

IRIS, DG INFSO and JRC-IPTS

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Evidence on ICT and social innovation in support of domiciliary carers of elderly people: challenges and opportunities for impact assessment

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The European Commission's Research-Based Policy Support Organisation



Why does policy need ‘evidence’ of ‘Impact’

How and why is it generated?

How is it used, and why?

What counts as ‘evidence’?

- **Research for Policy thought and practice continues to developed, and analysis become more sophisticated**
 - Evidence-based Policy and Practice (2009) Authors: Nutley, S. M. with Boaz, A. Routledge (London)
 - Evidence and Policy in Six European Countries: Diverse approaches and common challenges (2010) Authors: Jung, T., Nutley, S. M. with Morton, S, Boaz, A Evidence & Policy
 - Pawson, Ray. Evidence-Based Policy: A Realist Perspective. Sage Publications Ltd, 2006.
 - W Shadish, T Cook, D Campbell (2002) Experimental and QuasiExperimental Designs for Generalized Causal Inference
 - Carol Weiss, Evaluation: methods for studying programs and policies, Prentice Hall, 1998

Problem: How do we know an intervention, service, policy or system ‘works’, so we can decide to support it, or sell the idea to those we wish to influence?

- *Analyst:* Depends on who is asking the question, what they will do with the answer, who else will get that information, the resources and means we can deploy to get it, theoretical frameworks available etc.
- *Naïve startup:* how to *demonstrate* that what we are doing or proposing does what it is meant to do, and possibly some other things we probably had not thought of, when we don't really understand the ‘big picture’.
- *Policy Maker:* how to obtain ‘independent evidence’; why is something a “best practice”; which lobbyists to believe; how to get those projects you fund to generate good and appropriate evidence, (how to make evidence fit policy goals)

Evidence to makes things visible

**If there is no appropriate evidence, then it is
not even on the table.**

Evidence builds bridges

Good evidence costs money and needs expertise But 'reasonable' evidence, at the right time, can be sufficient for decision making

Different types of evidence and quality of data, e.g.:

- Success and failure stories
- User stories (currency of the user)
- Demonstrations 'it works' (the theatre of the demo)
- Sales figures
- Results of experiments (natural and controlled)
- Systematic reviews
- Official statistics, market statistics
- Uncontrolled surveys and big numbers
- In depth case studies of process and meaning

Problems:

- **Too much badly collected evidence, that is unconvincing to important players, or even misleading.**
 - e.g. a few happy customer stories, and few examples of problems, 'the 'wrong sort' of evidence
- **Different professional groups have different evidence standards**
 - E.g. medicine wants randomised controlled trials with objective measure;
 - Engineers want 'running code'
 - Some people want 'Big numbers'

Three questions we considered:

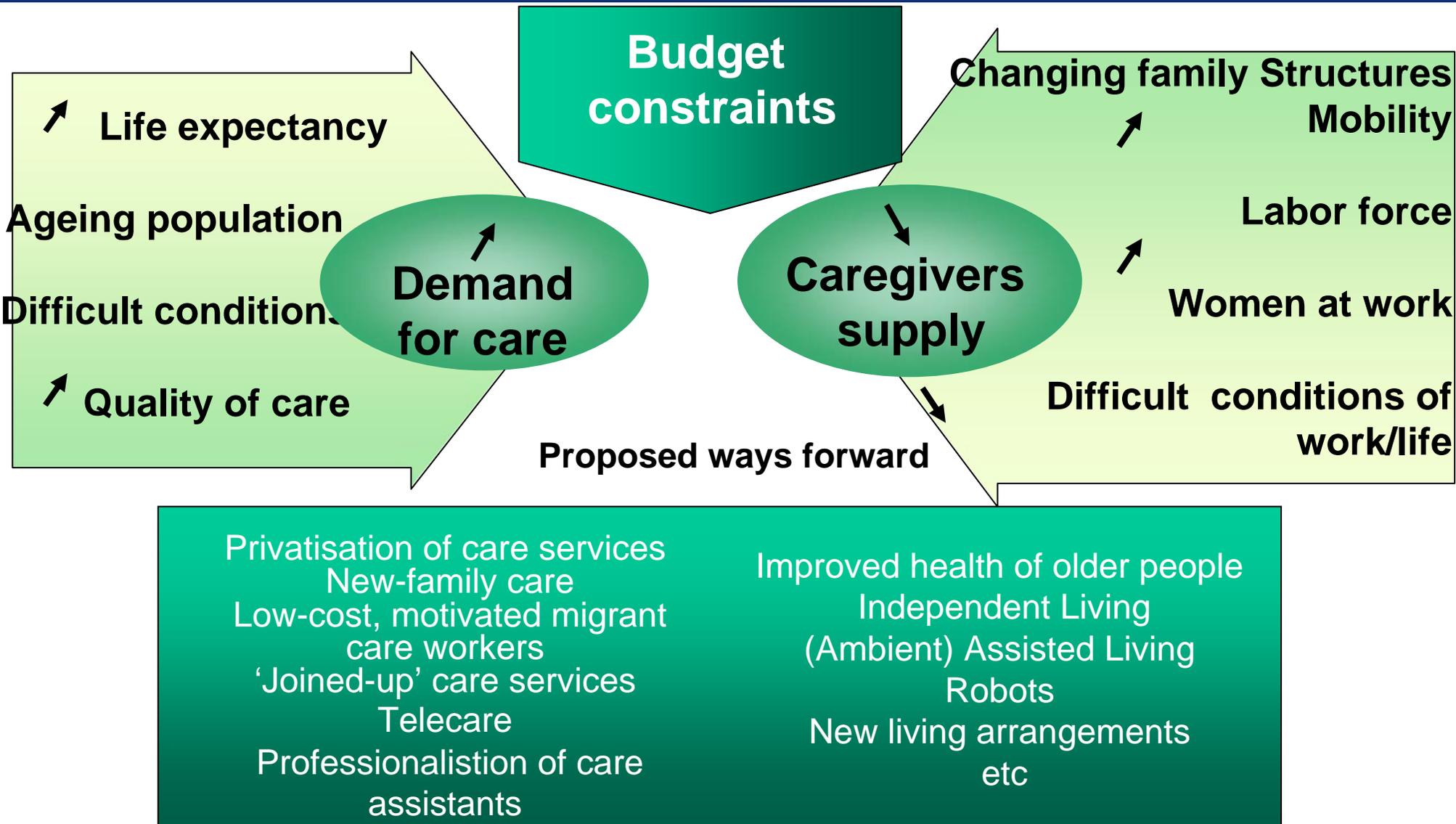
What sort of evidence is available?

What tools are available to collect it?

How can we improve the quality and range of evidence?

Impact of ICT-enabled services to support Informal domiciliary carers

Informal/family carers in Long Term Care of elderly people
ICT in Long Term Care (LTC)
Family carers in ICT



ICTs involved in many of these developments

Up to 10% of European Population care for an elderly member of their family to some degree

Family carers provide 80% of LTC to dependent older people in Europe

Informal care ‘big numbers’ :Annual costs: 120bn GBP for all informal care in UK, 12Bn GBP for Alzhimers’ carers in UK

Family Care breakdown leads to expensive and fatal hospitalisation and institutionalization

This will rise as demographic aging continues, affecting *all of us!*

Burden shifting from younger carers to older spouses.

There is very little systematic data collection about informal family carers

(%) (Czekanowski et al. 2008)

Kind of relationship	Total N = 5,920	Germany N = 1,002	Greece N = 1,013	Italy N = 990	Poland N = 999	Swede n N = 921	UK N = 995
Child	48.9	53.3	55.4	60.9	51.1	40.5	31.6
Spouse / partner	22.2	18.4	17.1	10.9	18.2	48.1	22.8
Daughter/son-in-law	11.0	9.0	13.9	9.7	13.4	4.5	15.3
Others*	17.9	19.3	13.6	18.5	17.3	6.9	30.4
Total	100	100	100	100	100	100	100

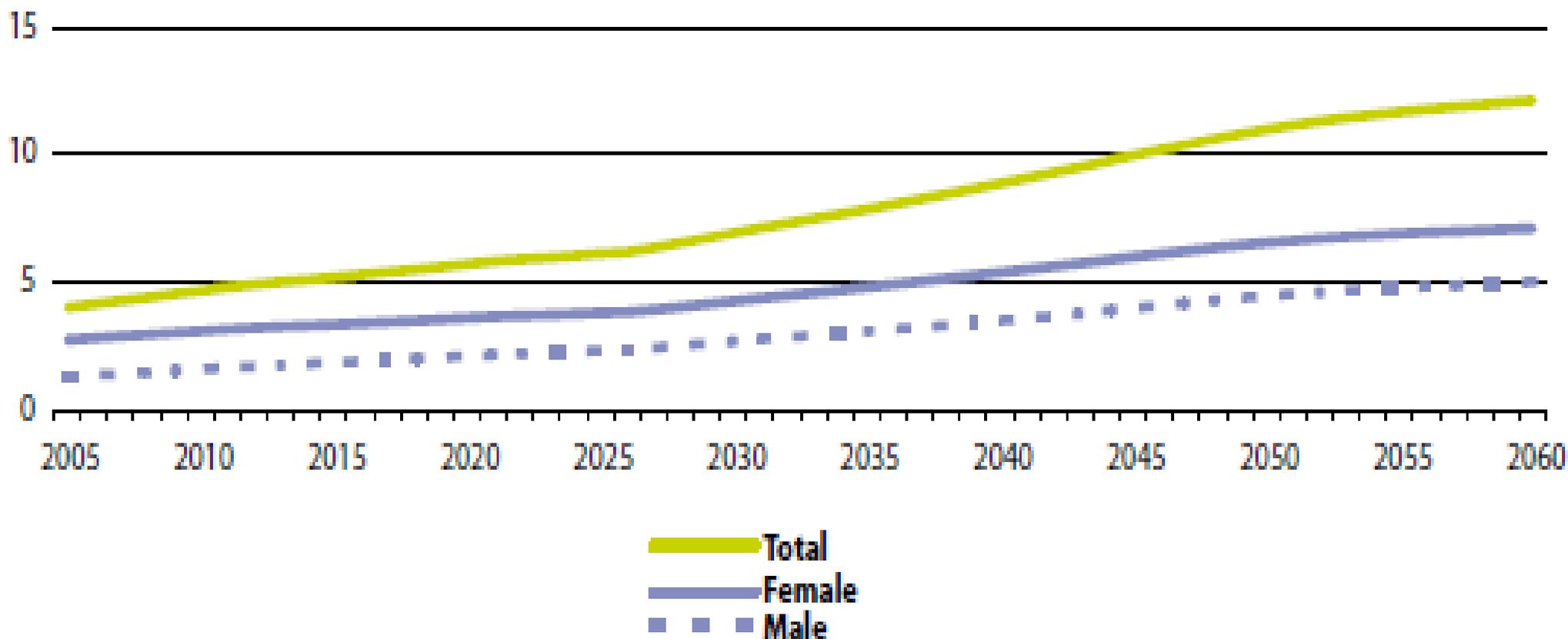
* Includes: nephews / nieces, siblings, uncles / aunts, cousins, grandchildren, close neighbours, etc.

EUROFAMCARE study

Clusters from EUROFAMCARE

1. Highly burdened, cohabiting, non-employed daughters(-in-law)	19.2
2. Highly burdened, non-cohabiting, employed daughters(-in-law) of moderately impaired recipients	11.7
3. Highly burdened wives	15.2
4. Moderately burdened husbands	7.7
5. Medium/low burdened relatives of highly impaired recipients	15.7
6. Low burdened children(-in-law) of moderately impaired recipients	13.2
7. Low burdened relatives of slightly impaired recipients	17.3

Proportion of population aged 80 or more, EU-27 (% of total population)



Carers can carry a heavy burden :

Poverty and unemployment

Isolation both physical and social

Physical and psychological stress

Not helped by

Lack of skills in caregiving (leading to poor caregiving)

Lack of knowledge of dependent's conditions and of LTC services leads to stress

Limited support by care services, as family sidelined or ignored by professional care and health services.

Many carers do not recognise themselves as carers, or do not admit to caring leads to stress, illness, leading to:

Limited uptake of support services

respite care, counselling, support groups, formal care support, training etc

Not part of mainstream Long Term Care Policy

Policy Challenges related to supporting carers

ICTs for Social Inclusion

Support the use and development of ICTs for participation in society, employment, etc;

MAINSTREAMING INTO->

Future of Long Term Care for the Elderly

Provision of Health, Social Care, Social Welfare in the medium to long term in response to demographic, economic and social change

Europe 2020 strategies

Digital Agenda

Platform for Poverty

New Skills for new Jobs

Social Inclusion

Active Aging

Aging at home

Reconciliation of work and family

Intergenerational solidarity

Flexicurity

Digital Inclusion

Member States, regional and local administrations

Extreme diversity of traditions and dynamics in LTC and the treatment of family carers

- Regime Approach common analytic tool, despite deep criticisms

Wide differentials in State spending on LTC Traditions of LTC organisation

- UK 'liberal' but high spending cut from 1980s.
- Scandinavia – little family responsibility, state provides all
- Germany – insurance base SS
- France – Broad coverage, highly regional
- Italy, Spain – family responsibility, direct payments and millions of illegal immigrants
- Eastern Europe – re-familisation post-communism.



A degree of convergence – reducing state role, similar interpretation of demographic change, and aging society. Need for 'aging in place', healthy aging to reduce costs. EU target: 2 more years of healthy life.

But different pathways.

- North – independent living, privatisation
- France – intergenerational solidarity; formalisation of paid assistants
- New Netherlands – family responsibility;
- South – (illegal) immigrants replace changing families.
- East – new social partners

Common Feature: Women's work and woman's responsibility

- 1. DG INFSO:** What evidence is there that ICT-enabled services and interventions are *effective*, and *cost effective*? Sufficient to convince public authorities in health and care that they should buy the services and technologies, so that the supply sector will commit to the expensive work of developing standards, mass-market solutions etc.
- 2. DG EMPL:** What place ICT-enabled services could play in sustainable Long Term Care policies over the next 2 decades? What cheap technologies could offer effective returns?

Many others need evidence to convince them to work with these ICT-services:

- Care managers (public and private)
- Care professionals
- Medical professionals of various sorts
- Carer support services
- Family Carers
- Employers of people with care responsibilities
- Policy makers in care, health, welfare
- Telecare and telehealth providers
- Big Tech firms
- **They need be convinced on a wide range of dimensions**

- **How to make carers visible in ICT (esp e.g. AAL; EiP AHA)?**
- **How to make ICTs visible in care and LTC?**

Evidence in ICTs and carers?

- Much Evidence case study based
- Low quality or small scale quantitative studies
- Qualitative evidence of medium quality
- A few bits of good quantitative evidence

How to collect and improve?

- LTC planning: demographic trends, modelling of disease and disability trends, DALYs
- Health: RCTs, 'quasi experiment', HTA, QALYs
- Social Care: Qualitative, mixed method
- Innovation: 'the next hot thing'; business plans and market projections

Services for carers: What works?

Mixed evidence from existing services. It depends who's asking and who is measuring, esp. *Cost-effectiveness*

- Intensive work in UK in 1990s.

**Expensive and complex, and little base-line data:
we do not know much about family care-givers**

What to measure for ICT-enabled services??:

- **Exploratory research** due to scarcity of data
- Countries analyzed:

UK/ England	CIRCLE (Centre for International Research on Care, Labour and Equalities) University of Leeds, Prof. Sue Yeandle, Gary Fry
Germany	Association of Senior Citizens' Organisations (BAGSO), Dr. Heidrun Mollenkopf
Italy	Istituto per la Ricerca Sociale (IRS), Sergio Pasquinelli
Spain	Consultores Euroamericanos Asociados (CEA) and Innovation Institute for Citizen Welfare (i2BC)

Kluzer et al. (2010). Long-term Care Challenges in an Ageing Society: The Role of ICT and Migrants – Results from a study on **England, Germany, Italy and Spain.**

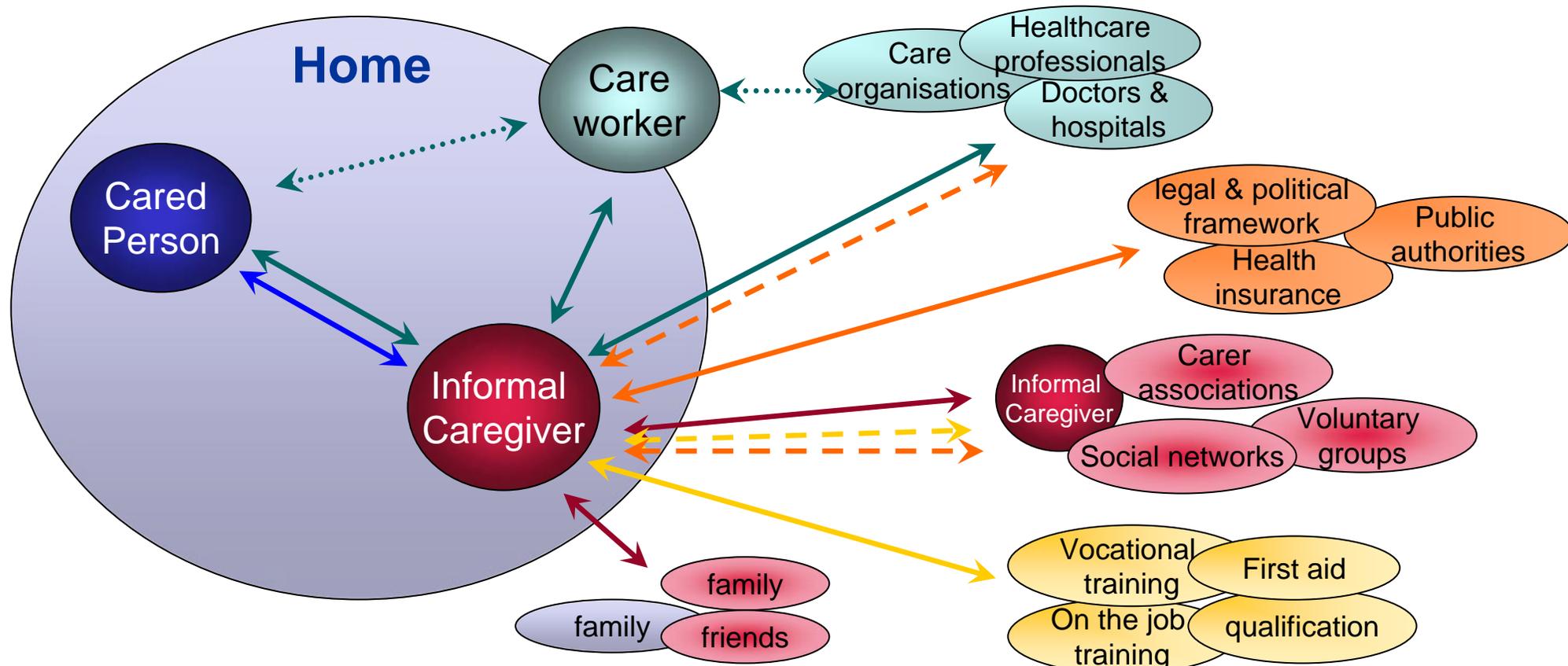
<http://ipts.jrc.ec.europa.eu/publications/pub.cfm?id=3299>

Critical Conditions

Work load & time schedule (often 24/7)
 Limited knowledge of LTC services
 Lack of information/coordination on care situation
 Limited experiences & skills
 Emotional stress & social isolation

Needs

Improved working conditions; stress relieve
 Information
 Communication, coordination
 Training
Social, emotional & peer support

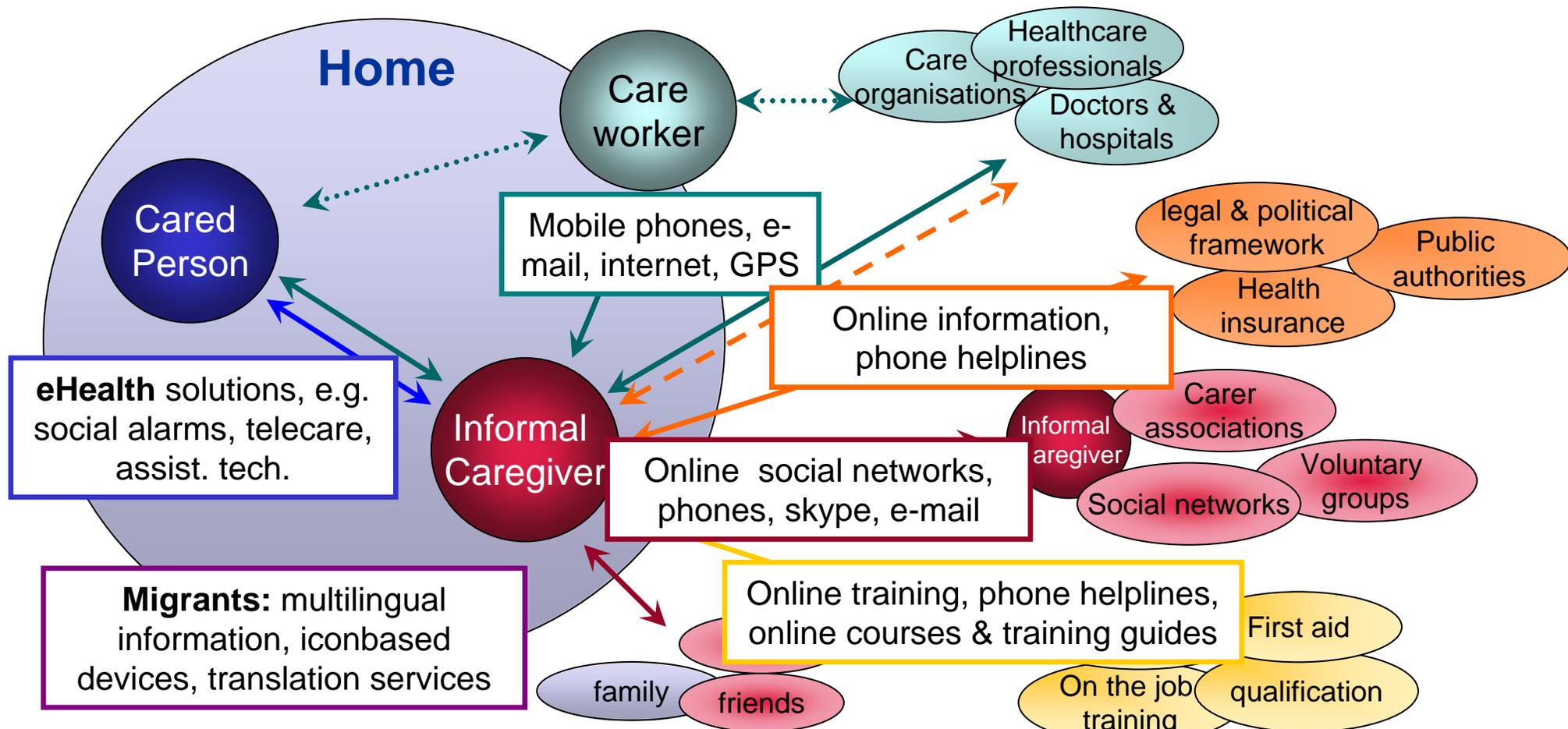


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ICTs for:

How do these affect/involve family carer(s)?

“Independent” Living for older people

Technology systems to allow elderly dependents to stay at home without continual formal or informal care support, thus relieving pressure on care-giver. It may allow caregiver to leave recipient alone, or help them in caregiving.

Smart homes
AAL
Telecare
E-health
Internet

Information and Learning

Tools that give access to information and training about caregiving, health and care issues for the dependent older persons, information and training about coping with caring; training for life

- language, other work skills, accreditation of skills etc;

Online training, assessment
Web information
TV-based
Phone support

Personal support and social integration

These provide a means of social, emotional & peer support, leisure, relief from isolation and chances for participation in work, civil society etc.

Telework
Internet for social networking, shopping,

Care Coordination

Tools for coordinating formal sector and informal and family-employed carers. Allows organisation of respite, sharing information on recipient's and carers needs etc.

Organisational IT
Social Networking over internet
Phone-based systems
government services etc

Opportunities to:

Support dependent older people

Support Quality of Care

Support Carers' Quality of Life

**Facilitate 'Participation'
in the economy and society**

**Support Family-employed
migrant care-givers**

Barriers

Carers' needs overlooked or bracketed
Lack of knowledge & awareness

ICT in
LTC
policies

Fragmentation
Unclear responsibilities
Lack of coordination
Lack of Awareness

LTC
Organis
tions

Lack of awareness
ICT access and skills
Privacy/security fears

Users of
ICT

ICT access restrictions at work
Lack of adapted content
Language barrier
Residence status -> barrier/incentive

migrant
specific

How are ICTs changing the possibilities, costs and expectations of LTC

'Macro' Analysis for policy makers

**Responsibility for provision of LTC for the elderly,
and allocation of finance (family, state, private, employers; gender)
Recognition of care responsibilities in citizen's lives**
*Information Society: Investments and policy in ICT
infrastructure and human capabilities*

'Meso' Organisations

**On-the ground organisation of care and health service provision
On-the ground organisation of employment and services**
Investment and Innovation in ICT-based solutions, human skills etc

'Micro' Carers in Everyday life

**Everyday caregiving and receiving experience and conditions
Quality of life and Quality of care**
*Local and individual use, benefits, problems
and integration of ICTs in everyday life*

**Dynamic picture at all levels, with different national inheritance and pathways,
and challenges such as demographic and cultural change**

There is a clear need and existing supply, and a number of policy challenges

But we need more, and *better quality evidence* to support policy decision making and encourage investment and innovation

Impact (+ve and –ve) on individual carers and dependents

Potential Impact if widely available and used

Impact on Quality of Care

Cost-based evidence: cost effectiveness

Potential and requirements for transferability and scaling

Potential for meeting Policy Challenges

Towards Systematic and scientific evidence collection to inform policy

Stimulate Impact assessment of initiatives to support informal carers: family *and* non-professional assistants (often migrants) – *putting numbers on stories*

Policy Questions

Can ICTs help support the creation of sufficient motivated and skilled informal carers?

Can ICT-enabled services improve the quality of care, quality of life of caregivers, and effectiveness and efficiency of care given?

“ICT-based solutions for caregivers: assessing their impact on the sustainability of long-term care in an ageing Europe “

CARICT

Funders JRC-IPTS and DG INFSO

Principal Contractors:

**European Centre for Social Welfare
Policy and Research in Vienna**

CIRCLE (Centre for International Research
on Care, Labour and Equalities) -
University of Leeds (England, UK)

INRCA (National Institute of Health and
Science on Aging), Italy

Institute of Sociology, Academy of Sciences,
Budapest, Hungary

Swedish National Family Care Competence
Centre, Sweden

Eurocarers



Swedish National
Family Care
Competence Centre



Conceptual framework for analyzing impact

Mapping & Analysis of 52 established initiatives

which promote the improvement of caring through ICT in 12 European countries

Development of multi-level Impact Assessment Methodology

measuring and assessing in quality terms the outputs and outcomes of ICT initiatives to support informal caregivers and family paid assistants

Extract Impact Analysis from 12 initiatives and Analysis of innovation processes

employing and evaluating the impact assessment methodology

Draw conclusions for potential future impact based on this existing data

What and where are the initiatives were we might find impact?

Maturity:

The large majority of initiatives (46 out of 52) are in operational status

Types of ICT used:

Four main types of ICTs

Support functions of ICT initiative

support to care recipient; support to quality of care through the carer; support to carer's quality of life; participation; migrant-related function

Care recipient's dependency scenario:

different needs of older dependent persons

Presence of impact assessment:

Initiatives were favoured if impact assessments had been conducted previously.

Main objective:

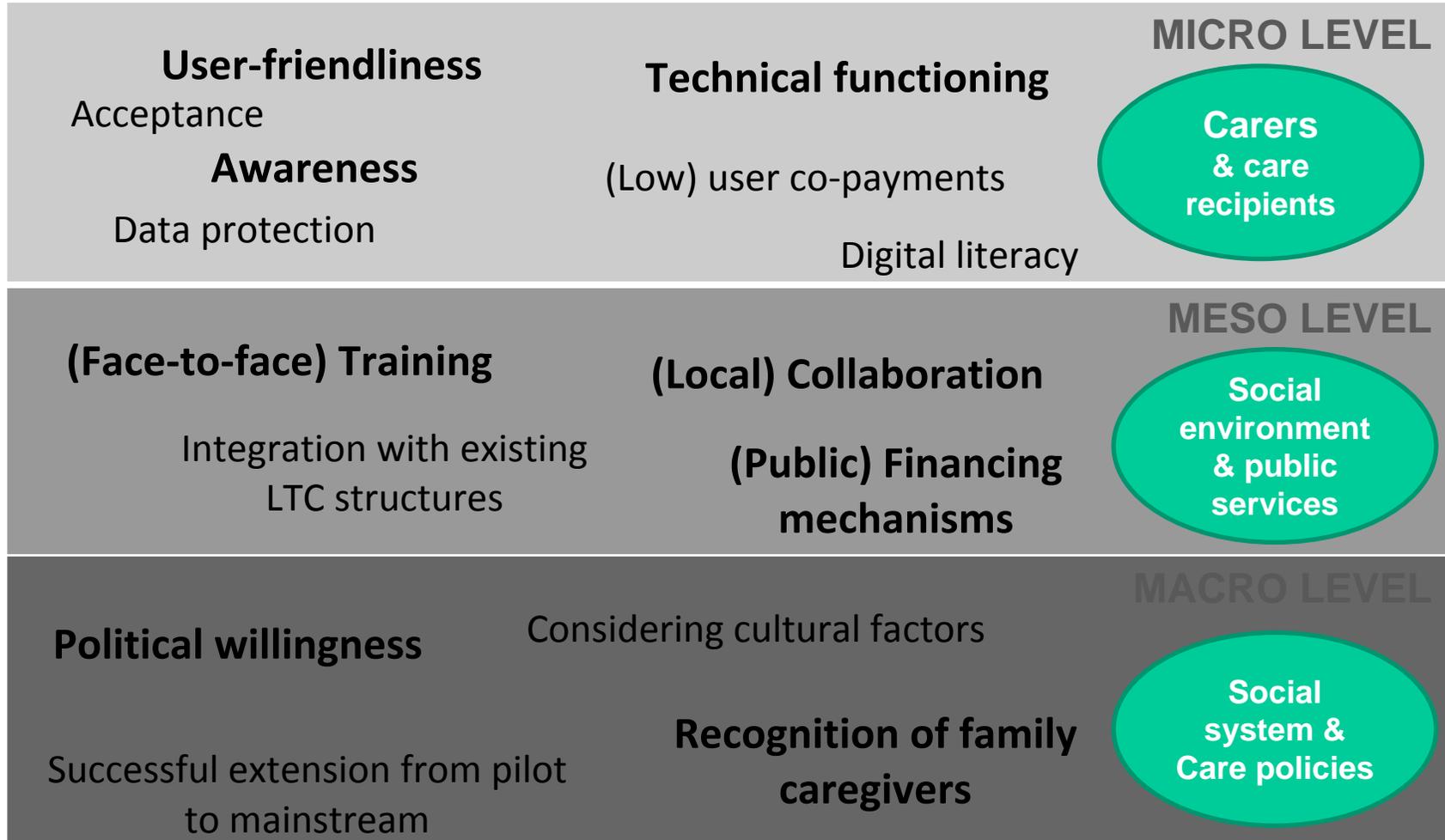
Functional functions of ICT-based services as well as to the conceptual framework of the project (see section 3.1): upgrading care quality; cost containment; transferring costs; empowering older people to live independently

Interestingness

May 2011 52 Mapped Initiatives By Country

UK	France	Sweden	Slovenia
Leeds City Council Telecare Service	Cyber France	My Joice TV	Red button telecare
Carers UK online forum:	Salveo	ACTION	My healthcare personal reminder
HFT (formerly Home Farm Trust)	Maison Vill'age	Family Care Support Portal (Anhörigstödsportalen)	Italy
Book Your Own Breaks	Forum aidants	GAPET	CAMPUS
Telecare Scotland	Web-napperon	IPPI & AMIGO	E-CARE
Just Checking	Open and distance learning	Hungary	C.A.S.A. (Care Assistants Search Agency)
Nottingham Community Housing Association	Germany	Skype care	Ring Project (Transferring supports for caregivers)
Ireland	SEKIS	Emergency alarm	T-Seniority Project
Fold Group	Pflege Wiki	MOHANET	Spain
Try It	Vitaphone	Életvonal 24	Andalusian Telecare Service
Emergency Response Ltd	SOPHIA	Body Guard	Un cuidador, dos vidas (A caregiver, Two lives)
Austria	PAUL	Czech Republic	Ser Cuidador (Being a caregiver)
Hilfswerk Notruf	Alzheimer Blog	Seniors' Telephone – Crisis Helpline (Zivot 90)	Tele-gerontologia
Alzheimer Website	Finland	Careion Emergency Care	
n@tzwerk pflege	Vivago Watch		Bonus: Employers for Carers (UK)
Plattform für pflegende Angehörige	The CaringTV (Hyvinvointi TV)		

EVALUATION



Lack of collaboration

(between formally qualified & informal carers; with local policymakers; between providers & health care sector)

Lack of training and resources

e.g. for local health care staff

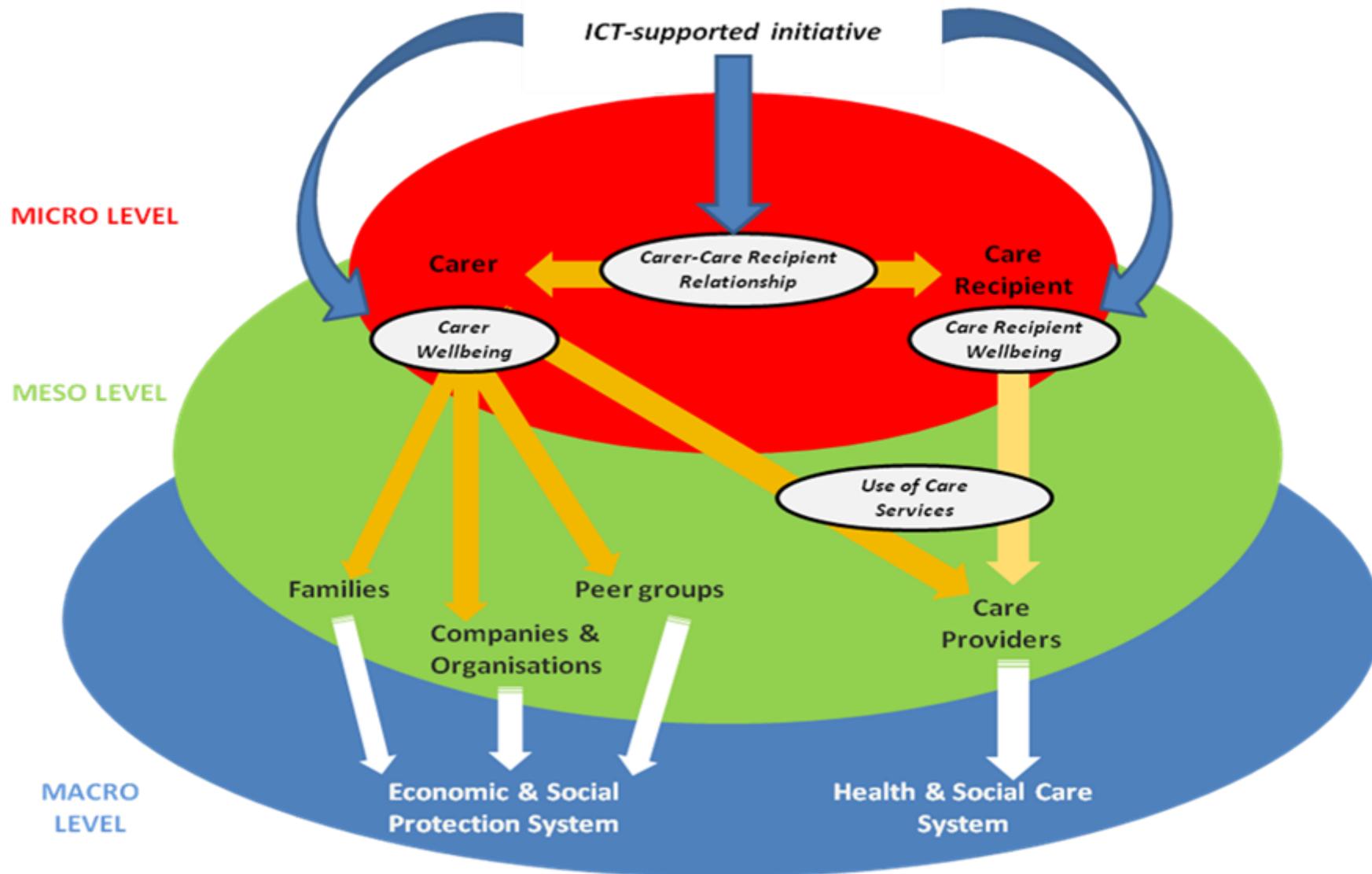
Cultural barriers

(prejudices, fears about older people and ICTs)

Fragmented policies for carers

Kick-start funding - what comes after?

- Many initiatives local and undocumented, which makes mapping difficult.
- While limited in some areas, *Needs and benefits are driving innovation* by people at all levels
- Heterogeneity of experimentation:
- Lots of *NGO and private-led initiatives*, with mixed funding, from public and out-of-pocket contributions. Transformatory projects public in LTC service; Career-focused websites
- **Little systematic evidence of impacts at any level**
- Some evidence for how success can be scaled or transferred to other contexts
- Few set up to 'scientifically' prove their benefit
- Real life Social Experimenters do not usually plan their creations as 'lab experiments';



Impact at Micro level:

1. Quality of Life of Informal Carer

- *reconciliation between care and work*
- *social life*
- *other dimensions of quality of life (health, leisure etc.)*

2. Quality of Life of Paid Assistant

3. Quality of Life of Care Recipient

4. Quality of Care provided by Informal Carer and Paid Assistant

Impact at Meso and Macro level

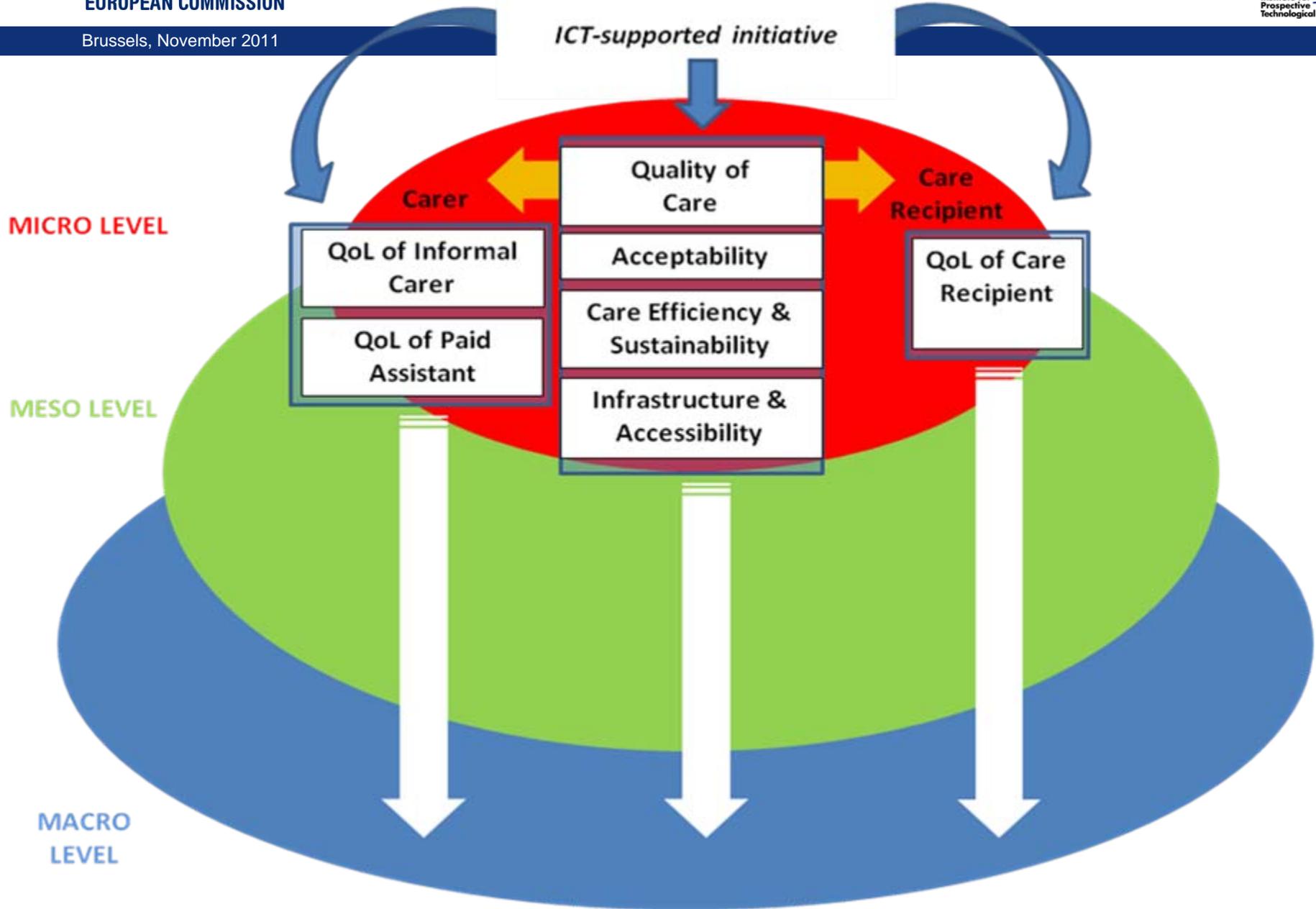
5. Care Efficiency & Sustainability

Mediating factors shaping potential for service impact

6. Acceptability of Service

7. Infrastructure & Accessibility

For some of these dimensions there are standard, tested, accepted and comparable measurement instruments that can be used to measure change or impact in a **sufficiently well design study.**



Dimensions by level of analysis (and examples of indicators) ECV draft proposal

<i>Dimension</i>		<i>Micro</i>	<i>Meso</i>	<i>Macro</i>
1. Quality of Life of Informal Carer	<i>reconciliation between care and work</i>	E.g. Possibility to balance well care & work activities	E.g. Efficiency at work	E.g. Number of carers that balance care & work activities
	<i>social life</i>	E.g. Positive social contacts & relationships	E.g. Reduction in family conflicts	E.g. Increased social cohesion & inclusion
	<i>other dimensions of quality of life (health, leisure etc.)</i>	E.g. Psychophysical health & life satisfaction	E.g. Number of non-stressed carers	
2. Quality of Life of Paid Assistant		E.g. Psychophysical health and independence level	E.g. Number of non-stressed carers	
3. Quality of Life of Care Recipient		E.g. Physical level; Psychological level; Independence level	E.g. Number of reported cases of abuse/neglect by family members	E.g. Target number of dependent older people supported
4. Quality of Care provided by Informal Carer and Paid Assistant		E.g. Improvement of caregiving activities by direct (e.g. training) or indirect (e.g. decreasing burden of carer) factors		
5. Care Efficiency & Sustainability		E.g. Care efficiency (in terms of quality and cost containment) and sustainability for care recipients and families	E.g. Efficiency and Sustainability for care providers	E.g. Efficiency and Sustainability for Social Protection and Care systems
6. Acceptability		E.g. Acceptability by carer and care recipient	E.g. Marketability of ICT devices (from ICT device producer point of view)	E.g. Resources of Care system to support ICT devices (e.g. public investments in ICT)
7. Infrastructure & Accessibility		E.g. Accessibility of initiative by carers	E.g. Availability of services (from care provider point of view)	E.g. Availability of services (from system point of view)

- Impact assessment in practice
 - What data was collected or is available and how was it used to create effective evidence?
 - What is the validity of any evaluation?
 - E.g. Control groups, theory driven, quality qualitative etc?
 - Standard indicators, standard instruments?
 - What can we learn about the outcomes of each service at our various levels of impact?

'Anglosaxon' area:

Just Checking (UK)
Telecare Scotland (UK)

'Continental' area:

SOPHIA (Germany)
Platform for Caring Family Members (Austria)

Scandinavian area:

ACTION (Sweden)
IPPI (Sweden)

Eastern European area:

Emergency Alarm (Hungary)

Mediterranean area:

CAMPUS (Italy)
E-CARE (Italy)
Cuidadoras en Red (Spain)

North America:

Caring for Others (Canada)
Resources for Enhancing Alzheimer's Caregiver Health I/II
(REACH I/II) (USA)

Main target users	Types of technology	Support functions	Types of ICT tool provided	Dimensions of impact			Outcomes and notes	
				Possible dimensions to assess	Evidence of assessment			
					Yes	No		
Care Recipients	Independent Living: carers' respite through social alarm tools	carers' quality of life <i>(direct or indirect)</i>	Telealarm system + call centre	1. QoL of Informal Carer	X		Survey assessed that psychological support provided by call centre improve carers' health-related QoL and give relief for more leisure time and a better reconciliation with work.	
		carers' social participation <i>(direct or indirect)</i>						
		dependent older person		3. QoL of Care Recipient	X			Survey assessed that the social alarm tool reduces rates of care recipients' admission to residential homes and hospitals.
		quality of care through carer <i>(direct or indirect)</i>						
			4. Quality of Care Provided by Informal Carer and Paid Assistant			X		
			5. Care Efficiency & Sustainability		X		Estimations were made to assess cost savings, confirming the ICT-based service is cost effective if compared to hospital / residential services.	
			6. Acceptability			X		
		7. Infrastructure & Accessibility		X		Preliminary assessment was done in order to adapt the service to different geographical and social contexts.		

Emergency Alarm (Hungary)

<http://www.maltai.hu>

Main target users	Types of technology	Support functions	Types of ICT tool provided	Dimensions of impact			Outcomes and notes
				Possible dimensions to assess	Evidence of assessment		
					Yes	No	
Care Recipients and Informal Carers	Independent Living: carers' respite through social alarm tools AND Care Coordination: management of health data with the support of care workers from formal sector.	carers' quality of life (direct or indirect)	Telealarm system + website	1. QoL of Informal Carer	X		Carers gained a better insight into how the condition affected the cared for person. Communication and relations with formal care workers is improved.
		carers' social participation (direct or indirect)					
		dependent older person		3. QoL of Care Recipient	X		Residential admission rates were reduced (using JC in integration with another service). JC was evaluated as an assessment tool for people with dementia living alone, allowing them to manage better their lives.
		quality of care through carer (direct or indirect)					
		4. Quality of Care Provided by Informal Carer and Paid Assistant			X		
		5. Care Efficiency & Sustainability		X		Cost effectiveness in comparison to an admission to institutional settings has been verified.	
		6. Acceptability		X		Possible wariness was largely overcome by the training, information and support provided with JC by the service provider.	
7. Infrastructure & Accessibility	X		Carers felt that the system is very easy to install.				

Just Checking (UK)

<http://www.justchecking.co.uk>

What impact of ICTs on carers? Can the experience be transferred elsewhere and used to inform policy....?

Very little systematic evidence collection, but what there is very positive and has been used to continue some services.

Analytically very hard to separate services for carers and services for the elderly

Joined up services using ICT can save €ms

Further analysis TO BE ANNOUNCED!
Workshop 21-22nd November, Brussels

- **Case study details allow us to explore important themes in innovation**
 - How did a service start, how did it survive, what decision points and successes and shocks made it what it is etc
- **Focus on reading of cases: e.g.**
 - Role of champions and innovation intermediaries
 - Influence of different types of users
 - Social learning processes
 - Shifts in expertise as innovation established
 - Integration and transformation of existing practices and structures
- **Focus on evidence in the innovation process**
 - Type of evidence produced in practice (scientific, business, practice; demonstrations; arguments, numbers; stories)
 - Role of this evidence in development of the service
 - Methods used to develop this evidence.

Innovation and implementation of ICT-enabled services for carers

- 1. It is not just about black-boxing a product or service;**
- 2. Services seldom have single type of impact;**
- 3. Range of unanticipated benefits and problems;**
- 4. ICTs can (should) become a support to redesigning care services from within;**
- 5. ICT support the re-orientation of formal care around the home-care environment;**
- 6. ICTs should and can help build trust and understanding between family, dependent, and various formal care services;**

Carer-representing organisations are becoming important stakeholders and sources of innovation and change

Telecarers, both professional and volunteers are new emerging players in the field of elder care.

- **Real life Social Experimenters do not usually plan their creations as ‘lab experiments’.**
- **Evaluation usually comes when a key funding decision needs to be made, but this can only be made on the basis of existing data.**
- **Tools *are* available to collect relevant data systematically right from the beginning**
- **Any transparently collected data can be used to develop evidence of impact.**
- **Effectiveness and cost-effectiveness is very hard to establish without good quality method.**

Can we stimulate the systematic evaluation of benefits and impact in this type of socio-technical experiment?

- Awareness of the internal and external benefits of evaluation.
- Need accessible methodological tools
 - CARICT produced a so-far inaccessible tool... to be continued (too ambitious, please give generously)
- Need a toolkit, based on standard tools, (questionnaires, research design): has to be flexible to accommodate the wide variety of types of services, not just ICT based.
- The right people have to know about it at the right time.
- **Project funders need to support quality data collection and analysis in the projects they fund.**