

# Access To Timely Formal Care (Actifcare) – Piloting Focus Groups Of A European Study

## Preliminary findings and experiences with focus groups with people with dementia



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### Background

Professional support may allow people with dementia to stay longer at home and might release informal carers [1]. However, available services seem to be underused and informal carers often seek help very late [2]. The uptake and utilisation of services is a complex process that is only partially understood [3]. Psychosocial and cultural aspects but also service-related aspects may play an important role [4].

The Actifcare project, conducted in 8 EU countries (DE, IE, IT, NL, NO, PT, SE, UK), seeks to explore the experiences of people with dementia (PwD), informal carers (IC) and healthcare professionals (HCP) within this process. Special attempts were made to include PwD because their contribution to qualitative research is still low [5]. We discuss experiences made with focus groups with people with dementia and report first preliminary findings.

### Methods

Focus groups with PwD, IC and HCP (Sept 2014 – April 2015). A questioning route was piloted in Germany (Sept 2014) that worked well with IC and HCP. Only one PwD could be recruited for the pilot. Though she apparently understood the questions, she consistently stated that no help was needed albeit she received professional care. Thus it was decided to use pictures as an additional stimulus for PwD.

Qualitative content analysis was applied using open coding in each country. Transnational findings will be analysed in a comparable way seeking to identify overarching themes.

Experiences with focus groups with PwD in all countries were collected in an open way, clustered and narratively reported.

### Results

#### Experiences with focus groups with people with dementia

Box 1 shows the experiences made when arranging and performing focus groups with PwD. Overall, the preparation was difficult and time consuming and performing focus groups with PwD turned out to be challenging.

#### Preparation

- Identification of eligible participants: experiences with formal care and able to share their views
- Approaching natural groups
- Dealing with concerns of the relatives
- Gatekeeper required
- Preparation of the moderator: familiar with local dialect or jargon, knowledge about the participants (support from relatives or healthcare professionals)

#### Performance

- Late cancellations, groups could not take place
- Informal atmosphere required (taking notes may be not appropriate)
- Accompanying person joined the discussion
- Keeping the focus on professionals support is difficult, PwD were “here and now”
- Strong guidance by the moderator required
- Sparse interaction between participants, more asking each in turn.
- Pictures not helpful, sometimes even confusing
- Group situation sometimes worsened speaking problems
- Stage of dementia determined level of contribution: groups with people with early onset dementia in an early phase differed considerably from other groups

#### Analysis

- Dealing with unreliable answers
- Interpreting short and ambiguous statements

Box 1: Experiences with focus groups with people with dementia.

#### Preliminary findings of the focus groups with informal carers

Table 1 displays the number of focus groups (participants) per country. The analysis is still in process. First preliminary findings of the IC focus groups in DE, IE, IT and NO are presented.

- |                                |   |
|--------------------------------|---|
| <b>Appropriate information</b> | <ul style="list-style-type: none"><li>• About services, about dementia and its consequences (especially right after getting the diagnosis)</li><li>• Professional guidance needed but not always available</li></ul>  |
| <b>Inner barriers</b>          | <ul style="list-style-type: none"><li>• Reticence of the IC</li><li>• Denying dementia</li><li>• Resistance of the PwD</li><li>• A strong sense of duty and responsibility towards the PwD</li><li>• Perception of IC that they provide the best care</li><li>• A crisis may be a trigger (for the IC or for the PwD)</li><li>• Bad experiences may be an obstacle for uptake of services</li><li>• Some IC also sought professional help as early as possible</li></ul>  |
| <b>System-related features</b> | <ul style="list-style-type: none"><li>• Need-tailored support (also for IC) facilitates use of services (especially difficult for people with early onset dementia)</li><li>• Flexible and reliable services that focus also on social aspects</li><li>• A key contact person who also acts proactively</li><li>• Good communication and cooperation among HCP and with IC</li><li>• Avoiding stigmatisation or labelling/offering every day activities</li><li>• Inequity caused by the system (out-of-pocket payment, distances, IC have to fight for appropriate professional support)</li></ul> |

Country	Number of focus groups (number of participants)		
	Healthcare professionals	Informal carers	People with dementia
DE	4 (16)	5 (21)	3 (10)
IE	3 (18)	3 (16)	2 (7)
IT	2 (9)	2 (8)	2 (6)
NL	2 (12)	2 (10)	2 (13)
NO	2 (12)	2 (7)	3 (10)
PT*	2 (12)	2 (11)	1 (4)
SE	2 (11)	2 (8)	-
UK*	2 (16)	3 (15)	1 (7)
<b>Total</b>	<b>19 (106)</b>	<b>21 (96)</b>	<b>14 (57)</b>

Table 1: Focus groups conducted per country.  
\*Further groups with people with dementia scheduled.

### Discussion

First preliminary findings of focus groups with IC indicate that use of services is a process influenced by inner barriers but also determined by features of the healthcare system, confirming current research [4]. Inner barriers may differ considerably between IC and this has to be taken into account. More elaborated strategies might be required, beyond providing information and offering services. The final findings will contribute to a better understanding and provide the basis for the development of suitable approaches or initiatives.

Focus groups are used increasingly in health research [6] but discussions are sparse whether and when focus groups with PwD are appropriate [7]. Though some advantages are described, e.g. group situation is relieving, interaction may enhance telling [7], we experienced a number of challenges. However, some of these difficulties are related to our research question. It was particularly difficult to identify PwD using services and able to report their experiences. An appropriate stimulus is required to facilitate remembering and speaking about experiences with professional support. A different approach may be necessary such as using the natural context for assessing the experiences of PwD [8].

#### References

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