D3.2

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Evaluation of cost and benefit/effect

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	for and partic	ipation by people with dementia				
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Partners:	TELLU Tellu AS (Norway)					
	FORGET	Forget-me-not AS (Norway)				
	SIDSELB	Sidsel Bjørneby Sole Proprietorship (Norway)				
	HOUSING21	Housing 21 (United Kingdom)				
	DSDC Trent Dementia Services and Development					
	Centre (United Kingdom)					
	BIS	BIS Berlin Institute for Social Research (Germany)				

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1. Introduction

This document includes the evaluation of the cost-benefit/effect of the Mylife product/service. We summarise the results from the field trials that were conducted in the Mylife project: Trial 1 during spring-summer 2012 and Trial 2 during late autumn 2012. The trials were conducted in the United Kingdom, Germany and Norway. The number of trial participants is:

Trial 1:

UK 10 pairs¹

Germany 13 pairs (1 dropout)

Norway 11 pairs (3 dropouts)

Trial 2:

UK 8 pairs

Germany 9 pairs

Norway 8 pairs

The trials resulted in a large amount of empirical data. In the future, these data will be used (a) in academic publications and (b) for creating marketing and promotional material. In this document, only aggregated results will be presented.

The field methodology behind the data collection is described in detail in Mylife Deliverable "D3.1 User test and field trial guidelines". The cost-benefit/effect methodology is available in Deliverable "D2.2 Cost-effectiveness methodology description".

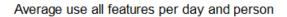
¹ "Pairs" mean pairs of carer(s) and the person they care for.

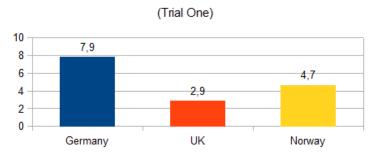
2. Benefit/effect of Mylife

2.1 Use, usefulness and ease of use

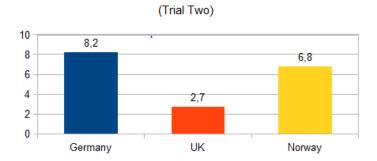
The average use varies strongly between the participating countries, but also for each country. Some participants used it a lot, some less. In an average of 64 days of use and 29 participants for trial one the features were chosen almost 10.000 (9.863) times, for the second trial it was an average of 50 days of use, 25 participants and 7.731 times choosing a feature.

The graphs below show which features – for each trial – were chosen the most.





Average use all features per day and person



It becomes obvious for both trials that the Today-feature seems to be the most important one as it is used far ahead of other features; also the calendar was chosen a lot². This can be explained by the fact, that these two features refer – by offering time orientation as well as an overview about daily activities and events - directly to the problems the target groups experience in daily life³.

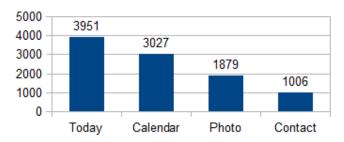
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² It is to be noticed that some users obviously mixed Today and Calendar and talked about these features as one.

³ Beside this, one have to differentiate the features shown on the tablet. For some participants some features were not available, because they were deactivated by the secondary user to avoid unneccessary information. The today feature can't be deactivated, so it is much more likely to be used.

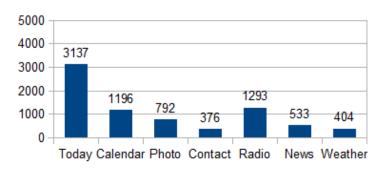
Usage of Mylife features (Trial 1)

(all countries, average: 64 days of use; n = 29)



Usage of Mylife features (Trial 2)

(all countries, average: 50 days of use; n = 25)



Beside these main features the radio seems to be very popular and was definitely the most-used feature for pleasure. The reason became clear in the interviews: The users do not have to adjust or search for the channel to listen to it anymore – they just have to push one button, so it is easier to use than the normal radio. People, that did not listen to the radio since for a long time ago (because to use their old one was too complicated) now started to listen to it again and really enjoyed its easy access. It is also an acknowledged fact that music has a positive therapeutic effect on persons with dementia⁴. Radio may have been experienced as a feature with similar effect.

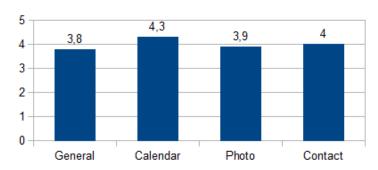
The secondary user was asked to assess the *usefulness* of the different features and the Mylife service in general. The person could rate on a scale from 1 (not useful) to 5 (very useful), the graph shows the average answer of this assessment. It becomes clear that the acceptance of the several features and the service in general is very high.

The calendar/today feature is in both trials assessed to be the most useful one of this service. This result is also confirmed by the interviews with the user, as this feature helps the most with dealing with the memory problems the target group experiences in daily life.

⁴ Cf. Hanne Mette Ochsner Ridder: «Forskning i musikterapi – personer med demens». DANSK MUSIKTERAPI 2012, 9(1). p. 3-12. In Danish. (This article includes a rich reference list of literature on music as theraphy for persons with dementia.)

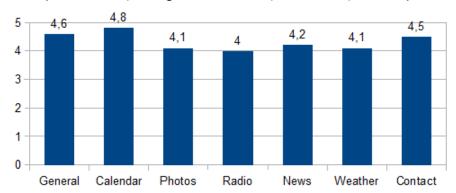
Trial1: How useful is Mylife/the feature

(after 8 weeks, average of the answers; all countries, n = 21-23)



Trial 2: How useful is Mylife/the feature

(after 8 weeks, average of the answers; all countries, n= 17-21)



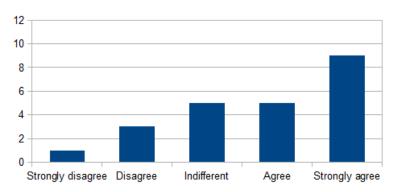
Other assessments seem to vary, if one compares the assessed usefulness by the secondary (questionnaire) and by the primary user (interview). This might be caused by the fact that the wishes and needs of the person with memory problems are not always obvious to their environment. E.g., the radio feature, rated with "just" a 4 above, was assessed as very helpful, entertaining and easy to use by the primary user. It was the most popular pleasure feature (see above), but for some reason rated as less necessary by the secondary users.

In general Mylife seems to be more popular in the second trial, every feature that was already implemented in the first trial, was assessed better in the second one. Even the rating of the Mylife service in general is much better than in the first trial (increased from 3,8 to 4,6).

One of the main ambitions of the Mylife project was to develop a product that is easy to use for persons with cognitive disability. This aspect has been examined in the field trials. The results show that the primary end users were able to use the service (Trial 1 before radio, weather forecast and newspapers were added to the system):

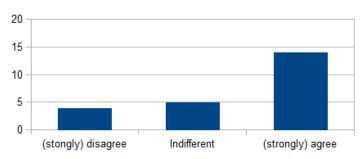
Trial 1: Mylife is easy to use

(secondary user, all countries; n = 23, after 8 weeks using it)



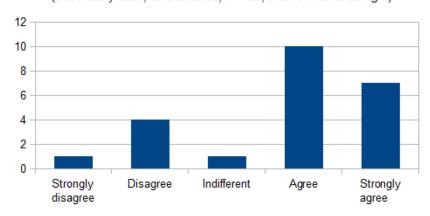
Trial 1: Mylife is easy to use

(after 8 weeks, n = 23)



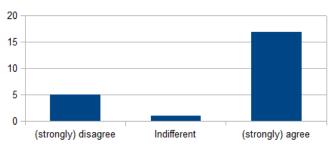
Trial 2: Mylife is easy to use

(secondary user, all countries; n = 23, after 8 weeks using it)



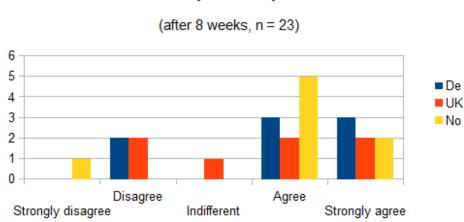
Trial 2: Mylife is easy to use

(after 8 weeks, n = 23)



The results show, that – after implementing additional features – the participants of the second trial assessed Mylife even a bit better than in the first trial with less features. This is surprising as the new features (when they are activated) lead to a submenu, which makes the system a bit more complex. The results make clear, that even if there is new and more complex menu navigation, the Mylife interface and system seems to be still easy and intuitive to use.

These results vary⁵ to some extent between the participating countries, as illustrated below. The variation is less caused by the specific country. The field trials also showed, that the ability to use Mylife (or the recognition of its easiness) is not related to computer experience, but strongly related to the cognitive condition (e.g. caused by dementia) of the user. Beside this, most of the people with memory problems and no experience in using such a technology found it easy to use and pointed out the simplicity of interface and operation.



Trial 2: Mylife is easy to use

Ease of use is the cornerstone for successful commercialisation. In this sense, the Mylife product

2.2 Wellbeing

Mylife's wellbeing effect for both primary and secondary end users has been documented through the analysis of data from "Appendix 6 – Wellbeing questionnaires" (cf. Mylife deliverables D2.2 Costeffectiveness methodology description and D3.1 User test and field trial guidelines).

The wellbeing data has been aggregated to describe the "total wellbeing" effect of Mylife⁶. For the primary end user, the wellbeing questionnaires included questions about:

⁵ Mainly, the variations reflect real differences in the user experience. Another reason for variation may be the natural "noise" that a qualitative field methodology may cause. For example, two researchers using a standardised and well-documented methodology – such as Mylife's test and trial guidelines – may act and communicate somewhat differently. Also, the secondary end users (carers) may act differently; one supports the primary end user a lot, while another carer might be more reluctant to provide support. Due to this «human factor», the conducting of field trials, interviews, tests etc. will always include certain uncertainties concerning data and observations.

⁶ As the end user's wellbeing may be affected by a number of small factors, we have to be careful when interpreting the data. For example, the overall feeling of wellbeing may suddenly increase because a friend drops a visit or someone calls, and it may decrease because of illness or just a small everyday quarrel with the spouse. Our data does not reveal such factors.

- feeling good about oneself, useful, relaxed, cheerful, lonely, muddled up, confident, interested in things, informed about what is going on, having enough contact with other people
- forgetting who people are, what day it is, what one is supposed to be doing
- being occupied / having things to do, able to get help when one needs it, able to make up one's own mind about things
- losing things (e.g. keys, glasses, purse)
- dealing with problems well

For the secondary end user, the wellbeing questionnaires included questions about whether or not (1) the carer's relative has:

- needed help
- had enough to do to keep her/him occupied during the day
- been lonely
- got enough support

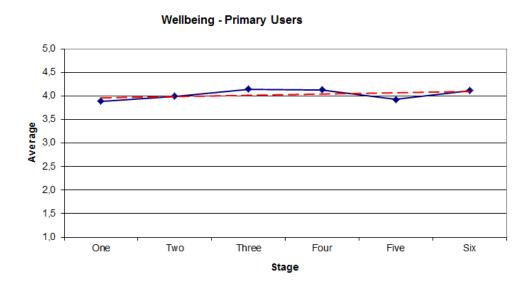
(2) the carer has:

- found it easy to communicate with her/his relative
- been concerned about the relative's needs
- been irritable with or worried about the relative

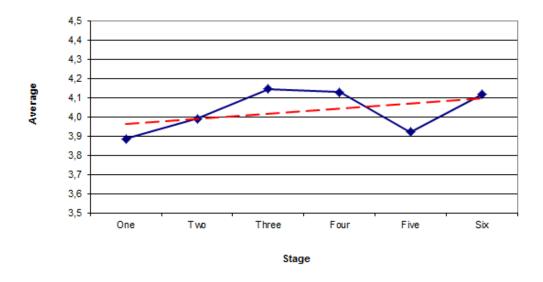
(c) the carer feels that

- the relationship with one's relative has been good
- the relative is too dependent on the carer
- she/he would have liked to have been able to do more for the relative

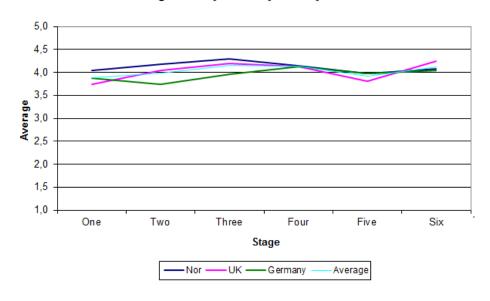
For primary end users, an increase of wellbeing can be observed, as shown in the average graphs for all three countries (dashed trend line, second graph with more detailed scale in the interval of observations):



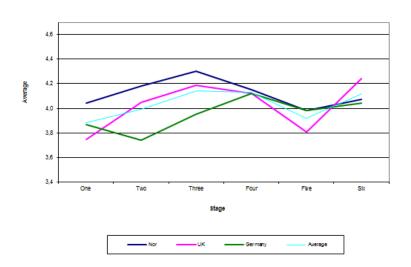
Wellbeing-Primary Users



Wellbeing - Primary Users by Country

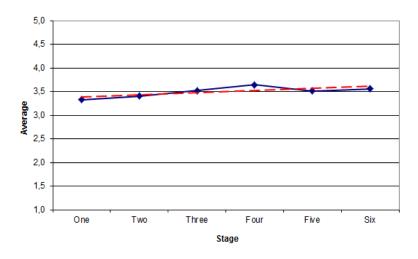


Wellbeing - Primary Users by Country

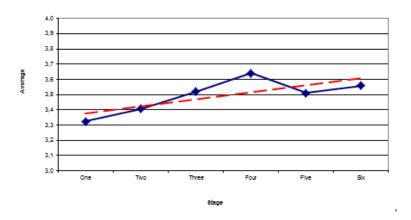


For secondary end users, an increase of wellbeing can also be observed, as shown in the average graphs for all three countries (dashed trend line, second graph with more detailed scale in the interval of observations):

Wellbeing - Secondary Users

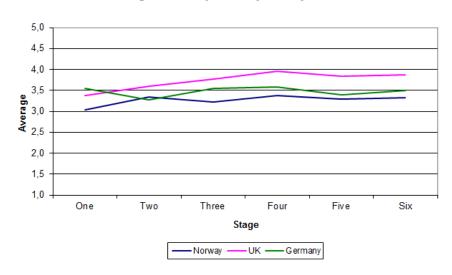


Wellbeing - Secondary Users

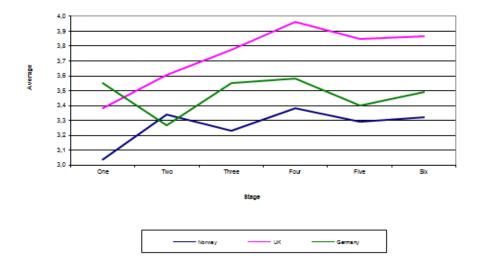


The secondary users' wellbeing by country shows that the increase is most in the United Kingdom.

Wellbeing - Secondary Users by Country



Wellbeing - Secondary Users by Countr



3. Cost of Mylife

3.1 Willingness to pay

The economic cost component of the Mylife product/service is three-fold:

- the purchase of the device
- the purchase of the software license
- the monthly fee for using the service

After the trials, the secondary users were asked to participate in a willingness to pay exercise. The exercise resulted in following statistics (questions to carers and primary users):

Would you be interested in buying Mylife?

	Yes	No	Pairs that answered
Germany	1	4	5
UK	6	2	8
Norway	6	1	7
SUM	13	7	20

Would you prefer buying or leasing?

	Buying	Leasing
Germany	6	2
Germany UK	3	3
Norway	3	4
SUM	12	9

Do you have Internet access at home?

	Primary	end user	Secondary end user		
	Yes	No	Yes	No	
Germany UK	5	6	6		
	7	1	8		
Norway	3	4	6	1	

If you were to buy Mylife, where would you expect to find it?

	A shop with health devices	Electronics shop	Pharmacist	Internet	Others
Germany	4	5	3	6	4
UK	3	5	0	5	2
Norway	5	3	1	1	
SUM	12	13	4	12	6

What would you be willing to pay for touch screen, docking station and the Mylife software?

	> 800 €	700 - 800 €	600 - 700 €	500 - 600 €	400 - 500 €	300 - 400 €	200 - 300 €	100 - 200 €	< 100 €
Germany					2		6	2	1
UK					2			4	
Norway			1	2	2	1	1		
SUM			1	2	6	1	7	6	1

What would you be willing to pay pay per month for the use of Mylife service?

	> 40 €	35 - 40 €	30 - 35 €	25 - 30 €	20 - 25 €	15 - 20 €	10 - 15 €	< 10 €
Germany				1	1	2	6	1
UK							2	2
Norway	3			1		2	3	
SUM	3			2	1	4	11	3

Our conclusion is that among the Mylife project's participants, there is a promising willingness to pay for the product/service. It should also be noticed that the users' opinion⁷ is based on use of a *prototype* with all its weaknesses, not on use of a commercial product. During the trials, a number of areas for improvement have actually been identified. These improvements should increase the potential customer's willingness to pay.

As far as the monthly fee is concerned, the sum of approximately 15 € per month corresponds well with the research team's assumptions of current price level for content subscriptions.

⁷ The primary and secondary users answered together.

Apparently, there is also a need to look for cheaper devices than the Motorola Xoom⁸ which was the trial equipment.

To sum up, the willingness to pay data demonstrates an overall positive effect of Mylife on the primary end users' wellbeing. It will also be reasonable to believe that the secondary end users have experienced Mylife as a positive factor in their caring situation.

3.2 Other aspects

The research team has not documented other significant cost elements of the Mylife service, such as social costs connected to reduced quality of care (e.g., carers relying too much on Mylife and ignoring to visit the person the care for, or that Mylife is used as medication reminder and the user forgets to follow the prompts), negative impacts on person with dementia (e.g., annoying or scaring content, or frequent contact requests without carer's response), or ethical aspects (e.g., feeling of being controlled or secretly monitored, or intrusive use of calendar appointments).

The management of calendar appointments is, however, an aspect that deserves a comment. Some primary users did indeed express a wish to be able to insert calendar appointments themselves in order to have a more autonomous control of their daily activities. The comments concerning this indicate that it may be experienced annoying that the secondary user must always update the calendar. "Do I really have to call my daughter to insert an appointment that only I know about?" is a "sigh" that describes this experience.

Opening the calendar for updates on the tablet itself is therefore an issue for the future development of the Mylife service.

Finally, our final recommendation is to provide proper "Useful tips" that assist the secondary users in administering the Mylife service, including possible negative effects of careless communication through the calendar or photo album (i.e., messages and text captions written by the carer).

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⁸ http://en.wikipedia.org/wiki/Motorola Xoom