Handbook on Monitoring the Human Rights of Older Persons and Long-Term Care

May 2017
About ENNHRI

National Human Rights Institutions (NHRIs) are state-mandated bodies, independent of government, with a broad constitutional or legal mandate to protect and promote human rights at the national level.

The European Network of National Human Rights Institutions (ENNHRI) brings together over 40 NHRIs across the wider European region. ENNHRI’s goal is to enhance the protection and promotion of human rights throughout Europe. It carries this out by assisting in the establishment and accreditation of NHRIs; co-ordinating exchange of information and best practice between members; facilitating capacity building and training; engaging with regional mechanisms; and intervening on legal and policy developments at the European level.

ENNHRI is one of four regional networks of NHRIs, which together make up the Global Alliance of NHRIs (GANHRI). Since 2013, ENNHRI has been constituted as an international not-for-profit association under Belgian law, with a Permanent Secretariat and registered office in Brussels.

In 2014, ENNHRI was awarded funding by the European Commission (DG EMPL) to carry out a project on The Human Rights of Older Persons and Long-term Care. Running from January 2015 to December 2017, the objectives of the project are to:

a) describe the human rights situation of older persons living in or seeking access to long-term care in Europe, particularly in relation to residential care; and
b) raise awareness of both the human rights standards protecting older persons seeking and in receipt of long-term care and the benefits of a human rights based approach to long-term care of older persons; and
c) develop or strengthen the capacity of NHRIs to monitor and support human rights based policies in this area.

As part of the Project, a Pilot Group of six European NHRIs carried out intensive monitoring within their jurisdictions, based on the human rights standards and the report of monitoring methodologies of NHRIs. They each drafted national reports, setting out their findings and recommendations.¹

¹ The Pilot Group members were: UNIA, the Interfederal Centre for Equal Opportunities, Belgium; The Office of the Ombudswoman of the Republic of Croatia; the German Human Rights Institute; The Office of the Commissioner for Human Rights Hungary; The Seimas Ombudsman’s Office of the Republic of Lithuania; The Romanian Institute for Human Rights. More information is available on www.ennhri.org.
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1. Introduction

Monitoring is one of the key responsibilities of NHRI s and human rights defenders, although the focus has been on “traditional” places of detention (prisons, police stations and centres for asylum seekers). More recently, attention is turning to other institutions in which individuals may be deprived of their liberty or in which human rights abuses may occur, particularly psychiatric institutions, centres for juveniles and long-term care settings for older persons. Long-term care in particular is a complex area and monitoring such places calls for a specific approach in order to understand the nuances of how human rights are implemented in all aspects of the daily lives and care of service users.

A high proportion of older persons in receipt of long-term care have dementia, cognitive impairments and/or communication problems, which can make interaction with older service-users challenging. Issues arise in relation to legal capacity, restraint, abuse and a lack of regard for dignity, autonomy and privacy. Human rights relating to long-term care are ill-defined in international and regional human rights treaties, and care providers and staff may be unused to scrutiny and oversight.

This Handbook seeks to offer guidance to NHRI s and other human rights defenders for monitoring human rights in the long-term care sector in Europe. It was originally written to support the monitoring phase of ENNHRI’s three-year project (the Project) on The Human Rights of Older Persons and Long-term Care, funded by the European Commission to increase awareness of the human rights of older persons living in or seeking access to formal long-term care services in Europe, as well as to develop the capacity of NHRI s to monitor and support human rights-based policies in this area. As part of the Project, six members of ENNHRI (in Belgium, Croatia, Germany, Hungary, Lithuania and Romania) carried out intensive monitoring within their jurisdictions between July 2015-March 2016. The objective of the monitoring work was to describe the human rights situation of older persons seeking and in receipt of formal, residential long-term care in order to increase awareness of the main human rights challenges and to share good practices within the long-term care sector throughout Europe. This revised version incorporates reflections from the monitoring teams on the monitoring process and methodology. ENNHRI hopes that the Handbook will incentivise all of its members to consider increasing its activities in the sector.

While the Handbook was written to guide NHRI s seeking to design and implement a full monitoring inquiry (incorporating visits to care homes), it recognises that NHRI s and other human rights defenders have diverse functions and seek to protect and promote human rights in different ways. As such, it also offers suggestions as to how human rights indicators can be collected from secondary sources.
Section Two of the report provides an overview of the legal human rights framework relevant to long-term care for older persons. Section Three gives guidance on developing the monitoring framework (what to monitor based on available data sources) while Section Four presents a strategy for data collection. Section Five discusses data analysis, write-up and reporting. Finally, Section Six outlines the Code of Conduct for human rights monitoring activities.

2. The Legal Framework: Human Rights Relevant to Long-term Care in Europe

Human rights monitoring (the activity of observing, collecting, cataloguing and analysing data and reporting on a situation or event) aims to check the conformity of the situation on the ground with national, regional and international human rights standards. At present, there is no international treaty setting out the human rights of older persons. Instead, the human rights that protect the rights of older persons seeking or in receipt of long-term care in Europe are scattered through various international and regional treaties.

In 2015, ENNHRI carried out a text-based analysis of these binding international and European conventions and related non-binding texts in order to identify the human rights standards relevant to the organisation and delivery of long-term care. The report sets out how relevant treaty bodies and the courts interpret the responsibilities of duty-bearers towards older persons in receipt of long-term care in Europe and so should be used in tandem with this Handbook.

ENNHRI’s analysis identified various rights, enshrined in at least one international/European binding treaty, that are particularly important in the context of older persons in LTC:

- Right to life
- Freedom from torture, degrading or inhuman treatment
- Freedom of movement, including freedom from restraint
- Right to autonomy
- Freedom of expression, freedom of thought, conscience
- Right to dignity
- Right to privacy and family life
- Right to participation and social inclusion
- Right to highest attainable standard of physical and mental health

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2 ENNHRI: Human Rights of Older Persons and LTC Project: The Application of International Human Rights Standards to Older Persons in LTC, www.enhr.org. Annexes to the report identify under which treaties each standard is protected and which treaty has been ratified by each European state. This makes it possible for monitoring teams in Europe to identify which of the relevant standards apply in their jurisdiction.
• Right to equal access to affordable health care services
• Right to an adequate standard of living
• Non-discrimination and equality
• Access to justice, including the right to an effective remedy

Although the binding human rights conventions do not include a specific right to long-term care, nor the right to have a choice of LTC service, the Committee on the Rights of Persons with Disabilities has confirmed that persons with disabilities have a right to choose the type of care, including residential, home or community care, and so older persons with a disability should not be admitted into residential care against their will.

3. Designing the Monitoring Strategy

Objectives and Approach of the Monitoring Work

Human rights monitoring is carried out for a variety of reasons:

• To assess the extent to which international human rights standards or norms are met in domestic settings;
• To raise awareness of inadequate standards and bring about behavioural change;
• To identify violations of human rights and prevent further abuses;
• To measure change/progress since previous monitoring activities or following a new policy measure.

Identifying the objective(s) of the monitoring work is the first step for monitoring teams and should be determined in line with the monitoring organisation’s mission and strategic priorities.

The objective of the monitoring work will also help to determine the methodological approach. Measuring change requires a “quantitative” methodological approach, whereby valid and reliable indicators are determined in advance and are captured from a powerful, random sample to allow for generalisation to the total population, in this case all older persons in receipt of long-term care.3

A more qualitative approach is more suitable for descriptive/explorative monitoring, particularly for awareness raising and stimulating systematic and long-term social or legal change. A qualitative (interpretive) approach also allows the monitoring team to get a more in-depth insight into how the care setting operates on a daily basis, which may in turn offer insights into how various factors, such as staff working practices,

staffing levels and resources, the physical environment and so on contribute to the human rights situation of older persons.

4. Data Collection

4.1 Proposed Schedule

Findings from ENHRI’s project on The Human Rights of Older Persons and Long-term Care indicated that the wider policy context has a strong bearing on the extent to which the rights of older persons seeking and in receipt of long-term care are upheld. Monitoring teams should thus consider having two parts to the investigation:

1. Analysing the policy context (macro-level)
2. Conducting monitoring visits to residential care homes (micro-level)

The resources available to the monitoring team will determine what and how much data will be collected both at the macro and micro level. Conducting at least some of the monitoring of national/regional policy prior to the visits to care homes can help the monitoring team to glean relevant background information for understanding the impact on older persons themselves. However, it may be useful to conduct some of the interviews with key policy-makers after the site visits in order to be able to discuss the findings and potentially feed into on-going policy development.

4.2 Monitoring the Policy Context

The purpose of analysing policies on long-term care is to understand how the organisation and delivery of long-term care reflects the relevant international human rights standards, particularly in relation to the accessibility, availability, affordability and quality of services.

Collecting relevant, contextual information on the policy context can help monitoring teams to build a clear picture of the way in which care is organised, whether there is cohesiveness in how policies and the roll-out of long-term care services and how well they take international human rights standards into account in planning service delivery. For example, they can show whether older persons in receipt of seeking care were consulted about the development of new policies and practices, whether account was taken of human rights law and obligations and whether opportunities exist for residents to seek more information or redress if necessary. Monitoring teams can collect this through secondary sources, complemented with interviews with relevant key informants.

Interviews will be useful for:

- complementing and expanding upon the documentation to be collected above,
- clarifying any details unclear from the documentary review
gaining insights into the extent to which human rights standards are taken into account when planning and delivering services;
Highlighting or explaining inconsistencies with prior collected evidence; and
exploring how contextual issues (financing, supply, training etc.) impact on the human rights situation of older persons at the macro-level.

### Making Use of Secondary Data

<table>
<thead>
<tr>
<th>Information</th>
<th>Sources</th>
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<tbody>
<tr>
<td>• An overview the existing legal framework and administrative structure (in order to see if it is sufficient to protect and promote the human rights of older persons in care);</td>
<td>Documentary Sources:</td>
</tr>
<tr>
<td>• The presence of waiting lists for services; how such waiting lists are organised;</td>
<td>• Legislation</td>
</tr>
<tr>
<td>• Care delivery model: public/private/voluntary/mix, mainly home or residential, formal or informal, supply v demand, do individuals have a choice of provider;</td>
<td>• Policies</td>
</tr>
<tr>
<td>• Bed numbers nationally/regionally vis-à-vis the population of persons aged 70+;</td>
<td>• Jurisprudence</td>
</tr>
<tr>
<td>• Financing: via general taxation, obligatory social security, voluntary private insurance; % GDP on long-term care; access for individuals with limited financial means;</td>
<td>• Recommendations from regional/international bodies</td>
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<tr>
<td>• Legal capacity legislation;</td>
<td>• Complaints received (where relevant)</td>
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<tr>
<td>• The cost of care, and any out of pocket payments for residents;</td>
<td>Interviews: 4</td>
</tr>
<tr>
<td>• Care staff average income vis-à-vis average industrial wage;</td>
<td>• Officials from the national/regional government department(s) with responsibility for overseeing long-term care for older persons</td>
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<tr>
<td>• Minimum training requirements for long-term care workers;</td>
<td>• Officials from the relevant regional/local authorities with responsibilities for overseeing/commissioning/providing long-term care for older persons (if necessary, a sample)</td>
</tr>
<tr>
<td>• Provision of training on human rights;</td>
<td>• Civil society advocacy organisations for older persons (national, community level)</td>
</tr>
<tr>
<td>• Minimum staffing levels;</td>
<td>• Civil society advocacy organisations for human rights</td>
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4 See Annex 4 for Sample Interview Guides.
• Access to and provision of medical treatment for individuals in long-term care;
• Current monitoring of long-term care services (national/regional quality standards in place; quality/health and safety), gaps in monitoring, prosecutions.

• Residential care home regulator
• Older persons in receipt of home-care and family members

### 4.3 Visits to Long-term Care Services

The Association for the Prevention of Torture (APT) suggests that following the following schedule can increase the success of monitoring visits to care homes – maximising the data that can be collected and cementing the rapport and respect between the care home and monitoring teams.

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<td><strong>1. Preparation</strong></td>
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<td>1. Selection of Care Homes</td>
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<td>2. Organise the monitoring team</td>
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<td>3. Determine the Objectives and Collect Preparatory Data</td>
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<tr>
<td><strong>2. Visit</strong></td>
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<tr>
<td>4. Initial interview with the Director</td>
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<td>5. Consultation of Registers and other documentation</td>
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<td>6. Visit of the premises</td>
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<td>7. Interviews with Staff</td>
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<tr>
<td>8. Interviews with Residents</td>
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<tr>
<td>9. Exit interview with the Director</td>
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<tr>
<td><strong>3. Follow-Up</strong></td>
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<tr>
<td>10. Write up notes</td>
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<tr>
<td>11. Visit report</td>
</tr>
<tr>
<td>12. Follow-up visit and activities</td>
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### Selection of Care Homes

The number of residential care homes that monitoring teams decide to visit will depend on the objectives of the monitoring work, the approach, and their resources. Ideally, care homes should be randomly selected – namely, each care home in the region/country should have an equal chance of being selected. This means that the monitoring team needs to start with a list of all care homes in the country/region. If this is not possible, it is important that care homes be selected according to various criteria in order to ensure adequate diversity in the monitoring work. Potential criteria in the case of long-term care include:

- ownership (public, for-profit and voluntary non-profit)
- type of care home
- geographic (urban, rural)
- size of care home (small, large)
- announced and unannounced visits (where relevant)

However, just because a home is selected, does not guarantee it will be willing to take part. Given the intensity of the site visits, they will require considerable cooperation from the Director, staff and residents of the care setting itself. Many settings will not have the capacity to facilitate such an extensive visit, and others may be suspicious or fearful of the consequences of such a visit and may therefore wish to refuse access.

Whether care homes can refuse access to the monitoring team depends on the mandate of the NHRI. Many NHRIs have been accorded the mandate of the National Preventive Mechanism (independent national monitoring body) for ascertaining the State’s implementation of the UN’s Operational Protocol on the Convention Against Torture (OPCAT). This mandate gives the NHRI the authority to enter institutions without prior authorisation to monitor the human rights situation therein.

Other NHRIs that do not have this mandate, as well as civil society organisations, will need to anticipate and minimise “refusals”, allowing enough time for drawing up the sample. Annex 2 provides a sample letter of invitation to care homes that appeals to care home directors to participate by highlighting the mandate of the NHRI and the importance of human rights monitoring. The letter also gives assurances at the outset of confidentiality and full disclosure about the purpose of the monitoring work, and that the visit is independent of the state. NHRIs can send an adapted letter to all, or selected, care homes, taking care to keep records of all refusals.

In ENNHRI’s project, NHRIs that did not have the NPM mandate experienced difficulties in accessing care homes to monitor, reporting several refusals. One monitoring team found success by approaching care homes known for their interest in protecting and promoting the human rights of residents. However this led to a potentially biased sample. Having to negotiate access also means that the monitoring team is making an “announced visit”, which itself has advantages and disadvantages, as outlined in the box below.

<table>
<thead>
<tr>
<th>Should visits be announced or unannounced?</th>
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<tr>
<td>The question of whether visits should be announced or unannounced is somewhat contentious, with advantages and disadvantages to each approach. The NPM function gives monitoring teams a powerful insight into how care settings, and other places in which individuals may be deprived of their liberty. They have the capacity to enter into any such setting, and may not be refused by any care home, even those which may have reason to fear the outcomes. This is a powerful advantage for the monitoring team. Indeed, in ENNHRI’s project on The Human Rights of Older Persons and Long-term Care, three of the monitoring teams, in Belgium,</td>
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</table>
Germany and Romania, were refused entry to several care homes, even after putting significant effort into developing a relationship with the care provider. While all providers stated that they were reluctant to allow access on the basis of limited resources (such as the challenge of freeing up staff to be interviewed), the monitoring teams could not be sure whether the care homes were in fact fearful of human rights concerns being found.

On the other hand, while unannounced visits are an essential part of the human rights monitoring system, NPM monitoring teams also need to remember that data collection will be more limited with unannounced visits. For example, it may not be possible to interview any/many family members during the course of an unannounced visit. As such, NPM monitoring teams should consider including some announced visits, or seeking to interview family members, key staff and other stakeholders at a later date in order to obtain a holistic view of the institution.

NPM teams also need to consider how best to balance their NPM and NHRI function, which requires them to protect and promote human rights, including through human rights education and awareness-raising programmes. Doing so requires the maintenance of a good relationship with all duty-bearers, which must be developed through mutual respect and bearing in mind the point of view of the care provider.

Regardless of whether or not the visit is announced, monitoring teams should endeavour to carry out some monitoring work in the evenings, at night or at weekends, when staff ratios tend to be lower, with fewer activities available for residents.

The length of time for each visit should seek to balance the time required for the monitoring team to collect all the information required, while also balancing the resource implications for care homes.\(^5\) If possible, monitoring teams should aim for visits of between one and three days (using teams of 2-3 staff or more), with adequate preparation, including making appointments with family members and staff either before the visit starts, or at the outset.\(^6\)

Organising the Monitoring Team

Human rights monitoring is complex and requires monitoring teams with a wide range of skills. The OPCAT gives useful guidance on carrying out “on the ground” monitoring visits, particularly in relation to the makeup of the monitoring team. In particular, the members of an NPM monitoring team should collectively have the

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\(^6\) APT, ibid. pp. 73-75 offers a useful outline of preparatory activities that may assist with the overall visit.
necessary expertise required to understand the dynamics of a particular institution/place of detention. In the case of care homes, the necessary expertise is likely to include individuals with a:

- Legal background
- Medical background (particularly geriatricians)
- Nurses
- Social workers/psychologists/advocates for older persons

Monitoring teams should also seek to have gender balance and the representation of ethnic and minority groups in the country. This is because, in most cultures, men and women have different opportunities to establish relationships based on trust with detainees and staff. Similarly, staff and residents of the care home may prefer to speak to members of ethnic and minority groups on the monitoring team.

The size of the monitoring team will depend on the objective of the visit, the size of the institution and how much is already known about the setting. The ideal size of a visiting team can be estimated as being between 2 and 8 people. The Association for the Prevention of Torture (APT) also recommends that all members of the monitoring team receive adequate training in the following areas before starting the monitoring work, as well as on an on-going basis.

<table>
<thead>
<tr>
<th>Training Requirements for Monitoring Teams</th>
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<tbody>
<tr>
<td><strong>Theoretical training should include at least the following:</strong></td>
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<tr>
<td>* the basic principles of monitoring, in particular confidentiality and the necessity to always bear in mind the security of the detainees;*</td>
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<tr>
<td>* the legal framework, in particular the relevant international standards, national laws and regulations;*</td>
</tr>
<tr>
<td>* key issues and problems relating to the deprivation of liberty.*</td>
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<tr>
<td><strong>Practical training should include at least the following:</strong></td>
</tr>
<tr>
<td>* the methodology of visits;*</td>
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<tr>
<td>* how to conduct private interviews with persons deprived of their liberty;*</td>
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<tr>
<td>* the behaviour to adopt with the authorities, staff, and detainees;*</td>
</tr>
<tr>
<td>* the basic security rules to respect during the visit;*</td>
</tr>
<tr>
<td>* report writing;*</td>
</tr>
<tr>
<td>* mechanisms for cooperation and communication within your own mechanism.*</td>
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7 ibid.
Determining the Objectives and Collecting Preparatory Data

Once the care homes have been selected, the monitoring team should seek to collect and analyse any available information on each care home (e.g. from their website, from inspection reports from a quality inspectorate, media etc). This will help to determine the objectives for each individual visit, vis-à-vis the objectives of the overall monitoring work, including any particular area of focus.

Throughout the course of each visit, monitoring teams may find it helpful to try and collect the following information:

- Social and Cultural Rights (respect for privacy, dignity, choice, autonomy, consultation and participation, consent)
- Staffing (staff ratio, qualifications, organisation of on-going training, staff-resident relations, salary, well-being, working hours, turnover, regulations)
- Physical Environment (layout)
- Service, activities available
- Governance and Management (operational management, residents’ records, care home philosophy, continuous improvement, contract between care home and resident, complaints procedure and register, registers of restraint/accidents)
- Health and Social Care (person-centred care and responsiveness to individual request, management of personal care, resident participation in the development of their care plan, administration of medication, medical examinations, fire safety, health and hygiene policy)
- Routines and Expectations (social and civic participation, socialisation and maintenance of relationships with family and friends, meals and mealtimes, menu sheets, death and dying)
- Personal Safety and Protection (management of finances, personal safety, restraint policy)
- Rights of care staff
- Price of care home for each resident

In particular, monitoring teams should be seeking to ascertain whether policies focus on a “blanket”, one size fits all approach, or seek to respond to individual needs and particular contexts and whether staff follow the various policies in everyday practice.

Initial Interview with the Director

Whether the visit is announced or unannounced, starting the visit with a meeting with the Director of the care home will help to explain the purpose and structure of the visit, including highlighting the need to interview residents and staff in private; introduce the monitoring team; and find out key information about the care home from the outset.

This meeting is also useful for alleviating any concerns from the Director, answering their questions and informing them about how any data collected from the visit will be used (in compliance with data protection legislation).
Consultation of Registers and other documentation

Monitoring teams should ensure to examine all available documentation, particularly:

- copy of (generic) contract with residents,
- policies and procedures on various aspects of the operation of the home (e.g. menu sheets),
- registers of restraint,
- policies on medication management,
- activities available for residents,
- internal rules,
- staff list,
- staff rota.

Visit of the premises

Different options are possible for seeing how the care home operates in practice, depending on the resources available and purpose of the visit and monitoring activity more broadly. The monitoring team could simply carry out a tour of all areas of the care home, either accompanied by staff or alone. This will give the team insights into the care home, seeing the typical layout of residents’ room, the general atmosphere, an impression of hygiene, what residents are doing etc.

Although much information can be obtained from such visits, several of the monitoring teams in ENNHRI’s project on The Human Rights of Older Persons and Long-term Care suggested that a longer period of participant observation would have been helpful in giving more insights into the day-to-day operations of care homes.

### Participant Observation

<table>
<thead>
<tr>
<th>Observation of a field setting involves prolonged engagement in a setting or social situation where the monitoring team use all of their senses to examine people in natural settings or naturally occurring situations.</th>
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<tbody>
<tr>
<td>Observation can provide monitoring teams with invaluable information, particularly when undertaken in conjunction with fact-finding interviews and document review. It can be used in the care home to examine how human rights law and care home policies are implemented in practice. Observation can be particularly useful when carried out at different times (weekdays, weekends, night time), to get a sense of how the care home functions throughout the week.</td>
</tr>
<tr>
<td>Prior to undertaking observation, the observer must have sufficient information about the process they intend to monitor and the standards to which those processes should adhere so that they can understand what is happening, what</td>
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</table>
should be happening, and what is missing from the proceedings they are observing.

Observers may unintentionally influence the behaviour of the individuals they are observing, leading them to act somewhat unnaturally (e.g. adhere strictly to the rules and regulations of the care home in a way they usually do not). As such, monitoring teams should carry out their observations for a few hours at a time over a minimum of three days (in order for those observed to become familiar with the observation work). While observation can be done individually, in pairs, and in teams, in the case of care homes for older persons, particularly small homes, the observation team should be kept small in order to reduce obtrusiveness.

Data collected through observation should be carefully recorded as objectively as possible in fieldnotes, including number of participants, timeline of activities, content of discussions, and other relevant observations. Diagrams, sketches, or maps of details may be helpful, as well as descriptions of gestures, physical appearance, or movements. Informal conversation and interaction with participants may also yield insights and should be recorded in notes.\(^8\)

**Interviews with Staff**

Staff are a vital component in how the human rights of older persons are upheld within care homes. The monitoring team may wish to consider interviewing a selection of the following:

- Administrative staff
- Domestic and housekeeping staff
- Pastoral staff
- Medical and nursing staff
- Social work
- Allied health professionals (physio-, occupational and speech and language therapists)
- Care Assistants
- Activities staff

Such interviews will be useful for:

- Gaining insights into day-to-day life in the care home
- Hearing the voice of staff and understanding their level of satisfaction with the care home and respect for human rights.
- Gaining insights into the extent to which human rights standards are taken into account when planning and delivering services
- Clarifying any details unclear from the review of care policies and procedures

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\(^8\) [https://assessment.trinity.duke.edu/documents/ParticipantObservationFieldGuide.pdf](https://assessment.trinity.duke.edu/documents/ParticipantObservationFieldGuide.pdf)
• Exploring how contextual issues (financing, supply, training etc.) impact on the human rights situation of older persons within care homes.

Individuals may be reluctant or unable to take part in an interview (time constraints, lack of knowledge of the area, fear of the consequences). During an interview, they may be reluctant to impart important knowledge. It is therefore important to plan the interview guides for each interview carefully, and to have a good understanding of the available techniques for building rapport, structuring the interview (question sequencing) and probing. This includes:

• Holding interviews in private
• Starting with neutral topics
• Showing an interest in the respondent’s answers
• Encourage the respondent to expand on their answers (“tell me more about that”, “describe how you felt…”)
• Respecting the moment that the individual is in (e.g. if their present reality is being a young
• Let their answers determine the direction the interview takes
• Keep language and questions simple
• Probing:
  ➢ “What do you mean by that?”
  ➢ Remain quiet and wait for respondent to continue
  ➢ Repeat what they have said and ask them to continue
  ➢ “Uh huh”, “I see”…

Another option is for monitoring teams to conduct focus groups, which can reveal a wealth of detailed information and deep insight. A focus group is a small group of six to ten people led through an open discussion by a skilled moderator. They are best suited to assess attitudes and influences that impact upon people’s behaviour. Focus groups are structured around a set of carefully predetermined open-ended questions – usually no more than 10 – but the discussion is free-flowing. Ideally, participant comments will stimulate and influence the thinking and sharing of others. Focus groups have some advantages over individual interviews, and vice versa (see the box below). Focus groups may be particularly useful for obtaining information from care staff on the role of human rights in the care home’s everyday policies and practices, particularly if staff have limited time to contribute to the monitoring work.
Annex 4 contains sample interview guides for some of these interviews, in order to provide insights into staff knowledge of human rights, in theory and practice.

**Interviews with Residents and Family Members**

In recognition of the centrality of participation to a human rights-based approach, monitoring teams should seek to ensure that the voice of older persons, and family members, are included as much as possible within each site visit. This includes not only individuals able to speak clearly and offer opinions on their care, but also to analyse the situation of individuals with cognitive impairments and/or communication problems.

**Case Studies with Older Residents**

To ensure that the voice of older persons is central to the human rights monitoring work, monitoring teams should seek to conduct “case studies” of 2-3 residents, either selected at random, or specifically selecting residents with dementia/cognitive impairment/dementia. This involves carrying out:

- An interview with the person in question:
- An interview with a family member
- Raising questions about this particular resident in interviews with the Care Home Director and each staff member to ascertain how the care home seeks to uphold their rights by taking into account their individual preferences and rights in how they live their daily lives and how they participate in decisions affecting their care.
- Review of care home documentation with a view to considering how the rights most pertinent to the individual are upheld.

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**Advantages and Disadvantages of Focus Groups and Interviews**

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<th>Advantages</th>
<th>Disadvantages</th>
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<tr>
<td>Interviews</td>
<td>• Depth&lt;br&gt;• Confidentiality&lt;br&gt;• Highlights individual’s knowledge on key topics&lt;br&gt;• More flexibility in organising and conducting the interview&lt;br&gt;• Personal contact allows a better response to visual cues</td>
<td>• More time consuming, resource intensive</td>
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<tr>
<td>Focus Groups</td>
<td>• Group interaction&lt;br&gt;• Can save time</td>
<td>• Difficult to organise and coordinate Challenges moderating&lt;br&gt;• Influences of 1-2 people can dominate&lt;br&gt;• More susceptible to bias</td>
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Interviews with Residents and Family Members

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Case Studies with Older Residents

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- Review of care home documentation with a view to considering how the rights most pertinent to the individual are upheld.
The basic objective of human rights is to empower individuals to fulfil their full potential by giving them the authority, capacities, capabilities and access needed to change their own lives and influence their own futures. As such, determining whether care homes comply with human rights legislation requires monitoring teams to understand how policies and practices impact on individuals' unique care experiences.

Case studies will require some preparation, and also the co-operation of the care home Director. With their assistance, monitoring teams should try to randomly select these individuals in advance of the visit to liaise with family/guardians and also to seek their consent and co-operation for the study. Some notice may mean family members may be able to attend or may be able to participate in a phone interview in advance of the site visit, to give information on their relative’s wishes and rights in the home.

The following suggestions may be of use in planning interviews with residents with severe dementia and/or cognitive impairments:

- Prior to the interview, make sure to obtain the resident’s consent to take part;
- Interviewing individuals in the morning rather than the afternoon;
- Carrying out interviews in a calm, quiet and restful place;
- Making sure there is eye contact and speak clearly, without shouting;
- Taking more time to allow individuals to respond and allowing greater flexibility;
- Being prepared to engage in trial and error – for example, some individuals with dementia will appreciate physical touch to make an emotional connection, while others will not like being touched by those they do not know.

In addition, innovative methods and approaches may help:

- Simply spending some time with the resident, rather than trying to conduct a formal interview may help to reveal how staff relate to them and how they are cared for.
- Don’t interrupt the participant’s thread of thought, yet you allow them interrupt you when an idea comes into their head. Try the technique of reflective listening, where you repeat back the meaning of what they have tried to say. This will help to ensure you have understood the true meaning, and help the participant to feel really listened to.

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9 For example, see:
- Using visual aids (photographs, pictures from magazines of different emotions, activities, likes and dislikes) to encourage residents to talk about their interests and draw out elements of their personality that may reveal how the care home needs to consider their personal preferences when upholding their rights.
- Try to avoid specific questions which may make the participant feel pressurized. Instead, gentle prompts and open questions can be more appropriate e.g. What activities do you like to do? (follow up: How do you feel about playing bingo?/reading).
- Responses should be determined by verbal and non-verbal behaviour, which includes speech, vocalisations, facial expression, eye contact, pointing, gesture and body language.
- Interviews should be terminated if residents indicate verbally or non-verbally that they are tired, uncomfortable or distressed.

Discussions with formal and informal carers can be used to complement the information from residents themselves (asking about likes, dislikes, preferences etc). This will also help to give an insight into staff’s intimate knowledge of each resident, which is required when upholding their rights. (For example, if a relative mentions that a resident loves knitting, and staff are unaware of this, it may highlight that there is a limitation in upholding the resident’s right to choice and education and life-long learning.

**Exit interview with the Director**

In recognition of the co-operation of the care home director/owner, the monitoring team should endeavour to have a brief exit meeting at the end of the visit to provide some initial feedback. In preparing for the departing interview the monitoring team should consider what elements to raise and in what order. The meeting could start with a request for clarification or discrepancies between the initial information provided by the director and the information collected during the visit from observation and interviewing the residents. The team might want to consider then highlighting some positive practices, so that they can establish a friendly rapport with the director. They may consider giving preliminary suggestions for improvements (if they feel this would be welcomed) and finally finish by stating that they will be sending a summary report (see Annex 6) with the principal recommendations and conclusions of their visit. Monitoring teams should note that it is not necessary to raise every possible issue on a single visit. The discussion with the director should aim to conclude on a positive note.

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**Follow-Up and thanking the Care Homes**

The visiting team should prepare a summary report for each care home they visit, which should be sent as soon as possible after the visit (see Annex 7 for a template). The individual responsible for drafting the report should take into account the (limited) resources available to the home, the support they receive from the state as well as its minimum obligations to residents. The monitoring team may be able to identify cost-effective ways of improving current practices or sources of support for the care home that do not involve a high financial cost. If resources allow, monitoring teams should endeavour to carry out follow-up visits to see if recommendations that they have made have been implemented.

### 5. Reporting

Annex 7 contains an outline of the report monitoring teams should use for their monitoring work. The outline encourages monitoring teams to collate and report on details of all the monitoring work thematically, rather than reporting on each site visit and stakeholder interview separately.

When reporting, monitoring teams should seek to identify key trends (e.g. what care home generally do well, common problems etc). In order to ensure that the reports are written carefully and objectively, monitoring teams should ensure that extensive notes are taken throughout the course of each interview/focus group, or that they are audio-recorded.

### 6. Code of Conduct and Ethical Considerations

**Code of Conduct**

The code of conduct set out by the UN\(^{11}\) provides a valuable guide for monitoring teams in carrying out their monitoring work.

1. **Use Monitoring to Improve the Protection of Human Rights**
   Human Rights Officers must relate their work to the overall objective of human rights protection. They can record observations and collect information for immediate action and later use. They can communicate the information to the appropriate authorities or other bodies. While exercising good judgement at all times, HROs should take initiative in solving problems and, provided they are acting within their authority and competence, should not wait for a specific instruction or express permission before acting.

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At the same time, Human Rights Officers must remember that, in undertaking the monitoring work, they enter into personal and moral relationships with those they study, be they individuals, households, social groups or corporate entities (this includes both older persons and care home owners, managers and staff). As such, participants to the study must be informed of the potential that violations of rights abuses may be reported to the relevant authorities (including the NHRI itself) before they have agreed to participate in the study.12

ii. Do no harm
In no way is the Human Rights Officer to act in such a way as to cause (heightened) danger to people. This also applies where there is a potential conflict between the officer’s need for information and the informant’s security; the security of the source of information has priority. The human rights officer must keep in mind the principle of no harm at all times.

iii. Know and respect your mandate
The mandate is the foundation which structures the human rights work. Understand the mandate, and keep it constantly in mind.

iv. Exercise good judgement and seek advice
There will always be situations when you have to exercise your own good judgement and use your common sense – however many instructions you have been given, whatever rules have been worked out, or however trained you are. Consult with your colleagues and superiors when dealing with a difficult case.

v. Be credible
Your credibility is an asset of utmost importance. Make sure that you keep your promises, and do not make promises you cannot keep. When you are perceived as credible and trustworthy, victims, witnesses and other informants will come to you with their information and for cooperation.

vi. Be impartial
The mission is impartial, and its human rights officers should behave in an impartial manner. When gathering information, make sure that your approach is objective, open to all sides of the matter under investigation.

vii. Be visible
Your involvement should be visible, both to the authorities and to the population. Often, presence has a deterring effect on the perpetrators of human rights violations.

viii. Show sensitivity
Remember that you are in a situation in which certain individuals may have suffered human rights abuses.

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In addition, monitoring teams should seek to take a holistic view of long-term care and each care setting, documenting both good and bad practice in relation to the protection of the human rights of older persons.

**Ethical Considerations**

While many of the ethical principles related to human rights monitoring are already outlined above, monitoring teams should highlight the need for obtaining consent from study participants, including in particular older persons themselves and for accessing any documents related to their care. In addition, it is important that research participants’ confidentiality is protected, both by holding the interviews in private and by removing any identifying details from their data. Monitoring teams should have a policy in place for keeping the data collected secure and anonymised. Rather than necessarily excluding individual rights-holders who are not capable of giving informed consent, it may be possible to obtain consent by clarifying their personal values, or from reference to a legal representative.

Should the monitoring team encounter allegations of rights abuses during the course of the monitoring phase, it is important that they look for confirming evidence rather than taking this at face value, both by seeking consistency and coherence from the person making the allegation and evaluating other sources where relevant. It is also important that the project has guidelines should the monitoring team encounter an emergency or extremely serious breach of human rights during the monitoring process. While this will be determined in part by the NHRI’s mandate, current good practice is for the human-rights monitor to maintain the boundaries of the project and refrain from intervening on-site, but to follow up and make referrals or report the violation to the relevant authority.

Covert visits (e.g. on the pretence that the human rights monitor is looking for accommodation for a relative) should be considered unethical practice and should not be used by human rights monitors.

7. **Reflections from ENNHRI’s Monitoring Teams**

As noted earlier, this Handbook was originally written to guide the monitoring teams from the NHRI’s of Belgium, Croatia, Germany, Hungary, Lithuania and Romania, as

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they prepared to monitor the human rights situation of older persons in their respective jurisdictions.

Following the monitoring work, all six monitoring teams were asked to reflect on the monitoring methodology that they used, and to share advice on what worked well for them and what they might do differently the next time around. While much of this advice has already been incorporated into this version of the Guidebook, here, the monitoring teams impart other key tips for any institution considering human rights monitoring work in the long-term care sector:

- “Access to care homes was the biggest challenge for us. It took a lot longer than the time we allowed ourselves.”
- “Carrying out follow up visits was crucial – it was heartening to see how many of the care homes had followed up on the recommendations that we had made.”
- “Although the visits were a lot of work for the Director and the staff of the care homes, they were by and large very co-operative – the vast majority of the people who work in the sector are extremely dedicated.”
- “The monitoring work would have been so much easier with a larger team – we were just three people and it was hard to dedicate as much time as we would have liked to interviewing residents.”
- “Even with the NPM function, we found it challenging to have unsupervised access to the care home. This is understandable – staff want to protect residents’ privacy, but after visits to the first few homes, we made it clear from the outset that we needed to have privacy to interview residents, and we wanted the opportunity to ask residents to take part ourselves, rather than the care home selecting residents for us.”
- “It is important to cross check certain issues when visiting care homes. For example if a resident claims to receive cold meals it is good to double check this information with other residents and care home stuff, or just try it for yourself.”
- “It can be emotionally challenging to hear disturbing stories. It’s good to be prepared in advance and have team debriefings to get support.”
Annex 1: Sample Letter of Invitation to Care Homes

Recipient Name
Address

Human Rights of Older Persons and Long-term Care

Dear X,

My name is X. I am a (Human Rights Officer) with the (NHRI), a statutory institution with a mandate to protect and promote human rights in (country). At present, (the NHRI) is carrying out a major inquiry on the human rights of older persons in receipt of long-term care. This will investigate the extent to which the human rights of residents in long-stay care settings are upheld and whether current legislative, regulatory and quality control systems offer sufficient human rights protection for older people in receipt of care.

A key element of the enquiry consists of the observation and monitoring of everyday practices in a small number of care homes, selected from a list of all care homes in the country. We would like to request your assistance by participating as one of the care homes.

The inquiry is not into individual organisations but is being conducted on a sector-wide basis across the country as part of our regulatory role in respect of human rights. The data from the monitoring visit will be analysed to furnish the Inquiry with evidence on how issues are dealt with across the country.

Para 4, Option 1
We very much hope that you will be prepared to take part. We are conducting this inquiry using our legal powers under (ACT). This gives the (NHRI) a range of powers including the ability to require organisations to facilitate the inquiry. At this stage we are asking for the information voluntarily. However it is very important that we gain a full picture of the human rights situation of older persons in long-term care to enable us to make meaningful and targeted recommendations. Therefore, if we have concerns regarding levels of cooperation, we will consider serving a statutory notice requiring access to the care home.

Para 4, Option 2
We very much hope that you will be prepared to take part. Our visit will give you the opportunity to participate in research that has the potential to reform care policies for the long-term care sector at national level. Moreover, it gives you the opportunity to showcase good practices you have developed to protect and promote the human rights of older persons in your care and to
discuss with experts in human rights how to improve current practices in the area of human rights protection and promotion in the care home.

Should you agree to take part, the visit (by a team of 3\textsuperscript{17} NHRI staff) should take no more than 2 days and will consist of:

- An initial interview with the Care Home Owner/Director
- A tour of the facility
- Interviews with medical staff, care assistants, activities staff (5-6 individuals in total)
- A review of (generic) care home documentation: copy of contract with residents, policies and procedures on various aspects of the operation of the home
- Interviews with residents and family members
- A brief exit interview with the Care Home Owner/Director at the end of the visit

The monitoring team will make every effort to keep disruptions to residents, family, staff and management to a minimum. In order to facilitate the visit, we would seek your co-operation to visit the home in advance in order to put up posters and a comment box to create awareness and interest in the study. We would also appreciate your co-operation to invite family members to take part in a focus group/interview with the monitoring team.

While we are confident that your home operates to the highest quality, please be aware that the (NHRI) has an obligation to report any allegations of serious violations and abuses of human rights.

I will contact you by phone during the coming week to ascertain your response to my request. In the meantime, you can contact me by phone (NUMBER) or email (ADDRESS).

Best wishes,

X

\textsuperscript{17} Amend as required
Annex 2: Poster for the Care Home

Human Rights of Older Persons & Long-term Care

Do you have anything to say on human rights in long-term care? We want to talk to you!

The (NHRI) is carrying out an inquiry on how well the human rights of older persons in care are upheld. This care home has agreed to participate in the study. We will visit the home on X DATE. If you will be here, we would love to talk to you and hear your views on the home. If you cannot attend on the day, you can leave any comments in the locked box below, or contact us to give us your views.

Contact:
Name
Address
Phone number
Email
Annex 3: Sample Consent Form for Older Persons

I confirm that I have read and understood the information sheet for the above study and have had the opportunity to ask questions.

I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.

I understand that sections of any of my medical notes and personal records may be looked at by responsible individuals from (NHRI) where it is relevant to my taking part in this Project. I give permission for these individuals to have access to my records.

I understand that this interview is to be taped for analysis purposes. I agree to this interview being audio recorded.

All the information collected by the study is completely confidential and is stored anonymously, without personal details. Audio tapes are anonymised and used for analysis purposes only and will be destroyed when no longer required.

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<th>Interviewer name</th>
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Annex 4: Sample Interview Guides

Older persons living in long-term care settings

Introduction
My name is X, from the (country) NHRI. Our role is to protect and promote human rights of everyone living in the country. We also have a mandate to make sure every institution and organisation, including residential care settings, uphold the rights of older persons. That means that the home here needs to always remember to take your views into account and make sure you are well-treated, have adequate choice and say in all aspects of your life and have enough food, privacy, dignity etc.

The interview should last half an hour to an hour. Everything you say will remain confidential. Quotes from this interview may appear in reports on the inquiry, but under no circumstances will your name or any identifying characteristics be included. Your participation in the interview is entirely voluntary, you are free to end the interview at any time and you can refuse to answer any question.

Background
Where are you from originally?
Are you married? Do you have family living nearby?
Do you have children?
Did you work outside the home? What did you do?
What hobbies/interests did/do you have? (PROMPT for example, watching sport, current affairs, watching tv, attending religious services)

Entry into Residential Care
How long have you been living here?
Can you tell me a little bit about coming to live here? Did you have a say?
Were you able to choose this home (as opposed to a different one)?
How did you feel about it at first? Now?
Did you have to wait long before you got a bed?
Who pays for your care here? (If relevant: how much do you pay?)

Life in Care
Can you tell me a little about your life here? PROMPT: what did you do yesterday?
What aspects of your life have changed since you came in here?

Meals
What time do you have breakfast? (Also, lunch, dinner)
What time did you used to eat breakfast before you moved in here?
What do you eat for breakfast / lunch / dinner?
Do you have a choice of meals? Can you say what you like and don’t like?
What do you think of the food overall?

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18 Chapter Seven of the Asia-Pacific Report (2012, op. cit.) is useful in planning the collection of primary data. See also Equality and Human Rights Commission, 2011, Close to Home, op cit.
**Healthcare and Medication Management**
How would you describe your overall state of health?
To what extent are all of your health needs met here? (eg physiotherapy, occupational therapy, medication)
How do you get on with the carers who look after you?
Do you need much help from them every day to carry out personal tasks (toilet, washing, eating)?
How quickly do care staff help you when you need it?
How do you feel when the care workers are with you?
Do you take any medication? When do you take it?

**Participation and Social Contact**
Do you go down to the (shops/village)? [If no] would you like to?
Do you do any activities here?
Is there anything you would like to do but it’s not available?
Do you have friends/family that come to visit you? (If yes) Do you have somewhere private to bring them?
Are you friendly with any of the other residents?

**Choice and Dignity**
How far does the care you get take account of your personal needs and wishes?
How well do you feel your dignity is maintained in your day to day life here?
Do you feel safe here?
Can you think of any time when you weren’t fully happy with the care you received here? Can you tell me what happened?

**Physical Environment**
Do you have your own bedroom?
What do you think of your bedroom?
Can you move around freely?
Is there anywhere you can’t access? (eg garden)?
How well do you feel your privacy is protected and respected?

**Complaints**
What would you do if you had a problem with the service here?

**End-of-life Care**
Have you made any plans for your death?

**Human Rights**
Can you tell me what human rights means to you?
How well do you think your human rights are upheld in your day to day life here?

**Overview**
Are you happy here?
What aspects of life here do you like most? Least?
Is there anything you would change about the care you get here?
Older persons living in long-term care settings (Communication problems/dementia)\textsuperscript{19}

Introduction
My name is X, from the (country) NHRI. I want to ask you about your life here. I won’t tell anyone else what you tell me unless you want me to. We can talk anywhere in here that is comfortable for you.

Would you like to help me?

What is your name?
Do you have any family?
Did you work outside the home? What did you do?

What hobbies/interests did/do you have? (PROMPT for example, watching sport, current affairs, watching tv, attending religious services)

How long have you been living here?

What is your favourite food? Do you have (favourite food) in here?
What do you think of the food overall?

Who looks after you now (ie care workers)? What do you think of him/her/them?

Do you feel safe here?

What aspects of life here do you like most? Least?
Is there anything you would change about the care you get here?

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\textsuperscript{19} This Interview Guide is intended as a rough starting point and will differ for each individual. The purpose is to try and include feedback for those living in care who have severe dementia/communication problems to the best of their ability and if they are interested to be included. Interviewers will have to use “trial and error” and see what is feasible with each individual. The images in Annex 5 (or similar) may be of use in prompting discussions.
**Family Member**

**Introduction**
My name is X, from the (country) NHRI. Our role is to protect and promote human rights of everyone living in the country. We also have a mandate to make sure every institution and organisation, including residential care settings, uphold the rights of older persons. That means that the home here needs to always remember to take your views into account and make sure your relative is well-treated, has adequate choice and say in all aspects of their life and have enough food, privacy, dignity etc.

The interview should last half an hour to an hour. Everything you say will remain confidential. Quotes from this interview may appear in reports on the inquiry, but under no circumstances will your name or any identifying characteristics be included. Your participation in the interview is entirely voluntary, you are free to end the interview at any time and you can refuse to answer any question.

**Background**
Can you tell me a little bit about (your relative’s) background, before he/she came to live here?

- Where is he/she from originally?
- Is he/she married? Family living nearby?
- Does he/she have children?
- What did he/she do for a living all their life?
- What hobbies did he/she have?
- What interests did he/she have (PROMPT for example, watching sport, current affairs, watching tv, attending religious services)?

**Entry into Residential Care**
How long has he/she been living here?
Can you tell me a little bit about their coming to live here?
Would you say he/she had a say in coming here?
Was he/she able to choose this home (as opposed to a different one)?
Did he/she have to wait long before being given a place here?
How did he/she feel about coming to live here at the time? Now?
What were your views on your relative coming here at the time? Now?
Did you feel you had a choice in him/her coming here?
What are your own views overall on the home?
Who pays for the care here? (If relevant: how much is the cost per month?)

**Life in Care**
Can you tell me a little about the day to day routine here?
What aspects of your relative’s life have changed since he/she came in here?

**Meals**
Can you tell me a little about mealtimes –

- Is there a choice of meals? Flexibility around mealtimes?
- How do you think your relative’s experience of mealtimes differs from before he/she moved in here?
- Are you satisfied with the quality of the food? Variety?
**Healthcare and Medication Management**
How would you describe your relative’s overall state of health?
Can you tell me a bit about his/her relationship with the carers who look after him/her?
Does he/she need much help from them every day to carry out personal tasks (toilet, washing, eating)?
How quickly do care staff help your relative when he/she needs it?

**Participation and Social Contact**
Does your relative take part in any activities here?
Is there anything you think he/she would like to do but it’s not available?
When you come to visit, to you have somewhere private to talk?

**Choice and Dignity**
How far does the care here take account of your relative’s needs and wishes?
How well do you feel his/her dignity is maintained in day to day life here?
Do you feel he/she is safe here?
Has he/she ever exhibited challenging behaviour (aggression, violence)?
If yes, how did the staff react? Were you happy with the outcome?
If no, have you ever seen any other resident exhibiting challenging behaviour? What happened?
Can you think of any time when you weren’t fully happy with the care your relative received here? Can you tell me what happened?
Has your relative ever been restrained? If yes, can you tell me what happened?

**Physical Environment**
Can your relative move around the home freely?
Is there anywhere he/she can’t access? (eg garden)?
How well do you feel the building accommodates his/her needs?

**Overview**
Is there anything you would change about the care you get here?

**Complaints**
What would you do if you had a problem with the service here?

**End-of-life Care**
Has your relative made any plans for his/her death?

**Human Rights**
Can you tell me what human rights means to you?
How well do you think your relative's human rights are upheld in day to day life here?
Care Home Owner (Entry Interview)

Introduction

My name is X, from the (country) NHRI. Our role is to protect and promote human rights of everyone living in the country, and to make sure that the state, and any organisation acting on behalf of the state, upholds the human rights of all individuals. We also have a mandate (under the relevant Act) to monitor the human rights situation. So I am here to explore how the home here takes into account the human rights of its residents. Human rights apply to all individuals and broadly means respecting each individual’s dignity, their right to privacy and to make choices and be involved in making decisions affecting their lives, and supporting them to participate in community life.

I want to first briefly introduce you to the monitoring team and explain our proposed methodology (INSERT DETAILS). The overall visit will last x days. Please be assured that the team will respect the rules of the care home at all times. I want to start by conducting a brief interview with you to obtain some information about the care home. The interview should last half an hour to an hour. Everything you say will remain confidential. The research is not into individual organisations but is on the sector in general. Quotes from the interview may appear in inquiry reports, but under no circumstances will your name or any identifying characteristics be included. Your participation in the interview is entirely voluntary, you are free to end the interview at any time and you can refuse to answer any question. I would also like to let you know that I will be available at the end of the visit for an informal chat to give you some feedback on our assessment of how the home upholds the human rights of the residents. Can you tell me when would suit you to meet?

Background and Staffing
How many residents currently live here?
How many staff are employed? Nurses? Care staff? Domestic?
What is the care staff to resident ratio during the day? At night?
Does the staff complement meet residents’ needs and wishes?
What are the qualifications of care staff?
What happens when you are short-staffed?
What is the average salary of staff here?
Do staff take part in training courses? How often?
What is the staff working week (hours per week)?
Do you have any information on staff turnover?

Organisation of Services
Can you tell me a little bit about the daily routine here?
What activities do you offer?
How are the tasks of staff organised?
How well do you feel the staff know and understand residents’ preferences?
What time do meals take place each day? (Can residents take meals earlier/later?)
Do residents have choices at mealtimes?
How do you facilitate individual dietary requirements?
How do you facilitate residents’ social, religious and cultural beliefs?
How do you ensure residents have the opportunity to participate in the organisation and activities of the setting?
How do you ensure residents' personal preferences and wishes are facilitated?

**Healthcare**

Do residents undergo an assessment upon admission? (health, risk assessment)
Do you take a history from each resident upon admission? (health, personal care needs, wishes and choices?)
How do you ensure continuity of care?
Does each resident have an individualised care plan?
Do you obtain input from the resident/family members into the care plan? How?
How are residents' medical needs catered for? (specialist services such as physiotherapy, occupational therapy?)
How often do residents have access to a general practitioner/geriatrician?
Can you tell me a little bit about medication administration, management and monitoring? [Probe: do you ever need to use medication to calm a resident?]
Is it ever necessary to restrain a resident if they become agitated?
Do you have a policy on challenging behaviour? On restraint? Safe handling of residents? Abuse prevention? Can you describe them to me?

**Choice and Autonomy**

Do you have any residents with severe communication problems/dementia? How do you ensure their needs are met?
Do any residents have a legal guardian to make decisions for them? Can you explain how this process affects the care home here?
What happens if a resident refuses food/shower/medication/treatment?

**Physical Environment**

How many residents are in each bedroom?
Is the building accessible for all residents? (locked doors)
Is there a space for residents to bring family/friends?
How do you protect residents' privacy for personal care tasks, phone calls etc?
How do you ensure residents' safety? (eg grab rails, stairs)

**Death and Dying**

Do you have procedures in place when a resident is dying?
Do you seek information from residents on their preferences for their death?
To what extent is it possible to take their wishes into account?

**Governance and Management**

What is the system for making complaints here?
What are the main challenges you face in running the home?
How do you provide information to residents about various aspects of the home (eg services available, programme of activities, complaints system, arrangements for visits from family/friends)
What are the policies around obtaining consent for treatment and care?
[eg resident doesn’t want a bath for five days running]
How do you take steps to ensure residents are protected from abuse?
[If applicable] Can you tell me a little about the outcome of your last quality inspection?

**Human Rights**
Can you tell me what human rights means to you?
Do you think about human rights when planning and delivering care? [If yes, which ones?]
How do you seek to make sure the human rights of each resident are upheld?
How do you seek to make sure the human rights of staff are upheld?
Do you feel fully informed of any responsibilities you might have in relation to the Human Rights Act?
Do you feel you need more information on human rights? On how to facilitate them? What kind of information?
How much support do you receive from the state in managing this care home?
Protecting human rights?
What are your views on how long-term care for older persons is organised in (country)?
Medical/Care Staff

Introduction

My name is X, from the (country) NHRI. Our role is to protect and promote human rights of everyone living in the country, and to make sure that the state, and any organisation acting on behalf of the state, upholds the human rights of all individuals. We also have a mandate (under the relevant Act) to monitor the human rights situation. So I am here to explore how the home here takes into account the human rights of its residents. Human rights apply to all individuals and broadly means respecting each individual’s dignity, their right to privacy and to make choices and be involved in making decisions affecting their lives, and supporting them to participate in community life.

The interview should last half an hour to an hour. Everything you say will remain confidential. The research is not into individual organisations but is on the sector in general. Quotes from the interview may appear in inquiry reports, but under no circumstances will your name or any identifying characteristics be included. Your participation in the interview is entirely voluntary, you are free to end the interview at any time and you can refuse to answer any question.

Background and Staffing
Since when have you been working here?
What is your background? (qualifications, experience)
Do you enjoy working here?
Are there any aspects of your job here that you don’t enjoy?
How many hours do you work every week?
Are you happy with your salary?
When did you last undertake any training course? What was it about?
Staff turnover in care homes is 50% on average. Would you say it is higher or lower here? What do you think is the reason for that?

Organisation of Services
Can you tell me a little bit about the daily routine here?
Can you tell me a little about the tasks you do every day?
How easy do you find it to communicate with residents?
How well do you feel you know and understand each resident’s preferences?
How do you ensure residents’ personal preferences and wishes are facilitated?

Healthcare
Can you tell me a little about the organisation of healthcare and medication management in the home?
Can you tell me a little about what you do if a resident becomes aggressive towards you?
What do you do if a resident wants to go to the toilet and you are busy with another resident?
Have you ever had to restrain a resident if they become agitated? (Can you tell me about an example – what were the circumstances, how did you restrain them?)
Can you tell me what you do if you are about to give medical care/bath to a resident and you sense they are uncomfortable in some way?

**Physical Environment**
How well do you feel the home provides for residents’ safety?

**Death and Dying**
Can you tell me a little bit about the care you provide when residents are dying? (when was the last time a resident died. Can you tell me about the care you provided? Did you take into account their wishes around their death? How?)

**Governance and Management**
How well do you feel the home is run?
If you were the manager, what would you do differently?

**Human Rights**
Can you tell me what human rights means to you?
Do you think about human rights when planning and delivering care? [If yes, which ones?] How do you seek to make sure the human rights of each resident are upheld?
How do you feel your own rights as a staff member are upheld?
Do you feel fully informed of any responsibilities you might have in relation to the Human Rights Act?
Do you feel you need more information on human rights? On how to facilitate them? What kind of information?
What are your views on how long-term care for older persons is organised in (country)?

Finally, do you think you would like to live here? Why? Why not?
Officials from the national government department(s) with responsibility for overseeing long-term care for older persons/regional authority

Introduction

My name is X, from the (country) NHRI. Our role is to protect and promote human rights of everyone living in the country, and to make sure that the state, and any organisation acting on behalf of the state, upholds the human rights of all individuals. We also have a mandate (under the relevant Act) to monitor the human rights situation. So I am here to explore how the home here takes into account the human rights of its residents. Human rights apply to all individuals and broadly means respecting each individual’s dignity, their right to privacy and to make choices and be involved in making decisions affecting their lives, and supporting them to participate in community life.

The interview should last half an hour to an hour. Everything you say will remain confidential. The research is not into individual organisations but is on the sector in general. Quotes from the interview may appear in inquiry reports, but under no circumstances will your name or any identifying characteristics be included. Your participation in the interview is entirely voluntary, you are free to end the interview at any time and you can refuse to answer any question.

Organisation of Long-term Care
Can you tell me about the organisation of long-term care in (country)?
PROMPTS:
Home care, residential care?
How many people in long-term care?
How is long-term care funded?
What percentage of residential care homes are public? Private? Voluntary?
Approximately what percentage of older people pay fully for long-term care services?

Access to Care
Is long-term care accessible to all? How do you ensure that is the case?
Is there a centralised waiting list for long-term care? How is it organised?
How do individuals access long-term care services?
What are the differences in access to long-term care for citizens and non-citizens (eg refugees/migrant workers/ethnic minorities?)
Do they have a choice of provider?
What happens to older people who can’t afford to pay for long-term care?
How can older people in need of care access information on the availability of long-term care services?
Does the state fund any national advocacy services that could support older people to access care? To support them while in care?
Do older people in care have access to general and specialised care services? (eg GP, physiotherapy etc)? On the same basis as those living in the community?

Rights in Care
How do you ensure older people living in residential care settings have access to treatment?
Are there any national guidelines on legal/mental capacity/consent for
care/guardianship? Restraint?

Regulation of Care
Is long-term care regulated?
IF YES, can you describe the regulation and inspection process?
How satisfied are you with the quality of the care?
Are there any minimum standards around the qualifications of staff in long-term care
settings?
What recourse would an older person have to make a complaint about their long-term
care provider in (country)? (ie to whom can they make a complaint?)
What are the minimum training requirements for long-term care workers?
Is there a minimum ratio of the number of staff working in residential care settings?

Commissioning Long-term care
When you commission homecare services, do you carry out an Equality Impact
Assessment to strategically assess the homecare needs of the older population?
Consultation with older people?

Does your regional authority give any training in human rights protection? Does it plan to in the future?

Views on Human Rights
Can you tell me what human rights means to you?
How does the department seek to uphold the rights of older people when organising
long-term care? [which ones?]
How do you seek to make sure the human rights of staff working in long-term care
settings are upheld?
Do you consider your obligations under the Human Rights Act by doing any of the
following when you design commissioning processes?
Do you feel fully informed of any responsibilities the state has in relation to the
Human Rights Act?
Do you feel you need more information on human rights? On how to facilitate them?
What kind of information?
How do you offer support to care providers to protecting the human rights of all older
people in receipt of long-term care? (home care and residential care)?
Do you have any views on the financial costs of protecting the human rights of older
persons in care to the state? (prompt: does cost influence the extent to which the
rights are protected/taken into account when commissioning care services?)
What do you think are the main barriers to promoting and protecting the human
rights of older people requiring or receiving long-term care?
What changes do you think need to be made to ensure that the human rights of older
people requiring or receiving long-term care are effectively promoted and protected?

Can you think of any examples of good practice you have come across where you
have seen the human rights of older people receiving long-term care other
organisations that others can learn from?
Civil Society Organisations (Ageing and Human Rights)

Introduction

My name is X, from the (country) NHRI. Our role is to protect and promote human rights of everyone living in the country, and to make sure that the state, and any organisation acting on behalf of the state, upholds the human rights of all individuals. We also have a mandate (under the relevant Act) to monitor the human rights situation. So I am here to explore how the home here takes into account the human rights of its residents. Human rights apply to all individuals and broadly means respecting each individual’s dignity, their right to privacy and to make choices and be involved in making decisions affecting their lives, and supporting them to participate in community life.

The interview should last half an hour to an hour. Everything you say will remain confidential. The research is not into individual organisations but is on the sector in general. Quotes from the interview may appear in inquiry reports, but under no circumstances will your name or any identifying characteristics be included. Your participation in the interview is entirely voluntary, you are free to end the interview at any time and you can refuse to answer any question.

Background
Can you tell me a little about your organisation?
Do you do any work around long-term care for older people? Describe it?
Do you do any work around human rights? Describe it?

Organisation of Long-term Care
Can you tell me your views on the organisation of long-term care in (country)?
PROMPTS:
Home care, residential care?
Views on how long-term care is funded?
What percentage of residential care homes are public? Private? Voluntary?

Access to Care
To what extent do older people in this country have access to long-term care when they need it?
Do they have a choice of provider?
What happens to residents who can’t afford to pay for their long-term care?
How can older people in need of care access information on the availability of long-term care services?

Regulation of Care
How satisfied are you with the quality of long-term care?
How satisfied are you with the regulation of long-term care?
How satisfied are you with the qualifications of staff? Staff ratio in care homes?

What recourse would an older person have to make a complaint about their long-term care provider in (country)? (ie to whom can they make a complaint?)
Views on Human Rights
Can you tell me what human rights means to you?
How well do you think the human rights of older people in long-term care are upheld in (this country)? Why?
How well do you think the human rights of staff in long-term care are upheld in (this country)? Why?
What do you think are the main barriers to promoting and protecting the human rights of older people requiring or receiving long-term care?
What changes do you think need to be made to ensure that the human rights of older people requiring or receiving long-term care are effectively promoted and protected?

Can you think of any examples of good practice you have come across where you have seen the human rights of older people receiving long-term care other organisations that others can learn from?
Training Body

Introduction

My name is X, from the (country) NHRI. Our role is to protect and promote human rights of everyone living in the country, and to make sure that the state, and any organisation acting on behalf of the state, upholds the human rights of all individuals. We also have a mandate (under the relevant Act) to monitor the human rights situation. So I am here to explore how the home here takes into account the human rights of its residents. Human rights apply to all individuals and broadly means respecting each individual’s dignity, their right to privacy and to make choices and be involved in making decisions affecting their lives, and supporting them to participate in community life.

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Background
Can you tell me a little about your organisation?
What training courses do you provide for staff working in residential care?
Do your training courses include material on the human rights of older people? (If yes, can you describe it – full module?, if no – why not?)

Views on Human Rights
Can you tell me what human rights means to you?
How well do you think the human rights of older people in long-term care are upheld in (this country)? Why?
How well do you think the human rights of staff in long-term care are upheld in (this country)? Why?
What do you think are the main barriers to promoting and protecting the human rights of older people requiring or receiving long-term care?
What changes do you think need to be made to ensure that the human rights of older people requiring or receiving long-term care are effectively promoted and protected?

Views on long-term care
Can you tell me your views on the organisation of long-term care in (country)?
PROMPTS:
Home care, residential care?
Views on how long-term care is funded?
To what extent do older people in this country have access to long-term care when they need it?
Annex 5: Sample Pictures for Interviews with Residents with Cognitive Impairments/Communication Problems

**Feelings**

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<thead>
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<th>I’m having fun</th>
<th>Mad</th>
<th>Tired</th>
</tr>
</thead>
<tbody>
<tr>
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<td><img src="image" alt="Having Fun" /></td>
<td><img src="image" alt="Mad" /></td>
<td><img src="image" alt="Tired" /></td>
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<table>
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<th>Funny</th>
<th>Frustrated</th>
<th>Calm</th>
<th>Lonely</th>
</tr>
</thead>
<tbody>
<tr>
<td><img src="image" alt="Funny" /></td>
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<td><img src="image" alt="Calm" /></td>
<td><img src="image" alt="Lonely" /></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Worried</th>
<th>Confused</th>
<th>Anxious</th>
<th>Hurt</th>
</tr>
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<tr>
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<td><img src="image" alt="Confused" /></td>
<td><img src="image" alt="Anxious" /></td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Sick</th>
<th>Excited</th>
<th>Sad</th>
<th>Afraid</th>
</tr>
</thead>
<tbody>
<tr>
<td><img src="image" alt="Sick" /></td>
<td><img src="image" alt="Excited" /></td>
<td><img src="image" alt="Sad" /></td>
<td><img src="image" alt="Afraid" /></td>
</tr>
</tbody>
</table>
Figure 5 Yellow Talking Mats ‘Activities’ symbols

- Music
- Reading
- Clubs/Groups
- Going for a Walk
- Chatting
- Television/Radio
- Trips
- Religion
- Games/Puzzles
Annex 6: Exit Report

Date

Name of Staff Member preparing report:

Name of Care Home:

Findings

Note the principal findings as factually as possible, related to the physical structure (size of rooms, accessibility, heat sources, etc), food and mealtimes, routines and stimulation, health care, protection of residents’ dignity and autonomy, availability of accessible information, privacy, end-of-life care, staffing and staff-resident relations, the governance and management of the home.

Conclusions

Highlight the positive and negative elements of the home in relation to how it upholds the rights of residents.

Recommendations for Action by Care Home
Annex 7: Example Individual Country Report Structure

Acknowledgements

Executive Summary

Introduction

Purpose of report

Mandate of the Monitoring

Methodology (including ethical principles)

Findings 1: Legislative and Policy Context

Findings 2: Human Rights Situation of Older Persons in LTC in Practice:

Entry into Long-Term Care: Access and Choice

Rights While in Care:

- The Right to Life
- Freedom from torture, violence and abuse
- Dignity
- Choice and autonomy
- Freedom of Movement and Restraint
- Participation and Social Inclusion
- Privacy and family life
- Freedom of expression, freedom of thought, conscience
- Highest attainable standard of health
- Age discrimination
- An adequate standard of living
- Education, training and life long learning
- Redress and Complaints
- Palliative and end-of-life care

Conclusion: Implementing a Human-Rights Based Approach in Long-Term Care: Key Challenges

Recommendations
Annex 8: Useful Training Manuals

   
   [http://www.ohchr.org/EN/PublicationsResources/Pages/MethodologicalMaterials.aspx](http://www.ohchr.org/EN/PublicationsResources/Pages/MethodologicalMaterials.aspx)

2. APT, 2004, Monitoring places of detention: a practical guide:
   

   

   

5. OHCHR, 2012, Human Rights Indicators:
   

6. The Center for Victims of Torture, Familiar Tools, Emerging Issues: Adapting traditional human rights monitoring to emerging issues:
   