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# Sources of Informal Care: Comparison of ELSA and GHS

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# **SOURCES OF INFORMAL CARE: COMPARISON OF ELSA AND GHS**

## **RESEARCH NOTE**

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Work Package 5 of the MAP2030 (Modelling Ageing Populations to 2030)<sup>1</sup> project includes an analysis of ‘the factors affecting receipt of unpaid care, using 2002 ELSA<sup>2</sup> data, with a view to modelling the availability of living children in the PSSRU model’. The context of this piece of work is described in the MAP2030 research proposal in the following terms:

Using projections of kin availability in the context of demand for long-term care will involve new work with a view to modelling the availability of key kin (particularly living children) in the PSSRU model, which the current model structure does not incorporate. We will use the 2002 ELSA data to analyse variations in receipt of informal care by disabled older people, conditioning on the availability of different types of kin, by age, gender, disability, marital status, household type, housing tenure and education, and link the analysis to receipt of formal services in the PSSRU model. (NDA Proposal, December 2005:16).

Because the PSSRU model utilises the General Household Survey (GHS) to link receipt of informal and formal care by disabled older people, comparability in the analysis of informal care between the GHS and ELSA is very important.

This paper describes progress made in the first stage of the analysis of informal care using the 2002 ELSA data. The analysis focuses on sources of informal care and, in particular, on receipt of informal care by disabled older people from their (adult) children. This is because a key aim of the analysis for MAP2030 is to incorporate the availability of living children in the PSSRU model and the availability of children is likely to be particularly relevant to the receipt of care from children.

The first stage of the analysis involves three steps. Step one is to identify sources of informal care for disabled older people using Wave 1 (2002) ELSA data. A number of different definitions of disability are explored. The second step is compare the results obtained using ELSA with those obtained using the 2001/2 GHS. A number of different definitions of informal care are possible using the GHS data and these are explored. After the first two steps are completed, the paper suggests how the definitions of informal care sources in ELSA and the GHS may be brought as close as possible in relation to receipt of care by disabled older people from their adult children. The third step is to compare the characteristics of people receiving care from their children in ELSA and the GHS, with the aim of establishing how far the samples of people receiving this form of care are similar in the two datasets. This first stage of the analysis of sources of informal care for MAP2030 will be followed by further stages involving an analysis of the factors affecting receipt of care from children using ELSA. This will include variables not included in the GHS, such as the availability of living

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<sup>1</sup> For a description of the MAP203 project, see [www.lse.ac.uk/collections/MAP2030](http://www.lse.ac.uk/collections/MAP2030)

<sup>2</sup> ELSA refers to the English Longitudinal Study of Ageing

children (by gender) and educational qualification of older people. Further stages will also involve similar analyses of the later waves of ELSA to explore trends in receipt of informal care by disabled older people.

### **Step One: Sources of informal care in ELSA (2002)**

The analysis of ELSA is confined to people aged 65 and over using Wave 1 (2002) ELSA data weighted using a weight created by the PSSRU to reflect differential non-response among the older population ('weight02'). There are 5,512 individuals aged 65 and over in the sample.

The analysis of informal care is confined to older people with a disability. Disability is derived from the variables 'HeADLa' and/or 'HeADLb'. Disability is defined as difficulty with one or more Activities of Daily Living (ADLs) or Instrumental Activities of Daily Living (IADLs), as defined by the PSSRU<sup>3</sup>. Two different versions of the PSSRU definition of disability are explored. The derivation of these definitions is described in greater detail elsewhere, but essentially the first definition includes all older people with difficulty with IADLs or ADLs, as defined by the PSSRU definition of disability (sample number = 1960). The second definition of disability is less inclusive, and was developed to mirror the results obtained using the GHS, in which ADLs (except bathing) are filtered according to whether the older person has difficulty using stairs (sample number = 1734). Information on disability is available for 5,389 older individuals in the sample and excludes 123 individuals for whom proxy interviews were conducted. Excluding these missing individuals, 36.4% of the older population had a disability using the more inclusive definition and 32.2% had a disability using the definition more comparable to that obtained using the GHS.

Sources of informal care for disabled older people are derived from two questions in ELSA: 'HeHpa' and 'HeHpb'. These questions were asked only of those people with difficulty with at least one of the activities of daily living or instrumental activity of daily living (included in 'HeADLa' and/or 'HeADLb'). 'HeHpa' identifies whether anyone helps the respondent with activities with which they have difficulty, while 'HeHpb' identifies who helps with these activities. The format of the two questions is given in Box 1 below.

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<sup>3</sup> ADLs included in the PSSRU definition of disability comprise bathing, getting in and out of bed, using the toilet, dressing and feeding; IADLs include shopping, cooking, personal/business affairs and practical activities, including housework.

**BOX 1**  
**ELSA QUESTIONS ABOUT HELP WITH ACTIVITIES WITH WHICH**  
**RESPONDENTS HAVE DIFFICULTY**

*IF difficulty with any of the activities in the two lists above: (HeADLa = 1, 2, 3, 4, 5, 6, 7, 8, 9 OR 10) OR (HeADLb = 1, 2, 3, 4, 5, 6, 7, 8, 9, 10, 11, 12 OR 13)*

**HeHpa**

Thinking about the activities that you have problems with, does anyone ever help you with these activities (including your partner or other people in your household)?

- 1 Yes
- 2 No

*IF someone helps with daily activities: HeHpa = 1*

**HeHpb**

Who helps with these activities?

PROBE: Does anyone else help you with these activities?

CODE ALL THAT APPLY

- 1 Husband or wife or partner
- 2 Mother or father
- 3 Son
- 4 Son-in-law
- 5 Daughter
- 6 Daughter-in-law
- 7 Sister
- 8 Brother
- 9 Grandson
- 10 Granddaughter
- 11 Other relative
- 12 Unpaid volunteer
- 13 Privately paid employee
- 14 Social or health service worker
- 15 Friend or neighbour
- 16 Other person

**[Multiple responses to HeHpb are recorded in variables hehpb01 to hehpb16]**

In secondary analysis of the ELSA data, sources of informal care were classified into five categories, as in earlier analyses using the GHS (Pickard *et al* 2007). The five categories were as follows: spouse, child, spouse and child, other and none. Respondents were classified as receiving help from a spouse where HeHpb = 1, receiving help from a child where HeHpb = 3, 4, 5 or 6 and receiving help from others where HeHpb = 2, 7, 8, 9, 10, 11 or 15. Respondents receiving help from a child and others or a spouse and others were classified as receiving help from a child or spouse respectively. Respondents receiving help from both a child and a spouse were classified separately. Respondents were classified as not receiving informal help when they said that no one ever helped them (HeHpa = 2) or when they did not receive help from an informal source (HeHpb = 12, 13, 14 or 16).

It should be noted that respondents in ELSA were asked specifically about difficulties that they have with activities 'because of a health or memory problem' and therefore the help they receive is likely to be related to difficulties arising from a health or memory problem. The importance of this will become more clear when comparison with the GHS is made.

The 2002 ELSA data were used to derive information on sources of informal care by disabled older people. The results, using the two different definitions of disability described earlier, are shown in Table 1 below.

**Table 1**  
**Informal care received by disabled people aged 65 and over, by source and definition of disability, England, 2002 (ELSA)**

Sources of informal care	Disabled People (ADLs not filtered)		Disabled people (ADLs filtered)	
	Sample number	%	Sample number	%
Spouse	418	21.3	385	22.2
Child	484	24.7	467	27.0
Spouse/child	114	5.8	111	6.4
Other	165	8.4	163	9.4
None	776	39.6	606	35.0
Total	1958	100	1733	100
Missing	1		1	

Source: ELSA Wave 1 (2002)

Notes: Filtering of ADLs uses difficulty with stairs (excluding bathing)

The analysis shows that sources of informal care vary somewhat by definition of disability. Among older people defined as disabled using the less inclusive definition of disability (ADLs filtered), which is more comparable to that obtained using the GHS, more disabled people have a source of informal care than when the definition, 'ADLs not filtered' is utilised.

Using the 'ADLs filtered' definition of disability, in the 2002 ELSA sample, the probability of a disabled older person receiving informal care is 65.0 %; the probability of receiving informal care from a spouse and/or child is 55.6%; and the probability of receiving informal care from a spouse is 22.2% and from a child is 27.0%. In the ELSA sample, 85% of those who receive informal care do so from a spouse and/or a child. The next section compares these results to those obtained using the GHS.

## Step Two: Comparison of sources of informal care in the GHS and ELSA

In the past, PSSRU analyses of the GHS data on receipt of help by disabled older people have adopted a fairly broad definition of informal care in terms of help with domestic tasks (Wittenberg *et al* 1998, Pickard *et al* 2000, 2007). However, this definition may not be comparable to that derived from the ELSA data, where the questions about help with daily living tasks are more restricted in some respects than those in the GHS (as explained below), although the ELSA questions do cover both help with both personal and domestic care tasks. The GHS data have therefore been re-analysed to derive a definition of informal care using the GHS that is more comparable to that derived from the ELSA data. This section describes the re-analysis of the GHS data on sources of informal care and then compares the results with those obtained using the ELSA data.

Questions in the GHS relating to help with daily living tasks are asked about specific tasks separately. With regard to the domestic tasks included in the PSSRU definition of disability, there are separate questions in the GHS about help with shopping, personal affairs and cooking, as well as a general question about help with domestic tasks (including vacuuming and laundry). With regard to personal care tasks, there are separate questions in the GHS

about help with bathing and feeding, getting in and out of bed and dressing (combined), and getting to the toilet (combined with help with stairs or getting around the house).

The format of the GHS questions varies depending on whether the questions relate to help with domestic tasks or personal care tasks. Questions about help with domestic tasks, which have been used as the basis of previous analyses, are more inclusive than questions about help with personal care tasks. Information is obtained about help received by anyone who does not perform a particular domestic task, whether or not they could perform this task if they had to. Box 2 illustrates the format of the GHS questions about help with one domestic task: shopping.

<b>BOX 2</b>	
<b>EXAMPLE OF GHS QUESTIONS ABOUT HELP WITH DOMESTIC TASKS: SHOPPING</b>	
<b>77. ShopOwn</b>	<p><b>If does not do the household shopping themselves (Shopping = 2)</b>  <b>Could you if you had to?</b>            Yes.....1 [go to Q78]            No.....2 [go to Q78]</p>
<b>78. ShpHlp</b>	<p><b>Who usually does this for you? Is it someone in the household, or someone from outside the household?</b>            Someone in the household.....1 [go to Q79]            Someone from outside the household.....2 [go to Q80]</p>
<b>79. ShpHlpA</b>	<p><b>If usually gets help from someone in the household (ShpHlp = 1)</b>            Who is the person in the household?</p>
<b>80. ShpHlpB</b>	<p><b>If usually gets help from someone outside the household (ShpHlp = 2)</b>            Who is the person from outside the household?            Son.....2            Daughter.....3            Brother.....4            Sister.....5            Other relation.....6            Friend/Neighbour.....7            Social Services.....8            District Nurse/Health Visitor.....9            Paid help.....10            Other.....15            Nobody does it.....16</p>

Questions about personal care tasks in the GHS take a different format from the questions about help with domestic tasks and are less inclusive. Questions about help with personal care tasks are *only* asked if the person is unable to perform the task without help from someone else or finds it fairly or very difficult to perform the task on their own.

Respondents who find it difficult to perform a personal care are first asked if anyone helps them and then asked about sources of help. Box 3 illustrates the format of the questions about help with personal care tasks, using bathing as an example.

**BOX 3**  
**EXAMPLE OF GHS QUESTIONS ABOUT HELP WITH PERSONAL CARE TASKS:**  
**BATHING**

- 40. CanHlp4** **If finds it difficult to bath, shower or wash all over (BathEasy = 3 or 4)**  
 Although you said you usually manage on your own, does anyone help you bath, shower or wash all over?  
 Yes.....1 [go to Q41]  
 No.....2 [go to Q44]
- 41.BthHlp** **If needs help to bath, shower or wash all over (Bath = 2 or CanHlp4 = 1)**  
 Who usually does this for you? Is it someone in the household, or someone from outside the household?  
 Someone in the household.....1 [go to Q42]  
 Someone from outside the household.....2 [go to Q43]
- 79.BthHlpA** **If usually gets help from someone in the household (BthHlp = 1)**  
 Who is the person in the household?
- 80. BthHlpB** **If usually gets help from someone outside the household (BthHlp = 2)**  
 Who is the person from outside the household?  
 Son.....2  
 Daughter.....3  
 Brother.....4  
 Sister.....5  
 Other relation.....6  
 Friend/Neighbour.....7  
 Social Services.....8  
 District Nurse/Health Visitor.....9  
 Paid help.....10  
 Other.....15  
 Nobody does it.....16

Earlier PSSRU analyses of sources of informal care have utilised the questions in the GHS on help with domestic tasks. The earlier analyses of informal care defined disabled respondents as being in receipt of help with domestic tasks if they had an informal care source for a domestic care task, irrespective of whether they could perform that task on their own if they had to.

However, this broad type of definition is not possible using the ELSA data because the latter only ask if respondents have help where they have difficulty performing a task or tasks. Indeed, the scope and format of the ELSA questions more closely resemble the GHS questions on personal care tasks. Both the ELSA questions on help with personal and domestic care tasks and the GHS questions on help with personal care tasks are only asked of people with, at minimum, difficulty performing the tasks, and both ask initially if anyone helps the respondent and then about sources of help.

In order to try and maximise comparability between the two surveys, the definition of informal care used for the GHS analysis has been redefined. In the revised definition,

respondents are included as receiving informal help with a task only where they have difficulty with or are unable to perform that task. This new definition of informal care receipt in the GHS analysis has the advantage of allowing for the inclusion of help with personal care as well as help domestic tasks.

The effect of adopting the revised definition of informal care in the GHS analysis is to create a somewhat more restricted definition of informal care than has been used previously in analysing the GHS data. For example, in the revised definition of help with informal care, individuals who are unable to perform personal care tasks but are able to perform domestic tasks are now only included as receiving informal care if they have an informal source of help with personal care. In the earlier definition of informal care, these respondents would have been included as receiving informal care if they had a source of informal help with domestic tasks, even if they were able to perform domestic tasks themselves.

In terms of the detail of the analysis using the new definition of informal care, GHS respondents were included as being in receipt of informal help with domestic tasks if they had an informal care source and were unable to carry out the task themselves if they had to (for example if ShpOwn = 2). People with difficulty with or unable to perform a personal care task were classified as receiving informal care if they had an informal care source. Sources of informal help within the household, that is help from a spouse, child or others, were identified using information on the relationship of the disabled older person to the person providing help, using variables such as ShpHlpA or BthHlpA, together with the 'Relto01' to 'Relto14' sequence of variables. Sources of informal help outside the household were identified using variables such as ShpHlpB and BthHlpB. Respondents were classified as receiving informal help from a child outside the household where, for example, ShpHlpB = 2 or 3 and help from others where ShpHlpB = 4 to 7.

Sources of informal help using the PSSRU's earlier definition of informal care are compared to sources of informal help using the revised definition in Table 2 below. The GHS analysis presented here uses the 2001/02 data, is confined to disabled older people in England and uses sample data weighted using the average of weights supplied with the dataset ('weight02'). There are 2,859 people aged 65 and over in the 2001/02 GHS sample in England. Of these, data on disability is missing for 109 people with proxy interviews. Of the remaining, 2,750 individuals, 739 are disabled (as defined in the PSSRU definition), that is 26.9% are disabled.

**Table 2**  
**Informal care received by disabled people aged 65 and over, by source and definition of disability, England, 2001/02 (GHS)**

Sources of informal care	Informal help with domestic tasks only		Informal help with domestic and/or personal care tasks ('Revised' definition)	
	Sample number	%	Sample number	%
Spouse	226	30.6	208	28.1
Child	244	33.1	204	27.6
Spouse/child	29	3.9	19	2.6
Other	122	16.5	93	12.6
None	117	15.9	215	29.1
Total	738		739	

Source: GHS (2001/02)



Using the new definition of informal help in the analysis of the GHS data, fewer respondents receive informal care than in earlier analyses. Around 70% of disabled older people receive informal help using the new definition, compared to around 85% using the old definition. Nevertheless, key conclusions relating to sources of informal care remain valid, whichever definition is used (cf Pickard *et al* 2007). Over 80 percent of disabled older people living in private households who receive informal care do so either from a spouse, a child or both. Of those receiving care from either a spouse or a child, approximately half receive care from a spouse and half from a child.

Sources of informal care using the previous definition of informal care and the revised definition using the GHS data can be compared to sources of informal care using the ELSA data (Tables 3 and 4 below). Using the definition of informal care employed in previous analyses, the proportions of disabled older people receiving informal care from different sources derived from the GHS is consistently higher than the proportions derived from the ELSA data (Table 3). This is the case whichever definition of disability is used to analyse the ELSA data. The reason is that, as indicated above, the previous definition of informal care employed to analyse the GHS is more inclusive than the definition possible using the ELSA data.

**Table 3**  
**Sources of informal care received by disabled people aged 65 and over:**  
**GHS definition of informal care in terms of domestic tasks and ELSA definitions of disability, England, 2001/2002**

Sources of informal care	ELSA Data		ELSA data		GHS data	
	Informal help with domestic and/or personal care tasks (ADLs not filtered)		Informal help with domestic and/or personal care tasks (ADLs filtered on stairs)		Informal help with domestic tasks	
	Sample number	%	Sample number	%	Sample number	%
Spouse	418	21.3	385	22.2	226	30.6
Child	484	24.7	467	27.0	244	33.1
Spouse/child	114	5.8	111	6.4	29	3.9
Other	165	8.4	163	9.4	122	16.5
None	776	39.6	606	35.0	117	15.9
Total	1958	100	1733	100	738	
Missing	1		1			

Source: ELSA Wave 1 (2002); 2001/02 GHS

Notes: Filtering of ADLs in ELSA sample uses difficulty with stairs (excluding bathing)

However, using the revised definition of informal care, there is a closer correspondence between sources of informal care using the GHS and ELSA data, particularly when disability is defined in terms of ‘ADLs filtered’ (Table 4, last 4 columns). Using the revised GHS definition of informal care and the ‘ADLs filtered’ definition of disability in ELSA, the proportion of disabled older people receiving care from either a spouse or a child is similar (58.3% in the GHS and 55.6% in ELSA). The proportion of disabled older people receiving care from their children is also similar in both datasets (27.6% using the GHS data and 27.0% using the ELSA data). The difference between the two data sets is greater with respect to care from spouses, where a higher proportion (28.1%) receive informal care in the GHS than in ELSA (22.2%). However, the reason for this may be that, as noted earlier, questions about help in ELSA relate to difficulties arising specifically from health or memory problems, whereas no such restriction is placed in the GHS. Thus, the GHS is more likely to include

help received because an individual does not perform a particular task for reasons other than health problems. This is particularly likely to affect spouse care because all of this is co-resident care and therefore most likely to be affected by the domestic division of labour.

**Table 4**  
**Sources of informal help with domestic and/or personal care tasks received by disabled people aged 65 and over: ‘Revised’ GHS definition of informal care and ELSA definitions of disability, England, 2001/2002**

Sources of informal care	ELSA Data Informal help with domestic and/or personal care tasks (ADLs not filtered)		ELSA data Informal help with domestic and/or personal care tasks (ADLs filtered on stairs)		GHS data Informal help with domestic and/or personal care tasks ('Revised' GHS definition)	
	Sample number	%	Sample number	%	Sample number	%
Spouse	418	21.3	385	22.2	208	28.1
Child	484	24.7	467	27.0	204	27.6
Spouse/child	114	5.8	111	6.4	19	2.6
Other	165	8.4	163	9.4	93	12.6
None	776	39.6	606	35.0	215	29.1
Total	1958	100	1733	100	739	
Missing	1		1			

Source: ELSA Wave 1 (2002); 2001/02 GHS

Notes: Filtering of ADLs in ELSA sample uses difficulty with stairs (excluding bathing)

A key conclusion from this analysis is that comparability in the analysis of sources of informal care using the GHS and ELSA data seems to be enhanced if the revised definition of informal care is used to analyse the GHS and if the ‘ADLs filtered’ definition of disability is used to analyse the ELSA data. Using these definitions, some similar observations can be made about sources of care received by disabled older people, whether the 2001/02 GHS or the 2002 ELSA data are used. The majority of disabled older people receive help with personal and/or domestic tasks either from a child or a spouse. Over a quarter of disabled older people receive informal help from a child only. Of those receiving informal care, over 80% receive care from a spouse, a child or both.

### Step 3: Disabled older people receiving care from a child in GHS and ELSA

The third step is to explore how far the definitions of informal care and disability, described in the section above, identify samples with similar characteristics. This section focuses in particular on disabled older people receiving care from their children. Receipt of care from children is particularly important in the present context because, as noted earlier, a key aim of the analysis for MAP2030 is to incorporate the availability of living children in the PSSRU model. The focus here is on people receiving care from a child only, since the characteristics of people receiving care from both a spouse and a child are likely to be somewhat different and require separate analysis (cf Pickard *et al* 2007).

Table 5 below summarises the characteristics of disabled older people receiving care from their children in the GHS and ELSA datasets. The characteristics described in the table are those that are likely to affect receipt of informal care [add refs] and are available in both the GHS and ELSA. The table shows the age, gender, marital status, household type and housing tenure of disabled older people who receive informal care from their children.

Table 5 shows that the characteristics of people receiving care from their children are similar in both data sets. In both ELSA and the GHS, receipt of informal care from children increases sharply with age. People receiving informal care from children are twice as likely to be women as men. They are almost always widowed, divorced or separated, either living alone or with others. They are more likely to be renters than owner-occupiers.

With regard to specific characteristics, the similarities between the datasets are sometimes striking (Table 5). The same proportion (33%) of disabled older women receive care from a child in ELSA and the GHS. The same proportion of widowed, divorced or separated disabled older people (48%) receive care from a child in both datasets. A similar proportion of non-home owning disabled older people receive informal care from a child (34% in ELSA and 32% in the GHS).

There are also some differences between the datasets in the characteristics of disabled older people receiving care from children (Table 5). People aged 85 and over are more likely to receive informal care from children in ELSA than the GHS (44% and 39% respectively). Single disabled older people living with others are more likely to receive informal care from children in the GHS than ELSA (74% and 64% respectively).

Nevertheless, there are overall strong similarities between the datasets in the characteristics of people receiving care from their children. And this in turn helps to confirm the definitions of informal care and disability that have been utilised here for the analysis of the GHS and ELSA.

Following discussion of these results, I would propose that the next stage in the analysis focuses on receipt of informal care by disabled older people from their children using the ELSA data, with disability defined in terms of 'ADLs filtered'. The analysis would examine characteristics of disabled older people not available in the GHS, in particular, the availability of living children, the gender of these children and the educational qualifications of the disabled older people.

**Table 5**  
**Characteristics of disabled older people who receive informal help with personal care and/or domestic tasks from children: comparison of GHS and ELSA data, England, 2001/2002**

Characteristics	ELSA data (ADLs filtered on stairs)			GHS data (‘Revised’ GHS definition)		
	Informal care from child	Sample base	% with informal care from child	Informal care from child	Sample base	% with informal care from child
<b>Age</b>						
65-69	45	312	14.4	21	114	18.4
70-74	76	362	21.0	39	151	25.8
75-79	87	379	23.0	37	174	21.3
80-84	114	349	32.7	50	152	32.9
85+	146	333	43.8	57	146	39.0
<b>Gender</b>						
Men	99	610	16.2	46	261	17.6
Women	368	1124	32.7	158	478	33.1
<b>De facto marital status</b>						
Single never married*	3	100	3.0	1	41	2.4
Married/cohabiting	48	771	6.2	27	329	8.2
Widowed/divorced/separated*	415	862	48.1	176	368	47.8
<b>Household type</b>						
Single, living alone	325	817	39.8	124	339	36.6
Single, living with others	94	146	64.4	54	73	74.0
Married/cohabiting	48	771	6.2	27	329	8.2
<b>Housing tenure</b>						
Owner	256	1089	23.0	98	402	24.4
Renter**	214	634	33.8	106	337	31.5

Source: ELSA Wave 1 (2002); 2001/02 GHS

Notes: \* = not cohabiting; \*\* = in the GHS renter excludes those who own and are, or are partner of, head of household; in ELSA, renter includes those living rent free in the household of family or friends.

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