

# **Standardised Evaluation Protocol (STEP) for National Background Reports (NABAREs) “STEP for NABAREs”**

## **Summary of Main Findings**

Three overviews (each 2 pages maximum) with bullet points, aimed at:

- Representative organisations of family carers and older people
- Service providers
- Policy makers

## **Introduction – An Overview on Family Care – 2-3 pages**

- Demographic trends related to family care-giving (supply and demand)
- The family network and reciprocity
- The public (State and local) care service provision.
- The care "market" (or privately paid care, including and distinguishing between both the "regular" and the irregular or illegal care market), problems in supply and demand.
- Other informal unpaid care (volunteers, neighbours, friends, church etc.)
- Estimated needs for care in >65 year olds based on disability levels (local or national data)
- A short overview on the current state of the socio-political discussion in each country related to the financial situation of long-term care insurance and health insurance and its consequences to family care. This will also include reference to the national socio-economic and demographic context.
- Country specific issues

## **1 Profile of family carers of older people**

Use any available sources of local or national data that give systematic statistics on caregivers:

### **1.1 Number of carers**

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### **1.2 Age of carers**

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### **1.3 Gender of carers**

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### **1.4 Income of carers**

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### **1.5 Hours of caring and caring tasks, caring for more than one person**

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### **1.6 Level of education and/or Profession/Employment of family carer.**

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### **1.7 Generation of carer, Relationship of carer to OP**

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### **1.8 Residence patterns (household structure, proximity to older person needing care, kinds of housing etc.)**

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### **1.9 Working and caring**

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### **1.10 General employment rates by age (part time/full time/ self-employed) for general population (special focus on women aged 45+) but if rates available for carers then they should be stated.**

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### **1.11 Positive and negative aspects of care-giving (Carers' health problems and estimated needs for their own care and support; Emotional aspects; Elderly abuse etc.)**

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### **1.12 Profile of migrant care and domestic workers (legal and illegal). Trends in supply and demand.**

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### **1.13 Other relevant data or information**

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## **2 Care policies for family carers and the older person needing care.**

*The focus should be on policies for carers and if there are local variations in such policies, or local autonomy in implementation. Where there are NO policies for family carers, they may be using ALL available policies for dependent or disabled OP, to obtain support in caring; therefore, these policies are important and need to be documented.*

### **2.1 Introduction: Family ethics and expectations – the national framework of policies and practices for family care of dependent older people.**

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#### **2.1.1 What are the expectations and ideology about family care? Is this changing? How far are intergenerational support and reciprocity important? Do minority groups have different ideologies?**

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#### **2.1.2 Are there any legal or public institutional definitions of dependency – physical and mental? Are these age-related? Are there legal entitlements to benefits for caring?**

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#### **2.1.3 Who is *legally* responsible for providing, financing and managing care for older people in need of help in daily living (physical care, financial support, psycho-social support or similar)?**

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#### **2.1.4 Is there any relevant case law on the rights and obligations of family carers?**

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**2.1.5 What is the national legal definition of old age, which confers rights (e.g. pensions, benefits, etc.)**

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**2.2 What national policies (general principles, orientation, action plans) currently exist for:**

**2.2.1 Family carers?**

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**2.2.2 Disabled and/or dependent older people in need of care/support?**

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**2.2.3 Working carers: Are there any measures to support employed family carers (rights to leave, rights to job sharing, part time work, etc)?**

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**2.3 Are there local or regional policies, or different legal frameworks for carers and dependent older people?**

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**2.4 Are there differences between local authority areas in policy and/or provision for family carers and/or older people?**

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**3 Services for family carers**

*Please tick and comment on the following services: tick if they are generally available, if they are statutory, public, private or voluntary and add comments to the ticked boxes if clarification is needed. For "tickung" enter an "x".*

Services for family carers	Availability			Statutory	Public, Non statutory	Voluntary		Private
	Not	Partially	Totally			Public funding	No public funding	
Needs assessment (formal – standardised assessment of the caring situation)								
Counselling and Advice (e.g. in filling in forms for help)								
Self-help support groups								
“Granny-sitting”								
Practical training in caring, protecting their own physical and mental health, relaxation etc.								
Weekend breaks								
Respite care services								
Monetary transfers								
Management of crises								
Integrated planning of care for elderly and families (in hospital or at home)								
Special services for family carers of different ethnic groups								
Other								

### 3.1 Briefly describe any examples of:

#### 3.1.1 Good practices

#### 3.1.2 Innovative practices

*in supporting carers, including post-caregiving services in case of death or institutionalisation of cared for person, new technologies etc. List them and provide a fuller description in the Appendix.*

## 4 Supporting family carers through health and social services for older people

*For the following section on services for older people, please give information/data on: availability, access, **utilisation and barriers to service use**, urban/rural differences, examples of how they support or create problems for older people and their family carers etc.*

***N.B Focus mainly on specific benefits and problems to carers in using these services, not a wide description of services.***

## **4.1 Health and Social Care Services**

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### **4.1.1 Health services**

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#### **4.1.1.1 Primary health care**

- Community and homecare teams (e.g. doctor, nurse, health visitor, physiotherapist etc.)
- Other home care health services (dental care services at home, home chiropody service, home lab tests etc.)?

#### **4.1.1.2 Acute hospital and Tertiary care**

- General provision for older people
- Are there special Geriatric facilities (Geriatricians, geriatric beds, assessment units, rehabilitation units etc)?

#### **4.1.1.3 Are there long-term health care facilities (includes public and private clinics)?**

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#### **4.1.1.4 Are there hospice/palliative/terminal care facilities?**

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#### **4.1.1.5 Are family carers expected to play an active role in any form of in-patient health care?**

*E.g. laundry, personal care, nursing assistance, meals, facilitating contacts with health care personnel, accompanying the patient to appointments, taking specimens and collecting results, being responsible for test results and discharge summaries and delivering them to the primary health care doctor etc. (Describe social expectations and norms.)*

### **4.1.2 Social services:**

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#### **4.1.2.1 Residential care (long-term, respite)**

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*4.1.2.1.1 Basic data on % of > 65s in residential care by age group and type of residential care (sheltered housing, residential homes).*

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*4.1.2.1.2 Criteria for admission (degree of dependency, income etc.)*

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*4.1.2.1.3 Public/private/NGO status.*

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*4.1.2.1.4 Does residential care involve the participation of carers or work with carers?*

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**4.1.2.2 Community care services (statutory coverage and whether aimed primarily at older people living alone or including support to family carers)**

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*4.1.2.2.1 Home-help*

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*4.1.2.2.2 Personal care*

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*4.1.2.2.3 Meals service*

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*4.1.2.2.4 Other home care services (transport, laundry, shopping etc.)*

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*4.1.2.2.5 Community care centres*

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*4.1.2.2.6 Day care ("protective" care)*

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#### **4.1.2.3 Other social care services**

*e.g. counseling agencies, technical aids, home adaptations, training of care-personnel and/or family carers for providing care at home*

Text to be entered here in standard format. Text to be entered here in standard format. Text to be entered here in standard format.

#### **4.2 Quality of formal care services and its impact on family care-givers: systems of evaluation and supervision, implementation and modeling of both home and other support care services**

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##### **4.2.1 Who manages and supervises home care services?**

Text to be entered here in standard format. Text to be entered here in standard format. Text to be entered here in standard format.

##### **4.2.2 Is there a regular quality control of these services and a legal basis for this quality control? Who is authorized to run these quality controls**

Text to be entered here in standard format. Text to be entered here in standard format. Text to be entered here in standard format.

##### **4.2.3 Is there any professional certification for professional (home and residential) care workers? Average length of training?**

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##### **4.2.4 Is training compulsory?**

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##### **4.2.5 Are there problems in the recruitment and retention of care workers?**

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#### **4.3 Case management and integrated care (integration of health and social care at both the sectoral and professional levels).**

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**4.3.1 Are family carers' opinions actively sought by health and social care professionals usually?**

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## **5 The Cost – Benefits of Caring**

*The GDP for the country? (Will be obtained from OECD and others cccentrally)*

**5.1 What percentage of public spending is given to pensions, social welfare and health?**

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**5.2 How much - private and public - is spent on long term care (LTC)?**

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**5.3 Are there additional costs to users associated with using any public health and social services?**

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**5.4 What is the estimated public/private mix in health and social care?**

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**5.5 What are the minimum, maximum and average costs of using residential care, in relation to average wages?**

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**5.6 To what extent is the funding of care for older people undertaken by the public sector (state, local authorities)? Is it funded through taxation or/and social contributions?**

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## 5.7 Funding of family carers

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### 5.7.1 Are family carers given any benefits (cash, pension credits/rights, allowances etc.) for their care? Are these means tested?

	Attendance allowance	Carers' allowance	Care leave
Restrictions			
Who is paid?			
Taxable			
Who pays?			
Pension credits			
Levels of payment / month			
Number of recipients in 2002			

### 5.7.2 Is there any information on the take up of benefits or services?

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### 5.7.3 Are there tax benefits and allowances for family carers?

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### 5.7.4 Does inheritance or transfers of property play a role in caregiving situation? If yes, how?

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**5.7.5 Carers' or Users' contribution to elderly care costs (check list of services and costs to user) (Use footnotes where necessary to explain specific points).**

	General access:			Access based on:		
	Free at point of use / wholly reimbursed	Partly privately paid / partly reimbursed	Completely privately paid	Means-tested		Based on severity
				Partly reimbursed	wholly reimbursed	
<b>a. Medical, nursing and rehabilitation services</b>						
General practitioner						
Specialist doctor						
Psychologist						
Acute Hospital						
Long-term medical residential care (for terminal patients, rehabilitation, RSA, etc.)						
Day hospital						
Home care for terminal patients						
Rehabilitation at home						
Nursing care at home (Day/Night)						
Laboratory tests or other diagnostic tests at home						
Telemedicine for monitoring						
Other, specify						

b.Social-care services	General access:			Access based on:		
	Free at point of use / wholly reimbursed	Partly privately paid / partly reimbursed	Completely privately paid	Means-tested		Based on severity
				Partly reimbursed	wholly reimbursed	
Permanent admission into residential care/old people's home						
Temporary admission into residential care/old people's home in order to relieve the family carer						
Protected accommodation/sheltered housing (house-hotel, apartments with common facilities, etc.)						
Laundry service						
Special transport services						
Hairdresser at home						
Meals at home						
Chiropodist/Podologist						
Telerecue/Tele-alarm (connection with the central first-aid station)						
Care aids						
Home modifications						
Company for the elderly						
Social worker						
Day care (public or private) in community center or old people's home						
Night care (public or private) at home or old people's home						
Private cohabitant assistant ("paid carer")						
Daily private home care for hygiene and personal care						
Social home care for help and cleaning services/"Home help"						
Social home care for hygiene and personal care						
Telephone service offered by associations for the elderly (friend-phone, etc.)						
Counseling and advice services for the elderly						
Social recreational centre						
Other, specify						

c. Special services for family carers	General access:			Access based on:		
	Free at point of use / wholly reimbursed	Partly privately paid / partly reimbursed	Completely privately paid	Means-tested		Based on severity
				Partly reimbursed	wholly reimbursed	
Training courses on caring						
Telephone service offered by associations for family members						
Internet Services						
Support or self-help groups for family members						
Counseling services for family carers						
Regular relief home service (supervision of the elderly for a few hours a day during the week)						
Temporary relief home service (substitution of the family carer for brief periods of time, for example, a week)						
Assessment of the needs						
Monetary transfers						
Management of crises						
Integrated planning of care for the elderly and families at home or in hospital						
Services for family carers of different ethnic groups						
Other, specify						

## 6 Current trends and future perspectives

Text to be entered here in standard format. Text to be entered here in standard format. Text to be entered here in standard format.

### 6.1 What are the major policy and practice issues debated on family care of the elderly in your country from the carers' point of view? Are older people and/or carer abuse among these issues?

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### 6.2 Do you expect there to be any changing trends in services to support family carers, e.g. more state or more family support, more services or more cash?

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### **6.3 What is the role played by carer groups / organisations, "pressure groups"?**

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### **6.4 Are there any tensions between carers' interests and those of older people?**

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### **6.5 State of research and future research needs (neglected issues and innovations)**

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### **6.6 New technologies – are there developments which can help in the care of older people and support family carers?**

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### **6.7 Comments and recommendations from the authors**

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## **7 Appendix to the National Background Report for <countryname>**

### **7.1 Socio-demographic data**

*This section is of specific importance for countries where little is known about family carers and the socio-economic conditions under which they care.*

#### **7.1.1 Profile of the elderly population-past trends and future projections**

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##### **7.1.1.1 Life expectancy at birth (male/female) and at age 65 years.**

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##### **7.1.1.2 % of >65 year-olds in total population by 5 or 10 year age groups**

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**7.1.1.3 Marital status of >65 year-olds (by gender and age group)**

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**7.1.1.4 Living alone and co-residence of > 65 year-olds by gender and 5-year age groups.**

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**7.1.1.5 Urban/rural distribution by age (if available and/or relevant)**

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**7.1.1.6 Disability rates amongst >65 year-olds. Estimates of dependency and needs for care.**

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**7.1.1.7 Income distribution for top and bottom deciles i.e. % aged >65 years in top 20% of income, or % > 65s in top 20%, and the same for poorest 20% income groups.**

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**7.1.1.8 % >65 year-olds in different ethnic groups (if available/relevant)**

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**7.1.1.9 % Home ownership (urban/rural areas) by age group**

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**7.1.1.10 Housing standards/ conditions if available by age group e.g. % without indoor plumbing, electricity, TV, telephone, lift (if above ground floor), etc.**

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**7.2 Examples of good or innovative practices in support services**

*Provide brief descriptions of the good practices or innovations listed under section 3.1.*

**8 References to the National Background Report for <countryname>**