
</tr>
<tr>
<td>Fermanagh</td>
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<td>1</td>
</tr>
<tr>
<td>Galway</td>
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<td>106</td>
</tr>
<tr>
<td>Kerry</td>
<td>3.0</td>
<td>55</td>
</tr>
<tr>
<td>Kildare</td>
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<td>64</td>
</tr>
<tr>
<td>Kilkenny</td>
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</tr>
<tr>
<td>Laois</td>
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</tr>
<tr>
<td>Leitrim</td>
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<td>17</td>
</tr>
<tr>
<td>Limerick</td>
<td>4.5</td>
<td>83</td>
</tr>
<tr>
<td>Longford</td>
<td>1.0</td>
<td>19</td>
</tr>
<tr>
<td>Louth</td>
<td>1.6</td>
<td>30</td>
</tr>
<tr>
<td>Mayo</td>
<td>2.7</td>
<td>50</td>
</tr>
<tr>
<td>Meath</td>
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<tr>
<td>Monaghan</td>
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<td>13</td>
</tr>
<tr>
<td>Offaly</td>
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<td>35</td>
</tr>
<tr>
<td>Roscommon</td>
<td>1.7</td>
<td>32</td>
</tr>
<tr>
<td>Sligo</td>
<td>1.9</td>
<td>36</td>
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<tr>
<td>Tipperary</td>
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<td>50</td>
</tr>
<tr>
<td>Waterford</td>
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<td>28</td>
</tr>
<tr>
<td>Westmeath</td>
<td>2.5</td>
<td>47</td>
</tr>
<tr>
<td>Wexford</td>
<td>3.2</td>
<td>60</td>
</tr>
<tr>
<td>Wicklow</td>
<td>4.1</td>
<td>76</td>
</tr>
<tr>
<td>Other</td>
<td>1.4</td>
<td>27</td>
</tr>
<tr>
<td>Total</td>
<td>100%</td>
<td>1,853</td>
</tr>
</tbody>
</table>
Figure 2.5 illustrates the capacity in which respondents answered the survey. Of the 1,842 respondents to this multi-option question, the greatest proportion identified themselves as a relative or friend of a home care recipient (27.3%, n=630), followed by members of the public (18.0%, n=416).

Figure 2.5 The capacity in which respondents answered the survey

<table>
<thead>
<tr>
<th>Q. Which best describes you?</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Other</td>
<td>12.1%</td>
<td>(280)</td>
</tr>
<tr>
<td>Prefer not to say</td>
<td>1.9%</td>
<td>(45)</td>
</tr>
<tr>
<td>Informal carer</td>
<td>13.2%</td>
<td>(305)</td>
</tr>
<tr>
<td>Member of the public</td>
<td>18.0%</td>
<td>(416)</td>
</tr>
<tr>
<td>Relative / friend of home care recipient</td>
<td>27.3%</td>
<td>(630)</td>
</tr>
<tr>
<td>Home care recipient</td>
<td>4.3%</td>
<td>(99)</td>
</tr>
<tr>
<td>Other health professional</td>
<td>12.0%</td>
<td>(278)</td>
</tr>
<tr>
<td>Health professional providing home care</td>
<td>5%</td>
<td>(116)</td>
</tr>
<tr>
<td>Homecare worker</td>
<td>6.1%</td>
<td>(141)</td>
</tr>
</tbody>
</table>

Multi Responses 2,310

2.3 Respondents’ professional profiles

Figure 2.5 (above) showed that 141 people indicated that they were a home care worker and 116 that they were a healthcare professional providing home care, but it should be remembered that respondents could respond to both categories. The respondents who are in either category were then asked to indicate what type of organisation they work in and the results are shown in Figure 2.6. Of the 224 respondents who provided an answer, 49.6% of respondents to the question (n=111) indicated that they are employees of the HSE, 29.5% (n=66) that they are employed in the private sector, and 21.0% (n=47) that they are employed in the voluntary/not-for-profit sector.

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15 It should be noted that respondents could select more than one response in answering this question. Of the 1,842 respondents a total of 2,310 answers were provided.
As illustrated in Figure 2.7, of the home care workers and healthcare professionals who responded and identified a particular service, the greatest proportion (32.0%; n=47) indicated that they worked in primary or community care and therapies, followed by those who work in home care or home help (20.4%, n=30).

16 Whilst 141 indicated that they worked in a particular organisation, 147 people (6 more) provided details of the service they worked in.
2.4 Services received by respondents

Figure 2.8 illustrates the profile of services that were received (or not) by the 1,742 who responded to this multi-option question in the consultation. The majority of the responses to this question (65.2%, n=1,202) indicated that they have never received any home help and home care services, with 356 (19.3%) indicating that they have received home help; 256 (13.9%) respondents have received Home Care Packages; and 30 (1.6%) have received intensive Home Care Packages.\(^{17}\)

**Figure 2.8 Home help and home care services received by respondents**

Q. Have you ever received any of the following home care services?

- Home help: 19.3% (356)
- Home Care Package: 13.9% (256)
- Intensive homecare packages: 1.6% (30)
- None of these: 65.2% (1,202)

Multi responses 1,844

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\(^{17}\) It should be noted that respondents could select more than one response in answering this question. Of the 1,742 respondents a total of 1,844 answers were provided.
Figure 2.9 shows of the 1,754 respondents to this multi-option question, GP services constituted the highest level of use (29.1%, n=755); followed by help from family, friends and neighbours (22.3%, n=579); and the public health nurse (18.9%, n=490)\(^\text{18}\).

\(^{18}\) It should be noted that respondents could select more than one response in answering this question. Of the 1,754 respondents a total of 3,405 answers were provided.

As illustrated in Figure 2.10 (overleaf) only a small proportion of respondents (11.7%, n=206) indicated that they are currently paying for home care services.
Figure 2.10 Are you currently paying for private home care services?

Q. Are you currently paying for home care services?

- 82.9% (1,466)
- 5.4% (96)
- 11.7% (206)

Responses 1,768

Figure 2.11 shows the number of hours care received by respondents from private providers, but these results should be interpreted with caution, given the low response rate to the question (n=196 responses; 7.5% of the total responses to the survey). The greatest number of respondents to the question (n=28, 14.3%) indicated that they have received 2-4 hours or 50+ hours. A further 27 respondents (13.8%) indicated that have received 1-2 hours private care per week.

Figure 2.11 Hours per week from private providers

Q. If you are currently paying for private home care services, how many hours do you receive from the private provider each week?

Responses 196

- 1-2 hours: 13.8% (27)
- 2-4 hours: 14.3% (28)
- 4-6 hours: 7.7% (15)
- 6-8 hours: 7.1% (14)
- 8-10 hours: 8.2% (16)
- 10-12 hours: 6.6% (13)
- 12-14 hours: 4.6% (9)
- 14-16 hours: 3.6% (7)
- 16-18 hours: 1.5% (3)
- 18-20 hours: 1.5% (3)
- 20-22 hours: 1% (2)
- 22-24 hours: 1% (2)
- 24-26 hours: 3.1% (6)
- 26-28 hours: 1% (2)
- 28-30 hours: 1% (2)
- 30-40 hours: 4.1% (8)
- 40-50 hours: 2.6% (5)
- 50+ hours: 14.3% (28)
2.5 Paying for care

As shown in Figure 2.12 (below), a relatively small proportion of survey-respondents (21.3% of respondents; n=365) indicated that have previously paid for private home care services.

Figure 2.12 Have you paid for private home care services in the past?

Respondents were then asked why they have, or are applying, for private home care: the results are set out in Figure 2.13. Of the 1,606 respondents to this question, 223 (n=13.9%) were topping-up services. Smaller numbers were: on a waiting list (n=40, 2.5%); applied but were not approved (n=39, 2.4%); or did not know about the service (n=30, 1.9%).
2.6 Conclusions

This analysis shows that most respondents were female; aged between 40-59; identified themselves as a relative or friend of a home care recipient, from the Dublin area. The consultation received submissions from respondents who had a range of experiences or views of home care, the health system in general and professionals involved in delivering services. Just over one-tenth of all respondents were from organisations, and these were in the public, private and voluntary sectors. The responses also included a range of organisations involved in health and social care in Ireland, including professional bodies, patient interest groups, advocacy bodies and public and private sector providers.
Part 3 Attitudes to home care services

This section sets out attitudes to the current home care system in Ireland and respondents’ views to the consultation on key aspects of service delivery. It sets out a summary of responses to the questions: what is good about the home care system and how the service works alongside primary care, hospitals and informal carers. The analysis also examines respondents’ views regarding information on home care and how tax-relief is used to support users of the service.

3.1 What is good about the home care system in Ireland

The consultation asked: ‘In your opinion, what are the good things about home care services in Ireland?’, and suggested that respondents should reflect on a range of specific questions that are set out below.

3.1.1 How you apply for home care

Positive responses, mainly from organisations, praised the application process and in particular the ease of use; the way in which home care can be accessed through the user’s GP and how applications can be made online, via the public health nurse or by self-referral. A respondent from the HSE sector stated that the application process is ‘relatively easy to access for older people, particularly if they are requiring additional supports post hospital stay’.

3.1.2 How your need for home care services is assessed

Positive responses, again mainly from organisations delivering home care, highlighted the importance of standardised assessments across providers, and the way in which findings are discussed between agencies and professionals to determine the support offered to the client. One staff representative body response stated that ‘the multi-disciplinary team approach to client assessment’ enabled a more integrated service to be tailored to the needs of the user. There was also an acknowledgement by a minority that processes and systems of care were improving, especially in the development of a common national standard for evaluating needs and planning integrated care, which again reflects the needs of each client.

3.1.3 Who can access services

Among those who identified strengths about home care, there was a degree of consensus that the service is universal, free and is designed to respond to the needs of the person:

*The availability of home care is a key support for older people, so the universality of home care is a good thing. There is a high level of commitment and engagement among staff involved in the provision of home care, from those carrying out assessments to the front-line providers to home care managers and others* (Academic institution).
An advocacy body felt that it enables people with complex conditions to have their needs met in an integrated way:

Some people with Motor Neuron Disease (MND) and their caregivers report good experiences of accessing services and that the quality of service they receive is very good’ (Advocacy body).

3.1.4 What home care services are provided

The provision of a range of services, more effective integration between primary health and social care, and the availability of specialist support in areas such as dementia, were also highlighted by respondents to this question. The concept of shaping home care services in response to the needs of the user was an important element shared by organisations, health professionals and users. Good practice was identified in pilot initiatives in integrated care management and innovative attempts to bring providers together, including community initiatives to deliver services tailored to individual cases:

In recent years a number of initiatives to include the Genio funded dementia care packages have been introduced and are good examples of linking community services that focus on living well and not just on health care needs (Advocacy body).

3.1.5 How home care services are provided

Those who praised home care services were also in broad agreement about the quality and professionalism of staff, training support and standards of care. They regarded the public health nurse as pivotal, not just in delivering services, but in helping families and users through the system of financial and care support. The two quotes below illustrate the emphasis placed on professionalism, relationship building and the importance of creating a sense of solidarity between care providers, families and their dependents:

The majority of the home care professions are excellent - caring, kind and going above and beyond the call of duty for their clients. In general, they are experienced and well trained for hands-on care of the more complex client (A health professional working in another sector).

My 93-year old neighbour receives home help once a day and is massively reliant on the care assistant who visits him, mostly from the point of view of someone taking an interest in him, getting to know him and his needs. His carer is fantastic, although at his age he really could do with a second visit (Family member or friend of someone who receives home care).

Moreover, some respondents indicated that the service engenders a supportive relationship between families and the people they care for:

Family members can focus on meaningful visits instead of just going to the house to clean and do jobs (Family member or friend of someone who receives home care).
Positive responses highlighted the way in which the service maintained the dignity of older people by empowering them to stay at home, and by allowing relatives to balance other work and household commitments.

*Home care services are an amazing support to those who need it and to those who are devoted to caring for their family and relations. Without it, it would not be possible to allow people to remain in their own homes. It sustains familiarity for the person in need of care and support. Home care services may support one to continue living a meaningful and contributory life to their family and community (A health professional working in another sector).*

A few submissions to the consultation highlighted the importance of a whole family approach, by bringing older people, their carers, health professionals and family into decisions about their care:

*The fact that someone can be kept in their own home and community and minded and cared for there, is the best hope for most families who want a little extra help in caring for a loved one. Meals on Wheels is an amazing point of contact for older people too (Family member or friend of someone who receives home care).*

A positive response from an advocacy body stated that ‘people are supported to make their own decisions on their care through the provision of home care services’. Older users were viewed by some respondents as being at the heart of the service, again stressing the independence and control that people can exercise over their care:

*Home care services ease the dependence on family members and give back independence to the person being cared for from their dependence on family members (Family member or friend of someone who receives home care).*

It was also highlighted by an advocacy organisation that the way services are provided creates employment, locally delivered services and cost savings for the State, by enabling people to stay at home longer. Some organisational submissions emphasised that this created financial savings by reducing pressures on nursing homes, hospitals and acute wards, and also tackled the challenges of delayed hospital discharge.

### 3.1.6 How home care services are monitored and appeal process

A number of mainly organisational responses highlighted the importance of quality assurance systems, and in particular, the way in which providers are approved and monitored by the HSE; the process of regular reviews of providers; and the introduction of minimum quality-standards for home care provision in service delivery tenders. There was also acknowledgement of the importance of the Garda vetting process for home care staff. Finally, the facility for appeals to be lodged was recognised in several organisational responses.
3.2 Service integration and working together

This section summarises the respondents’ views on the way in which home care works with other health and social care services, as well as informal carers, families and local community networks.

3.2.1 Home care services and primary care and other community services

Figure 3.1 (below) shows that 43.8% (n=669) of respondents to this question thought that home care worked well alongside primary care and other community services, whilst a similar proportion (43.2%, n=660) thought that they did not. Primary and community services include: GP services; public health nursing; physiotherapy; occupational therapy; and respite care.

Figure 3.1 Home care services working alongside primary care and other community services

<table>
<thead>
<tr>
<th>Q. Do you think that home care services work well alongside primary care and other community services to meet the needs of people who receive home care?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Don’t know</td>
</tr>
<tr>
<td>No</td>
</tr>
<tr>
<td>Yes</td>
</tr>
</tbody>
</table>

Some respondents pointed to useful instances of inter-departmental cooperation led by occupational therapists and primary-care teams. Similarly, a number of respondents felt that public health nurses played a vital role in coordinating services, and that mental health services work well with home care providers. Some of those that responded to this question indicated that home care providers work well with housing agencies, social workers and families, as well as informal carers.

The main issue for respondents across sectors and organisations was the need for better integration at all levels of the system. For example, an advocacy body commented:

[There is a] need for better coordination of care pathways along the care continuum, particularly given that care is currently fragmented across care episodes, providers,
settings and services. What is required therefore, is an infrastructure that can adapt to the needs of the individual person, not just the categorisation of applicants into ‘silos’. Currently, each part of care is covered by different financial resources and therefore different rules govern eligibility, allocation and administration (Advocacy body).

It was felt that there needs to be better communication and integration between GPs, the public health nurse and critical services, such as occupational therapy and speech therapy, as well as housing adaptations and community development organisations, especially in handover arrangements. Here, a number of respondents suggested that information technology, integrated datasets and electronic sharing could be better used to ensure that professionals and service providers had access to information about the care recipient (condition, medicines and particular needs) so as to plan care programmes.

A number of patient-interest groups and advocacy bodies pointed out that people with high levels of support needs face long term restrictions on their ability to live independently, drive or use public transport, return to work or education, as well as participate in leisure and social activities. It was indicated that person-centred care needs to be developed, in which money follows the patient through the health and care system:

The problem with interactions between home care and primary care/other community services is that funding does not currently follow the person. Home care services should be seen as one element of a suite of services and supports that may be required to enable a person with a condition such as MS [Multiple Sclerosis] to continue to live in their community of choice, and there should be flexibility within funding mechanisms and structures so that funds can be used to access a range of different services including home care, personal assistance, nursing, physiotherapy, occupational therapy, speech and language therapy, neuropsychology, vocational rehabilitation, aids and appliances (Patient-interest group).

3.2.2 Home care services and hospitals

Figure 3.2 (below) shows that 27.8% (n=424) of respondents to the question agreed that home care services work well alongside hospitals to meet people’s needs, while 54.8% (n=834) felt that they did not and 17.4% (265) stated that they did not know.
Some respondents pointed out that home care enables safe discharge of patients from hospitals, and the coordination of respite and step-down services has improved, along with the coordination between nurses and occupational therapists.

However, hospital discharge processes were also an area of concern during handover arrangements; delayed discharge; lack of coordination between key professionals; poor communication between agencies and service providers; and a lack of standardisation in processes across the country. Respondents indicated that this is especially the case for people with complex conditions and support needs, including a neurological or intellectual disability, dementia, motor neuron disease, mental illness, visual and hearing impairment and palliative care. Some respondents suggested a standardised evaluation tool for discharged patients, better working between the statutory and private providers and nationally adopted protocols to ensure consistency between HSE areas.

An advocacy body suggested establishing a centralised, ring-fenced fund for Intensive Home Care Packages for people who require high levels of support in order to be discharged from hospital quickly. This particular respondent proposed a Hospital Discharge Protocol that provides for a named key worker or case manager to coordinate the necessary services, and the use of a Single Assessment Tool\textsuperscript{19} that could evaluate ‘physical needs, medical needs, family and social issues, and wider participative/rehabilitative needs e.g. vocational rehabilitation’ (Advocacy body).

Other respondents were also keen to show that a more integrated approach could help address hospital delayed discharges, save money, achieve better health outcomes for users and increase efficiencies via more seamless service planning:

\textsuperscript{19} SAT is a standardised assessment used to assess the health and social care needs of people (primarily those over the age of 65 years) who may be looking for support (including Nursing Homes Support Scheme (A Fair Deal) or the Home care Package (HCP) Scheme.)
There is significant scope for greater integration of our care services including primary and home care. A new home care regime must be patient-centric, with all services working in a coordinated manner to achieve the best possible health outcomes for the patient. When this is achieved, we believe that this will deliver better value for Irish taxpayers, relieve the current and increasing demand-led strain on our health services and most importantly deliver better health outcomes (Private home care provider).

3.2.3 Home care services and informal carers

The last question relating to service integration asked: ‘Do you think home care services work well alongside informal carers to meet the needs of people who receive home care?’ Figure 3.3 (overleaf) indicates that 40.0% (n=604) thought these services worked well together, and 45.5% (n=687) felt that they did not.

A number of carers and families highlighted rights to the service, rationing hours, regional variations in assessments, and most of all investment, as weaknesses in this part of the care system. The availability of services on bank holidays, overnight, at the weekend and to people aged under-65, also need to be clarified in terms of the service scope and what entitlements families, informal carers and users should have access to in the future. An advocacy body underscored the point made by a number of respondents that there should be a single assessment of need to cover under-65s as well as older people, in a process that supports a whole life approach to care. In addition, a number of respondents felt that home care rights needed to be enshrined in law with guaranteed levels of service eligibility, costs, quality and standards set out in a more explicit and understandable way.

Informal carers in particular, felt that there was a lack of information, especially about the detailed operation of services and what they could expect from different providers; how they worked together (and who was responsible for coordination); up-to-date information about the
progress of applications and service planning; and what to do when things go wrong, likewise a union/staff representative body stated:

*Transparent information should be provided to patients, informal carers and for healthcare providers on how to apply for home care services, how they are assessed, access to services, what services are provided and by whom, as well as how home care services are monitored and how decisions can be appealed. Liaison with informal carers is needed to ensure informal carers are appropriately supported (Union/staff representative body).*

Similarly, a number of people felt that a more rigorous, independent and transparent system of monitoring and public reporting on the performance of the home care service nationally was needed. Informal carers also felt that the stress and anxiety they faced and the value of the work they undertake needs to be better recognised and compensated:

*There are not enough respite hours, not enough home help hours, not enough help given to informal carers. Informal carers, when then have ceased caring, should be given a full contributory pension when of age. Informal carers, especially long term informal carers, should receive a special reference from the Government to place in their C.V. to show why they have not worked outside the home for that amount of time (Informal carer not paid to provide care).*

An example of the need to focus on user-centred care was in respite services with a number of informal carers in particular, stressing the need for less disruptive forms of in-home respite. This would require more careful service planning, but the impact on the health of the carer, family relations and most of all, users, would represent a significant return on such investment:

*[It] can be a very inflexible service. It is difficult to access, time allocated is the bare minimum and this restricts the building of a relationship that elderly people value. Sometimes you have an elderly and disabled person in the same household and two separate carers going in who will do the same but separate tasks for people. No holistic approach with the family e.g. around shopping and cooking. Better to have one carer for both people and longer hours allocated (A health professional providing home care services).*

### 3.2.4 Integrating home care at the point of delivery

A number of respondents proposed the concept of a locally based brokerage function to work at the interface between health and social care, related services in housing and transport, and to create seamless support between hospitals and community healthcare services. One advocacy body suggested creating *Community Development Officers* in each HSE region who could integrate services, promote public health and help vulnerable groups to access a range of health services and welfare entitlements. A separate advocacy body noted

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*Community healthcare services are the broad range of services that are provided outside of the acute hospital system and include primary care, social care, mental health, and health and wellbeing services. These services are delivered to people in local communities through the HSE and its funded agencies. There are 9 Community Healthcare Organisations (CHOs) responsible for the delivery of primary and community-based services responsive to the needs of local communities.*
that the presence of a case management function\(^{21}\) in some sectors has enabled the establishment of timely information, liaison with the necessary service providers and access to consistent and professional expertise in one location, and is the type of service that might be usefully transferred into the home care sector. The integration of primary care and community-based services is also viewed as problematic, especially when the user needs are multiple and complex forms of support are required. There was a consistent message from respondents about the siloed nature of the system with a lack of coordination between services, organisations and professionals. It was felt that the way in which care visits are limited to a range of specific tasks and the turnover in care staff, adds to the disjointed nature of service delivery from a user perspective.

3.2.5 Integrated Care Programme for older people

Several respondents have drawn attention to the development of Integrated Care Programmes (ICPs) as a way of coordinating and delivering better home care. Integrated Care Programmes (ICPs) involve multi-disciplinary services centred on patients and service users, including public and private providers, patient groups, clinicians and the voluntary sector. This approach addresses many of the concerns raised in the consultation, especially when ensuring that clients receive a continuum of support, according to their individual needs, throughout their journey in the health and social care system. One advocacy body drew attention to the potential of applying the Integrated Care Programme for Older Persons’ (ICPOP) across the home care service. ICPOP is a HSE initiative that aims to develop integrated pathways for older people with complex health and social care needs, shifting the delivery of care away from acute hospitals towards community based, planned and coordinated services. The advocacy body pointed out that this would involve a proactive approach to risk stratification, enabling the early identification of vulnerable people and a more coordinated approach to service planning. The submission also emphasised the importance of electronic health records and information sharing amongst all staff involved in delivering care for specific clients.

It was perceived that there is also scope to increase rehabilitation services at home and in local hospitals to address delayed discharge beds amongst those aged 65 years and over. However, some respondents pointed out that by focusing purely on older people, other vulnerable groups who may benefit from rehabilitation, such as young, chronically sick people and those with multiple conditions, could become excluded. An advocacy body also emphasised that home care policy should not be restricted to older people as there were other groups that could be supported to live independently and safely through such integrated packages.

3.2.6 Integrated care and people with dementia

One submission from an advocacy body, along with a statutory provider, emphasised the importance of models of integrated care, specifically for people with dementia. They pointed out that people with dementia disproportionately occupy long stay beds in hospital (and acute units), with their health often deteriorating faster in such settings. They recommend a person-centred model that has been tested in nine sites, looking at different aspects of care, service delivery and inter-organisational working. Their response challenges the current approach to

\(^{21}\) Case management aims to offer a single point of contact to integrate inpatient care, day care and community services for each patient and service user.
service commissioning by working with people with dementia, their carers and families, to
design a service they think works best for them within an outcome framework. The underlying
message here involved a range of outcomes and was not purely concerned with care, but
which also address the autonomy of the individual, empowerment and social connectivity.
The model involves carers who have been trained in a dedicated module about dementia and
that emphasises communication skills, the need to build relationships and to listen to users
and their families.

3.3 Access to information and advice

3.3.1 Where to access information on home care

The consultation asked if ‘you, a relative or friend needed home care services, who would
you ask for information first’; the results are summarised in Figure 3.4. Most of the 1,272
respondents to this question said they would contact the public health nurse (34.7, n=441); their GP (29.1%, n=370) or a HSE service directly (15.7%, n=200), such as a social worker,
occupational therapy or area office. A further 4.5% (n=57) said they would not know where to
locate information, 4.4% (n=56) cited the Citizens Information Service, 3.8% (n=48) said a
friend or relative who had experience of the system, 3.0% (n=38) an NGO and 2.7% (n=34)
stated a general internet search.

Figure 3.4 Who would you ask first for information on home care services

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<tr>
<th>Q. If you, a relative or friend needed home care services, who would you ask for information first?</th>
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<tr>
<td>PHN</td>
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<td>GP</td>
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<td>HSE service</td>
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<tr>
<td>Don't Know</td>
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<tr>
<td>Citizen Information</td>
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<tr>
<td>Friend or relative</td>
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<tr>
<td>NGO</td>
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<tr>
<td>Internet</td>
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<tr>
<td>Other</td>
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</tbody>
</table>

Responses 1,272
3.3.2 Problems accessing information and priorities for respondents

Respondents were then asked: ‘If you have any comments on this issue (who would you ask for information first) to indicate them in more detail’. More accessible information on how to access services across home care was highlighted by respondents:

*Not enough information and (it is) very hard to get. At least 5 phone numbers before you get someone who will always give you another number that never works or doesn't get back to you. Then when you do get someone its fill out this form and we'll get back to you* (Family member or friend of someone who receives home care).

A number of respondents pointed out that this is already a stressful time for patients, families and informal carers and that ‘*access to home care services are hidden in a maze*’ (Family member or friend of someone who receives home care); whereby information is critical, especially during points of crises, or when a number of decisions need to be made quickly (such as around hospital discharge processes). One organisation stated ‘it's like you’re begging asking for home care’ (Advocacy body).

There was acknowledgment that the public health nurse is an important point of contact for information, especially to help navigate users through the system. However a number of respondents felt that a dedicated service was needed to help link the client with the services, with access to the information in a timely and practical manner:

*HSE need to create a family liaison team with officers who can assist family/next to kin navigate services available when a loved one wishes to remain in their own home but require assistance in the home due to deteriorating health/mobility* (Family member or friend of someone who receives home care).

Respondents were aware that information was available, and many had accessed forms, guides and the Citizens Information Service, but felt that a more tailored guidance was needed for people looking for different care pathways. The use of information technology was cited as a strategic approach to publicity, and clear guides were the priority for most respondents who commented upon this question. A simple route map about how to access services, especially those related to particular points of the care pathway, was suggested by one respondent:

*[I] would prefer more information on the network of home care services - a flow chart showing what is available and the path to be followed to access different services. Felt I had to navigate this blind and make the connections for myself rather than being shown the overview. As a result, feel there may be services I failed to access* (Informal carer not paid to provide care).
3.4 Tax relief

3.4.1 Awareness of tax relief

Respondents were asked if ‘you are aware that tax relief is available to people that pay for home care services’. Of the 1,412 that answered this question most respondents (54.3%, n=767) were aware of the option, but 45.7% (n=645) were not.

Figure 3.5 Awareness of tax relief for home care services

3.4.2 Challenges in the operation of tax relief in home care

Some people acknowledged that tax relief was an incentive; however, it was pointed out that:

A lot of older people fall outside the tax net - it is more of an incentive for working relations to pay. It would be better to give more hours to older people as an allowance (Family member or friend of someone who receives home care).

A home care provider in the voluntary sector suggested that there needs to be some form of rebate system for those people who are paying for home care from savings, whilst others felt that the eligible limits needed to be increased to allow more people to benefit from the scheme. In contrast, many people felt they had to give up taxable work to look after a dependent, and felt that the system was cumbersome, difficult to apply for and hard to understand the eligibility criteria:

This excludes people who don’t live with someone who pays income tax. This encourages dependence and prevents independence. If I pay home care now which I can't really afford, my dad can claim tax credits to the point of essentially paying no
income tax and earning a little on credits. If I live independently, I can’t claim anything because I can’t work. That is not fair. Also, it's not fair to families who can’t work because they’ve to provide so much care at home. The person who earns more can get money back but the person who gets a pittance on welfare gets nothing, not even paid for the care hours they do (Member of the public).

Others felt that eligibility should include family members who are able to show they are the primary carer; that allowance thresholds should be lowered and that systems for reclaiming funds should be significantly streamlined. Similarly, some felt that some form of information and technical assistance is needed for applicants, especially as:

[I]t can be hard to find time to apply for this when you are coordinating all aspects of your parent's care’ (Family member or friend of someone who receives home care).

3.5 Conclusions

It should be emphasised that respondents who answered the specific question highlighted many strengths of home care delivery in Ireland. However, the overwhelming view was that home care needed significant investment and improvement in quality to meet the needs of service users. The integration of services was also seen as important, especially involving hospital discharge processes, community care and support for informal carers. Access to information, especially on how to navigate the home care system, how to access specific services and on financial supports, particularly tax-relief, were also highlighted.
Part 4 Shaping the future of home care in Ireland

The Department’s consultation invited responses on how the system can be improved; participation and choice; standardisation of services; quality standards; training for care workers; paying for home care and buying extra hours. This part of the report provides feedback on these issues.

4.1 How can the system be improved?

The consultation asked: ‘In your opinion how could home care services in Ireland be improved’, and respondents were asked to consider seven aspects of the service. These seven areas are discussed in this section of the report; however, it is important to note that respondents were asked for a general comment rather than an answer to each question in turn. Additional themes are therefore identified in this part of the analysis.

4.1.1 How you apply for home care

There were a limited number of responses on the application process itself, but respondents who commented wanted to see a simple, easy to understand, as well as a streamlined process that avoided the need for multiple form filling for different (but related) services. Some respondents felt that standard application forms should be available at a range of places where users and family members are most likely to be (GP surgeries, libraries, post offices and so on), along with practical information for families and clients to enable them to make applications in an easy and efficient way.

4.1.2 How your need for home care is assessed

A reoccurring theme across respondents’ answers was the need to ensure equal access to the system and to address variations between CHS and CHOs, service areas and demographic groups, including people under 65:

I think we need a joined-up approach that looks at the person’s needs as a whole - medical, personal, emotional, mental, social, family. At the moment, everything is piecemeal - the personal alarm application goes to one place, Meals on Wheels application to another, Home Care Package to another. It can get complicated very

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22 Community Healthcare Services (CHS) are the broad range of services that are provided outside of the acute hospital system and include primary care, social care, mental health and health and wellbeing services. These services are delivered through the HSE and its funded agencies to people in local communities, as close as possible to people’s homes.

23 The HSE has established nine Community Healthcare Organisations (CHOs) across the country as a new means of delivering these services.
quickly. I know that different Departments provide the funding for the different aspects but a one-stop-shop portal that the person or their family members can access and select what's needed would be so much easier to build a holistic package that fits the individual. In addition, there needs to be some standard applied to all home care providers (Family member or friend of someone who receives home care).

A union/staff representative body pointed out that the needs of older people should take into consideration complex conditions, multiple morbidities and cognitive impairments in the assessment process. It was felt that the proposed Single Assessment Tool should be rolled out as soon as it was practical:

*The earliest possible deployment of the Single Assessment Tool (the interRAI/MDS tool) in Irish home care must be seen as a high priority as this has been shown to be an effective instrument for measuring quality as well as defining need, developing prompts for care planning, and linking to care in both hospitals and nursing homes in jurisdictions where it has been fully implemented* (Union/staff representative body).

A different union/staff representative body pointed out that they have experienced duplication of assessment by primary care services, prior to the approval of a package, and that different assessments have undermined the development of a clear care pathway. One regulatory body also emphasised that it is important that all potential recipients of home care can be assessed using the same criteria. Their submission states that:

*These assessments should place the care recipient at the centre of the process and should also incorporate the views of their family/representatives as well as their community and primary caregivers. The assessments should also look at an applicant’s needs in terms of rehabilitation and reablement. Such a focus would have a dual benefit of providing support to the person in their own home whilst also improving their capacity to care for themselves thereby reducing their dependence on support* (Regulatory body).

The regulatory body also pointed out that these assessments should be subject to regular, annual, or more frequent reviews and ensure that family members, carers and relevant health and social care staff are included in the reassessment process. Their submission stresses that it is important that an assessment of financial means forms part of the single assessment exercise, which would help ensure transparency in respect of the threshold at which the Government feels individual contributions to personal and/or nursing care should commence.

Respondents also indicated there should also be an assessment of the informal carer as well as formal care services as part of the application process. This needs to ensure that the informal carer is capable of providing the level of care proposed, and where appropriate, identify additional resources or supports that may assist the carer in carrying out their role. It was considered that the assessment should also seek to examine and inform interventions where the carers’ responsibility is deemed to have a negative health impact on the carer. A union/staff representative body stated that such care assessments are a legal requirement in the United Kingdom and argued that a similar model should be considered in Ireland.
4.1.3 Who can access the service

There was strong endorsement, mainly from the NGO sector, that a universal statutory right to home care would cover all ages, and introduce a robust regulatory regime that would protect the rights of people entitled to apply for the service.

4.1.4 What home care services are provided

An advocacy body proposed the adoption of the Law Reform Commission (LRC) definition of professional home care services as a starting point to broaden the range of services and needs that should be addressed within the policy. The LRC recommended in 2011 that professional home care should be defined as services which are required to ensure that an adult can continue to live independently in their own home; this may include, but is not limited to the services of nurses, home care attendants, home help, various therapies and personal care. The Commission also recommended that palliative care be included in the definition of professional home care.

A range of services were identified by survey respondents for inclusion in the statutory scheme, which include:

- Personal and domestic care;
- Public health nursing;
- Companionship;
- Support for reablement;
- Day-care services;
- Support for community activities;
- Nutritional care;
- Specialist home care (e.g. for dementia);
- Energy efficiency schemes;
- Transport schemes;
- Carer-support;
- Assistive technology, aids and appliances;
- Night-time and weekend care;
- Personal assistance;
- Meals-on-Wheels;
- Respite care;
- Educational/vocational support;
- Supported housing;
- Housing adaptation support;
- Therapies (e.g. physiotherapy).

It is important to note that a large number of respondents repeated the point that the service needs to be broader and not confined to a narrow range of tasks or set time allocation:

*The amount of time needed to support an older person to, for example, have a shower will vary depending on the individual, their physical and mental health and their cognition. The delivery of care needs to be go beyond narrow definitions of the task e.g. provision of shower, to include social interaction where the home help can sit down and...*
Another advocacy body stated that there is currently no single definition of what constitutes an ‘intensive’ Home Care Package, and in particular, how people with complex conditions (and who are not over 65) are best supported in their own home. They argued that early discharge from hospital to the home would enable restorative care options; better integrate housing and reablement services; and ultimately produce better health outcomes for users. One advocacy body also pointed out that a delayed discharge prevents individuals from commencing vital community neurorehabilitation and reintegration into their communities and family life.

4.1.5 How home care services are provided

A number of respondents felt that the Nursing Homes Support Scheme should be extended to home care, with a stronger emphasis on integrating respite care, nutritional programmes, rehabilitation services, Meals on Wheels and so on:

Overall, while there are individual stories where home care services work well, the experience of home care services in general point to the reality that they are ad hoc, piecemeal, fragmented, limited and lacking in flexibility to respond to the ABI [Acquired Brain Injury] population. The service is not needs led, the amount of financial resources in a particular CHO area determines the service, leading to delayed discharges and lengthy waiting times to gain access to the service (Advocacy body).

Linked to this, many respondents want to see services better integrated through a multi-disciplinary approach that brings the necessary services together at the point of delivery. Here, a Key Liaison Officer function was proposed (and had been noted that it existed before in some areas) to link assessment, through to the type of care mix provided and to incorporate necessary services in housing, community-based programmes (especially around companionship and social connectedness) and transport. A submission by an advocacy body highlighted the importance of transport in rural communities, but also suggested the development of wider community initiatives to assist home care such as car share schemes, which involves volunteers using their own vehicle to provide door-to-door services to health appointments and social care facilities.

A reoccurring message, although expressed in various ways was home care services require a more participatory co-design approach to involve all stakeholders, build trust between the carer and those being cared for, and not solely rely on a standardised, off-the-shelf package:

The home care should be assessed with the family and the client included, most times the client doesn’t have a say. I know of one lady who had her home care changed because her needs were increased, she should have been given the option of who she wanted and her care plan to be changed to facilitate her with her current care provider, very upsetting changing her routine and the carer she was used to and trusted, her new care is a disaster! ([Former] Home care /Home-help).
4.1.6 How home care services are monitored

There was a common view across respondents that the regulatory environment needed to be strengthened, especially to implement agreed standards, establish a register for carers, similar to nursing, and to extend Garda vetting of the home care workforce. A number of advocacy bodies suggested the need to move away from a tendering process to a licensing system for home care services, with some arguing that market procurement has increased prices and reduced services, especially where there are a small number of larger contractors in the market place.

It was felt that HIQA had considerable experience and expertise in monitoring and compliance processes, and that a comprehensive home care system would cover themes such as governance, accountability, policies, management of complaints, workforce management and safeguarding. It was also suggested that a service provider would register once to provide a specific type of service, with there being no requirement to re-register, and each type of service would have a distinct set of regulations and standards.

4.1.7 Appealing decisions about home care

Respondents to this area, in summary, felt that there needs to be a more responsive appeals and complaints process, as well as a whistle-blowing service for users, families and care staff.

4.1.8 The need of a statutory basis to home care

There was broad support for the proposal, in the Department's consultation paper, that the new home care policy should be a statutory scheme. A number of respondents pointed out that the lack of a legal definition and related guarantees of service delivery has resulted in an inconsistent and regionally varied system, and makes it difficult to align funding with user needs. It was also felt that this has also led to inconsistent practices and a lack of contractual enforcement to support how and when services are delivered. For example, a union/staff representative body noted particular cases where a care agency withdraws care if the client is admitted to hospital, arguing that providers should not be permitted to withdraw from a contract until an alternative provider has been identified. This practice, they point out, often happens without the knowledge of the client, and has led to significant delays in hospital discharges. There has also been criticism of the withdrawal of packages in some areas after patients have been admitted to hospital for 21 days, which again leads to poor continuity of care, duplication of application processes and delayed discharges.

4.1.9 Better support for carers

Families, service users, the statutory sector and private providers also highlighted that carers need to be better supported in terms of salaries, terms and conditions and opportunities for advancement. It was suggested that if training and skills were set to recognised national standards, this would help strengthen caring as a valued career. It was affirmed that resources need to be increased to develop the workforce (this is developed in section 4.5 on training for carers). One advocacy body stated that the pool of carers is declining and that they experience higher levels of stress and poor health than the rest of the population. It was
also argued that their largely unpaid effort makes a significant financial contribution to the delivery of home care in Ireland.

4.1.10 Person and community centred care models

A theme running through the consultation responses was that people need to be at the heart of the design, delivery and evaluation of services. Some respondents highlighted the need to move away from a medicalised model of service delivery to a person-centred approach that involves individualised care plans, personalised budgets\textsuperscript{24} and client directed payments\textsuperscript{25}, to enable the user to determine the best mixture of services. A union/staff representative body specifically highlighted the importance of a biopsychosocial model of care, which views rehabilitation and social support being of equal importance to pharmacological and technological interventions. Another union/staff representative body also highlighted the importance of a case management approach in which all of the professionals, services, families and carers adopt a similar strategy which focuses on the needs and independence of the person being cared for. However, an advocacy body pointed out that case management approaches are only effective when they are properly integrated with community-based services; housing availability to meet a range of needs; psychosocial approaches to complement medical services; and rapid access to dedicated services, such as dementia and end of life care. It was also acknowledged that there are some good practices within the sector:

\textit{My sister was discharged after 3 days with a broken elbow from hospital, she was 85 with multiple health problems. The hospital had a pilot Crest team (Clinical Resource Efficiency Support Team), who sent in a nurse to assess the situation. A physio attended my sister in the home for her elbow, another for her balance, following it up with a seminar later on how to avoid falls which my sister attended. Result: having had 3 falls with broken bones in previous three years, she has had not one fall for seven years now. Her elbow healed 90\%} (Family member or friend of someone who receives home care).

A number of respondents answering this question argued that community-centred services could be to offer holistic support and integrate local initiatives into the care planning process. For example, it was felt that better use could be made of reablement and housing adaptations that allow older people to stay in their homes for longer. In their submission, an advocacy body called for a funding stream for housing associations, which would allow for an amalgamation of packages to broaden the range of supported housing developments. It was viewed that the use of telecare, developing lifetime homes standards so that the property can adapt to the life-course and assistive technology, could be developed to support mainstream home care visits.

A voluntary/not for profit home care provider emphasised the importance of preventative home help, which assists people to plan for living independently and stresses the need to improve the provision of, as well as the integration with, Day Centres and Respite Centres in a more locally focused approach, for those older individuals who are at risk of loneliness.

\textsuperscript{24} Personalised budgets give people more control in accessing health funded personal social services and gives them greater independence and choice in accessing services which best meet their individual needs.

\textsuperscript{25} This is a similar concept that has also been used by respondents and allows people to choose how their support is provided and gives them control over an individual budget on their care services.
Institute of Public Health in Ireland

4.2 Participation and choice

4.2.1 User control over the range of services provided

The importance of user involvement and choice, as central components of home care policy is illustrated in Figure 4.1 (below); it illustrates that 93.6% (n=1,433) of respondents to this question felt that the ‘people who receive home care should have more of a say in the range of services that are provided for them’, with only 3.1% (n=47) feeling that they should not.

Respondents made the point that consultation is critical to the development of a partnership approach to service design and implementation, and ensuring that there is a clear alignment between the needs of users and the range of services provided. Here, it was felt effective systems are needed to properly listen to stakeholders and to put users, families and informal carers at the core of the service. In their written submission a voluntary/not for profit home care provider delivering services stated that:

*choice in terms of service provider is important but it is secondary to cho[ice] within the service that a person is receiving* (Voluntary/not for profit home care provider).

A home help emphasised the issue of listening to users and the importance of recognising relationships built:
How is that right for an elderly care patient - they are afraid to change their schedules and/or request the additional help they need in case they lose the very person they adore and trust. It should be possible to ask for more help and know you’ll be able to get the person you trust - what else do they have that can help keep them stable - it’s not all about the tablets and medication - these home care staff are family to them! (A home care worker).

As previously noted, resources were cited as being at the heart of many issues in home care policy, with a number of respondents feeling that the Nursing Homes Support Scheme (NHSS)\(^{26}\) needs to be extended to the home care sector. However, some respondents noted that it is not just the amount of money which is invested, but how the money is spent, giving users a greater say in the range of services. For example, a number of organisations pointed to models of Customer Directed Care\(^{27}\), whereby the mixture of services, quantity and coordination are based upon direct payments that reflect the priorities of the user and not just health providers. Personalised budgets would enable money to be allocated on the basis of need, and give the user greater control in coordinating services as their care needs change.

[Service delivery] might, for example, take the form of a personalised budgets type of system similar to that being piloted across the disability sector, whereby individuals can tailor their home care package according to their specific needs and desires (within the bounds of their assessed needs). Important in any such system however is that family carers are not unduly overburdened with the administrative responsibilities of such a scheme (Advocacy body).

Respondents also recognised limitations to ‘choice’; as well as constraints as to how far users can realistically shape or direct services. For example, it was noted that not all older people and vulnerable people have the capacity to choose or even consent to the type of care they need (or are offered). However, there were patient advocacy models, especially in the disability sector, that are suggested as a way to create a more inclusive approach to participation. It was recognised that connecting complex systems, professionals, services, budgetary entitlements, users, informal carers and family members, is not a straightforward process, and there is acceptance of the institutional challenges and time required to create a genuine person-centred home care system.

Furthermore, respondents to this question also felt that choice and information go hand in hand. It was felt that that there was a lack of information regarding the performance of providers; there was also a broadly held view that the regulatory environment needed to be developed, specifically to support users in making decisions. For example, it was suggested that there should be more formal, structured and accessible HIQA reports on provider performance; a more visible vetting of the home care workforce, especially as turnover rates are high; a streamlined whistle-blowing service to improve accountability; and advocates to help users make informed choices about their care.

A number of respondents drew attention to the provisions of the Assisted Decision-Making (Capacity) Act (2015), and how this act has protected the rights of users in determining the

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\(^{26}\) Referred to by some respondents as a Fair Deal.

\(^{27}\) Person-directed (or centred) aims to treat service users as individual people and meet their needs in a flexible, timely and responsive way. In addition, enabling people to optimise health and well-being means that people experience an integrated service which provides joined up care.
care they receive. The Act provides a statutory framework for individuals to make legally-binding agreements to be assisted and supported in making decisions about their welfare, as well as their property and personal affairs. This assistance and support is particularly required when the person lacks the capacity to make decisions unaided, and it was felt by some respondents that these provisions could be extended to the home care sector.

4.2.2 User control over who provides the services

Figure 4.2 (below) shows the responses to the question: ‘Do you think that people who receive home care should have a choice in who provides their care?’ The diagram shows that that 87.5% (n=1,338) of respondents agreed with the statement, with 6.1% (n=94) feeling that users should not be involved in such decisions.

Respondents to this question recognised that there are a variety of suppliers, people and organisations that often present a complex environment for the public to navigate. It was also noted that constantly changing staff can be inefficient, be upsetting to vulnerable people and break the relationship that is often built up between care staff, users and families:

This chopping and changing of carers is very inefficient as each carer must become familiar with the unique needs of each client as well as the administrative resources required to support each change of carer. In a service industry such as home care where time is a commodity, this inefficiency is a costly and wasteful use of resources. Enabling care recipients to have a greater say in who is delivering their care is a very positive first step to developing the necessary trust between the key parties involved (Advocacy body).

Many respondents argued that their choice of provider was restricted between State services and profit motivated private providers. Some emphasised that the HSE has been affected by
spending cuts and a freeze on recruitment, and felt that the care workforce experiences high turnover, low pay, poor morale and a weak skills base. Choice it was felt is especially problematic when it comes to complex conditions such as dementia, palliative care, people with disabilities:

"Given the extreme vulnerability of those receiving the care, it is imperative that their views on who provides the care are taken on board and that in the recruitment and training of home care personnel, attention is paid to recruiting only those who have empathy and understanding of that vulnerability. Equally, the number of times that we have heard that “we’re not allowed to do that” or “we’re not trained to do that” reflects huge inflexibility and a lack of common sense when it comes to the delivery of basic personal hygiene to service users. We all recognise that nobody can do pretty much anything useful if they spend only 30 minutes. Agreeing upfront and in detail those areas where the home help can add value to the home experience should be (but is not) done (Family member or friend of someone who receives home care).

4.3 Standardisation of services

The consultation paper invited responses on consistency of service provision in home care policy in Ireland in the future, and asked whether it was necessary to standardise seven separate aspects of service delivery. These are considered in turn below.

4.3.1 Standardisation of approaches in applying for home care

Respondents were asked: ‘Do you think that the same approach should apply across the country in relation to how you apply for services?’, and the results are set out in Figure 4.3. This shows that 94.9% (n=1,353) of people who responded to this question thought that they should, while 2.4% (34) thought that they should not. Most respondents who answered this question felt that a standard application process should be a feature of any future policy.
Figure 4.3 Standardisation in applying for home care

Q. 'Do you think that the same approaches should apply across the country in relation to how you apply for home care?'

- 94.9% (1,353)
- 2.7% (38)
- 2.4% (34)

Responses 1,425

4.3.2 Standardisation of approaches in how needs are assessed

Respondents were asked: 'Do you think that the same approach should apply across the country in relation to how your need for services is assessed?', with the results being set out in Figure 4.4. This shows that 92.3% (n=1,310) of people who responded to this question thought that they should, whereas 4.6% (n=66) thought that they should not.

Figure 4.4 Standardisation in needs assessment

Q. Do you think that the same approach should apply across the country in relation to how your need for services is assessed?

- 3.1% (44)
- 4.6% (66)
- 92.3% (1,310)

Responses 1,420
A significant number of respondents who answered this question were concerned about regional variations in the way needs application processes and access were conducted. A union/staff representative body pointed out that the experiences of social workers varied considerably across the country, regarding the way needs are assessed, the availability of support and specific practices, such as hospital discharge processes. They also noted:

[There is] a narrowing of the scope of home care services towards personal care alone, thereby not acknowledging the valuable role that home care services provide in terms of health promotion, social and carer support (Union/staff representative body).

One respondent from a public interest group identified the need for a seamless approach based upon a standard needs assessment that addressed the level of dependency, the preference of the user, the role of the family and the quality of local community infrastructure:

A standard needs assessment is essential in order to help determine an individual’s eligibility for or entitlement to benefits or services on the basis of agreed and transparent criteria… A realistic assessment of the support needs of carers – physical, social and psychological geographical factors can influence needs, e.g. access to transport, but in general, a level playing field is fairest to all, using a common-sense approach (Public interest group).

4.3.3 Standardisation of approaches in terms of who can access services

Figure 4.5 (below) shows the responses to the question: ‘Do you think that the same approach should apply across the country in relation to who can access services?’, it shows that 93.4% (n=1,321) respondents to the question agreed, while 3.0% (n=43) did not.

Figure 4.5 Standardisation in who can access services

Q. Do you think that the same approach should apply across the country in relation to who can access services?

- 3.5% (90) Don't Know
- 3.0% (43) No
- 93.4% (1,321) Yes

Responses 1,414
4.3.4 Standardisation of approaches in what services are provided

Respondents were asked: ‘Do you think that the same approach should apply across the country in relation to what home care services are provided?’. Figure 4.6 (below) shows that 91.5% (n=1,291) of the people who responded to this question thought that they should and 4.9% (n=69) thought that they should not.

Figure 4.6 Standardisation of home care services provided

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<td>Yes</td>
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<td>No</td>
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Responses 1,411

4.3.5 Standardisation of approaches in how home care services are provided

Figure 4.7 (overleaf) shows the responses to the question: ‘Do you think that the same approach should apply across the country in relation to how home care services are provided?’ It shows that 90.1% (n=1,270) agree with the statement and 5.9% (n=83) disagree.
There was overwhelming support across respondents from different sectors, type of providers and professional areas for a standardised service. Inequities across the system nationally are, however, a concern amongst health professionals delivering the service:

I am a health professional working in one county, in this county there are 3 areas and the way home care is provided in each of these 3 areas is completely different. These areas are sometimes only a street away, meaning that neighbours are sometimes receiving different levels of service. I previously work[ed] in a bordering county and home care services were managed completely differently. I think this is ridiculous, no one is taking overall responsibility for this (A health professional providing home care services).

The majority of respondents answering this question felt that there needs to be a transparent resource allocation model to support a standard level of care, but which is also flexible enough to respond to different socio-economic, demographic and settlement characteristics. In short, ‘standardisation is good, so long as it is not to the lowest common denominator and innovative person-centred services are lost’ (A health professional providing home care services). Here, it was felt that a national system should reflect access to services, and in particular, take account of the needs of more isolated rural communities; population density; the distribution of the Travelling community; the needs of ethnic minorities; variations in the age profile and conditions such as dementia, as well as all levels of disabilities:

A core set of home care services should be provided nationally but local variation should be possible to respond to local needs (for example, local cultural or linguistic needs). This approach also allows for local services to be improved incrementally until there is more uniformity in provision across the country. If implemented into the current service landscape, complete standardisation in terms of what is provided would either result in an excessive delay (until every area was up to a similar level of provision) and/or a lack of ability to respond to specific local needs. The standardisation of home care
care services is likely to strongly inhibit the ability to provide the type of flexible and responsive services that are recommended as best practice, which support personhood… and are highly valued by older people and their carers (Academic institution).

The issue of nutrition, for example, illustrated the need to define the range of support that is covered by home care policy, and how these in particular, relate to the Meals on Wheels service. The service is acknowledged by the respondents as a vital one, but viewed as hampered by patchy regional coverage, inconsistent standards, insecure funding and poor conditions for workers and volunteers. It was requested that the HSE implement a standard national approach with improved multi-annual funding to better reflect costs and deliver services; develop quality standards; and strengthen the governance, skills and regulation of local providers. The development of a social enterprise model was also considered an important part of the delivery of the home care policy through well-resourced and financially secure local groups.

4.3.6 Standardisation of approaches in how home care services are monitored

Respondents were asked: ‘Do you think that the same approach should apply across the country in relation to how home care services are monitored?’ The results are set out in Figure 4.8 (below) that 93.5% (n=1,319) of respondents to this question answered yes and 2.8% (n=39) answered no.

For many respondents, delivery should be based on monitoring through an outcomes approach that puts the best medical and social outcomes for the user at the heart of the process. Some respondents criticised home care because they felt it was too concerned with delivery by agencies, professionals and business concerns, and less concerned about the circumstances of carers, families and the user. Nutrition was again identified by an advocacy
body to illustrate the importance of common monitoring systems. This advocacy body cited the Care Quality Commission in the UK, which has set standards on nutrition and hydration, monitoring the intake of supplements and penalises providers who fail to comply with agreed targets. Similarly, they cite a Dutch Malnutrition Steering Group that introduced new protocols and standards of care, including screening tools, training and monitoring systems, which they indicate significantly reduced cases of malnutrition and dehydration across the sector.

Some respondents also indicated that there needs to be an overarching system of registration (of carers and providers) and (unannounced) inspections, so as to maintain quality standards and place the emphasis on user control over service delivery.

4.3.7 Standardisation of approaches in how you can appeal a decision

Finally, in this section, respondents were asked: ‘Do you think that the same approach should apply across the country in relation to how you can appeal a decision about your home care?’. Figure 4.9 shows that 94.1% (n=1,317) of respondents to this question agreed with the proposition and 1.7% (n=24) did not.

Figure 4.9 Standardisation in appealing a decision

![Figure 4.9 Standardisation in appealing a decision](image)

A lack of information about the appeals process and the implications regarding the choice of care provider was highlighted by a number of respondents, especially family members and informal carers:

*The inordinate delays in the process and the absence of guidelines on the appeal process. No explanation was provided when application was rejected. There is no monitoring of the process. You are at the mercy of the HSE in terms of selection of carers and with no input into the selection process. You are expected to feel fortunate just to get someone, but it is important that the carers [are] matched to the needs of the recipient (Family member or friend of someone who receives home care).*
Respondents were also concerned that the complaints process should be led by people external to the delivery process in order to improve standards, strengthen scrutiny and build trust in the wider home care system. This was illustrated by the person, who commented that:

*The provision that the assessment needs to be carried out by a person/s with expertise and experience working in that specific area. Local HSE personnel are not equipped to do this in general. That the services are provided in line with an independent assessment of need carried out by a person/organisation with expertise in this area and an appeals process… monitoring is critical to good practice and professional development and training of carers - it needs external scrutiny’* (Family member or friend of someone who receives home care).

Linked to this, the opportunity for a confidential whistle-blowing system was highlighted. It was deemed that this needed to address the fear of losing services, which one respondent suggested, prevented many from providing an honest assessment of the care they receive:

*Clients are vulnerable elderly people generally. They are afraid to report problems in case it will fall back on them. If they live alone it is their word to the providers. I feel that a camera should be installed to record the delivery of the care* (Member of the public).

### 4.4 National quality standards

#### 4.4.1 Views on common national quality standards

Respondents were asked: ‘Do you think that the same national quality standards should apply to all (public, private and not-for-profit voluntary) providers of home care?’ and 92.8% (n=1,329) agreed that the same standards should apply across sectors, with only 3.4% (n=49) saying they should not and 3.8% (55) stating that they did not know.
4.4.2 Setting standards of care

There was a consensus amongst the organisations, professions and users that delivery of home care needed to be consistent across the public, private and voluntary sectors, especially in terms of standards, service coverage and setting hours which were appropriate for the different needs of the user. Respondents who answered this question felt that the key people involved in service design and delivery, including carers, the public health nurse, occupational therapists and social workers, should all play a role in setting and maintaining standards of care. They also felt that standards should not rely on auditing and ‘tick box’ implementation, but should encourage flexibility in responding to different client needs. The standards framework also needs to include processes for appropriate risk assessment, safeguarding and more innovative use of telemonitoring. For example, a voluntary/not for profit home care provider cited a software system which requires home support workers to log-in by telephone on arrival to and departure from a person’s home. The need for basic standards of care was a consistent theme in the consultation, as set out by the same organisation:

National standards can provide a framework for those providing care, and an indication for those in receipt of care as to the level of professionalism and basic standards of care they can expect to receive. The issue of national standards for home care has been an identified issue for some time (in the National Carers Strategy, 2012) specifically raises this issue as a matter of national policy… If these standards are drafted and come into effect, it is vital that all providers of home care, regardless of their status as public, private, or not-for-profit, be held to the same account. Having differing standards across home care providers runs the significant risk of developing a two or three-tiered home care provision sector (Voluntary/not for profit home care provider).
4.4.3 Standards based on the needs of the person

Again, the person-centred nature of home care it was felt should be a priority in setting standards, regardless of the type of provider or the service being delivered, with one respondent arguing that:

*We need to move away from the term home care and start with the person-centred service. Clearly whoever is providing the service should adhere to the strictest standards that apply to their profession* (Full time carer to children with impairments).

Similarly, it was voiced that monitoring the compliance with standards needs to accommodate the qualitative experiences of users, and not be confined to performance metrics and target indicators:

*When standards are put in place they should look at the “happiness” or quality of life of the end user, it should not just be about health and safety and form filling* (Family member or friend of someone who receives home care).

The issue of skills and training is considered below, but it is clear that many respondents determine this as an integral part of service quality, maintaining standards and compliance processes. Here, it was acknowledged that as well as competencies to do the job, there also needs to be closer attention on the welfare of all of those delivering home care:

*All carers should have a standard level of quality, and there should be mandatory supervision sessions for carers so that their mental health and wellbeing is also being cared for in caring for others. There should also be on going checks on carers to make sure that standards of care are being maintained and a quarterly review system with the client and family members to ensure that their needs are being met. Also, a dedicated support line for client and family members… are essential as elderly people have special needs and they can easily be abused psychologically, physically and financially. We have all read horror stories of shocking abuse of elderly people who should have 'advocates' to speak on their behalf if necessary and advise the person of their rights and options* (Member of the public).

Similarly, a voluntary/not for profit home care provider emphasised the need to look beyond care skills and to include budgeting, home management, community connecting, developing friendships and behavioural support. It was felt that this was essential in the case for people with intellectual disabilities, including those under-65, to support someone living at home by integrating with local community programmes.

4.4.4 Compliance and standards of care

A number of respondents also wanted to see transparent reporting, especially the compliance against standards and specific service reports; bench-marking against other European Union (EU) countries; and specialist inspections for clients with complex conditions such as motor neurone disease, multiple sclerosis, Huntington’s disease, dementia, people with heart disease, strokes and those receiving palliative care. A robust system, standardised across all sectors, was viewed as critical:
Without regulation, standards, protocols and policies cannot be assessed, nor is there a benchmark to assess the carers or their training, except by internal audits. While the HSE have tendered their home care services to private companies for some years now, the regulation of these services is essential (A health professional working in another sector).

Standards and how they are monitored, it was felt will require new processes, but a number of respondents highlighted the need for a proportionate system of reporting, especially in the community sector. Some respondents were keen to emphasise the need to ‘be careful not to choke voluntary services with paperwork’ (Family member or friend of someone who receives home care), and that ‘common sense should prevail at all times’ (An informal carer not paid to provide care).

4.5 Training for care workers

The issue of training and the need for consistent standards has been highlighted throughout the consultation document. Figure 4.11 shows that 92.1% (n=1,310) respondents, to this question, felt that ‘formal home care workers should have to complete a minimum level of training that would be set by the Government’, 3.8% (n=54) said that this was not needed and 4.1% (n=58) stated that they did not know.

**Figure 4.11 Training for care workers**

Q. Do you think that formal home care workers should have to complete a minimum level of training that would be set by the Government?

<table>
<thead>
<tr>
<th>Response</th>
<th>Percentage</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>92.1%</td>
<td>1,310</td>
</tr>
<tr>
<td>No</td>
<td>3.8%</td>
<td>54</td>
</tr>
<tr>
<td>Don't know</td>
<td>4.1%</td>
<td>58</td>
</tr>
</tbody>
</table>

Responses 1,422

4.5.1 A strategic approach for care workers

A number of respondents, including employers across the private, public and voluntary sectors, felt that a more strategic approach to setting national quality standards was needed. Here, it was felt that there should be clear skills identified within and between Home Helps,
Home Care Assistants, Senior Assistants and so on. A representative body pointed out that specialist teams of carers should be put in place to deal with users with more complex conditions, especially with those linked to Intensive Home Care Packages. It was considered that this would also involve a review of pay and conditions as well as the standardisation of contracts between HSE and non-HSE staff, including terms of conditions and allowances.

The idea of career progression, it was felt, is important, especially as the carer labour market will grow significantly over the next 30 years. One private home care provider stated:

The workforce needs to increase by 48% just to meet demographic growth over the next 10 years and probably a further 30-50% to meet both the replacement rate… and changes in [G]overnment policy-making home care more accessible (Private home care provider).

It was suggested that this might also involve a potential programme of Continuing Professional Development, on-line delivery, in-service-training, qualifications and a focus on applied competencies and how they are supported:

While minimum training levels are important, the sector also needs to look toward the development of additional qualifications and ongoing development for workers. For example, investments in childcare and early childhood education have gone some way towards professionalising the sector and creating career paths for workers in the sector. A similar model needs to be developed for the home care and long term care sector (Academic institution).

4.5.2 Improving workforce conditions in the care sector

There is a view across respondents that morale among carers is poor, with turnover being high, salaries are low and employment often insecure. The precarious conditions of migrant workers was also highlighted, as well as the need to fully support, what is now, a vital and valued part of the carer workforce in Ireland. Several advocacy bodies argued that vital consideration needs to be given to the cost of carers working in remote rural regions compared with those in high density urban neighbourhoods. A National Home Carers Award was also suggested as a way to build awareness and recognition of the work, although most respondents highlighted the need to improve basic pay, so as to strengthen the quality of the carer labour market. Overall, it was felt there is a need to value the workforce in the context of delivering a new home care policy in Ireland:

Carers in general do a superb job of caring for their patients. However, their pay is poor, the hours aren't steady and there is often poor management. No wonder they do not stay. Care agencies that are private appear to be trying to grow their client base without looking at the needs of the clients (A health professional providing home care services).

4.5.3 A new approach to qualifications and defining skills

The predominant issue in this set of responses was the need for national standards, based upon an agreed skills framework that sets out the competencies, knowledge and learning opportunities for carers. It was broadly accepted that Quality and Qualifications Ireland (QQI) Level 5 was an appropriate minimum standard, but that different pathways were required to care for clients with different levels of need, especially when caring for people with a range of physical and intellectual disabilities, and to strengthen interpersonal as well as care skills. As
noted below, respondents felt that narrowly defined standards and fixed sets of skills were limited, and that applied learning opportunities (possibly in the context of Continuous Professional Development\(^{28}\) - CPD) should inform a national skills strategy. It was felt that standards needed to be properly assessed and tested to ensure that staff could apply the right skills within a range of actual care environments, and this could be the basis of a comprehensive register of care practitioners in Ireland.

There was significant discussion about the scope of service training and what constitutes appropriate care work. For example, a number of respondents wanted to see training focused on malnutrition and diet; dental health; food hygiene; incontinence; manual handling and lifting and falls prevention. These responses highlighted the need to clarify the core function of (the various) roles within care work and the linkages to the suggested skills framework. It was recognised that there is a need to support high dependency cases with complex conditions and co-morbidities, and make better use of assistive technologies and tele-learning were also highlighted:

*Carers need to have some understanding and training in specific conditions such as dementia and other degenerative conditions such Parkinson’s disease. They need to know how to cope with and manage elderly people presenting with aggression and depression* (Family member or friend of someone who receives home care).

### 4.5.3 Person-centred care training approaches

One respondent emphasised that ‘*the focus of that training should be on developing cultures of person-centeredness*’ (Informal carer not paid to provide care). A range of respondents felt that standards and qualifications are important, but that does not mean we should lose sight of empathy, interpersonal relations and an ability to communicate effectively with the user. The ability to communicate it was also felt should extend to a good understanding of English, something which was highlighted as a critical part of any skills framework for carers. It was acknowledged that many people without professional qualifications provide excellent compassionate services, so they should be valued and supported within the care system:

*The minimum level of training must include analysis of the motivations of the person providing care… The “right” persons need to deliver these supports [and] seeing the person as a person and treating them with dignity, kindness and compassion* (Member of the public).

### 4.6 Paying for home care

#### 4.6.1 Increased investment in home care

A significant number of submissions emphasised the need for increased investment in home care services, with an advocacy body observing that, despite the growth in the population between 2006 and 2015, the allocation of Exchequer funding for home care declined during

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\(^{28}\) Continuing Professional Development refers to the process of tracking and documenting the skills, knowledge and experience that staff gain both formally and informally as they work.
this period, resulting in a shortfall of 10% by 2015. In a similar vein another advocacy body recommended:

*Funding in excess of €100m is required at a minimum to bring core community services for HCPs [Home Care Packages], Home Help, and residential care supports through the Fair Deal scheme to more sustainable levels.*

A number of respondents felt that the Fair Deal\(^29\) programme could be extended beyond Nursing Home support to cover home care services. Arguing that an integrated home care budget was required, but that a more objective needs based and transparent resource allocation model was required to maintain investment in home care. A representative body for healthcare professionals stated that funding-levels for home care should be 'gerontologically informed and adequate (in terms of capital investment, operational funding, and manpower) to meet both the complexity of care and to comply with national quality standards'.

4.6.2 A needs led approach to funding

There were also requests for the establishment of a demand-led, customer directed scheme, with an advocacy body arguing that ‘the creation of a statutory entitlement to home care [...] means that the service must be provided notwithstanding any budgetary constraints’. In this respect, another advocacy body also emphasised the need for a rights-based approach that involves establishing:

*A basic, universal, standard set of care that covers nursing, rehabilitation, reablement, therapies, counselling and personal care and which is provided free of charge to all those assessed as in need. A level of care framework is developed using data from SAT (Advocacy body).*

The development of a sustainable funding-model for home care was a key concern for many respondents, with a number calling for a centralised, ring-fenced budget at a national level. The introduction of Activity-Based Funding (ABF)\(^30\) to support the provision of integrated care across the health system was also advocated, with a statutory healthcare body calling for a ‘whole-system approach to funding which supports the patient-journey from acute hospitals, disability services and long term care’.

Various options for the financing of home care were proposed by respondents, including social insurance, increased general taxation and increased corporation tax. For instance, an advocacy body asserted that ‘a social insurance model would increase the visibility of long term care, pool risk, provide contributions over a lifetime and funding would be ring-fenced’ (Statutory healthcare body).

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\(^29\) Fair Deal, is a scheme under which the cost of nursing home care is managed through the HSE paying either the full or part of the cost and by allowing those charged with paying the resident’s portion of the cost to defer the charge.

\(^30\) ABF is an approach to health and care funding, which sees providers funded in line with the activity that they undertake.
4.6.3 Means tested user-contributions

The consultation paper highlighted the fiscal constraints within which the statutory scheme for the financing and regulation of home care would be developed. Respondents’ views were sought on the introduction of means tested user-contributions for home care services; along with their willingness to purchase additional hours of care if state-funded services were limited.

As illustrated in Figure 4.12, which summarises the responses to the question, ‘Taking account of limited state resources, do you think that people who receive home care services should make a financial contribution to the cost based on their ability to pay’. The majority of respondents to this question (57.0%, n=786) felt that they should make a financial contribution, with 32.2% (n=444) rejecting the proposition, and the remaining 10.8% (n=149) indicating that they did not know.

Figure 4.12 Means tested user contributions

Amongst those respondents who indicated their support for the introduction of user-contributions, there was a degree of consensus that such a funding model would be more equitable than the current system, ensuring that those without the financial means to contribute would receive the care that they required. One private home care provider commented: ‘those who are able to contribute should, as this enables more people in greater need to be supported’. Likewise, a healthcare professional observed that ‘means testing [is] needed’ and called into question whether it is fair that ‘people in €1 million houses [get] intensive home care packages whilst poorer applicants are on a waiting list’. However, some respondents emphasised that the contributions required from those service users with sufficient means should be affordable, with a union/staff representative body cautioning that:

Older people should not be seen as a “soft target” but rather any changes in terms of co-payments should be on a similar basis as other forms of healthcare such as
medications, and public hospital and OPD (Out Patient Departments) charges (Union/staff representative body).

A wide range of views were expressed about how means testing should be implemented, with recommendations including:

- the introduction of a minimum income threshold, in beneath which service users would not have to contribute;
- the introduction of a maximum expenditure threshold above which no contribution would be required;
- user contributions required to be assessed on a case-by-case basis;
- user contributions only to be sought from those in the highest tax bracket; and
- user-contributions to be cognisant of the contributions (through taxation and national insurance) made by a service user throughout their life.

It was suggested that means tested user contributions could only be legitimately introduced if the service provided was comprehensive and of a high quality, and as long as if service users were given a choice of carer and influence over the services provided.

The viewpoint that home care services should be freely available to everyone was expressed by many of the respondents who rejected the proposal for the introduction of means tested user-contributions. An advocacy body argued that:

[T]he cost of looking after the old and infirm should be provided free by the State’ and a not-for-profit service-provider called for ‘universal healthcare through a universally, publicly funded system [...] based on need and not on ability to pay’

A number of respondents also argued that since older people have paid taxes throughout their lives to support others, they should in turn be cared for by the State; with a family member/friend of a home care service user stating:

This is a basic level of care in society and many of these people have paid taxes all their lives and are entitled to this basic level of dignity and care (Family member/friend of a home care user).

Similarly, an advocacy body representative commented:

Serious consideration must also be [given to] how much an individual has already contributed to society. If a middle-income person has worked all his/her life and paid significant taxes (and hence social contributions to others less well off in society), is it fair to now ask that person to pay again when he/she needs some support? (Advocacy body).

Other respondents expressed concern; one family member or friend of someone who receives home care stated, those ‘on the basic state pension of €230 [...] could not afford to pay towards [a] home care package’. Others indicated that the introduction of user-contributions would increase the incidence of poverty; or would create a risk that a person with limited resources may forgo services, and as a consequence, cost the State more for acute-care provision.
4.7 Buying extra hours

The final question asked was: ‘If the State could only provide a certain amount of home care services based on health need, would you be prepared to purchase additional hours with your own money, if you needed them?’. Figure 4.13 shows that 61.4% (n=826) of respondents to this question would buy additional hours, 20.0% (n=269) stated that they would not and a significant number, 18.6% (n=250), were not sure.

Figure 4.13 Extra hours

4.7.1 Willingness to pay

A number of respondents who said that they would pay for additional hours pointed out that they already had to supplement the care they received from their own resources. This includes additional support and respite care to support and deal with more complex medical conditions and neurological problems. For some, this is an acceptable family responsibility, whereas others feel forced to buy extra care because core hours appear to be rationed:

*The State will only provide a certain amount of home care services that generally do not meet patients in their own homes needs so yes, I had no choice but to purchase extra hours care in the past to ensure my family were adequately cared! (Family member or friend of someone who receives home care).*

For those who said they would not be willing to pay for extra hours, the main issue was affordability:

*When I was caring for my mother-in-law I spent all my savings in paying for extra home help so that I could honour the promise I made to her that while it was within my call I*
would allow her to die at home... At the moment I am just barely able to survive on my old age pension and have no savings left to allow me to pay for extra help (Someone who receives or has received home care).

This is a recurring theme for respondents who have left work and so no longer have the resources, or who have other dependents with often complex medical conditions to look after. An informal carer (not paid to provide care) stated that: ‘I quit my job to care for my son. We don't have the money.’ A number of respondents identified housing and transport costs being an issue and the way in which inflation affects older people’s services, thereby leaving little additional finance to buy extra care. As many informal carers are not in work, they rely on social welfare to support their own needs, as well as those who they care for:

"A lot of people who care were full-time workers and are now either aged or not able to work anymore due to illness. Therefore, they are dependent on the financial means of their spouses or families or some people only social welfare payments (Informal carer not paid to provide care)."

4.7.2 Means testing and state provision

Some respondents felt strongly that means testing should be the basis of decisions, and that assets should be included in assessing the ability of whether a person can afford extra hours. Others argued that tax relief should be easier to access for those families who did buy extra care, and that applicants should have an automatic right to the service, especially if they are paying income tax. Similarly, some respondents felt that some innovative thinking would help address the funding shortfall, with one respondent suggesting a loan scheme, especially if it helped people stay in work whilst looking after dependents:

"I think that a lending scheme should [be] made available to family or clients to enable them to purchase increased home care at this time in order to assist with the financial burden at this stressful time. Often family members have to give up work during this period which increases their financial difficulties (Home care/home help)."

There were also concerns regarding the way in which home care is funded, which might result in a two-tier system, with the State paying directly for those most in need, and those outside the system providing for their own services privately:

"We will always do what is best to care for those we love, but the level of care should be the same for all. If people do not have the financial resources to care for themselves/ageing family members it does not make them less important, and families should not have to face stress and 2 tier systems of the haves and have nots. I thought we were trying to move away from this system of thinking and acting (Member of the public)."

Some respondents felt that the answer was a more progressive tax system which paid for universal care based upon need. The argument presented by a number of respondents was that those who had paid taxes all their lives should not be effectively doubled-charged for a service later in life.
4.8 Final comments

Respondents were asked if they had any other comments on the home care system in Ireland and how it should be developed. In the main, comments tended to support the points made throughout the consultation, and helped reinforce the key priorities that are developed further in the next section. One of the key themes running through this analysis is a concern to put people at the heart of service planning and delivery:

_We have forgotten that these people are real people who have led vibrant lives, paid taxes, contributed to the society we live in today and who need our help and care when they find themselves at their most vulnerable_ (Informal carer not paid to provide care).

The need for a person-centred care model cuts across sectors, providers, professions and users, and linked to this highlighted the need for a consistent policy characterised by a number of elements including:

- An integrated policy based on a clear legal definition of the scope and content of home care and how it supports older and younger people in need of support at home, and specific services such as disability, dementia, nursing homes and day care centres.
- A focus on agreed outcomes, centred on the needs of the users and their mental and physical wellbeing.
- Tackling loneliness and isolation should be embraced in the delivery of the service, allowing people to live at home safely, and with dignity, for longer.
- Connecting with policies on housing and especially adaptations; life-time homes; fuel poverty; transport; and access to community development networks should be part of a more seamless service, offering support as the needs of the user change.
- The work of informal carers needs to be better recognised and valued in terms of financial allowances, while the carer workforce should be better supported, skilled and rewarded. This could be done by scrapping zero and low hours-contracts across the sector.
- One respondent suggested a dedicated research programme should be developed on home care through the Health Research Board (HRB), HSE and the Department of Health, supported by professional bodies and academics. It highlighted that home care is a neglected area of research, and a more structured approach would inform policy development, help prepare guidelines and services, as well as offer critical insights into the performance of the system across Ireland.
Part 5 Key themes from the consultation

The quantitative data, qualitative comments and written submissions, raise a range of issues for consideration during the designing of a new home care policy in Ireland. This section sets out the key messages highlighted by respondents to the consultation in relation to the future of home care service-provision.

5.1 The development of a statutory home care system

There was strong endorsement for the Government’s proposal of a statutory based home care system. The consultation responses indicated that this would give people a statutory entitlement to home care in accordance with people’s assessed needs; it would create a standardised service; agree eligibility criteria; establish a new regulatory system; and determine the financial resources to meet demand.

The Department’s consultation paper indicated the need to effectively integrate the work of the Oireachtas Committee on the Future of Healthcare, the National Carers Strategy, the Positive Ageing Strategy and the National Dementia Strategy. Respondents also felt that there should be a commitment to connect the aims of these policies at the point of delivery in home care, and apply learning from the new community nursing services and the Task Force on Personalised Budgets in the disability sector.

Respondents also identified the need to more effectively integrate home care with housing, transport, especially in rural areas and community development, as well as the capacity of social enterprises to deliver services. It was noted that policy development, implementation and evaluation could be supported by a dedicated programme of research, which looked at, for example, long term needs and international models of good practice.

5.2 The need for a clear definition of home care services

Respondents felt the legislative and policy basis should define home care and the specific services that enable people to live independently in their own home. A number of respondents thought that this should address socio-psychological needs, loneliness, companionship, as well as a range of everyday domestic services that would help the user and their families. Some respondents suggested a life-course approach, which would broaden the scope of the service to people below 65 years of age and enable full-time (24-7) services to be tailored to the needs of people with complex neurological conditions and a range of disabilities. While respondents did want to see a standardised policy framework, they also acknowledged the need to implement services flexibly in response to local demographic profiles, settlement patterns and the needs of people with more complex health conditions.
5.3 A person-centred model of home care

A number of respondents, from a range of sectors, suggested that services should be designed around the needs of the user, rather than for the convenience of the supplier, with the users, as well as their informal carers and families, helping to shape the type, level and quality of the services they receive. Continuity of service, building a relationship between carers, health professionals and the user, along with being able to choose services, organisations and staff were other suggestions made by respondents that should be part of the new approach. Some suggested that personalised budgets and direct payments could help to shift the design and delivery of care to achieve the best health outcomes for the users and their families. In this respect, a number of private, public and voluntary organisations advocated a mainstreaming client-directed care model which is already piloted by the HSE. A comprehensive information strategy building awareness of services and how to access them was viewed as a priority by respondents.

5.4 The roll-out of the Single Assessment Tool (SAT)

The roll-out of the Single Assessment Tool was supported by organisations, sectors and professional bodies. It was felt the SAT would enable an effective and fair appraisal of the support needed, determine resources and ensure equity of service delivery across the country. Work has already been carried out developing the approach, with respondents encouraging its adoption in the new home care system but stressed the need to monitor and review cases on a regular basis.

5.5 A more integrated approach to service delivery

It was felt that the Single Assessment Tool could, in turn, help to inform a more integrated approach to service delivery. Attention was drawn to the need for a case management process and the success of the HSE/Genio pilot projects in the dementia sector. The roll-out of the Integrated Care Programme approach was also seen as a priority, as it would be able to connect the outcomes of the SAT with a user orientated approach and a more holistic set of supports to meet the social and psychological, as well as medical needs, of users.

5.6 Better integrating the community and voluntary sector

A number of respondents also emphasised the need to better integrate the voluntary sector, community support and social enterprises into home care services. It was suggested that this might involve day care centres in respite and in-home respite services, as well as tackling isolation and loneliness for users, informal carers and families. Respondents highlighted
important innovations in community transport, social car schemes, Meals on Wheels and befriending, all of which could be better mapped and connected into home care policy within specific areas.

5.7 Housing options for older people

The consultation responses emphasised the relationship between home care and housing options for older people which would enable them to live independently for longer in a range of community settings. It was suggested that supported housing is not well developed and that improvements might include dwelling adaptations, and more formal housing-with-care alternatives. The use of telecare was also highlighted as a way of helping some carers and users live more safely at home, and to monitor service delivery and compliance with standards. It was suggested that the lack of supported accommodation has resulted in more older people using residential care facilities or staying in hospital longer than necessary, reiterating the need for a well-integrated housing supply with home care policy.

5.8 Skills and training in the home care sector

There was broad agreement that skills and knowledge needed to be strengthened and attention was drawn to the value of the QQI programme, the HSE/Genio module for carers working with people with dementia and the way in which professions such as nursing, occupational therapy and social work have dedicated training to caring in the community. Respondents concerned with this issue highlighted the need for additional training to examine: the different skills needed in the workforce; how standards are set and assessed; and the need for specialist training in caring for people with a range of disabilities. Some felt that an emphasis should be placed on learning on-the-job and argued that the best carers are often those with compassion, empathy and an awareness of the wider social needs of their clients. Respondents also considered that training should help build caring as a career with appropriate conditions and pay, progression and opportunities to deepen expertise and experience. There was a concern that staff turnover, low and zero-hour contracts, stress and poor morale, were damaging the delivery of home care. It was also felt that informal carers should be better supported and trained to help deliver the best care for their friends and family members.

5.9 The regulation of home care

A consistent message was that a new system for the regulation of home care in Ireland needs to be developed. A number of respondents, from across all sectors, suggested that HIQA should assume oversight responsibility for providers, services and facilities related to the delivery of home care. This list is not exhaustive, but respondents felt it should prioritise setting standards; developing a register of providers; accrediting and monitoring provider
performance; ensuring compliance with agreed training standards; developing a Code of Conduct for providers; undertaking inspections; taking enforcement action where services do not meet required standards; and developing good practice for carers, families and home care providers.

5.10 Funding home care

The issue underpinning many of these priorities and the wider delivery of home care is finance. There was agreement that resources allocated to home care were insufficient, and that users’ needs should determine the level of protected (ring-fenced) investment in services. A number of respondents argued that a resource allocation model should ensure that resources are invested across services, clients and regions, in a way that achieves the best health outcomes. Such decisions, it was felt, should take account of local circumstances (say between urban and rural areas or across Ireland), the complex needs of particular groups and what is available within the community to support service delivery. However, there was a wide range of opinions expressed on how to finance home care and some of the ideas presented included: a universal national care system funded through taxation; a social insurance model; and co-financing between the State and means tested contributions from the individual.
Annex I: Long version of the survey

Improving Home Care Services in Ireland:

Have Your Say!
Your Opinion Matters
This public consultation is being carried out to help the Department of Health to develop plans for a new statutory scheme for home care services.

We would like to find out what people think about current home care services – what is working well and what needs to be improved. We would also like to hear the public’s views on what the future scheme should look like. A report of the findings of this consultation process will be published. These findings will help the Department to develop the new home care scheme.

This stage of the consultation is particularly aimed at people who use home care services, their families and the general public. However, everyone with an interest, including: health and social care providers; health and social care workers; advocacy groups; those providing complementary services (such as meals-on-wheels and social activities); and representative organisations is welcome to participate.

It is important to say that this consultation paper is just the start of a broader consultation process on home care. The Department also intends to consult by:
- Meeting with individuals and groups so they can tell us directly what they think;
- Meeting with home care service provider organisations and other organisations that represent people that use home care services so they have the opportunity to put forward their views; and
- Asking everyone with an interest in home care services to tell us what they think of our plans when they are developed.

Given that the Department will be consulting again throughout the process of developing the new home care scheme, this consultation does not attempt to address every issue related to home care.

Structure of this Consultation Paper
There are four sections in this paper:
- Section 1 gives some information and background to home care in Ireland;
- Section 2 asks you to tell us a little about yourself;
- Section 3 asks you to tell us about your experiences of home care;
- Section 4 asks for your views about the current home care system and your ideas for the future.

How to take part
You can fill in the consultation online at: http://health.gov.ie/consultations/

If you prefer, you can download a copy of this document at http://health.gov.ie/consultations/ and post it to us at:
- Home Care Consultation
- Room 204
- Department of Health
- Hawkins House
- Hawkins Street
- Dublin 2, D02 VW90
Alternatively, if you would like a paper copy to be sent to you, please contact the Department of Health using the contact details written above or by calling (01) 6354402 or (01) 6354732.

You can also contact the Department at these phone numbers or at our email address (homecareconsultation@health.gov.ie) if you have any questions about this document.

**Easy Read Version**
A shorter, “easy read” version of this consultation paper is also available on the Department’s website. If you would like to receive a paper version of the easy read consultation paper, please contact the Department at the phone number, email address or postal address above.

**Closing date**
The closing date for submitting your views is **Monday 2 October 2017**.

**Data Protection and Privacy Provisions**
The information shared by you in this consultation will be used solely for the purposes of policy development and handled in accordance with data protection legislation. An analysis of submissions received as part of the public consultation will be published online which will include a list of organisations and representative bodies that responded. Comments submitted by individuals may be used in the final consultation report but these will be anonymised. All personal data is securely stored and subject to data protection laws and policies. For more information, see [http://health.gov.ie/data-protection/](http://health.gov.ie/data-protection/).

Please note that submissions received by the Department are subject to the Freedom of Information (FOI) Act 2014 and may be released in response to an FOI request.

**SECTION 1 – INTRODUCTION AND BACKGROUND**

**Note:** Before you begin to answer the questions, you might find it helpful to read this section which has information about home care in Ireland and the consultation process. An Easy Read version of this information is available from the Department of Health’s website at: [http://health.gov.ie/consultations/](http://health.gov.ie/consultations/).

1. **Introduction**
It is widely accepted that most people want to continue to live in their own homes throughout their lives. The Government wants to improve community based services so that people can live with confidence, security and dignity in their own homes for as long as possible. In order to help make this happen, the Department of Health is developing a new scheme that will improve access to the home care services that people need, in an affordable and sustainable way. The Department will also introduce a system of regulation for home care so that the public can be confident that the services provided are of a high standard.

The Government’s commitment to improving home care can be seen in its Programme for Partnership Government[^1]. The Programme makes several references to home care including commitments to: (i) review the management, operation and funding of national

home help services; (ii) increase funding for home care services; and (iii) introduce a uniform home care service so all recipients can receive a quality support, seven days per week where possible. The recently published Report of the Oireachtas Committee on the Future of Healthcare also shows support for improving home care from across the political system.

2. Scope of this Consultation – What is home care?

The focus of this public consultation is on home care services. However, this raises an important question – what is home care?

The meaning of home care can differ significantly between countries and, as such, there is no standardised definition. However, a recent evidence review by the Health Research Board titled “Approaches to the regulation and financing of home care services in four European countries” states that:

“Home care in Ireland is typically understood as home help services, which include cleaning, cooking and other light household tasks that a person is unable to do themselves due to old age or disability. The scope of home help has subsequently developed to include more personal care assistance such as support with personal hygiene, washing, and dressing also.”

While the home care service in Ireland is mainly used by older people, it is also provided, in a limited way, to some people with disabilities and other identified care needs. This includes services for people leaving hospitals who need support.

The key home care services provided by or funded by the HSE are home help, home care packages and intensive home care packages. These services are explained below.

Home Help Service
The HSE home help service visits people to help with:
- Personal care (washing, changing, oral hygiene, help at mealtimes);
- Essential domestic duties related only to the individual client (lighting a fire / bringing in fuel, essential cleaning of the person’s personal living space).

Home Care Packages
HSE Home Care Packages aim to help people with medium-to-high support needs to continue to live at home independently. Home Care Packages consist of community services and supports which may be provided to assist a person, depending on their individual assessed care needs, to return home from hospital or residential care or to remain at home where mainstream or normal levels of services are insufficient.

The services provided in a Home Care Package include more home help hours in addition to the average level available locally. Packages may also include nursing and therapies (for example - physiotherapy, speech and language therapy, occupational therapy), respite care and aids or appliances. The services delivered are based upon the assessed client needs and the level of other supports already provided such as home help services or informal care by family, friends or neighbours to the client.

Intensive Home Care Packages
Intensive Home Care Packages allow people who require a very high level of assistance to be discharged home from hospital or avoid admission. It is a limited service that includes supports over and above those provided as part of a standard Home Care Package or current community services.

3. Other Services and Supports
In addition to home care as described above, it is recognised that many other services may be necessary to support people in their own homes. These include primary and community care services (GP; public health nursing; physiotherapy; speech and language therapy; occupational therapy; day centres; and respite care) and specialist services including geriatrician-led teams. Personal Assistants also play an important role in helping some people with disabilities to live independent lives. Home Support provides personal and/or essential domestic care and support for some disabled people to facilitate participation in social and leisure activities. Aids and appliances or house adaptation grants also help individuals make changes to their homes that are required to meet their particular needs.

Furthermore, many people are looked after by carers, family and friends. Care provided by family and friends can be called informal care. These carers make a vital contribution to the health, well-being and quality of life of those that they care for.

While all of these other services and supports are important to enable people to live independently in their own homes for as long as possible, this public consultation is focussed primarily on home care services, that is home help services, home care packages and intensive home care packages.

The Department recognises the need for those providing home care services to work effectively with other community and primary care service providers. This will help to ensure that services delivered best meet the needs of the service user.

4. Who provides home care in Ireland and how is it funded?
Formal home care is professional care paid for by recipients, family members or the State. In Ireland, formal home care services are provided by the Health Service Executive (HSE), private providers and not-for-profit voluntary providers.

The HSE directly employs a range of staff to provide home care services. The HSE also contracts not-for-profit providers and private providers to supply services on its behalf.

The HSE will spend approximately €370 million on home care services in 2017. This funding will enable the HSE to provide 10.57 million home help hours to support about 49,000 people. In addition, the HSE expects to provide 16,750 Home Care Packages and 190 Intensive Home Care Packages for clients with complex needs in 2017.

5. How is home care accessed?
When individuals need home care, they or someone on their behalf, can apply to the HSE for services. HSE staff then carry out assessments of the individuals’ need for home care services. The HSE staff then prioritise and allocate the services based on the assessed need.
There is currently no charging or means testing for HSE funded home care services. However, there is more demand for home care services than there are resources available to deliver them.

Many people also purchase home care services directly from private providers. These services can act as a top-up to services funded by the HSE or can be instead of HSE funded services. Tax relief may be available for the purchase of private care in certain circumstances which may encourage those with the means to do so to pay for services.

6. Why we need a new Home Care Scheme
The National Positive Ageing Strategy\(^3^4\) recognises that population ageing is a success story. It goes on to state that “later life can and should be a time for active citizenship, for continued contribution and participation in local community affairs, for engaging in the kinds of activities that enhance physical and mental health, and a time for involvement with family, friends, neighbours and the wider community”. Home care is an important part of the services that some people will need in order to help them do this. It can also help to reduce the need for long term nursing home care. However, the reality is that the vast majority of older people lead active lives in their communities without the assistance of formal home care.

Equally, a person’s disability should never dictate the path that they are able to take in life. What should count is the person’s abilities, their talents and their determination and aspiration to succeed. People with disabilities are writers, artists, entrepreneurs, everyday people who work in offices and shops, who pay taxes and contribute to society and who personify the core principles of community inclusion and active citizenship. Home care can be a support to help those with disabilities who need it in order to live ordinary lives in ordinary places and participate in and contribute to the life of the community.

Formal home care services can also be a crucial support for carers. These services can also help people to avoid having to be admitted to hospital as well as help them to return home sooner after a hospital stay.

Although the Government is committed to increasing funding for home care services, the supply of such services is unlikely to keep up with the increasing demands without reform of the home care system. This means that the Department of Health needs to develop a new scheme that operates in a consistent and fair manner for all those who require it. Two of the main reasons why we need a new home care scheme are outlined below.

(i) Unmet Need and Population Changes
Despite the significant level of spending on home care referenced in Section 4 above, there is unmet need. This means that the level of services cannot keep up with demand, resulting in approximately 4,600 people now on waiting lists for home care. This number includes new applicants and those who are receiving services but are seeking additional resources or care hours.

The level of unmet need is likely to increase in the years to come because demand is growing for the HSE’s home care services. A key reason for this additional demand is the expected increase in the number of older people in the country. The number of people over the age of 65 will double in the coming years while the number over the age of 85 will treble.

Further detail on this issue can be seen in the figure below which shows the substantial growth in the number of adults aged 60 and older that will be seen between 2011 and 2046.

Figure 1: Pyramid for males and females, 2011-2046 (estimated)

Information from the TILDA\textsuperscript{35} study shows that older people are more likely to have difficulty with basic activities of daily living such as: dressing; walking across a room; bathing/showering; eating; getting in or out of bed; and using the toilet. Older people are also more likely to have difficulty preparing a hot meal; doing household chores; shopping for groceries; making telephone calls; taking medications; and managing money. Some people with disabilities may also face difficulties with some of these tasks. In light of this, home care will continue to be an increasingly important part of the supports we offer into the future.

(ii) Consistency in Service Provision
The provision of home help and home care packages has a basis in law but there is no statutory entitlement to these services. Services are not means tested or ‘limited’ in any other way. For instance, services are not restricted to medical card holders and no charges apply for these services (unless a person procures these services privately).

This absence of a statutory underpinning for home care provision has led to inconsistencies in how State funded home care is delivered across the country. This means that the availability of services can vary from place to place and at different times of the year. This

\textsuperscript{35} This information is from The Irish Longitudinal Study on Ageing - TILDA (wave 2, 2012). The Irish Longitudinal Study on Ageing (TILDA) is a large-scale, nationally representative, longitudinal study on age ing in Ireland, the overarching aim of which is to make Ireland the best place in the world to grow old.
Institute of Public Health in Ireland

contrasts with the Nursing Homes Support Scheme – “A Fair Deal” which is consistently applied throughout the country.

A statutory scheme for home care would help to introduce clear rules in relation to what services individuals are eligible for and how decisions are made on allocating services. For that reason, developing a new statutory scheme will be an important step in ensuring that the system operates in a consistent and fair manner for all those who need home care services.

7. Why we need Regulation of Home Care Services

There is also a need to ensure that home care services, whether funded by the HSE or privately funded by individuals, are regulated appropriately.

Unlike other health and social care services, such as long term residential care (for example, nursing homes or residential centres for people with disabilities), there is currently no statutory regulation of home care services. A recent national opinion poll commissioned by the Health Information and Quality Authority (HIQA) found that 76% of people that responded mistakenly thought that home care services are independently regulated or monitored.

While a statutory regulatory regime is not in place, a significant step towards quality assurance for home care services was taken in 2012 when the HSE introduced a single procurement framework for external providers. This included quality standards in terms of governance and accountability, person-centred care, complaints management, training and qualifications. Providers are monitored through Service Level Agreements with the HSE and are required to provide a range of information in relation to the services they provide.

Some of the reasons why a system to regulate home care services, whether HSE funded or privately funded, is required, include:

- to ensure that all users are treated with dignity and respect while promoting their independence and choice;
- to promote client safety;
- to promote equity and freedom of choice for service users;
- to improve performance and quality;
- to provide assurance that core standards are achieved;
- to provide accountability both for levels of performance and value for money; and
- to bring Ireland in line with best international practice.

8. Home Care working with other Services and Policies

It is important to recognise that the new statutory home care scheme will not be developed in isolation. It will be designed to complement and integrate effectively with other health and social care services such as long term residential care (including the Nursing Homes Support Scheme), primary and community services as well as hospital services.

The new scheme will also be developed in the context of relevant existing policies such as the Report of the Oireachtas Committee on the Future of Healthcare, National Carers Strategy, the Positive Ageing Strategy and National Dementia Strategy, among others.

Work currently underway such as the development of new community nursing services and the Task Force on Personalised Budgets in the disability sector will also be considered.

**SECTION 2 – YOUR DETAILS**
In this section, we ask you to tell us a little about yourself so we can look at the responses received from different points of view. This is the only reason for collecting this information.

(Note: If you are making a submission on behalf of an organisation or representative body, please complete Part B.)

Part A – to be completed by individuals.

Your name (optional): If you would prefer to not give your name, please skip to the next question.

**Title**

**First Name**

**Surname**

What is your gender:

Male ☐ Female ☐ Prefer not to say ☐

Your age:

Under 40 ☐ 40 – 59 ☐ 60 – 69 ☐

70 – 79 ☐ 80 – 89 ☐ 90 + ☐

Prefer not to say ☐

What county do you live in?

Of the list below, which best describes you: (you can select more than one)

Someone who receives or has received home care ☐

Family member or friend of someone who receives home care ☐

Member of the public ☐

An informal carer (not paid to provide care) ☐

Home care worker ☐

A health professional providing home care services ☐

A health professional working in another sector ☐

Prefer not to say ☐

Other, please provide details ____________________________
(If you are NOT a home care worker or healthcare professional, please ignore the following two questions)

If you are a home care worker or a healthcare professional, please indicate what type of organisation you work in:
- HSE
- Private Sector
- Voluntary/Not for Profit Sector

If you are a home care worker or a healthcare professional, please indicate what service you work in:
- Home care/home help
- Primary/community care and therapies
- Meals on Wheels
- Respite care
- None
- Other, please specify: __________________________

PART B – This section only needs to be completed by organisations or representative bodies (you do not need to fill in the section below if you are responding as an individual)

Organisation

☐ I am the authorised representative on behalf of an organisation/body.

Please state name and address of organisation:

[Blank space]

Title

First Name

Surname

Job Title
Please state category of organisation:

- Union/staff representative body □
- Regulatory Body □
- Public Interest Group □
- Advocacy Body □
- Representative Body □
- Patient Interest Group □
- Academic institution □
- Private Home Care Provider □
- Voluntary/Not for Profit Home Care Provider □
- Other, please specify: ________________________________

(Note: If you are responding on behalf of an organisation, you do not need to complete Section 3)

SECTION 3 – YOUR EXPERIENCES

Have you ever received any of the following home care services? (You can select more than one):

- Home Help □
- Home Care Packages □
- Intensive Home Care Packages □
- None of the above □

Have you ever received any of the following services? (You can select more than one):

- Meals on wheels □
- Day centre □
- Residential respite care □
- Respite care in your home □
- Therapies such as Occupational Therapy, Rehabilitation □
- Public Health Nursing □
- GP services □
- Help from family, friends or neighbours □
- None □
- Other, please provide details ________________________________

Are you currently paying for private home care services?

Yes □ No □ Prefer not to say □

If you are currently paying for private home care services, how many hours do you receive from the private provider each week?

______ hours
Have you paid for private home care services in the past?
Yes ☐ No ☐ Prefer not to say ☐

If you have or are currently paying for private home care, please state why:
Did not know about HSE services ☐
Applied to the HSE but was not approved ☐
on a waiting list ☐
Top up to HSE services/needed more hours ☐
Prefer not to apply to the HSE ☐
This question does not apply to me ☐
Other, please specify:_____________________________________________

SECTION 4 – TELL US WHAT YOU THINK
This section asks for your views about how home care currently works and your ideas for the future.

Here we are asking about **formal home care services**. By this we mean care that is provided by a professional and is paid for by the HSE, the person receiving home care or by family members.

In this section you will be asked to give your opinion on the different home care services, the strengths of the current home care system and what could be improved. This information will help the Department to decide what should stay the same and what needs to be done differently.

**General Questions**

1. **In your opinion, what are the good things about home care services in Ireland?**

When giving your answer to this question, you may wish to think about the following:

- How you apply for home care
- How your need for home care services is assessed
- Who can access services
- What home care services are provided
- How home care services are provided
- How home care services are monitored
- How you can appeal a decision about your home care

__________________________________________________________________________
__________________________________________________________________________
________________________________________

Institute of Public Health in Ireland
Question 2, 3 and 4 ask whether the different services that are needed to help people stay at home work well together. This information will help to inform how services can work better together in the future.

2. Do you think that home care services work well alongside primary care and other community services to meet the needs of people who receive home care?

Note: Primary and community services include GP services, public health nursing, physiotherapy, speech and language therapy, occupational therapy, and respite care.

Yes  No  Don’t know

3. Do you think that home care services work well alongside hospitals to meet the needs of people who receive home care?

Yes  No  Don’t know

4. Do you think that home care services work well alongside informal carers to meet the needs of people who receive home care?

Note: informal carers are family and friends that provide care and support

Yes  No  Don’t know

If you have any comments in relation to how well home care services work with other providers of care, please include them below:

__________________________________________________________________________

__________________________________________________________________________

Questions 5 and 6 ask for your views in relation to choice of home care services and providers.

5. Do you think that people who receive home care should have more of a say in the range of services that are provided to them?

Yes  No  Don’t know
6. **Do you think that people who receive home care should have a choice in who provides their care?**

Note: Home care can be provided by the HSE, not-for-profit providers and private providers.

Yes _____ No_____ Don’t know _____

If you have any comments in relation to choice of home care services and providers, please include them below:

_______________________________________________________________________

_______________________________________________________________________

_______________________________________________________________________


7. **In your opinion, how could home care services in Ireland be improved?**

Note: When giving your answer to this question, you may wish to think about the following:

- How you apply for home care
- How your need for home care services is assessed
- Who can access services
- What home care services are provided
- How home care services are provided
- How home care services are monitored
- How you can appeal a decision about your home care

__________________________________________________________________________

__________________________________________________________________________

_________________________________________________________

Questions on Information in relation to Home Care Services

This section asks who you would contact if you needed information on home care services. It also asks whether you are aware of the tax relief that is available for privately purchased home care.
8. If you, a relative or friend needed home care services, who would you ask for information first?

__________________________________________________________________________

If you have any comments on this issue, please include them below:

__________________________________________________________________________

__________________________________________________________________________

9. Are you aware that tax relief is available to people that pay for home care services?

Note: tax relief reduces the amount of tax that an individual has to pay.

Yes _____ No_____

If you have any comments on this issue, please include them below:

__________________________________________________________________________

__________________________________________________________________________

Question on Standardisation

At the moment, home care services operate in different ways across the country. This means that the amount and type of home care available can vary depending on where you live or the time of the year. Many other countries have home care systems that make sure that home care is provided in the same way across the country.

10. Do you think that the same approaches should apply across the country in relation to the following?

• How you apply for services        Yes ___ No___ Don’t know___
• How your need for services is assessed Yes ___ No___ Don’t know___
• Who can access services          Yes ___ No___ Don’t know___
• What home care services are provided Yes ___ No___ Don’t know___
• How home care services are provided Yes ___ No___ Don’t know___
• How home care services are monitored Yes ___ No___ Don’t know___
• How you can appeal a decision about your home care

Yes ___ No___ Don’t know ___

If you have any comments on this issue, please include them below:

__________________________________________________________________________

____________________________________________________

____________________

______

_____________________________________________________________

_______

__________________________________________________________________________

_____________________________________________________________

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__________

Question on Quality Standards

At the moment, there are no national standards for home care. This means that the quality care can differ among home care providers. Other countries have introduced home national standards. We would like to know your views on whether or not you think national quality standards should apply in the future to home care providers in Ireland.

Note: National standards would mean that every home care provider would have to meet a minimum standard of quality in order to continue providing home care services.

11. Do you think that the same national quality standards should apply to all (public, private and not-for-profit voluntary) providers of home care?

Yes _____ No_____ Don’t know _____

If you have any comments on this issue, please include them below:

__________________________________________________________________________

____________________________________________

__________

____________________

____________

____________________________

____________________________

Question on Training for Care Workers

Currently, there is no minimum level of training required in order to be a home care worker in Ireland, though many have completed relevant training. Other countries have introduced minimum training levels in order to help ensure a better quality of service. We would like to know whether or not you think this would be a good idea for Ireland.
12. Do you think that formal home care workers should have to complete a minimum level of training that would be set by the Government?

Note: formal home care workers are people who are either self-employed or work for a home care service provider organisation

Yes _____ No_____ Don’t know _____

If you have any comments on this issue, please include them below:

__________________________________________________________________________

__________________________________________________________________________

__________________________________________________________________________

Questions on Funding

In Ireland, there is no means test for home care services that are funded by the HSE. People who receive these services do not have to pay for them. This is different to many other countries which have some form of charging or means test.

13. Taking account of limited State resources, do you think that people who receive home care services should make a financial contribution to the cost, based on their ability to pay?

Yes _____ No_____ Don’t know _____

If you have any comments on this issue, please include them below:

__________________________________________________________________________

__________________________________________________________________________

__________________________________________________________________________

14. If the State could only provide a certain amount of home care services based on health need, would you be prepared to purchase additional hours with your own money, if you needed them?

Yes _____ No_____ Don’t know _____

If you have any comments on this issue, please include them below:
Other issues

15. If there are any other comments that you would like to make, please include them below.

____________________________________________________________

____________________________________________________________

____________________________________________________________

Thank you for completing this consultation.

If you would like to receive a copy of the results of this consultation, please provide your postal or email address
Annex II: Easy read version of the survey
Introduction
The Government wants to improve home care services so people can live in their own homes for as long as possible.

You can help with this by answering the questions about home care services in this document. We would like you to tell us the good things about home care services in Ireland. We also want your ideas about how home care services could work better.

How to take part

You can fill in the consultation online at: http://health.gov.ie/consultations/

If you prefer, you can download a copy of this document at http://health.gov.ie/consultations/ and post it to us at:

- Home Care Consultation
- Room 204
- Department of Health
- Hawkins House
- Hawkins Street
- Dublin 2, D02 VW90

Alternatively, if you would like a paper copy to be sent to you, please contact the Department of Health using the contact details written above or by calling (01) 6354402 or (01) 6354732.

You can also contact the Department at these phone numbers or at our email address (homecareconsultation@health.gov.ie) if you have any questions about this document.

Find out more
You can read more about home care services and the Government’s plans in a longer document called “Improving Home Care Services in Ireland – Have your Say!” It is available online at http://health.gov.ie/consultations/or we can post you a copy.

Closing date
The last day you can send us your comments is 2 October 2017.

Freedom of Information
Please note that submissions received by the Department are subject to the Freedom of Information (FOI) Act 2014 and may be released in response to an FOI request. You can contact the Department for more information on this.

Before you begin
Before you begin to answer the questions, you might find it helpful to read this section which has information about what home care is, who provides it, how to access it, and, why we need to change the way home care services work in Ireland.

What is home care?
Home care services provide help to people that need it so they can live in their own homes. For example, home care services help people to:

- Get washed and dressed
- Prepare food
- Use the toilet
People may need home care services if they:

- Are older
- Have a disability
- Need help at home so that they don’t have to move to a nursing home
- Need help at home after being in hospital

People who need help to live at home may be looked after by family, neighbours or friends. People may also be looked after by someone who is paid to look after them.

**Who provides formal home care in Ireland?**
Formal home care is professional care paid for by the Health Service Executive (HSE), family members or the person receiving care.

Formal home care services are provided by the HSE, private companies and not-for-profit companies.

The HSE employs a range of staff to provide home care services. The HSE also pays other companies to provide services for people.

**HSE Home Care Services**
The main home care services paid for and provided by the HSE are:

- Home help
- Home care packages
- Intensive home care packages

<table>
<thead>
<tr>
<th>HSE Home Care Services</th>
<th>About each service</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Home help</strong></td>
<td>The HSE home help service visits people to help with:</td>
</tr>
<tr>
<td></td>
<td>- Personal care (for example, washing, getting dressed, help at mealtimes);</td>
</tr>
<tr>
<td></td>
<td>- Household chores (for example, lighting a fire or bringing in fuel, cleaning).</td>
</tr>
<tr>
<td><strong>Home care package</strong></td>
<td>Home care packages help people who need a higher level of support to live at home.</td>
</tr>
<tr>
<td></td>
<td>The services provided in home care packages include more home help hours and can</td>
</tr>
<tr>
<td></td>
<td>also include nursing and therapies such as speech and language therapy and</td>
</tr>
<tr>
<td></td>
<td>physiotherapy.</td>
</tr>
<tr>
<td><strong>Intensive home care package</strong></td>
<td>Intensive home care packages are provided to people who need very high levels of care.</td>
</tr>
<tr>
<td></td>
<td>These people could need extra help to be allowed home from hospital or to avoid</td>
</tr>
<tr>
<td></td>
<td>moving to a nursing home.</td>
</tr>
</tbody>
</table>
We would like to hear your views about home help services, home care packages and intensive home care packages.

**How to get home care services**
People who need home care can apply to the HSE for these services. HSE staff talk to the individual about their needs and the services that are available.

At the moment, there are no charges or means test for HSE funded home care services. You do not need a medical card to get home care services from the HSE.

The HSE cannot provide all of the home care services that people would like to receive. This means that people may have to wait for services or may not get all the services they would like to receive.

Many people purchase home care services directly from private companies.

**Why do we need to change the way home care services work?**
People are living longer and the number of older people is increasing. People with disabilities are also living longer, more fulfilling lives. These are things to celebrate!

But, as people get older, they can need more support so that they can continue to live at home. We need to change the way home care services work to better meet these needs.

At the moment the way that the home care service works is different across the country. A new approach is needed so that the service is the same, no matter where you live.

It is also important that companies providing home care services have to follow the same rules and regulations.

We also want the home care services to work well with other services people need such as GPs, public health nursing, physiotherapy and occupational therapy.
YOUR DETAILS
In this section, we ask you to tell us a little about yourself so we can look at the responses received from different points of view. This is the only reason for collecting this information.

Your name (optional): If you would prefer to not give your name, please skip to the next question.

Title

First Name

Surname

What is your gender:
Male □ Female □ Prefer not to say □

Your age:
Under 40 □ 40 – 59 □ 60 – 69 □
70 – 79 □ 80 – 89 □ 90 + □
Prefer not to say □

What county do you live in?

Of the list below, which best describes you: (you can select more than one)
Someone who receives or has received home care □
Family member or friend of someone who receives home care □
Member of the public □
An informal carer (not paid to provide care) □
Home care worker □
A health professional providing home care services □
A health professional working in another sector □
Prefer not to say □
Other, please provide details _____________________________

(If you are NOT a home care worker or healthcare professional, please ignore the following two questions)

If you are a home care worker or a healthcare professional, please indicate what type of organisation you work in:
HSE □
Private Sector □
Voluntary/Not for Profit Sector □
If you are a home care worker or a healthcare professional, please indicate what service you work in:
Home care/home help □
Primary/community care and therapies □
Meals on Wheels □
Respite care □
None □
Other, please specify: ____________________

YOUR EXPERIENCES

Have you ever received any of the following home care services? (You can select more than one):
Home Help □
Home Care Packages □
Intensive Home Care Packages □
None of the above □

Have you ever received any of the following services? (You can select more than one):
Meals on wheels □
Day centre □
Residential respite care □
Respite care in your home □
Therapies such as Occupational Therapy, Rehabilitation □
Public Health Nursing □
GP services □
Help from family, friends or neighbours □
None □
Other, please provide details ____________________

Are you currently paying for private home care services?
Yes □ No □ Prefer not to say □

If you are currently paying for private home care services, how many hours do you receive from the private provider each week?
______ hours

Have you paid for private home care services in the past?
Yes □ No □ Prefer not to say □
If you have or are currently paying for private home care, please state why:
Did not know about HSE services
Applied to the HSE but was not approved
On a waiting list
Top up to HSE services/needed more hours
Prefer not to apply to the HSE
This question does not apply to me
Other, please specify:_____________________________________________

TELL US WHAT YOU THINK
This section asks for your views about how home care currently works and your ideas for the future.

Here we are asking about **formal home care services**. By this we mean care that is provided by a professional and is paid for by the HSE, the person receiving home care or by family members.

In this section you will be asked to give your opinion on the different home care services, the strengths of the current home care system and what could be improved. This information will help the Department to decide what should stay the same and what needs to be done differently.

**General Questions**

15. *In your opinion, what are the good things about home care services in Ireland?*

When giving your answer to this question, you may wish to think about the following:
- How you apply for home care
- How your need for home care services is assessed
- Who can access services
- What home care services are provided
- How home care services are provided
- How home care services are monitored
- How you can appeal a decision about your home care

__________________________________________________________________________
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__________________________________________________________________________
Question 2, 3 and 4 ask whether the different services that are needed to help people stay at home work well together. This information will help to inform how services can work better together in the future.

16. Do you think that home care services work well alongside primary care and other community services to meet the needs of people who receive home care?

Note: Primary and community services include GP services, public health nursing, physiotherapy, speech and language therapy, occupational therapy, and respite care.

Yes _____  No_____  Don’t know _____

17. Do you think that home care services work well alongside hospitals to meet the needs of people who receive home care?

Yes _____  No_____  Don’t know _____

18. Do you think that home care services work well alongside informal carers to meet the needs of people who receive home care?

Note: informal carers are family and friends that provide care and support

Yes _____  No_____  Don’t know _____

If you have any comments in relation to how well home care services work with other providers of care, please include them below:

__________________________________________________________________________
__________________________________________________________________________
__________________________________________________________________________

Questions 5 and 6 ask for your views in relation to choice of home care services and providers.

19. Do you think that people who receive home care should have more of a say in the range of services that are provided to them?

Yes _____  No_____  Don’t know _____
20. Do you think that people who receive home care should have a choice in who provides their care?

Note: Home care can be provided by the HSE, not-for-profit providers and private providers.

Yes _____ No_____ Don’t know _____

If you have any comments in relation to choice of home care services and providers, please include them below:

__________________________________________________________________________
__________________________________________________________________________
__________________________________________________________________________

21. In your opinion, how could home care services in Ireland be improved?

Note: When giving your answer to this question, you may wish to think about the following:
- How you apply for home care
- How your need for home care services is assessed
- Who can access services
- What home care services are provided
- How home care services are provided
- How home care services are monitored
- How you can appeal a decision about your home care

__________________________________________________________________________
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__________________________________________________________________________
__________________________________________________________________________

Questions on Information in relation to Home Care Services

This section asks who you would contact if you needed information on home care services. It also asks whether you are aware of the tax relief that is available for privately purchased home care.
22. If you, a relative or friend needed home care services, who would you ask for information first?

____________________________________________________________________________________

If you have any comments on this issue, please include them below:

____________________________________________________________________________________

____________________________________________________________________________________

____________________________________________________________________________________

23. Are you aware that tax relief is available to people that pay for home care services?

Note: tax relief reduces the amount of tax that an individual has to pay.

Yes _____  No_____

If you have any comments on this issue, please include them below:

Question on Standardisation

At the moment, home care services operate in different ways across the country. This means that the amount and type of home care available can vary depending on where you live or the time of the year. Many other countries have home care systems that make sure that home care is provided in the same way across the country.

24. Do you think that the same approaches should apply across the country in relation to the following?

- How you apply for services Yes ___  No___  Don’t know___
- How your need for services is assessed Yes ___  No___  Don’t know ___
- Who can access services Yes ___  No___  Don’t know ___
- What home care services are provided Yes ___  No___  Don’t know ___
- How home care services are provided Yes ___  No___  Don’t know ___
- How home care services are monitored Yes ___  No___  Don’t know ___
- How you can appeal a decision about your home care Yes ___  No___  Don’t know ___
Question on Quality Standards

At the moment, there are no national standards for home care. This means that the quality of home care can differ among home care providers. Other countries have introduced national standards. We would like to know your views on whether or not you think national quality standards should apply in the future to home care providers in Ireland.

Note: National standards would mean that every home care provider would have to meet a minimum standard of quality in order to continue providing home care services.

25. Do you think that the same national quality standards should apply to all (public, private and not-for-profit voluntary) providers of home care?

Yes _____  No _____  Don’t know _____

If you have any comments on this issue, please include them below:

__________________________________________________________________________
__________________________________________________________________________
__________________________________________________________________________

Question on Training for Care Workers

Currently, there is no minimum level of training required in order to be a home care worker in Ireland, though many have completed relevant training. Other countries have introduced minimum training levels in order to help ensure a better quality of service. We would like to know whether or not you think this would be a good idea for Ireland.

26. Do you think that formal home care workers should have to complete a minimum level of training that would be set by the Government?

Note: formal home care workers are people who are either self-employed or work for a home care service provider organisation
### Questions on Funding

In Ireland, there is no means test for home care services that are funded by the HSE. People who receive these services do not have to pay for them. This is different to many other countries which have some form of charging or means test.

27. **Taking account of limited State resources, do you think that people who receive home care services should make a financial contribution to the cost, based on their ability to pay?**

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
<th>Don’t know</th>
</tr>
</thead>
</table>

If you have any comments on this issue, please include them below:

__________________________________________________________________________

__________________________________________________________________________

__________________________________________________________________________

28. **If the State could only provide a certain amount of home care services based on health need, would you be prepared to purchase additional hours with your own money, if you needed them?**

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
<th>Don’t know</th>
</tr>
</thead>
</table>

If you have any comments on this issue, please include them below:

__________________________________________________________________________

__________________________________________________________________________

__________________________________________________________________________

### Other issues


15. If there are any other comments that you would like to make, please include them below.

__________________________________________________________________________
__________________________________________________________________________
__________________________________________________________________________
__________________________________________________________________________
__________________________________________________________________________
__________________________________________________________________________

Thank you for completing this consultation.

If you would like to receive a copy of the results of this consultation, please provide your postal or email address


Annex III: Authorised organisational submissions

This list details the organisations from which authorised submissions were received. In order to be classified as an authorised organisational submission, respondents were required to indicate that they are the authorised representative of an organisation and to identify the organisation from which the response was being made. Note some organisations submitted more than one response.

A Plus Community Care
Acquired Brain Injury Ireland (ABII)
Age Action
Age Action Glor Group
Age Friendly Ireland
All Party Oireachtas Group on Dementia
Alzheimer Society of Ireland
An Saol Foundation
Assisted Living Solutions
Association of Occupational Therapists in Ireland (AOTI)
Baile Mhuire Limited
Beaumont Hospital
Care About You
Care Alliance Ireland
Cavan Older Person’s Council
Centre for Economic and Social Research on Dementia (CESRD), NUI Galway
Citizens Information Board
Clarecare
Claregalway and District Day Care Centre
Clonmellon Senior Citizens
Convent of Mary, Charleville, Co. Cork
COPE Galway
Cork-Kerry Community Healthcare (Home Care Service), HSE
Croi na Gaillimhe SVP
DEBRA Ireland
Dementia Services Information and Development Centre
Dental Health Foundation
Disability Federation of Ireland
Dublin Home Care Partners Consortium
Dublin North City and County CHO, HSE
East Galway Older Persons Interagency Group
Family Carers Ireland
Family Carers Ireland Milltown-Malbay Support for Carers
Health and Information Quality Authority (HIQA)
Health Informatics Society of Ireland Nursing and Midwifery (HISINM)
Home and Community Care Ireland (HCCI)
Home Response and Assistance Limited
HomeCareDirect
HSE Clinical Strategy and Programmes Division
HSE Disability Services, St. Finbarr's Hospital, Cork
Huntington's Disease Association of Ireland
Inclusion Ireland
Irish Association of Social Workers Special Interest Group in Ageing (SIGA)
Irish Council for Social Housing
Irish Heart Foundation
Irish Home Care
Irish Hospice Foundation
Irish Medical Organisation
Irish Motor Neurone Disease Association (iMNDA)
Irish Nurses and Midwives Organisation
Irish Rural Link
Irish Senior Citizens Parliament
Irish Wheelchair Association
Johnstown Meals on Wheels
Kerry Parents and Friends Association
La Verna Day Care Centre
MARCOH Care Ltd
Migrant Rights Centre Ireland (MRCI)
Monsignor McCarthy Family Resource Centre
Mother McAuley Centre
MS Ireland
National Clinical Programme for Rehabilitation Medicine (NCPRM)
National Dementia Office and Genio joint submission
National Disability Authority
National Federation of Voluntary Bodies
National Head Medical Social Workers Forum
National Meals on Wheels Network
National Rehabilitation Hospital
Neurological Alliance of Ireland (NAI)
North Dublin Homecare Limited
North Tipperary Farm Family Group
Nursing Homes Ireland (NHI)
Nutricia Advanced Medical Nutrition
Occupational Therapy Department, Mayo PCCC
Office of Nursing and Midwifery Services Director, HSE
Older Persons' Integrated Care Team (OPICT), Co. Louth
OneTouch Telecare Limited
Our Lady's Hospice, Harold's Cross, Dublin 6
PSP Association Ireland
Publicpolicy.ie
Purple House Cancer Support
RAH Home Care Limited
Rehab Group
Retired Civil and Public Servants Association
RHS Home Care Services
Royal College of Physicians of Ireland (RCPI)
SAGE
Salthill Active Retirement Association
Sandra Cooney's Home Care
Shankill Old Folks Association
Siel Bleu Ireland
SIPTU
Social Justice Ireland
Social Work Department, Mater Misericordiae University Hospital
St. Augustine's Past Pupils Club
St. Michael's Centre
Stillorgan /Kilmacud Active Retirement Association
Tallaght Hospital Social Work Department
THE HomeShare
Uplift
Victoria Healthcare Organisation Limited
West Cork Carers Support Group
Wicklow Dementia Support
### Annex IV: Table of acronyms and abbreviations

<table>
<thead>
<tr>
<th>Acronym</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>ABF</td>
<td>Activity-Based Funding</td>
</tr>
<tr>
<td>ABI</td>
<td>Acquired Brain Injury</td>
</tr>
<tr>
<td>CHO</td>
<td>Community Healthcare Organisations</td>
</tr>
<tr>
<td>CHS</td>
<td>Community Healthcare Services</td>
</tr>
<tr>
<td>CPD</td>
<td>Continuous Professional Development</td>
</tr>
<tr>
<td>ESRI</td>
<td>Economic and Social Research Institute</td>
</tr>
<tr>
<td>GP</td>
<td>General Practitioner</td>
</tr>
<tr>
<td>HIQA</td>
<td>Health Information and Quality Authority</td>
</tr>
<tr>
<td>HSE</td>
<td>Health Service Executive</td>
</tr>
<tr>
<td>Home help</td>
<td>The HSE home help service visits people to help with: personal care (for example, washing, getting dressed or help at mealtimes); household chores (for example, lighting a fire or bringing in fuel or cleaning).</td>
</tr>
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<td>Home care packages help people who need a higher level of support to live at home. The services provided in home care packages include more home help hours and can also include nursing and therapies such as speech and language therapy and physiotherapy.</td>
</tr>
<tr>
<td>Hospital discharge process</td>
<td>This is the transition handled from hospital to home, a rehabilitation (rehab) facility or a nursing home.</td>
</tr>
<tr>
<td>HRB</td>
<td>Health Research Board</td>
</tr>
<tr>
<td>ICPOP</td>
<td>Integrated Care Programme for Older Persons’</td>
</tr>
<tr>
<td>ID</td>
<td>Intellectual Disability</td>
</tr>
<tr>
<td>Intensive home care package</td>
<td>Intensive home care packages are provided to people who need very high levels of care. These people could need extra help to be allowed home from hospital or to avoid moving to a nursing home. Intensive home care packages give a level of service that is over</td>
</tr>
</tbody>
</table>
and above the services provided as part of a standard home care package.

IPH Institute of Public Health in Ireland
LRC Law Reform Commission
MND Motor Neuron Disease
MS Multiple Sclerosis
Neurological A neurological disorder is any disorder of the nervous system.
NGO Non-Governmental Organisation
NHSS Nursing Homes Support Scheme
Occupational therapy Occupational therapy aims to improve people’s ability to do everyday tasks if they are having difficulties.
OPD Out Patient Department
PHN Public health nurse
QQI Quality and Qualifications Ireland is an independent State agency responsible for promoting quality and accountability in education and training services in Ireland. QQI maintain the NFQ (National Framework of Qualifications) as a system of levels for relating different qualifications (i.e. Awards) to one another.
Belfast
Institute of Public Health in Ireland
Forestview
Purdy’s Lane
Belfast
BT8 7AR
Telephone: + 4428 90648494

Dublin
Institute of Public Health in Ireland
700 South Circular Road
Kilmainham
Dublin 8
D08 NH90

Telephone: + 353 1 478 6300

Email: info@publichealth.ie
Website: www.publichealth.ie
Twitter: @publichealthie