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# **COULD PROFESSIONALS AND VOLUNTEERS OF THE SOCIAL AND HEALTH CARE NETWORK ASSESS THE NEEDS OF INFORMAL CAREGIVERS OF PERSONS WITH DEMENTIA (IC-D) MORE EFFECTIVELY ?**

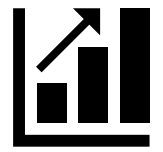
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**University of Applied Sciences and Arts Western Switzerland (HES-SO)**

29.04.2021

**2nd International CNHW Conference**

# Background



- 155'000 people with dementia in Switzerland in 2019
- projection x2 until 2050 (Association Alzheimer Suisse 2019)



- 60% live at home with the support of **one or more informal caregivers** and various professionals and volunteers (Association Alzheimer Suisse 2019)

- ➔ about **160'000 IC-D** in Switzerland (Otto, Leu et al. 2019)
- ➔ provide half of care hours/costs i.e. **CHF 5.5 billion** (ECOPLAN 2019)



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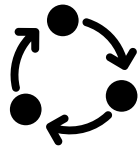
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IC-D have a significantly higher risk of negative health and quality of life outcomes (Brodaty and Donkin 2009; Perrig-Chiello, Höpflinger et al. 2010; Schulz and Martire 2004)



subjective burden and health problems of IC-D have a direct impact on the risk of early institutionalization (Gaugler, Kane et al. 2003) and abuse (Wiglesworth, Mosqueda et al. 2010)



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# Informal caregivers of a person with dementia...

...are under pressure

...have many and varied  
needs that are difficult to  
identify

...often ask for support too  
late, and lack information





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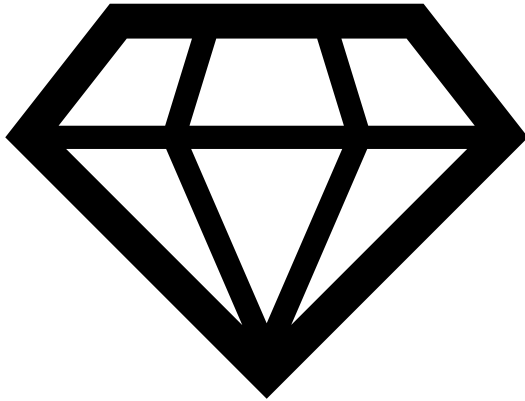
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IC-D are indispensable treasures, as they provide highly individualized and flexible care to their sick loved ones. Without them the health care system would not work!

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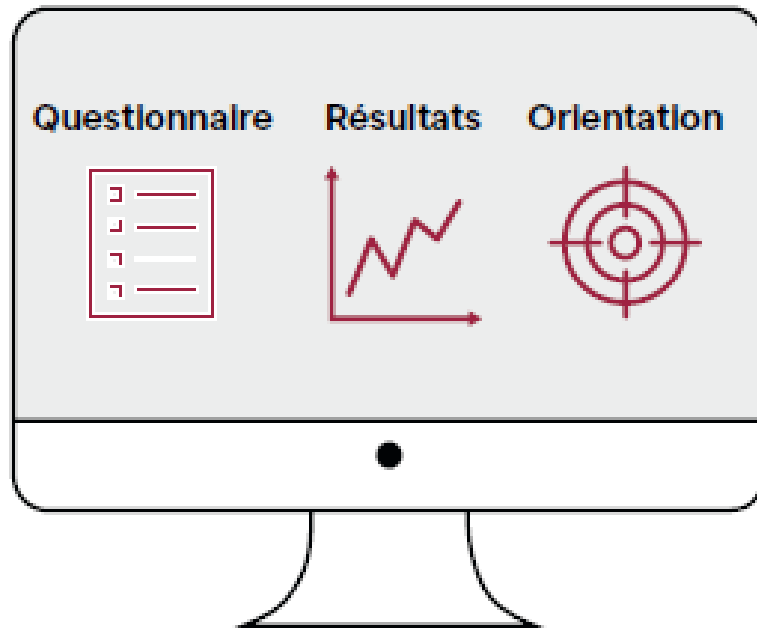
# Aim

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## Plateforme en ligne



The overall goal of the project **MeetMyNeeds** is to develop an online platform for a systematic, accurate and comprehensive assessment of the needs of IC-D, and to refer them to relevant services.

# Research question

What are the strenghts and the limitations in **current practices in the assessment of IC-D needs** ?



From the perspective of professionals/volunteers



From the perspective of IC-D



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# Method



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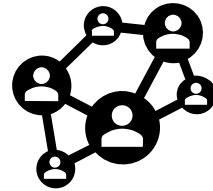
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## Survey 1 (online)



### Thematics

- Use of systematic tool
- Consistency within organization
- Duration
- Training
- Reassessment
- Storage
- Transmission
- Feedback

## Survey 2 (online/paper)



### Thematics

- Easy to find support
- Interest / lack of interest of providers for their needs
- How their needs are assessed





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# Results



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## Who responded to survey 1

- 63 support providers
- Diversity of profiles
- Working in this activity: 2 to 35 years
- Meet between 1 and 110 **IC-D** per year



	n	%
Nursing	29	46
Social work	17	27
Volunteers	5	7.9
Neuropsychologist (3) or psychologist (1)	4	6.4
Physicians (2 general practitioners, 1 geriatrician, 1 psychiatrist)	4	6.4
Ergotherapist	2	3.2
Pharmacist	1	1.6
Spiritual counsellor	1	1.6

## Who responded to survey 2

- 36 **IC-D**
- Between 25 and 87 years old
- Highly diversified levels of education
- **IC-D** for 4 months to 15 years
- **IC-D** from 1 to 168 hours/week



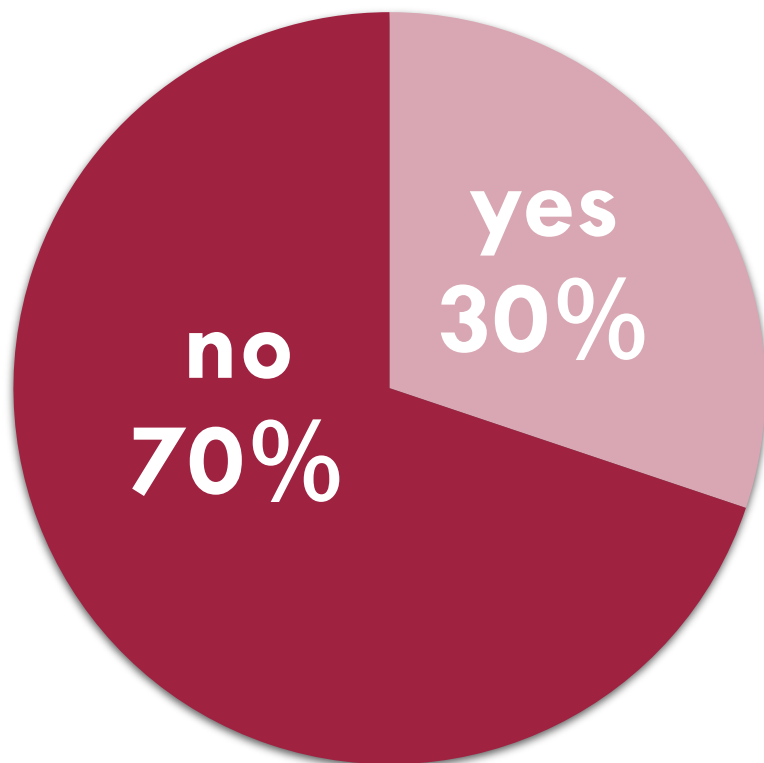
Relationship with the cared person	Details	n	%
Spouses	12 wives and 8 husbands	20	55.5
Child	9 daughters and 1 son	10	27.8
Other family member	1 daughter-in-law, 1 granddaughter, 1 unspecified	3	8.4
Other relationship	1 friend, 1 ex-husband	2	5.6



# Results



## Use of systematic tool (N=63)



- Interview guide (n=3)
- Tool or grid (n=4)
- Internally developed tool (n=2)
- Systematic assessment of patient's needs (n=7)
- Systematic tool focused on IC-D (n=4)
- Systematic needs assessment (n=2)

- Ask questions (n=15)
- Listen to needs (n=11)
- Discuss with IC-D (n=6)
- Needs spontaneously told by IC-D (n=6)
- Analyze the situation (n=5)
- Observe IC-D (n=3)



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# Results



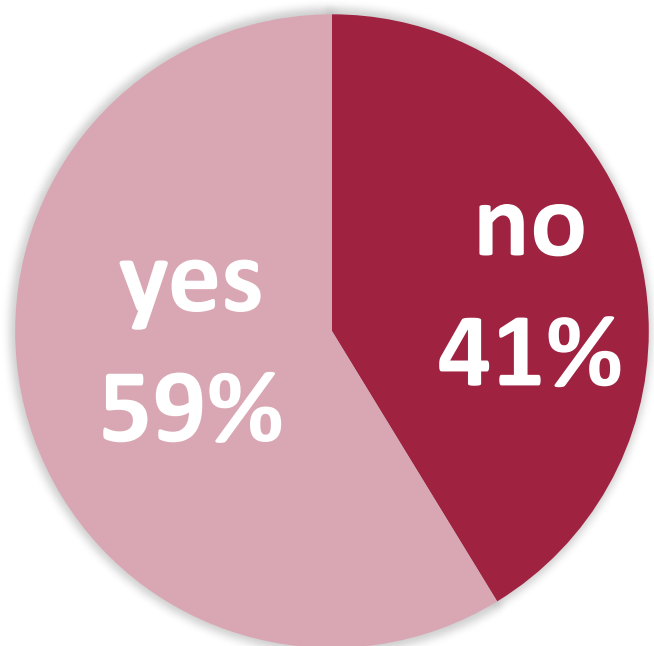
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## Consistency within organization (N=63)



- Each person does it differently (n = 13)

- Closely related to the lack of a common tool (n = 6)

« Nous ne disposons pas d'une grille ou procédure spécifique pour évaluer les besoins des proches aidants au sein de notre organisation. Ainsi, chaque assistante sociale évalue différemment les besoins des proches aidants. » <sup>ID 21</sup>

- Tools are available, but they are not used consistently (n = 3)



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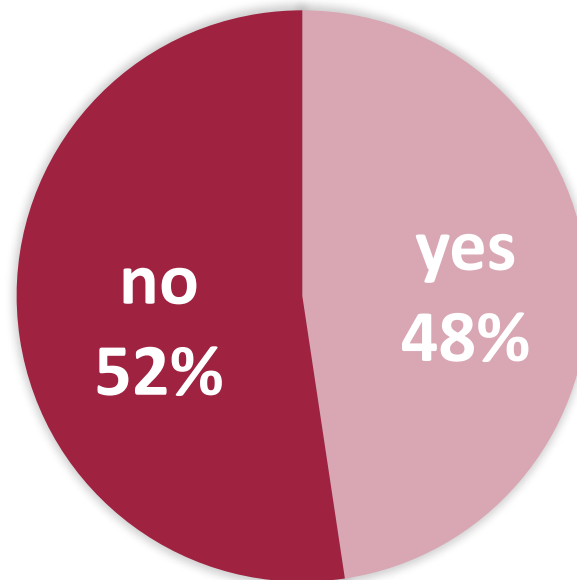
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## Duration (N=55)

- median 45 minutes (Q1 = 15, Q3 = 75)
- 1/4 report using 15 minutes or less (27.3%, n=15)



## Training (N=55)





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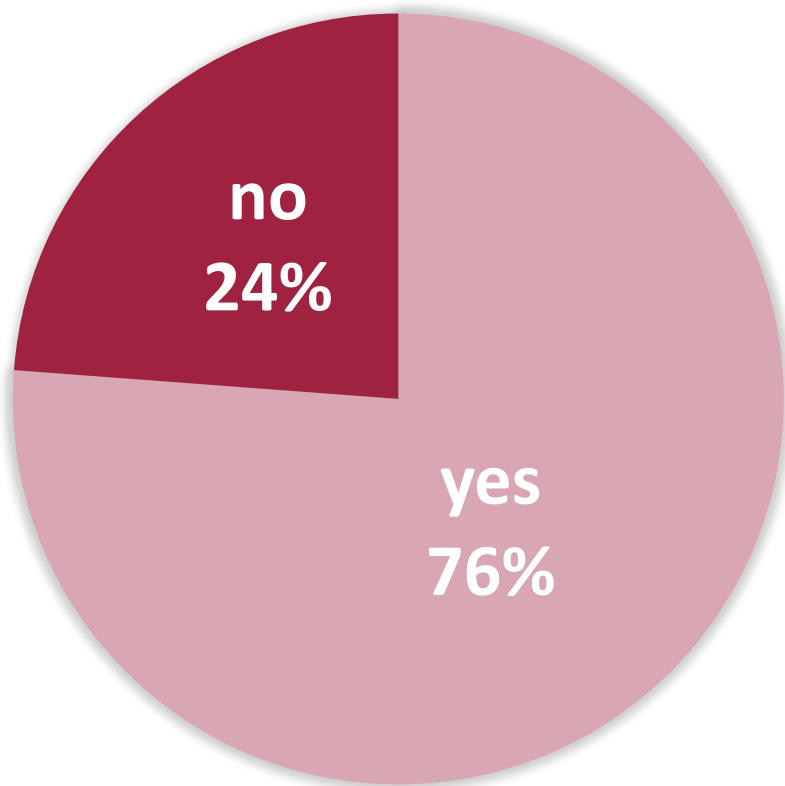
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## Reassessment (N=63)



	n = 30
after 1 week	3
< 1 month	8
1-3 months	10
3-6 months	4
6-12 months	5

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# Results

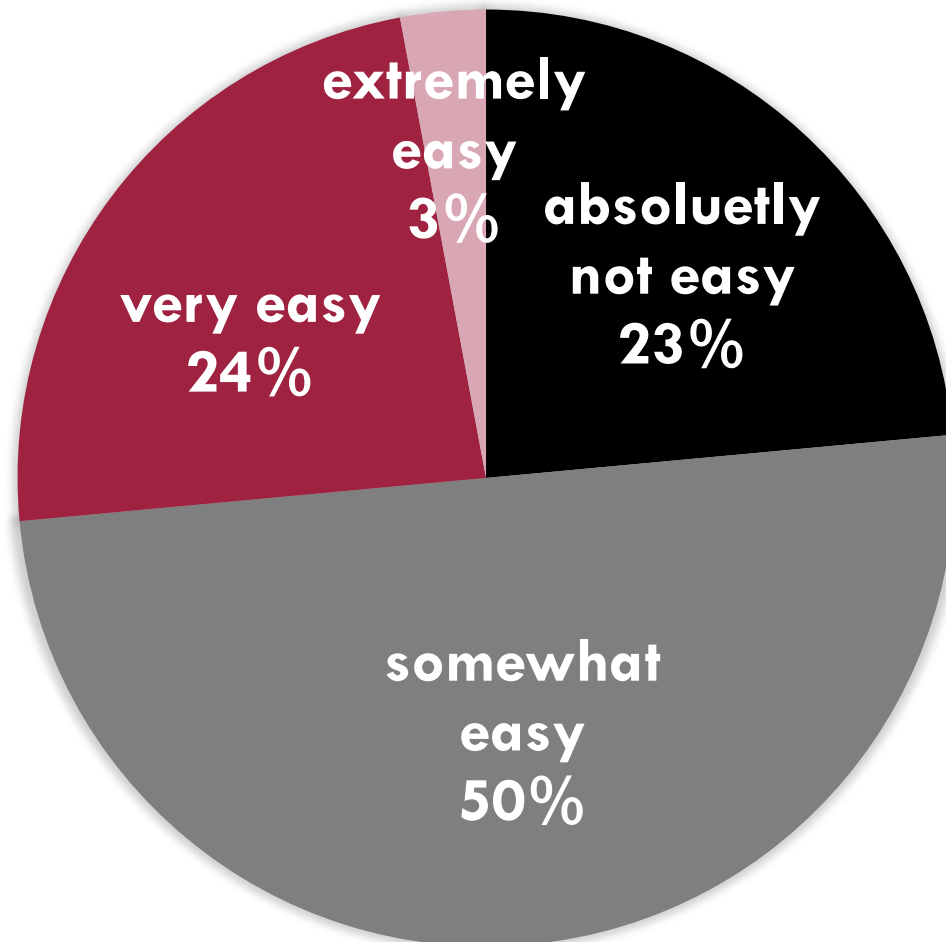


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## Easy to find support (N=34)



- Lack information and support
- Difficulty to find appropriate support

- Well-informed by physician, coordination center, course for IC-D or family member
- Information must be proactively searched
- Represents a significant workload
- Gap between knowing about help and receiving it
- Administrative difficulties are often an obstacle

- Excellent care and follow-up from social and health network

- IC-D working in care  
"I think my profession helped me to know quickly where to get the help we needed."

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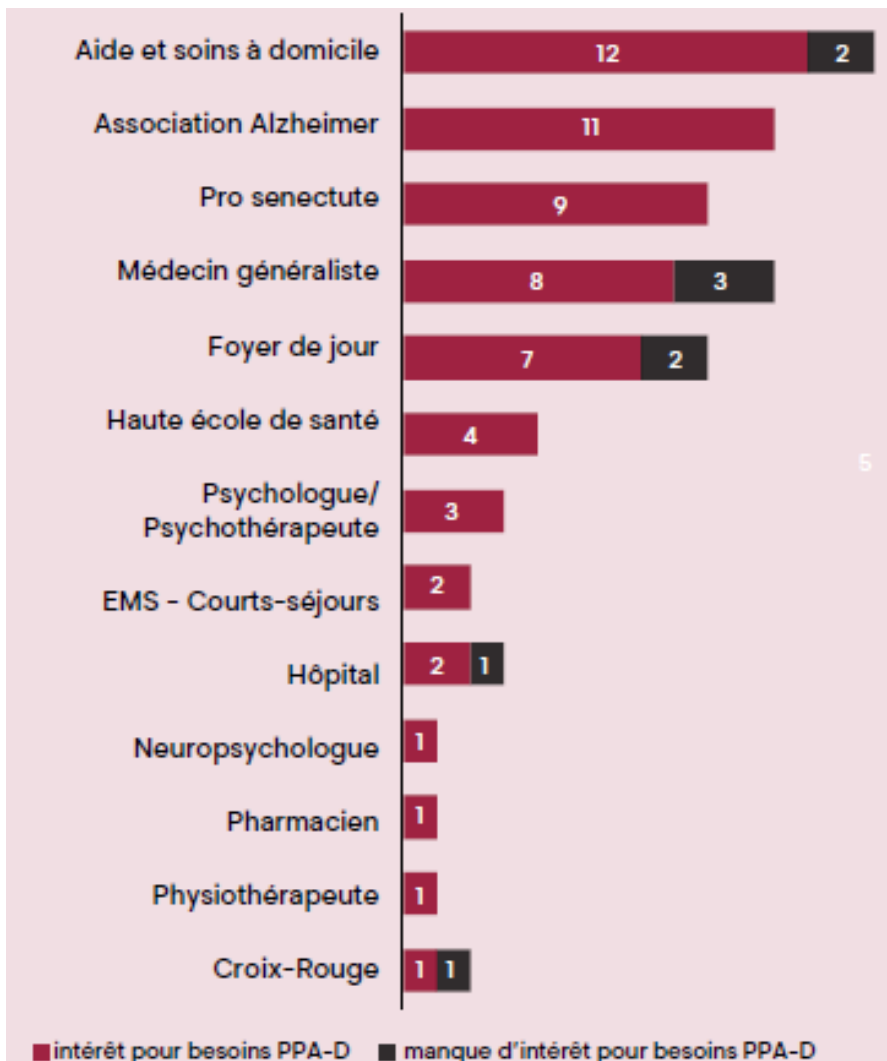
# Results



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## Interest / lack of interest for they needs (N=36)



→ IC-D report that a majority of providers consider their needs, particularly within dementia organizations

- Receiving information, advice or answers to their questions (n = 11), concrete help (n = 5), discussions (n = 5), visits, contacts or follow-up (n = 5)
- Feeling listened to (n = 3), the attention they received was kind or empathetic (n = 3)
- Providers were available (n = 2) or understanding (n = 2)

- Lack of support or information (n = 6)
- Lack of comprehension for their situation (n = 4)
- Solutions not adapted to their needs (n = 2)
- Interested contacts (e.g. for organization) (n = 2)

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## How their needs are assessed (N=21)

➔ Nearly two-thirds of IC-D described how professionals/volunteers evaluate their needs (58.3%)

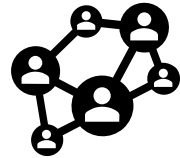
- asking questions (n = 10)
- talking with them (n = 6)
- listening to them (n = 1)



... during an interview (n = 4), contact by phone (n = 2), during a visit (n = 2) or by setting up a medical follow-up (n = 1).



# Discussion – summary of results



Providers do assess the needs of **IC-D**



Average 45 min to do so



70% of providers use **NO** systematic procedure



100% have **NO** specific tool to assess the needs of **IC-D**



Most **IC-D** perceive interest for their needs



Some **IC-D** perceive a lack of individualization of the support, a focus on the person with dementia or feel instrumentalized





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# Discussion – strengths & limitations



**Novelty:** very few studies about evaluation practices

**Sample diversity:** various professions and volunteers working in diverse organizations + different profiles of IC-D

**Triangulation:** integration of two points of view

**Generalization?** Study conducted only in the canton of Fribourg

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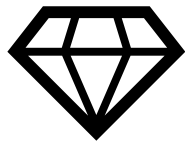
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# Our conclusions

An **online platform** would allow



**empowering IC-D** in becoming aware of their needs and identifying the support services relevant to them



**reducing provider's burden** in keeping their human skills for more specific tasks (in-depth evaluation, support, most vulnerable IC-D...)

# Contacts

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