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<b>Abstract</b>	This deliverable outlines the processes and practices used by the partners to translate the survey instruments and interview guides. The English version of the surveys and interview guide, which forms the basis for translations, is attached to this deliverable.

**DISCLAIMER**

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## VERSION HISTORY

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26.06.2024	1.0	Eila Kankaanpää	Draft circulated for comments
10.07.2024	2.0	Hilda Bø Lyng, Siri Wiig	Comments and amendments
15.07.2024	3.0	Shalini Frøiland	Final draft circulated for approval
31.07.2024	FINAL	Shalini Frøiland	Uploaded to EU portal

## 1 EXECUTIVE SUMMARY

The Support4Resilience (S4R) project is dedicated to developing, implementing and evaluating a research-based Toolbox to support healthcare leaders in improving healthcare workers' and informal caregivers' resilience and mental wellbeing in elderly care.

S4R will identify resilience and mental wellbeing factors among healthcare workers and informal caregivers; explore their perspectives and needs; develop new theory on the relationship between individual and organizational resilience, and mental wellbeing; and develop policy recommendations and cost-effective interventions. The Toolbox with tailor-made resources for policy and practical use will be available through an open access S4R Resource Bank.

In this deliverable titled “Translate Survey and Interview Guides,” the consortium has chosen to outline the processes and practices used by the partners to translate the survey instruments and interview guides. These tools will be used to collect data from leaders, workers, and informal caregivers. The same survey instruments will be employed during the baseline assessment and in the evaluations of effectiveness and cost-effectiveness. Additionally, the interview guides will be used in the process and implementation evaluations. The English version of the surveys and interview guide, which forms the basis for translations, are attached to this deliverable. All additional documents, translated and stored by the consortium and its partners, are utilized for ethical processes within each country conducting data collection in various languages. These translated survey instruments will also be used by UiS to develop the digital survey for the S4R Toolbox in multiple languages. .



## 2 SURVEY AND INTERVIEW GUIDES

The Deliverable 1.1 “Identification of quantitative instruments and interview guides” of the S4R project, reported the contents of the survey instruments and interview guides that will be used in collecting data from leaders, workers and informal caregivers.

Survey and interview guides will be used in six European countries (Norway, Finland, Spain, Italy, Romania and the Netherlands) and in Australia.

### 2.1 Questionnaires

The consortium has chosen the following questionnaires to be used in baseline measurement and evaluation.

Leaders: 61 items

- A. Short Warwick-Edinburgh Mental Wellbeing Scale (SWEMWBS) 7 items
- B. Connor-Davidson Resilience Scale (CD-RISC) 10 items
- C. Resilience Capacity Scale (RCS) 33 items
- D. Copenhagen Burnout Inventory (CPI) 7 items
- E. Intention to turnover (MOAQ) 3 items
- F. Self-assessed health (SAH) 1 item

Healthcare workers: 61 items

- A. Short Warwick-Edinburgh Mental Wellbeing Scale (SWEMWBS)\* 7 items
- B. Connor-Davidson Resilience Scale (CD-RISC) 10 items
- C. Resilience Capacity Scale (RCS) 33 items
- D. Copenhagen Burnout Inventory (CPI) 7 items
- E. Intention to turnover (MOAQ) 3 items
- F. Self-assessed health (SAH) 1 item

Informal caregivers: 49 items

- A. Short Warwick-Edinburgh Mental Wellbeing Scale (SWEMWBS) 7 items
- B. Connor-Davidson Resilience Scale (CD-RISC) 10 items
- C. Family Involvement in Care Questionnaire (FICQ) 13 items
- D. Caregiver Self-Assessment Questionnaire 18 items
- E. Self-assessed health (SAH) 1 item

Additionally, information on respondent characteristics such as age, gender, education, and work experience will be collected. Informal caregivers will also be asked about the length of time they have been supporting their family members and how many hours they spend each week providing care.

### 2.2 Interview guides

The interview guides for individual informal caregivers and focus groups of healthcare workers and leaders have been completed. These interviews will be semi-structured, allowing the interviewer to ask follow-up questions and introduce new questions as



needed. Each of the three groups (leaders, workers, informal caregivers) has a tailored interview guide.

For leaders and workers, the topics include:

- Education and experience
- Descriptions of day-to-day work, patient safety, and recruitment practices
- Existing leadership support and practices, including adaptations when facing workplace challenges
- Proposals for new solutions to enhance resilience.

For informal caregivers, the themes include:

- The support they receive from various sources
- Strategies to strengthen the involvement of informal caregivers
- Contributions of other stakeholders to elderly care.

All groups will discuss their beliefs about what contributes to resilience, as well as the perceived challenges and stressors within their specific, situational contexts.

## 2.3 Translation process and practices

All surveys and interview guides were available in English, with some questionnaires also available in other languages. These translated questionnaires will be used if possible, and if a questionnaire has already been translated and published in the country's language, it can be used if it is identical to S4R. We recognized that the vocabulary was so specialized that professional translation services could not be used. Therefore, the translations were carried out by researcher groups within the partner organizations. Partner researchers from the same country collaborated on translating the surveys and interview guides.

Most of the questionnaires are validated and widely used internationally, so some were already available in local languages. Most were suitable as is, but any adaptations needed have been documented and will be reported in the publications. The "Family Involvement in Care Questionnaire", originally designed for next of kin assessing care provided in hospitals or clinics, needed changes. Some questions were dropped as they weren't suitable for informal care at home, and other questions required minor adjustments.

At the time of sending this deliverable, all surveys and interview guides have been translated and made available for the University of Stavanger (UiS) to digitalize in seven languages. UiS will be responsible for storing the different versions and developing the digital survey links.



### 3 APPENDICES

#### Appendix 1: S4R questionnaires with response categories

##### **Support4Resilience outcome measures (for survey questionnaire)**

Please note that the MBI survey (might be changed) is still investigated for use in terms of licenses.

Leaders: 61 items

- G. **Short Warwick-Edinburgh Mental Wellbeing Scale (SWEMWBS)** 7 items
- H. **Connor-Davidson Resilience Scale (CD-RISC)** 10 items
- I. **Resilience Capacity Scale (RCS)** 33 items
- J. **Copenhagen Burnout Inventory (CPI)** 7 items
- K. **Intention to turnover (MOAQ)** 3 items
- L. **Self-assessed health (SAH)** 1 item

Healthcare workers: 61 items

- G. **Short Warwick-Edinburgh Mental Wellbeing Scale (SWEMWBS)\*** 7 items
- H. **Connor-Davidson Resilience Scale (CD-RISC)** 10 items
- I. **Resilience Capacity Scale (RCS)** 33 items
- J. **Copenhagen Burnout Inventory (CPI)** 7 items
- K. **Intention to turnover (MOAQ)** 3 items
- L. **Self-assessed health (SAH)** 1 item

Informal caregivers: 49 items

- F. **Short Warwick-Edinburgh Mental Wellbeing Scale (SWEMWBS)** 7 items
- G. **Connor-Davidson Resilience Scale (CD-RISC)** 10 items
- H. **Family Involvement in Care Questionnaire (FICQ)** 13 items
- I. **Caregiver Self-Assessment Questionnaire** 18 items
- J. **Self-assessed health (SAH)** 1 item

\***Short Warwick-Edinburgh Mental Wellbeing Scale (SWEMWBS)** used for cRCT in NO and FI

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#### Characteristics

##### 1. Age

##### 2. Gender

- 1. Male
- 2. Female
- 3. Other

##### 3. What is your education (all groups)?

- 1. PhD
- 2. Master's degree
- 3. Bachelor/ three years of higher education (university or similar)
- 4. Less than three years of higher education (university or similar)
- 5. Secondary school
- 6. Primary school
- 7. None

**4.Length of time provided support for relatives (Informal caregivers)**

1. Less than 1 year
2. 1 – 5 years
3. 6 – 10 years
4. 11 – 15 years
5. 16 – 20 years
6. 21 years or more

**5.How much time do you spend on a weekly basis with the person (s) you are caregiver for (informal caregivers)?**

1. 1-5 hours a week
2. 5-10 hours a week
3. 10-20 hours a week
4. 20-30 hours a week
5. Most of the week
6. Live together

**6.Length of work experience (as a healthcare worker for healthcare workers and as a leader for healthcare leaders)**

1. Less than 1 year
2. 1 – 5 years
3. 6 – 10 years
4. 11 – 15 years
5. 16 – 20 years
6. 21 years or more

**A. Short Warwick-Edinburgh Mental Wellbeing Scale (SWEMWBS)**

Unidimensional, 7 items, 5-point Likert scale

1. I've been feeling optimistic about the future
2. I've been feeling useful
3. I've been feeling relaxed
4. I've been dealing with problems well
5. I've been thinking clearly
6. I've been feeling close to other people
7. I've been able to make up my own mind about things

Response categories

1. All of the time
2. Often
3. Some of the time
4. Rarely
5. None of the time

**B. Connor-Davidson Resilience Scale (CD-RISC)**

Unidimensional, 10 items, 5-point Likert scale

Instructions: For each item, please mark an "x" in the box below that best indicates how much you agree with the following statements as they apply to you over the last month. If a particular situation has not occurred recently, answer according to how you think you would have felt.

1. Able to adapt to change
2. Can deal with whatever comes
3. Tries to see humorous side of problems
4. Coping with stress can strengthen me



5. Tend to bounce back after illness or hardship
6. Can achieve goals despite obstacles
7. Can stay focused under pressure
8. Not easily discouraged by failure
9. Thinks of self as strong person
10. Can handle unpleasant feelings

Response categories

1. Not true at all
2. Rarely true
3. Sometimes true
4. Often true
5. True nearly all of the time

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**C. Resilience Capacity Scale (RCS)**

Multi-dimensional, 33 items, 5-point Likert scale

10 capacities (leaders, healthcare workers, NOT informal caregivers include some capacities)

**ITEMS**

1. During stressful situations, we cooperate and support each other
2. We work together to resolve problematic situations
3. We listen carefully to each other when trying to solve problems
4. We experiment with alternative ways we might accomplish our work
5. We adjust our approach/es to overcome obstacles
6. We develop innovative ways of working
7. We optimise the resources we have to accomplish our work.
8. We have risk management strategies for day-to-day tasks
9. We have risk management strategies for emerging or unexpected events
10. We have open discussions related to possible risks
11. We have a good mix of skills and knowledge needed to carry out our work
12. We have a good "map" of each other's talents and skills
13. We share our unique skills and knowledge across specialties
14. We have a nearly ideal 'mix' of staff - a diverse set of people who bring different perspectives and skills to our work
15. Local management quickly adapts when conditions affecting staff/patients arise unexpectedly
16. Local management effectively monitors, prioritises and manages issues as they happen
17. Local management optimises resources and staff strengths to achieve outcomes
18. In team discussions, everyone's opinion is taken into consideration
19. In this unit, we do not hesitate to speak out openly if we think differently about a situation or solution
20. Staff in this unit seek out and act on feedback to improve our work
21. There are key staff who play an important role in implementing new knowledge and practices at [this facility]
22. There are key staff who motivate me and others in a positive way
23. There are key staff who transfer knowledge among team members and across specialities
24. The learning environment at [this facility] allows us to gain important insights from what we do well
25. The learning environment at [this facility] encourages us to continually improve how we do our work
26. The learning environment at [this facility] provides us with the space and time to learn from each other
27. There is well-functioning collaboration between units/departments at [this facility]
28. The exchange of information between units / departments runs smoothly at [this facility]
29. At [this facility], patients experience good continuity of care
30. [This facility] has clear strategies, plans and procedures to perform our work
31. At [this facility], we have the tools and information we need to do a good job



32. We know when and how to get help to manage issues or problems at [this facility]  
 33. Staff know what is expected of them at [this facility]

Response categories

1. Strongly disagree
2. Disagree
3. Neutral
4. Agree
5. Strongly agree

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**D. Michigan Organizational Assessment Questionnaire. Intention to turnover (MOAQ)**  
 3 items, Likert Scale

1. I often think about quitting
2. I will probably look for a new job the next year
3. I will actively look for a new job in the next year.

Response categories

1. Strongly disagree
2. Disagree
3. Slightly disagree
4. Neither disagree nor agree
5. Slightly agree
6. Agree
7. Strongly agree

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**E. Copenhagen Burnout Inventory (CPI) 7 items**

1. Is your work emotionally exhausting?
2. Do you feel burned out because of your work?
3. Does your work frustrate you?
4. Do you feel worn out at the end of the working day?
5. Are you exhausted in the morning at the thought of another day at work?
6. Do you feel that every working hour is tiring for you?
7. Do you have enough energy for family and friends during leisure time (inverse scoring)?

Response categories

1. Never/almost never
2. Seldom
3. Sometimes
4. Often/To a high degree
5. Always/To a very high degree)

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**F. Family Involvement in Care Questionnaire (FICQ)**

13 items, 5-point Likert scale

1. I have the opportunity to ask questions about my family member's illness/condition
2. I understand the information I receive regarding my family member's illness/condition
3. I receive sufficient information regarding my family member's care
4. I can participate in discussions about which examinations/treatments that should be done
5. I participate in discussions about the goal of my family member's treatment
6. I would have liked to be more involved in planning my family member's care
7. The staff treats me with respect



8. The staff responds to my needs/wishes
9. It is easy to get in touch with the staff when I feel the need
10. I'm well received by the staff
11. I feel confident in the staff
12. I receive the emotional support I need in my family member's care
13. I have the opportunity to help my family member with everyday chores he/she usually manages on his/her own (e.g. going to the toilet, shaving/brushing hair or helping with meals)

Response categories

1. Fully agree
2. Largely agree
3. Somewhat agree
4. Fully disagree
5. Not relevant

**G. Self-assessed health (SAH) 1 item**

1. In general, would you say your health is:

- Poor
- Fair
- Good
- Very good
- Excellent

**H. Caregiver Self-Assessment Questionnaire**

18 items, Yes/No

During the past week or so, I have:

1. Had trouble keeping my mind on what I was doing
2. Felt that I couldn't leave my relative alone
3. Had difficulty making decisions
4. Felt completely overwhelmed
5. Felt useful and needed
6. Felt lonely
7. Been upset that my relative has changed so much from his/her former self
8. Felt a loss of privacy and/or personal time
9. Been edgy or irritable
10. Had sleep disturbed because of caring for my relative
11. Had a crying spell(s)
12. Felt strained between work and family responsibilities
13. Had back pain
14. Felt ill (headaches, stomach problems or common cold)
15. Been satisfied with the support my family has given me
16. Found my relative's living situation to be inconvenient or a barrier to care
17. On a scale of 1 to 10, with 1 being "not stressful" to 10 being "extremely stressful" please rate your current level of stress
18. On a scale of 1 to 10, with 1 being "very healthy" to 10 being "very ill", please rate your current health compared to what it was this time last year

Response categories for 1-16

1. Yes
2. No

Response categories for 17 and 18: A number from 1 to 10.

## Appendix 2: S4R Leader Interview Guide

# Focus group interviews: Leaders

### *General pointers to the interviewer*

- Leaders in this setting are frontline leaders who have a formal designated role in organizing and structuring the workers in the unit, and who work closely alongside the healthcare workers. They may or may not have financial and/or staff responsibilities.
- The semi structured approach provides the interviewer with the opportunity to ask follow-up questions and include new questions if required.
- For the majority of the questions, we seek understanding and descriptions of their actual day-to-day work and not how they would like to perform the work if they had more resources/time etc.

### **Semi-structured guide**

#### **General information:**

**Aim:** to seek information on their background and current leadership position to set the scene.

**Pointers to the interviewer:** These questions need to be answered by all participants in the focus group (go round the table making sure each leader answers questions 1-4).

- 1) What is your professional background?
- 2) What type of leadership position do you have?
- 3) For how many years have you been working in a leadership position?
- 4) How many workers are you currently managing?

#### **Work as done:**

**Aim:** to seek understanding of their everyday work.

**Pointers to the interviewer:** Focus on getting descriptions of their actual day-to-day work and not how they would like to perform the work if they had more resources/time etc.

- 5) Briefly describe your **work situation and typical work tasks** (e.g., roles, responsibilities, type of patients cared for, etc.)?
- 6) Can you describe your organization's process for **recruiting new healthcare personnel** and what they do to **retain healthcare personnel**?

#### **Resilience in Healthcare:**

**Aim a:** to seek descriptions of what they believe contributes to the provision of high quality care and what and why positive outcomes occur in their everyday practices.

**Aim b:** to seek information of what type of adaptations that take place to maintain services when facing challenges, changes, pressure, and variations.

**Pointers to the interviewer:** Resilience in healthcare emphasizes the importance of understanding and learning from what goes well in the organization. Examples of factors that can contribute to positive outcomes are competence, technology, people, and financial resources. The term adaptation is similar in meaning to terms like adjustments, transformations, reorganizations, and workarounds. Use the term(s) best

*understood by the informants. Ensure that the informants talk about what resources they currently have available to them and not what they would like to have. The focus here is mainly on everyday work, however they might also talk about how they have handled more critical situations like Covid-19, which is also valuable to know about.*

- 7) **What works well** in your day-to-day work? What are you/is your unit good at and why?
- 8) What **contributes to the provision of quality** care for elderly in your unit (what types of solutions, practices, resources, knowledge and information improve everyday work)?
- 9) What types of **adjustments/workarounds/adaptations** do you use to handle **challenges** (e.g., lack of resources, peak situations), **changes** (e.g., policy and organizational changes) and **variations** (e.g., patient needs, team composition, available resources, competence) in your day-to-day work?

#### **Patient safety:**

*Aim: to seek understanding of common adverse event/near misses/everyday events that happen in their workplace, how they foresee such events, and what they do to avoid them happening. Furthermore, we are interested in information on how they prepare for crises and adverse events.*

- 10) What are common **adverse/serious events, near misses and everyday events** in your workplace, and how can these be mitigated?
- 11) How does your unit/organization **prepare for crises and adverse events?**

#### **Mental wellbeing:**

*Aim: to explore current challenges and stress factors for leaders in their day-to-day job.*

**Pointers to the interviewer:** These questions concern the leader as an individual, and not at the organizational level.

- 12) What type of **challenges** (e.g., technological, resources, workflow, information exchange, competence, etc.) do you have to deal with in your day-to-day work?
- 13) What type of **stress** factors (e.g., emotional, ethical, workload, time management, etc.) do you encounter in your day-to-day work?

#### **Leadership support:**

*Aim: to seek information of what and how leaders provide support for their staff.*

**Pointers to the interviewer:** Particular themes of interest are how leaders work to develop psychological safety within their work environment and how they facilitate for staff involvement in decision making.

- 14) What **kind of support** (individual, structural, relational, organizational, etc.) do you provide for your **staff**? (Could be e.g., confirmation, acknowledgement, mentoring, education and training opportunities, provision of meetings arenas, informal gatherings.)
- 15) In what way do you as a leader support the development of an **atmosphere** where staff feel they can **talk openly** about difficult situations such as adverse/serious events?
- 16) To what extent (and if so: when and how) are staff **involved in decision making**?

#### **Informal caregivers:**



**Aim:** to understand how leaders support and facilitate involvement of informal caregivers in service provision and care decisions, and how they involve other types of stakeholders.

**Pointers to the interviewer:** Of particular interest are approaches to involving informal caregivers in care provision and decisions, and how, when and why this happens.

Examples of other types of stakeholders might be local organizations (e.g., cancer organizations, the Red Cross) or interest groups (e.g., groups providing activities for elderly).

- 17) How are **informal caregivers** involved in care provision and decisions in your unit/organization? In what ways can **involvement of patients and informal caregivers** be strengthened in your unit?
- 18) Do you involve **other stakeholders** (e.g., local organizations and interest groups) in providing quality care for the elderly in your unit and if so, how?

**Overall:**

**Aim:** To obtain information on support, resources, and solutions perceived to improve their work situation.

**Pointers to the interviewer:** Ensure that the informants talk about what resources they currently have available to them and not what they would like to have when describing suggested support, resources, and solutions.

- 19) Could you give three suggestions for how your current work situation could be improved? The more specific the better.
- 20) Is there anything else you would like to add?



## Appendix 3: Healthcare workers Interview guide

# Focus group interviews: Healthcare workers

### General pointers to the interviewer

- By workers we mean personnel who work at the frontline providing care for elderly patients; this could be all types of paid staff such as nurses, care assistants, physiotherapist, etc.
- The semi structured approach provides the interviewer with the opportunity to ask follow-up questions and include new questions if required.
- For the majority of the questions, we seek understanding and descriptions of their actual day-to-day work and not how they would like to perform the work if they had more resources/time etc.

### Semi-structured guide

#### General information

**Aim:** to seek information of their background and current position to set the scene.

**Pointers to the interviewer:** All questions need to be answered by all participants in the focus group (go round the table making sure each worker answers questions 1-4).

- 1) What is your professional background (education, training)?
- 2) What type of position do you have?
- 3) For how long have you been working in elderly care?
- 4) How is your position structured? Do you work closely with your leader? Do you work in a team?

#### Work as done:

**Aim:** to seek understanding of their everyday care work and tasks.

**Pointers to the interviewer:** focus on getting descriptions of their actual day-to-day work and tasks and not how they would like to perform if they had more resources, time, etc.

- 5) Briefly describe your **work situation and typical work tasks** (e.g., roles, responsibilities, type of patients cared for, etc.)?

#### Resilience in Healthcare:

**Aim a:** to seek descriptions of what they believe contributes to the provision of high quality care and what and why positive outcomes occur in their everyday practices.

**Aim b:** to seek information of what type of adaptations that take place to maintain services when facing challenges, changes, pressure, and variations.

**Pointers to the interviewer:** Resilience in healthcare emphasizes the importance of understanding and learning from what goes well in the organization. Examples of factors that can contribute to positive outcomes are competence, technology, people and financial resources. The term adaptations is similar in meaning to terms like adjustments, transformations, reorganizations, and workarounds. Use the term(s) best understood by the informants. Ensure that the informants talk about what resources they currently have available to them and not what they would like to have. The focus here is mainly on everyday work, however they might also talk about how they have handled more critical situations like Covid-19, which is also valuable to know about.



- 6) **What works well** in your day-to-day work? What are you/is your unit good at and why?
- 7) What **contributes to the provision of quality** care for elderly in your unit (what type of solutions, practices, resources like e.g., technology, people, knowledge and information improve everyday work).
- 8) What types of **adjustments/workarounds/adaptations** do you use to handle challenges (e.g., lack of resources, peak situations), changes (e.g., in patient conditions, deterioration, patient flow) and variations (e.g., patient needs, team composition, available resources, competence) in your day-to-day work?
- 9) How are adjustments/workarounds/adaptations initiated? Agreed upon among colleagues in your unit or individually initiated?

#### **Patient safety:**

*Aim: to seek understanding of common adverse event/near misses that happen in their workplace, how they foresee such events, and what they do to avoid them happening. Furthermore, we are interested in information on how they prepare for crises and adverse events.*

- 10) What are common **adverse/serious events, near misses and everyday events** in your workplace, and how can these be mitigated?
- 11) Do you perceive your unit/organization **to have an atmosphere** where staff can **openly discuss** adverse/serious events, and if so, what factors contribute to having an open atmosphere?
- 12) How does your unit/organisation **prepare for crises and adverse events?**

#### **Mental wellbeing:**

*Aim: to explore current challenges and stress factors for workers in their day-to-day job.*

**Pointers to the interviewer:** These questions concern the worker as an individual, and not at the organizational level.

- 13) What type of **challenges** (e.g., technological, resources, workflow, information exchange, competence, etc.) do you have to deal with in your day-to-day work?
- 14) What type of **stress** factors (e.g., emotional, ethical, workload, time management, etc.) do you encounter in your day-to-day work?

#### **Leadership support:**

*Aim: to seek information of how and when staff experience support from their leaders.*

**Pointers to the interviewer:** Particular themes of interest are what is done to achieve psychological safety within their work environment and how leaders facilitate for staff involvement in decision making.

- 15) What **kind of leadership support** (individual, structural, relational, organizational, etc.) is provided for **staff in your unit**? (Could be e.g., confirmation, acknowledgement, mentoring, education and training opportunities, meetings arenas, informal gatherings, etc.)
- 16) To what extent are staff involved in **decision making**?
- 17) How are the **ideas, solutions, and feedback** that staff provide received by your leader?
- 18) Do you have **opportunities for professional development**, and if so, what kind of training do you get?
- 19) How do you view your **career prospects** at your workplace?

**Informal caregivers:**

**Aim:** to understand how involvement of informal caregivers in service provision and decisions related to care is facilitated by the staff, and how other types of stakeholders are involved in the provision of care.

**Pointers to the interviewer:** Of particular interest are approaches to involving informal caregivers in service provision and care decisions, and how, when and why this happens. Examples of other types of stakeholders might be local organizations (e.g., cancer organizations, the Red Cross) or interest groups (e.g., groups providing activities for elderly).

- 20) How are **informal caregivers** involved in care in your unit/organization? In what ways can involvement of patients and informal caregivers be strengthened in your unit?
- 21) Do you involve **other stakeholders** (e.g., local organizations and interest groups) in providing quality care for the elderly in your unit, and if so, how?

**Overall:**

**Aim:** To obtain information on support, resources, and solutions perceived to improve their work situation.

**Pointers to the interviewer:** Ensure that the informants talk about what resources they currently have available to them and not what they would like to have when describing suggested support, resources, and solutions.

- 22) Could you give three suggestions for how your current work situation could be improved? The more specific the better.
- 23) Is there anything else you would like to add?



## Appendix 4: Informal caregivers Interview guide

# Individual interviews: Informal caregivers

### General pointers to the interviewer

- By informal caregivers we mean actors who care for elderly patients without a formal role, e.g., family, neighbours, or friends.
- The semi structured approach provides the interviewer with the opportunity to ask follow-up questions and include new questions if required.
- For the majority of the questions, we seek understanding and descriptions of their actual day-to-day care work and not how they would like to perform the care work if they had more resources/time etc.

### Semi-structured guide

#### General information

**Aim:** to seek information on their background and current position to set the scene.

**Pointers to the interviewer:** These questions need to be answered by all participants in the focus group, go round the table making sure each informal carer answers questions 1-4.

- 1) Who are you caring for (relative, neighbour, or else)?
- 2) How long have you been caring for an elderly person?
- 3) Do you share the caring responsibility with someone else?
- 4) How do you organize the care work, meaning, do you do this beside a paid job or fulltime?

#### Work as done:

**Aim:** to seek understanding of their everyday care work and tasks.

**Pointers to the interviewer** Important to focus on descriptions of their actual day-to-day tasks and not how they think they should or would be performing the work or had hoped to be working.

- 5) Briefly describe your **carer situation and typical everyday care tasks**.
- 6) How do you experience caring for an elderly person?
- 7) Do you feel you have appropriate information to care for an elderly person? If not, which type of information is needed?

#### Resilience in healthcare:

**Aim a:** to seek information of what they experience as positive outcomes in the carer situation and why, and what they believe contributes to the provision of quality care

**Aim b:** to collect information of what type of adaptations are made to sustain care when facing challenges, changes, pressure, and variations.

**Pointers to the interviewer:** Resilience in healthcare emphasizes the importance of learning from what goes well. Examples of factors that can contribute to positive outcomes are competence, technology, financial resources, people, information, practises, and adaptations,

- 8) **What works well** in your day-to-day care work? What are you good at providing/performing and why?
- 9) **What contributes to the provision of quality** in care in your situation (what type of solutions improve your day-to-day carer situation).

**Pointers to the interviewer:** Ensure that the informants talk about resources and solutions they currently have available and not what they would like to have. The term *adaptations* is similar in meaning to terms like *adjustments*, *transformations*, *reorganizations*, and *workarounds*. Use the term(s) best understood by the informants. The focus here is mainly on everyday work, however they might also talk about how they have handled more critical situations like during Covid-19, which is also valuable to know about.

- 10) What type of **adjustments/workarounds/adaptations** do you use to handle challenges (e.g., lack of information), changes (e.g., in the patient's condition, deterioration) and variations (e.g., in the patient's needs, support, competence) in your day-to-day carer situation?

#### Patient safety:

**Aim:** to seek an understanding of common adverse event/near misses (with potential for resulting in an adverse event but which instead ended well) that take place in their situation and how they try to mitigate them.

**Pointers to the interviewer:** Furthermore, we are interested in information on how they prepare for crises and adverse events.

- 11) What are common **adverse or serious events and near misses** in your carer situation, and how do you try to mitigate them?
- 12) How do you prepare for challenging situations and crises (e.g., when the patient is deteriorating).

#### Mental wellbeing:

**Aim:** to seek information on challenges and stress factors for informal caregivers in their day-to-day carer situation.

**Pointers to the interviewer:** These questions concern the carer at the individual level.

- 13) What type of **challenges** (e.g., technological, resources, workload, information exchange, competence, etc.) do you have to deal with in your day-to-day carer situation?
- 14) What type of **stress factors** (e.g., emotional, ethical, workload, time management, etc.) do you encounter in your day-to-day carer situation?

#### Support:

**Aim:** to seek information related to the support they receive from different actors, how the involvement of informal caregivers can be strengthened, and how other types of stakeholders contribute to the care of elderly.

**Pointers to the interviewer:** Other types of stakeholders might be local organizations (e.g., cancer organizations, the Red Cross, etc.) or interest groups (e.g., groups providing activities for elderly).

- 15) What **kind of support** do you receive from the government, coordinators, healthcare leaders, healthcare workers, family, friends, informal caregiver associations/organizations in your situation?
- 16) In what ways should **informal carers** be **involved in patient care / care work?** And how can the **involvement of patients and informal caregivers be strengthened** in situations like yours?
- 17) How do **other stakeholders** (e.g., local organizations and interest groups) contribute to high quality care of elderly in your experience?

#### Overall:

**Aim:** To obtain information on support, resources, and solutions perceived to improve their work situation.



**Pointers to the interviewer:** Ensure that the informants talk about what resources they currently have available to them and not what they would like to have when describing suggested support, resources, and solutions.

18) Could you give three suggestions for how your current carer situation could be improved? The more specific the better.  
Is there anything else you would like to add?