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# AN ONLINE PLATFORM TO ASSESS THE NEEDS OF INFORMAL DEMENTIA CAREGIVERS (IDC) AND REFER THEM TO THE RELEVANT SUPPORT SERVICES

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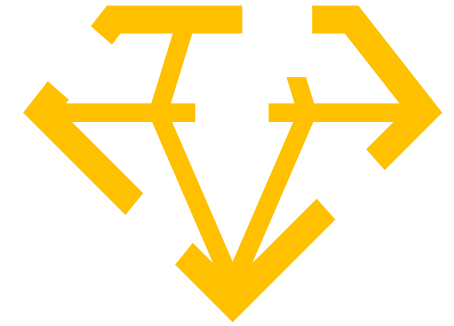
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# Challenges

**Many IDCs, projections of strong increase**  
**High risk for exhaustion with severe consequences**  
**Many unmet needs**



## Getting support: a long path



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# Solutions?

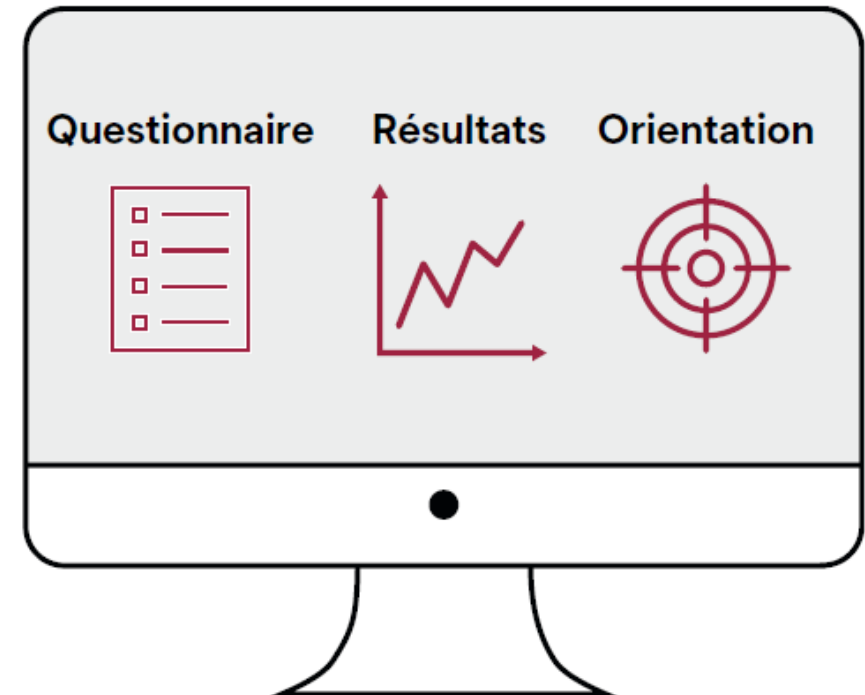
**Case management ?** Requires substantial professional resources

## Online platform?

Many IDC are elders which now often use online tools but these need to be adapted

-> **participative development**

### Plateforme en ligne





# Context for platform development

**In practice: support providers use heterogeneous and non-validated/non-specific instruments to assess the many and diverse needs of IDC**

**Systematic review: most questionnaires are poorly validated, and the best validated one covers limited needs**

Kipfer, S., & Pihet, S. (2019). Reliability, validity and relevance of needs assessment instruments for informal dementia caregivers: a psychometric systematic review. *JBI Database System Rev Implement Rep*. doi:10.11124/JBISRIR-2017-003976



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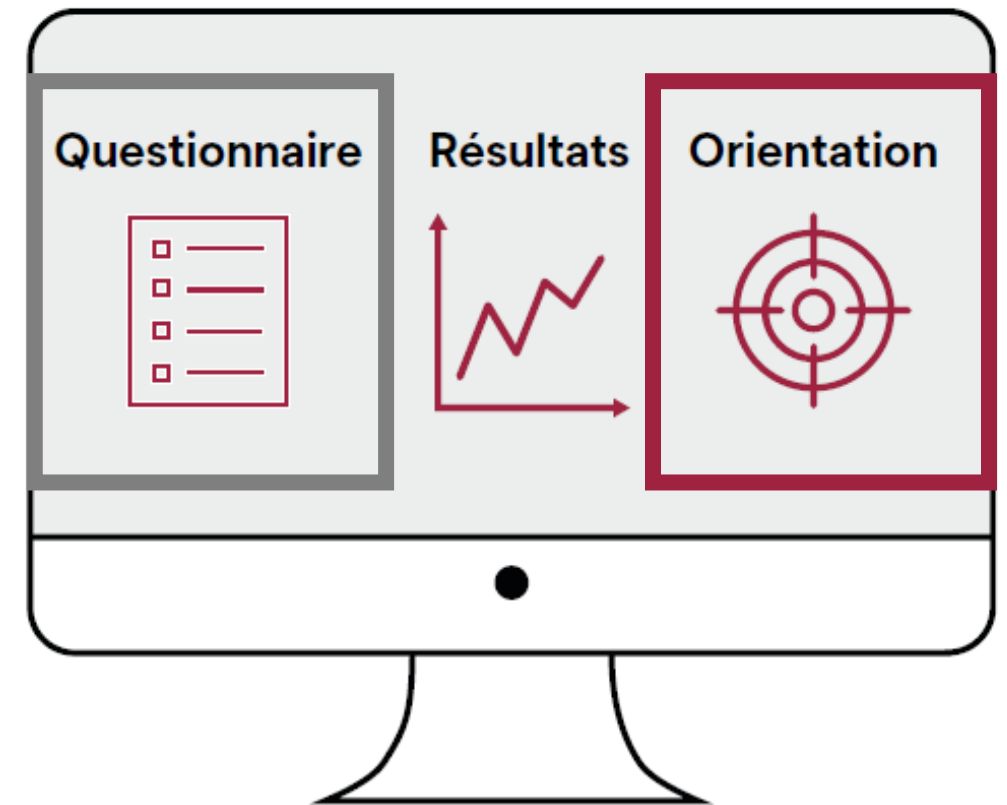
# Questions

How to assess the many and diverse needs of IDC?

How to refer IDC to the most relevant support services?

What are the preferences for an online platform ?

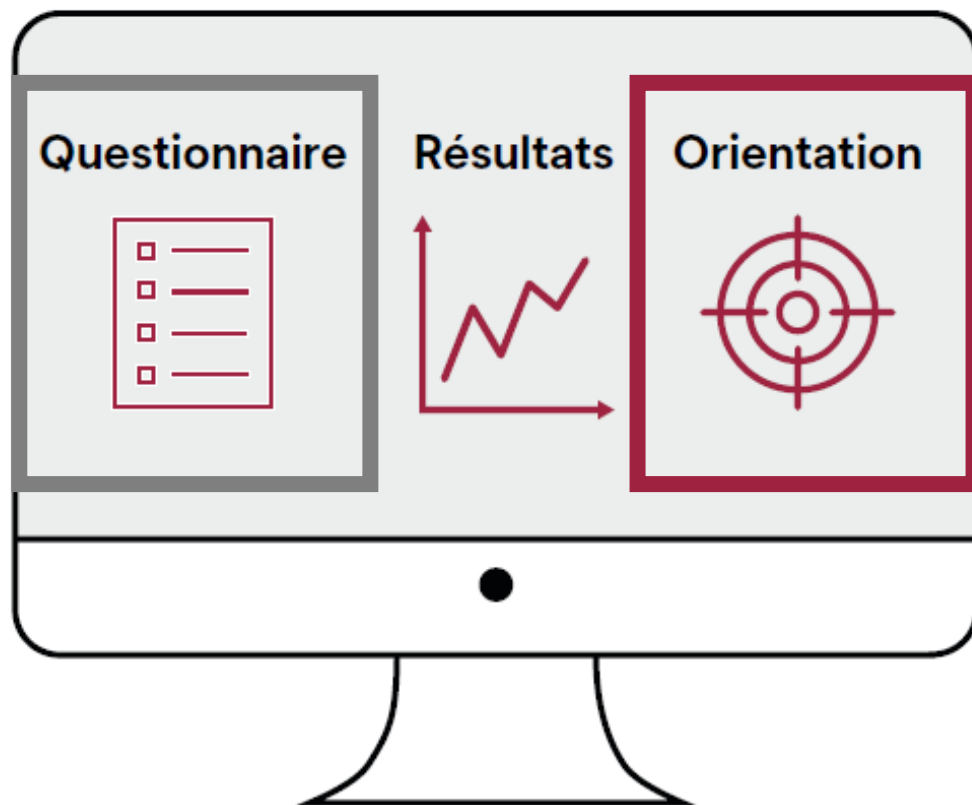
Plateforme en ligne





# Methods

## Plateforme en ligne



## Online survey - service providers

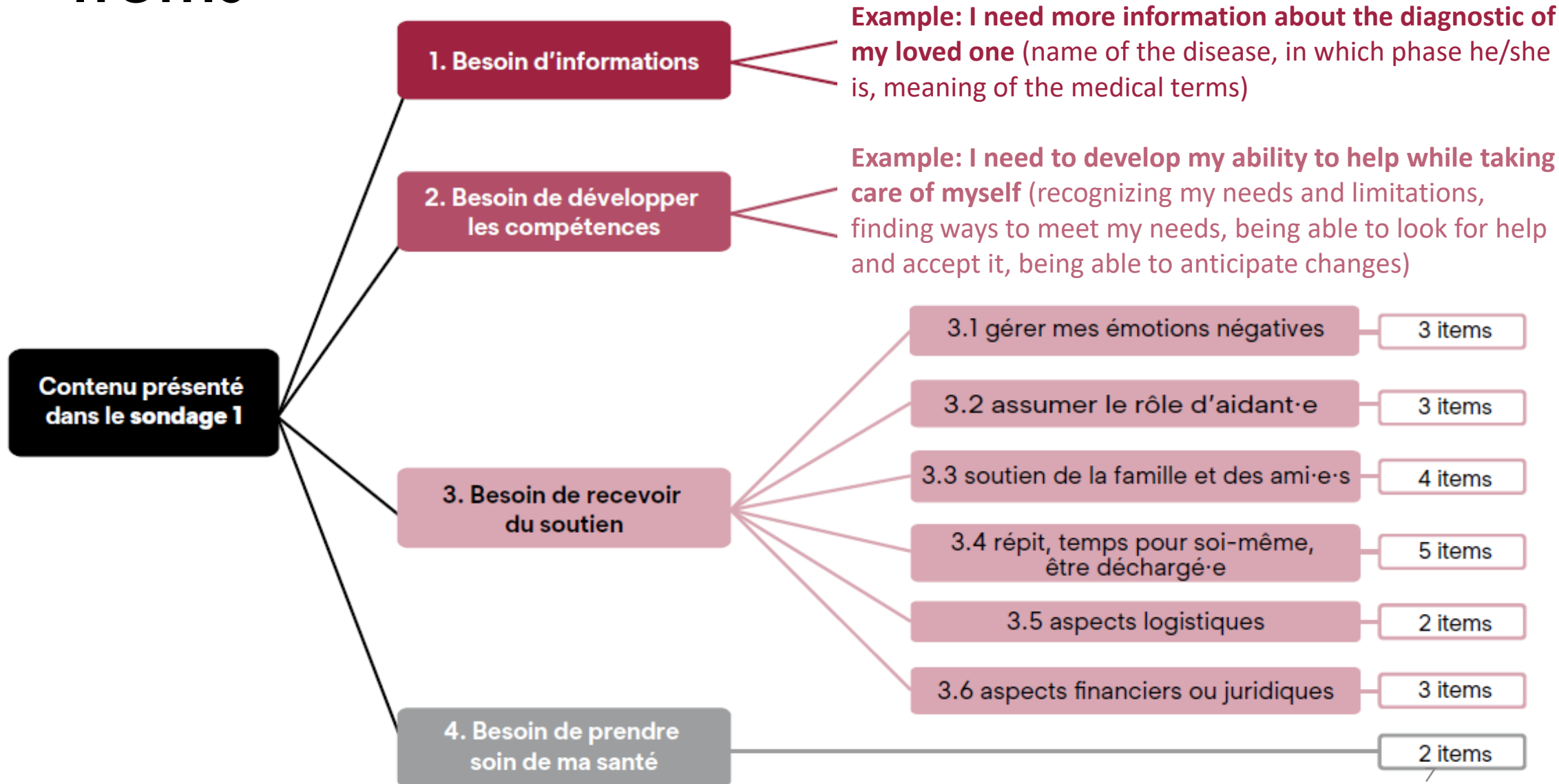
- Relevance of 46 items measuring needs
- Support services answering each need
- Relevance and clarity of screenshots

## Online or paper survey – IDC

- Relevance & clarity of 35 items measuring needs
- Preferences for screenshots



# Items





# Results - samples



## Support providers

- N=42 with very diverse profiles
- Working in this activity: 2-35 years (Med=7)
- Meet between 1-110 IDC /year (Med=10)

Type of support provider	n	%
Social work	15	36
Nursing	14	33
Physician (2 general practitioners, 1 geriatrician, 1 psychiatrist)	4	10
Neuropsychologist (2) or psychologist (1)	3	7
Volunteers	3	7
Ergotherapist	2	5
Spiritual counsellor	1	1.6

## IDC

- N=28 with very diverse profiles
- Between 25-87 years old (Med=66)
- Highly diversified levels of education
- IDC for 1-15 years (Med=4)
- IDC from 1-168 hours/week (Med=40)

Relationship with cared person	Details	n	%
Spouses	9 wives, 7 husbands	16	57
Child	7 daughters, 1 son	8	29
Other family member	2 daughter-in-law, 1 granddaughter,	3	11
Other relationship	1 friend	1	3





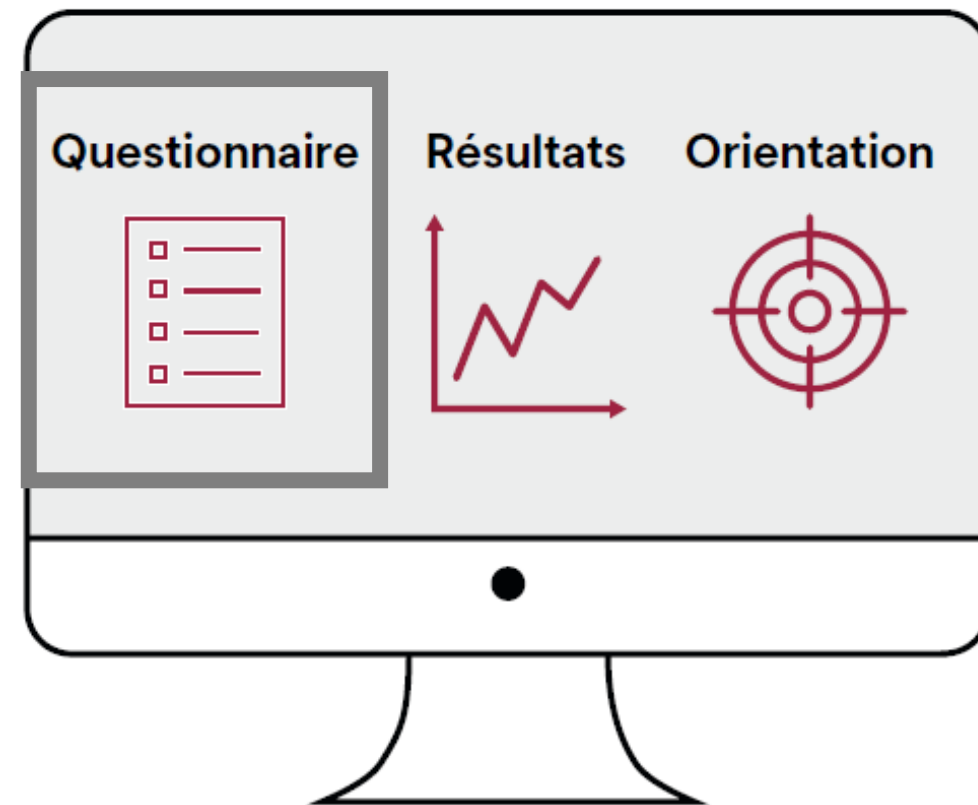
# Results

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- Items are relevant for 86% of providers and 72% of IDC on average
- Items are easy to understand for 93% of IDC on average
- Items extensively cover the needs for providers and IDC
- Reduce number of items

## Plateforme en ligne





# Results

This document asks me the questions I should have thought of before  
*Ce document me pose les questions auxquelles j'aurais dû penser avant*

Targets many problems encountered while accompanying a loved one for which few professionals question us; this type of evaluation should be automatically proposed to caregivers to detect and prevent their exhaustion

*Cible beaucoup de problématiques rencontrées dans l'accompagnement d'un proche pour lesquelles peu de professionnels nous interrogent; ce type d'évaluation devrait être proposée automatiquement aux proches aidant·e·s en détection et prévention de leur épuisement*



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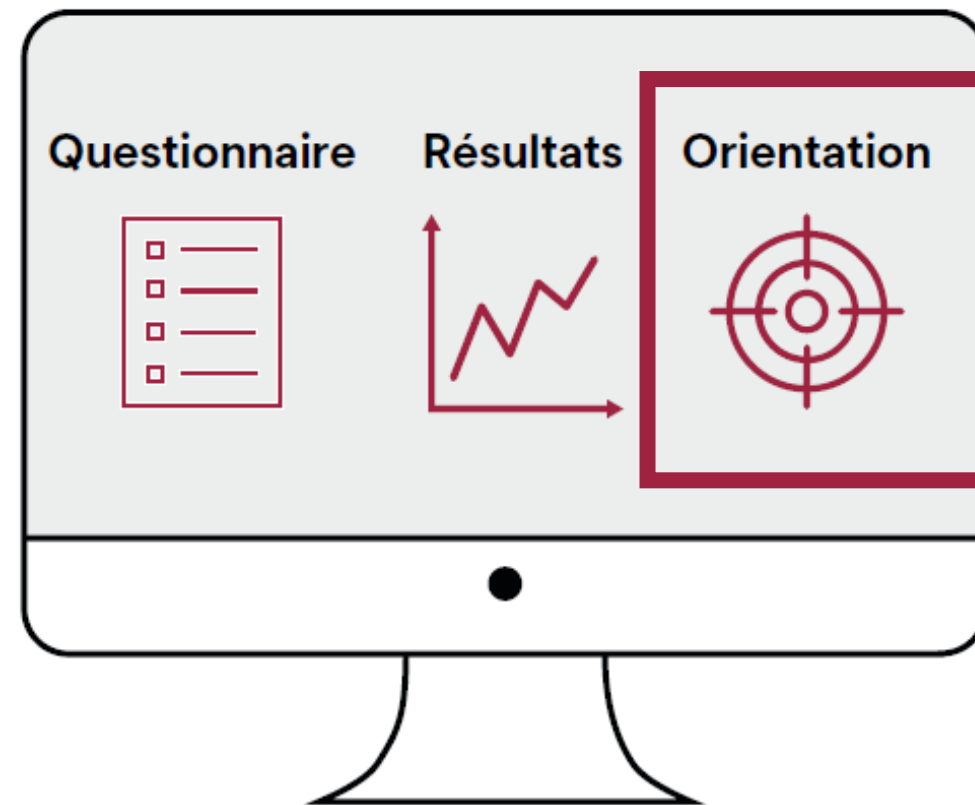
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# Results

For each specific need, on average

- 49% of providers refer, 13% (n=5) have a support service answering the need optimally and 14% (n=6) partly
- support services answering optimally differ between different needs

## Plateforme en ligne





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# Results

For the same need, different providers offer different types of answers that they consider optimal :

**I need more information about the diagnostic of my loved one**

- 3 physicians «during my consultations in the hospital/at my office»
- 2 neuropsychologists «during diagnostic neuropsychological examination»
- 2 nurses «I give information about the disease and answer their questions»
- 1 social worker «I organise a meeting with physician and/or psychologist»

**Then we need to document quality, but how?**

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# Results

## Strong agreement between service providers et IDC

- 4-point Likert scale
- Chapters of questions rather than long list
- Pay attention to font size and contrast
- Be aware of the symbols used

Caractéristiques	Prestataires d'offres (n = 42)		PPA-D (n = 28)
	pertinence	clarté	préférence
	n (%)	n (%)	n (%)
<b>Échelles de réponses</b>			
4 boutons	35 (83,3)	27 (64,3)	19 (67,9)
7 boutons	4 (9,6)	2 (4,8)	5 (17,8)
2 options oui-non	3 (7,1)	13 (31,0)	4 (14,3)
<b>Organisation des items</b>			
Par domaine de besoins	37 (88,1)	36 (85,7)	22 (78,6)
Longue liste de questions	4 (9,5)	5 (11,9)	6 (21,4)



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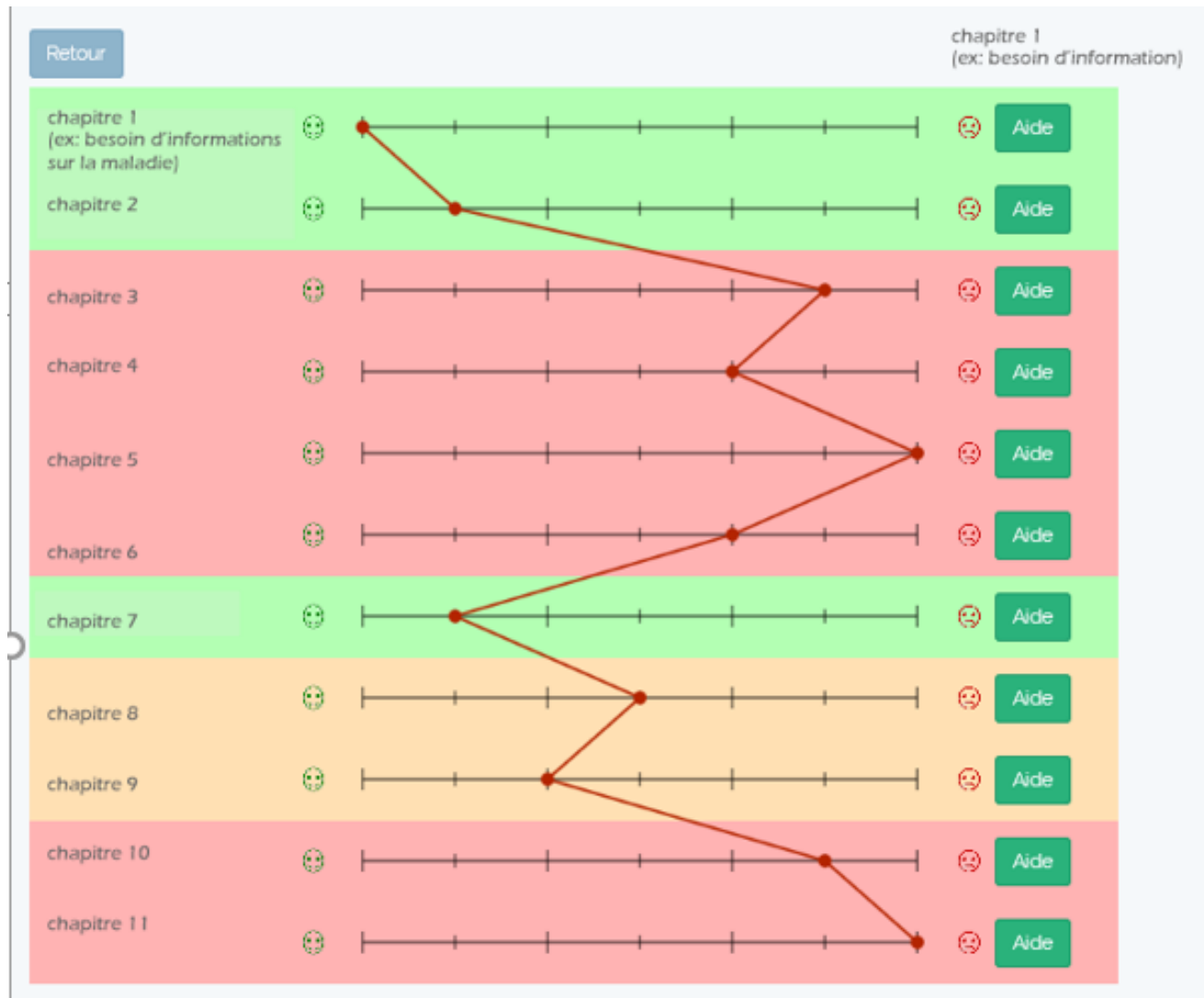
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# Results

Graph presenting  
participant's needs

Find balance  
between sobriety  
and cheerfulness





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# Discussion

## Strengths

**Content validity of questionnaire is optimal** thank to evidence-based + participative approach

**Participative development** of content and characteristics of the platform, involving **diverse** support providers and IDC

## Limitations

Length of survey -> **attrition** among professionals

**Digital literacy** not explicitly evaluated

Platform available **only for IDC**, not for other informal caregivers



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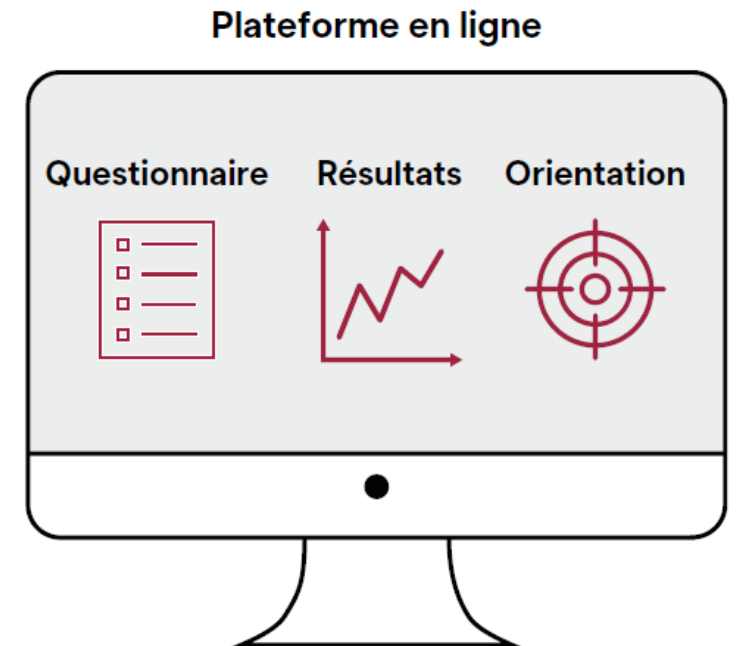
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# Conclusion

The platform will facilitates orientation within the complex network by

- **empowering IDC** in becoming aware of their needs and identifying the support services relevant to them
- **reducing providers' burden** in keeping their human skills for more specific tasks



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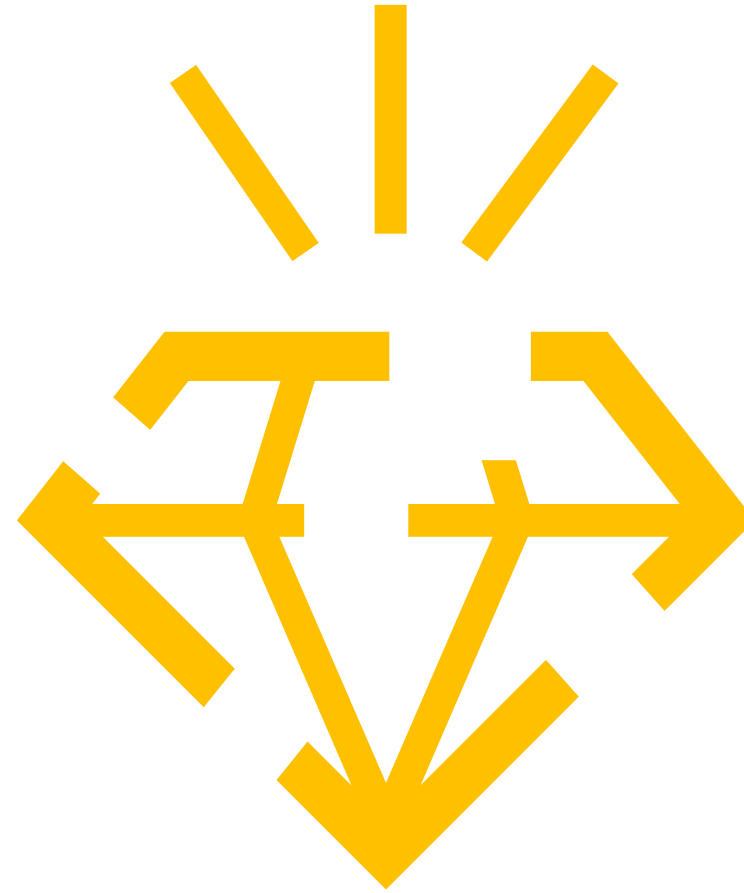


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**Merci pour votre attention!**  
**Avez-vous des questions?**