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Assessing the Impact of ICT-based Solutions for Carers in Europe: Preliminary Findings from the CARICT Project

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Francesco Barbabella[1, 2], Andrea Schmidt[1], Frédérique Lamontagne-Godwin[1], Ricardo Rodrigues[1], Georg Ruppe[1], Giovanni Lamura [1, 2]

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Linke Wienzeile 246
A – 1150 Vienna
Tel. +43-1-4950442 Fax. +43-1-4050442-40 e-mail: institut@zsi.at
www.zsi.at

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[1] European Centre for Social Welfare Policy and Research, Vienna, Austria

[2] Italian National Institute of Health and Science on Aging (INRCA), Ancona, Italy

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Abstract

Some evidence suggests that information and communication technologies (ICT) can be an efficient mean to improve not only the quality of care provided to dependent older people but also the support for informal carers and privately employed care workers. However, there is a lack of research on ICT-based initiatives and their impact on carers in the European context. Moving from the preliminary findings of the CARICT project, the paper discusses the first attempt that has been made in Europe to assess the impact of ICT-based initiatives for carers. First, an overview of the developed methodological framework is presented: it includes both a conceptual framework and an impact assessment methodology (IAM) for evaluating multidimensional outcome. Furthermore, an overview of ICT-based solutions in Europe is provided through the analysis of 52 operational initiatives and selected as good practices. Finally, some recommendations and guidelines for further research in the field are discussed.

1. The role of information and communication technologies in home care

There is common consensus that the long-term care needs affecting older people suffering from diseases are mainly met by family carers, even in countries where the availability of care services is more widespread (Bolin/Lindgren/Lundborg 2008). However, in several European countries an increasing number of households provide daily care to dependent older family members through the help of privately paid migrant care workers, who are themselves also mainly women, employed, often on an undeclared basis (Fujitsawa/Colombo 2009). In this context, both family carers and paid assistants can suffer stress, depression or other negative effects related to caregiving activities (Schulz/Beale 1999).

On the background of this situation, it is not surprising that in recent years Information and Communication Technologies (ICT) have been increasingly perceived as a potential resource to provide a cost-effective way to improve the quality of care provided to dependent older people and, at the same time, to ease the burden of carers. As some studies have confirmed previously, ICT services for carers may have potentially important effects on the reduction of stress levels among carers and increasing in their quality of life (e.g. Magnusson/Hanson/Nolan 2005), as well as their social participation (e.g. Bledsoe/Morre 2010; Mahoney 2010).

However, little systematic account has been made of the large diversity of ICT initiatives for informal carers and privately paid assistants in European countries, focusing not only on potential benefits and the measuring of the impact of such initiatives but also on barriers and success factors across countries from a policy perspective.

Despite the increasing awareness of the potentialities of ICT tools in the field of home care, there is a lack of evidence at European level about this kind of interventions for carers. In fact, it can be argued that most of the research carried out on ICT concerns their impact on the care recipients and on the formal sector, and very few exercises have been carried out for carers, providing not enough evidence (Schulz/Lustig/Handler/Martire 2002).

The project "CARICT – ICT-based solutions for carers: Assessing their impact on the sustainability of long-term care in an ageing Europe" has been carried on in order to fill this gap: it is a one-year project (December 2010-December 2011) which involved six partners all over Europe[3]. Among its aims there are the mapping and analysis of evidence in the European context, as well as the development of a first methodological framework able to take into account the multidimensional outcomes of ICT-based solutions for carers.

Next chapters present some of the preliminary findings of the study. First, the methodological framework for impact assessment is described, providing a summary of the concepts outlined for the project, as well as a brief overview of the prototype of impact assessment methodology developed. Furthermore, the main results from the analysis of 52 European good ICT-based initiatives are provided in order to better understand their characteristics and success factors. Finally, some proposals for future research are presented on the basis of evidence gained during the project.

2. The methodological framework for impact assessment

This chapter presents a summary of the methodological framework developed by the CARICT project. In particular, the conceptual framework and the prototype of Impact Assessment Methodology (IAM) are described in order to give a global view of the main methodological issues to consider in carrying on an impact assessment of ICT-based initiatives for carers. The full methodological framework is available as one of the final project reports (Barbabella et al. 2011).

[3] More information on the project is available on-line: www.euro.centre.org/detail.php?xml_id=1850; http://is.jrc.ec.europa.eu/pages/EAP/eInclusion/carers.html (last access: 20 February 2012).

By the context of the CARICT project, an ICT-based initiative is defined as a service that addresses one or more carers' (i.e. informal carers or privately paid assistants) and/or care recipients' needs through technological devices that allow any kind of telecommunication (among the users and/or between users and care providers or professionals), integrated or not in a wider intervention programme (which can include other non-telecommunication facilities). Even if a service addresses primarily care recipients' needs, it could have been included in this study if there could be evidence of a (direct or indirect) positive impact on the carers.

2.1 The conceptual framework

The conceptual framework has been developed on the basis of the research focus and from available evidence in the European field (see for instance: Kluzer/Redecker/Centeno 2010; EMPIRICA/WRC/TUW 2010). It includes:

- a classification of the *type of technology* used by the ICT-based initiatives for carers, overcoming other classifications of ICT tools already used in the field of home care but addressing mainly frail older people's needs (e.g. ambient assisted living devices, smart homes). Four categories were identified:
    - *Independent Living*: technology systems that allow elderly dependents to stay at home without continual formal or informal care support, thus relieving pressure on carer;
    - *Information & 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.;
    - *Personal Support & Social Integration*: this provides social, emotional & peer support, leisure, relief of isolation and chances for participation in work, civil society etc.;
    - *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.;
- a classification of *support functions* provided by ICT-based initiatives in order to address carers' and care recipients' needs. Five categories were identified:
    - *dependent older person*: the aim is to improve their care, or changing the conditions of care. The carer is not the primary focus of this initiative, but will be implicated in the service;
    - *quality of care through carer*: the aim is to improve or change conditions of care of the dependent older person by supporting or assisting the informal carer or family employed care assistant in providing care at home, and improving the quality of care given;
    - *carer's quality of life*: the aim is to support carers in their personal and emotional life, and in the case of family-employed care workers, to enable them to balance their work with other aspects of their life;
    - *carer's social participation*: the aim is to enable carers to participate in aspects of life outside the home;
    - *migrant-related*: the aim is to provide language learning, cultural integration, translations of skills training and advice and combating specific isolation of migrant care workers;
- a classification of *types of carers* on the basis of their care obligations and their status. Two main categories were identified:

- *informal carers*: they are motivated to care mainly by family (i.e. relatives) and friendship relationships (i.e. friends and neighbours) with the dependent older person, or by civic engagement (i.e. volunteers);
- *paid assistants*: they are motivated to care by a wage provided by the care recipient or his/her family. This category includes privately employed care workers, both nationals and migrants (even if illegally employed or with no permit of stay). This category does not include personnel of care organisations or from the formal care sector.

Concerning the object of the study, it can be summarised by the following research question:

What are the consequences and the potential of the adoption of ICT-supported initiatives in supporting carers of dependent older people?

Indeed, the object is the carer-care recipient dyad, to be investigated through the fundamental relation which ICT-supported initiatives try to impact. In this regard, the key issue of the study is the carer of a dependent older person and the ways ICT are useful for improving his/her well-being: this is a challenge for policy makers to facilitate the adoption and use of such tools at an individual level in dependency contexts, as well as at the organisational level in optimising care services and relative resources.

This leads to a second assumption: we cannot only consider the individual level of the impact, but we should also cover wider dimensions of the effects. The focus of the analysis can be split into three levels:

a) *micro-level*: it represents the lowest level of analysis. The micro level deals with the interactions between the people involved in the considered dyad (carer and care recipient), related human behaviours and health statuses;

b) *meso-level*: it is a middle level in which social groups and organisations are considered (e.g. communities, neighbourhoods, companies). In this sense, local care providers are supposed to benefit from an efficient use of ICT-supported initiatives in order to optimise care services and related resources. Moreover, ICT can also improve other areas like family reconciliation (e.g. activities with relatives), community living (e.g. peer group memberships) and companies or civil society organisations (e.g. work reconciliation and social participation issues);

c) *macro-level*: it is the higher level that deals mainly with the impact on broad institutions like health and social care system (e.g. a better health condition of carers and care recipients leads to a decrease of care service use), as well as with the economic and social protection system (e.g. a better engagement of carers in the labour market).

Figure 1 is a graphic representation of the conceptual framework, showing both the actors considered and the levels of analysis.

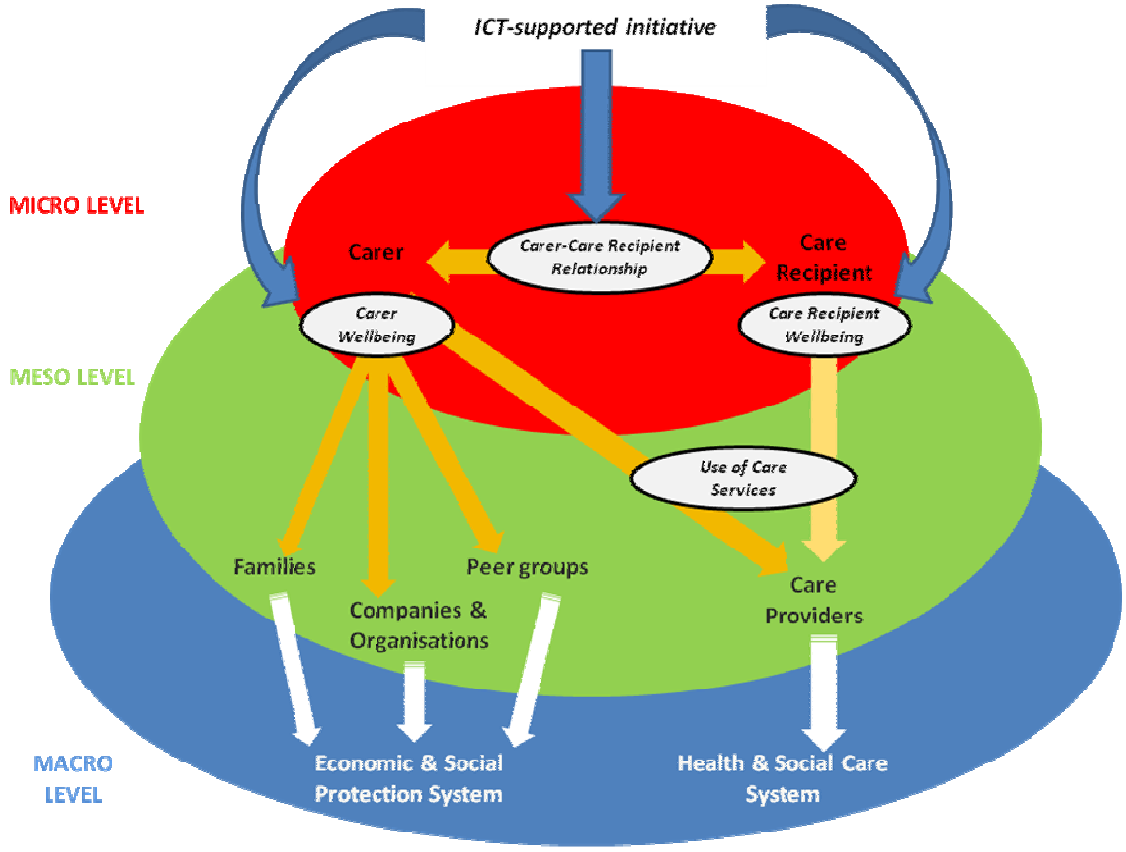

Fig. 1: The impact of an ICT-supported initiative at micro-, meso- and macro-levels

2.2 The prototype of Impact Assessment Methodology

On the basis of the conceptual framework developed and of a comprehensive literature review carried out (Hoffmann/Barbabella/Rodrigues/Lamura 2011), a first attempt to build an IAM was made.

The IAM has been layered in three levels: (a) dimensions of impact, (b) levels of analysis, and (c) indicators. Below the structure is summarised:

- dimensions of impact:
  1. Quality of Life of Informal Carer:
     - 1.1. reconciliation between care and work;
     - 1.2. social life;
     - 1.3. health-related quality of life;
  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;
  5. Care Efficiency & Sustainability;
  6. Acceptability;
  7. Infrastructure & Accessibility;

- levels of analysis: each dimension has been articulated at all three levels of analysis (micro, meso, and macro), already identified in the conceptual framework;

- indicators: a series of indicators have been selected among a range of standardised and validated published instruments, which have been in some cases partly adapted to the specific peculiarities of the ICT-based initiatives. A total of 77 indicators have been developed, providing for each one a standardised definition, the role of ICT tools (why the indicator can assess an important aspect of ICT impact), the methods of collection (including available tools from the literature), some possible conceptual or methodological limitations, and main sources used.

When an ICT-based initiative is implemented, the first step is to identify the possible dimensions of its impact, since the final primary users can be different. Furthermore, there is need to understand the context of analysis and its audience. Is the assessment going to be an internal evaluation of the initiative, underlining weaknesses and strengths? Or is it meant to be an instrument for policy makers in order to understand possible impact of the service if applied on a large scale? Clarifying these points is fundamental in order to develop a tailored methodology for the specific initiative.

Concerning the data collection procedure, every impact assessment should be built on data gathered at micro-level. Once micro-level data is collected, meso- and macro-level data can be built as aggregations or simulations/predictions on a large scale. However, the methodological framework does not recommend any specific research design and methodology of data collection, since they should be selected case-by-case on the basis of contextual factors (e.g. practical constrains) and initiative peculiarities (e.g. type of technology, care recipient's type of impairment etc.). Specific designs and measures are mentioned in the developed IAM as widespread instruments in the field, but of course other available ones can be found in literature and practice.

Finally, ethical issues need to be mentioned. In general, there is need to find a balance between what are the ethical limits in approaching users and the benefits occurred in using the ICT solutions: practitioners and researchers should keep in mind the importance of such issues in carrying on an ICT-based service or a study. The IAM summaries the main important ethical issues, as a proper memorandum for researchers.

3. An overview of existing ICT-based solutions for carers in Europe

In the present chapter results are presented concerning the mapping of existing ICT-based solutions for informal carers and privately paid assistants in Europe, carried out in the course of the CARICT project in 2011. The mapping exercise and the complete set of case studies are available online (Schmidt et al. 2011).

The distinction of five care regimes (Simonazzi 2009) served as a basis for ensuring geographical and welfare state diversity. 52 initiatives in 12 countries (UK, Ireland in the Anglo-Saxon care regime; Austria, France, Germany in the Continental care regime; Sweden, Finland in the Scandinavian care regime; Hungary, Czech Republic, Slovenia in the Eastern European care regime; Italy, Spain in the Mediterranean care regime) were selected through the mapping exercise (out of 75 initiatives which had been identified previously), with a minimum of three initiatives per country (where possible). The large majority of initiatives had to be beyond pilot status, while ensuring diversity of technologies and support functions. In particular, the classification of four different types of technologies as well as the five different support functions (provided by the conceptual framework described above) served as a grid to select the most relevant initiatives.

Data collection was based on secondary data (i.e. literature review and review of grey literature: presentations, project reports, on-line data bases etc.) and primary data (i.e. interviews with national experts, at least four per care regime). Project partners reported information gathered through a common template. Content analysis served to structure the interpretation of qualitative data gathered in open-

ended questions. Also, answers from the multiple choice questions were used to complement the analysis by describing the sample in quantitative terms, and observing commonalities or differences in the four main parts of the template. The analysis of results was carried out at three levels – micro, meso, macro –, in line with the conceptual framework described previously.

3.1 Results

The ICT-based initiatives for carers in Europe analysed comprise a number of different types of technologies, ranging from simple websites and on-line fora to video phone tools connected to TV sets or computers, or to the instalment of complex systems monitoring the older dependent person. Some of the initiatives were targeted only towards carers, while others benefited both older dependent persons and their carers (either directly or indirectly).

In short, the ways in which carers are supported vary largely and it is thus difficult to find a single meaningful way of comparison across countries. Nonetheless, some findings emerged from the systematic overview of ICT-based services for carers, while it is important to mention that the collected case studies by no means are representative or exhaustive sets of ICT-based initiatives. Hence conclusions drawn from the analysis are valid as a first step, yet need to be followed up by more detailed analyses in the future.

3.1.1 Micro-level

At the user level (micro level) and in line with the literature on technology adaption among older people (see, for example, Wang/Redington/Steinmetz/Lindeman 2010: 5ff.) some of the case studies have shown that overcoming prejudices and initial resistance of older people and their families regarding the use of new technologies is crucial. As an example, in one of the case studies in Hungary, the providers of a communication tool called Skype Care (directed towards older dependent persons as well as carers), not only had trouble in overcoming scepticism on behalf of older people and social workers before being used, but the widely spread view of the inability of older people (and their carers) to use the communication software Skype even led to endangering the sustainability of funding streams. The Swedish initiators of the web portal ACTION[4] were able to overcome a similar problem via face-to-face trainings for users which proved to be highly successful. Also, the importance to train care workers (e.g. answering calls from informal carers in a local call centre) in using ICT tools was mentioned to be an important, but often neglected factor.

Another essential aspect at the user level was found to be the flexibility of services to be adapted to the needs of carers, especially with ICT for information and learning such as online courses or training modules. That is, the possible existence of previously acquired knowledge should be taken in consideration when designing initiatives, as the feedback from users in the Ring Project[5] (Italy) showed. Also, data protection concerns were mentioned as barriers, in particular for monitoring mechanisms in the homes of older persons, which may increase the feeling of safety for the carer (see e.g. “Just Checking”, UK). Nonetheless, evidence shows that effectiveness of the service and user satisfaction are predominant factors for adoption rather than, for example social acceptance of technologies (Hogenbirk/Liboiron-Grenier/Pong 2005).

Among the most relevant ICT solutions for informal carers to reconcile work and care are online respite care booking systems such as the initiative Book your own breaks in the UK or My Joice TV[6] in Sweden: not only do they provide the possibility for carers to book a replacement for themselves in advance, they also contribute in important ways to a better integration between the informal and the formal care sector. Others, such as the German initiative SOPHIA[7] also introduce an improved link with formal care workers

[4] www.actioncaring.se (last access: 20 February 2012).

[5] www.comune.torino.it/pass/php/4/ring.php (last access: 20 February 2012).

[6] www.myjoice.com (last access: 20 February 2012).

[7] www.sophia-tv.de (last access: 20 February 2012).

and volunteers, by allowing older people to get in touch with a local call centre, from which carers are contacted in cases of emergency. Hence, telecare solutions relieve carers from their duties to be present around the home of the older person constantly, which is likely to reduce their stress levels substantially, as proven by some previous evaluations such as telecare provided by Leeds City Council[8] in the UK. In particular, these technologies may become increasingly important in the future as a rise in the number of dementia patients is expected (Alzheimer's Disease International 2010).

As previous evaluations of ICT services for migrant care workers have shown (Kluzer et al. 2010) their existence is strikingly limited. The mapping exercise once more confirmed this lack of ICT support tailored to the needs of privately paid assistants, although some successful examples of support towards migrant care workers could be found (such as the care assistants search engine CASA[9], in the Italian Lazio region, or the initiative CAMPUS[10] which offers online courses for carers in seven different languages). Other successful services, for example in the case of online fora like the Carers UK forum[11] or the French initiative Forum Aidants[12] are simply not available in the native language of the migrants and therefore less easily accessible for them.

3.1.2 Meso-level

It is interesting to see that the range of actors involved in setting up ICT services for domiciliary carers is rather diverse, comprising local governments, non-profit organisations, civil associations, private companies and research institutions. More often than not, it has been cooperation between these different actors that led to successful implementation of ICT services for carers. Policy incentives, reimbursement models, grants or other funding mechanisms at local level may contribute substantially to 'kick-start' innovative ideas from the ground, especially in markets where such technologies are less wide-spread. These findings are largely in line with the literature on technology marketability and diffusion of business models (see e.g. Rogers 2003). The Swedish initiative My Joice TV, for example, was set up by a middle-aged son whose mother was unable to answer the phone but not willing to move to a care home. The son established collaboration with the company Ericsson and together they developed a communication system which requires not more than a TV set, broad band internet connection and a small device from which calls can be made in a very easy-to-use format. By that, carers are not only able to keep in touch with their older relatives on a regular basis, it also allows for better social integration of older people and a relief of the care burden for informal carers, as confirmed e.g. by a study of a similar Finnish initiative called Caring TV[13].

As mentioned previously, integration of ICT services with (locally) available structures within the formal care sector may play an important role in implementing them successfully, not least by reducing investment costs, which are frequently mentioned as barriers to implementation in contexts of ICT use (e.g. Stroetmann/Jones/Dobrev/Stroetmann 2006).

3.1.3 Macro-level

Generally speaking, the policy environment in which ICT initiatives for carers are being set up was found to influence the success or failure of such initiatives in important ways, especially when it comes to initiating services and taking initiatives beyond their testing phases. While comprehensive evaluation studies on the

[8] www.leeds.gov.uk/Health_and_social_care/Services_for_older_people/Services_and_equipment_to_help_you_live_at_home.aspx (last access: 20 February 2012)

[9] www.casa-project.eu (last access: 20 February 2012).

[10] www.anzianienonsolo.it/?page_id=21 (last access: 20 February 2012).

[11] www.carersuk.org/forums/ (last access: 20 February 2012).

[12] http://forums.agevillage.com/ (last access: 20 February 2012).

[13] www.caringtv.fi (last access: 20 February 2012).

potential impact of ICT services on carers are scarce (or strongly technology-driven), and cost-benefit analysis are often inconclusive, small-scale studies do show that ICT solutions entail a number of opportunities for socially isolated groups such as family carers or migrant care workers, who are limited in time and resources to benefit from support services.

Given the need for balanced long-term care solutions in times of demographic ageing, lack of care personnel and budgetary constraints, ICT solutions may therefore come into play as comparatively cost-efficient solutions (especially when integrated with existing care services) and a way to support informal carers in their roles. By that, psychological and economic costs may be reduced, on the one hand by allowing for better reconciliation of work and care of informal carers, avoiding the risks of burn-out of migrant care workers and family carers, and on the other hand by supporting policies for autonomous living and active ageing strategies, as laid down for example in the European Commission's documents on the European Year for Active Ageing and Solidarity between Generations 2012[14], and largely corresponding to older people's preferences for care in their own homes (European Commission 2007).

4. Final remarks: directions for further developments

As mentioned above, the CARICT project represents a first step for the analysis of ICT-based solutions for carers in Europe. Evidence gained throughout the project allows us to propose some directions of future research in the field.

First, further improvements of the methodological framework can lead to differentiate it on the basis of three parameters: types of technologies, categories of carers, and caregiving contexts. Such a declination can carry many benefits and would facilitate the work of researchers and practitioners (who have to apply the methodology), as well as of policy makers (who can better understand differences in impact and potentialities of the initiatives). In this way, there would be also a better linkage and aggregation from one level to another (micro to meso to macro); overlaps might therefore be avoided.

Furthermore, many gaps in current practice of impact assessment were found. The main one concerns the lack of evidence at meso- and macro-levels: research focuses mainly on individual effects, and the meso- and macro-levels are substantially missing. Promoting research for understanding impact on organisational stakeholders and overall care and social protection systems is one way to gain valuable knowledge for optimising public resources and allowing a better integration among different services.

Finally, an overarching issue emerged concerning the focus of such IAM, its audience and purposes. Even if the focus of the methodological framework is the impact on carers, it is quite evident that some kind of impact on care recipient should be taken into account too. However, since some outcomes for care recipients were included in the framework and some other not because of project assumptions, there is risk to do not capture all interesting and useful effects. Further research could clarify if there is need to integrate the framework with other available ones, focused mainly or exclusively on dependent older people, in order to build a unique and exhaustive framework in the field of ICT-based services in home care.

[14] For further information, see http://ec.europa.eu/social/ey2012.jsp (last access: 20 February 2012).

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