

U65 Service Provider Survey Terms and Conditions

Introduction and Background

Current disability policy in Ireland is aimed at supporting people, with disabilities, to live independently in their own homes. There has been an increased focus on autonomy and self-determination and several initiatives have been developed aiming to transform disability services from a traditional and congregated model of care, towards a model whereby people with disabilities are supported to live a life of their choosing within their own local communities.

The scope of decongregation initiatives to date has, however, not always included younger people with disabilities residing in nursing home settings, while there is a specific policy and strategy in place for moving individuals from traditional institutions into the community, no policy to cover individuals under the age of 65 in nursing homes is in place. There is currently limited data available on the numbers and support needs of this population which impacts on the ability of the HSE and other Agencies to accurately forecast and plan for the needs of this population.

As part of the Planning appropriately for Younger People in Nursing Homes (SRF Project) and in response to the recommendation 6.1 of the Ombudsman's Report "[Wasted Lives: Time for a better future for younger people in nursing homes](#)", the HSE is undertaking a comprehensive national survey of persons under 65 in nursing homes.

1. To gather a comprehensive profile of the number of residents aged under 65 currently residing in registered nursing homes across the Republic of Ireland.
2. To ascertain the current and future support needs of this population to inform person centred model of services to address the needs of this population and those who wish to transition to a more appropriate community setting.
3. To identify residents who are not in a setting as per their will and preference and who wish to transfer from a nursing home setting to a more appropriate community environment.

Why have I been invited to participate in this survey?

We are issuing an invitation to all Persons in Charge of registered nursing homes, to participate in this survey, to assist us in developing a baseline profile of residents, under 65 years of age, currently residing in nursing home settings.

The information we gather will assist the HSE and other Agencies in planning and identifying the resources required for people, under the age of 65 with disabilities, to live in accordance with their expressed will and preference.

Do I have to participate in this survey?

Taking part in this survey is completely voluntary; nursing home providers are under no obligation to participate, however, in providing details of the residents aged under 65 in your care a complete profile of this population can be gathered.

If I agree to participate in the survey, is there any preparation work required in advance to complete the survey?

Nursing Home Resident Profile Information: completed by the nursing home provider. **It is recommended that Residents care plans are to hand when completing the resident profile part of the survey as this section contains question on residents' medical conditions, support needs, supports assessed and funding source details. Click here for summary of the questions (pdf link of questions)**

The survey contains 21 questions to be completed by the nursing home provider and will take approximately 20 to 25 mins (based on completing for 10 residents). The survey questions are split into two parts:

- i) Service Location Details (HIQA ID, CHO area) and name of person completing the survey.
- ii) Resident profile information and presentation per person (medical conditions, support needs, supports assessed and funding source details).

How is the survey data being collected?

An online quantitative data survey is being conducted with registered Nursing Home providers (HIQA designated centres) using Smart Survey software. All the data collected via Smart Survey is encrypted at all times, data is transmitted via an encrypted collection and stored in an encrypted format in a secure server in the UK. Smart Survey uses the best of industry standards for encryption to stay secure with regular testing.

What will happen with the information and personal data I provide?

Any information that you provide as part of this survey will be protected in accordance with the General Data Protection Regulations (GDPR) and will only be accessible to staff working for the HSE for the purpose of service planning and analysis and/or to follow up with individuals to discuss their support and transition wishes.

Contact details that you provide will be kept on a secure, password-protected database and will only be used to contact you about participation in the survey.

How do we keep your records secure and confidential?

The HSE is committed to ensuring that service user information is secure with us and with the third parties who act on our behalf. We have a number of security precautions in place to prevent the loss, misuse or alteration of your information. All staff working for the HSE has a duty to keep information about you confidential. The HSE has strict information security policies and procedures in place to ensure that information about you is safe, whether it is held in paper or electronic format.

Retention period

The HSE will only retain information for as long as necessary. Records are maintained in line with the recommendations of the HSE retention policy, which can be found at <https://www.hse.ie/eng/about/who/qid/healthcarerecordsmgt.pdf>

Legal basis for processing this information

The Health Service Executive (HSE) must comply with the Data Protection Acts 1988-2018 and the General Data Protection Regulations (GDPR). We respect your right to privacy and to the protection of your personal information. The following are the data sharing terms for data gathering by HSE in relation to the identification of under 65s residing in the Service Provider's facility and their support needs

Data sharing terms between the Health Service Executive (“HSE”) and nursing homes and other residential facilities (each a “Service Provider”)

These Data Sharing Terms (the “Terms”) are the terms for the sharing of personal data (including health data) between the Service Provider and the HSE for the purposes of the following data processing operation:

1. The gathering by the HSE of a central record of relating to the number of persons under 65 years who are residing in nursing homes and other residential facilities and relating to the health conditions and related support needs of those service users, with the view to the HSE then seeking to provide alternative, more appropriate residential care and support services for these service users (“the Under 65 National Survey Project”).
2. The Under 65 National Survey Project is being undertaken in line with and in response to:
 - a. the Recommendations 6.1 in the Ombudsman’s Report entitled *Wasted Lives: Time for a better future for younger people in Nursing Homes* (2020) (recommending the development of a comprehensive national survey to identify all persons under the age of 65 resident in nursing homes and the establishment of a database of such information); and
 - b. the recommendations in the *Time to Move on from Congregated Setting – A Strategy for Community Research Inclusion Report* (2012).
3. The data processing being undertaken in respect of the Under 65 National Survey Project is considered necessary because the HSE does not have a central record of persons under 65 years in nursing homes and other residential facilities for older persons and this data processing is considered the most efficient and optimum way to gather the most current and accurate information concerning such persons and their needs.
4. It is recognised that the HSE and the Service Provider are separate data controllers in respect of the personal data of the residents that they process (and will process as part of the Under 65 Project). Each of the HSE and the Service Provider will comply with their respective obligations as data controllers under relevant data protection law in respect of the Under 65 National Survey Project.
5. The HSE U65 National Survey project team will use the survey software package supplied by SmartSurvey UK, www.smartsurvey.co.uk) to securely gather the data, as described in paragraph 6 below. Smart Survey is located in the UK and the data will be securely transferred to and hosted in the UK by Smart Survey (a HSE data processor) during the data collection process. The HSE relies on the EU Commission’s adequacy decision in relation to the UK in order to justify the transfer of personal data to the UK.
6. The data gathering required in order to establish the central record consists of gathering of data directly from the Service Providers, via information to be completed by each Service Provider in respect of each resident under 65 years in their facility. This information will be provided by the completion of a questionnaire by the Service Provider via the Smart Survey secure portal (“the U65 Service Provider Survey”) The Service Provider U65 Survey will be entirely voluntary on the part of each Service Provider.
7. The Service Provider will provide the information and undertake the data processing required in order to complete the Service Provider Survey, in respect of each of its residents, including by ensuring that the data provided is accurate and up-to-date.

8. As a separate exercise, the Service Provider will also facilitate each participating resident to help he/she (or, as appropriate his/her authorised representative) to complete the Individual Resident Survey (as described and defined below), including by facilitating him/her with access to an appropriate device and with internet access, by confirming information for him/her (e.g. in relation to their support services) and by allowing him/her appropriate privacy to complete it.
9. The Individual Resident Survey will be entirely voluntary on the part of each resident
Gathering of data directly from the resident/service user, again by the completion of a questionnaire by the resident or their authorized representative via the Smart Survey secure portal ("the Individual Resident Survey") will not form part of the central record. This data will be held as a separate operational record to provide local HSE CHO teams with details of the individuals who wish to be contacted by the HSE.
10. To meet the HSE's transparency obligations, the HSE has prepared (a) an information leaflet for residents, and (b) a dedicated webpage link, which is referred to in the information leaflet). The Service Provider will provide copies of the information leaflet to all of its residents under 65 and will facilitate residents to access the link so that they can view all other transparency information related to the Under 65 National Survey Project.
11. The HSE has assessed that its legal basis for the processing of the personal data is under Article 6(1)(e) GDPR and, in respect of the health data, Article 9(2)(h) GDPR. For the purposes of Article 9(3) GDPR, there are medical professionals who sit on the HSE's U65 Ombudsman Report Recommendations Implementation Steering Committee for the Under 65 National Survey Project, and the project manager is a registered nurse. Further justification for the HSE's legal basis can be provided to the Service Provider on request.
12. In terms of further compliance with Article 9(3) GDPR, the Service Provider will ensure that its processing of the personal data is undertaken under the supervision of a healthcare professional who owes the relevant residents a duty of professional secrecy, for example its director of nursing or equivalent.
13. The HSE has explained in its resident information leaflet how service users may exercise their rights under the GDPR, e.g. to access their personal data. The Service Provider will facilitate service users in exercising their rights, including by making appropriate devices and internet access available to them so that they may submit their requests electronically to the HSE. The HSE and Service Provider will provide each other with all reasonable assistance to enable each other to respond to rights requests relating to personal data processed as a result of the Under 65 National Survey Project.
14. The HSE and the Service Provider will cooperate with each other in relation to any personal data breaches which concern the personal data processed as a result of the Under 65 National Survey Project, where any such breaches are relevant to each other's obligations as data controllers. This cooperation will include, as appropriate: notifying the other data controller about any suspected or actual personal data breaches that affect that data controller's obligations; assisting that data controller in ascertaining the cause of the personal data breach; assisting that data controller in remediating and/or mitigating the personal data breach; and providing all reasonable assistance to that data controller to facilitate handling of the personal data breach in an expeditious, efficient and GDPR-compliant manner.
15. The Service Provider will as part of the completion of the U65 Service Provider survey provide point of contact details for the purposes of the Under 65 National Survey Project and its

obligations under these Terms. The HSE's point of contact will be Sibéal Cummins, contactable at Under65s.Survey@hse.ie