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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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Challenges

Many IDCs, projections of strong increase
High risk for exhaustion with severe consequences
Many unmet needs
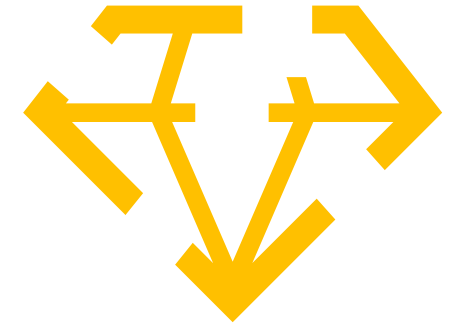
Getting support: a long path

Identify need	Identify appropriate support	Accept support	Ask for this support

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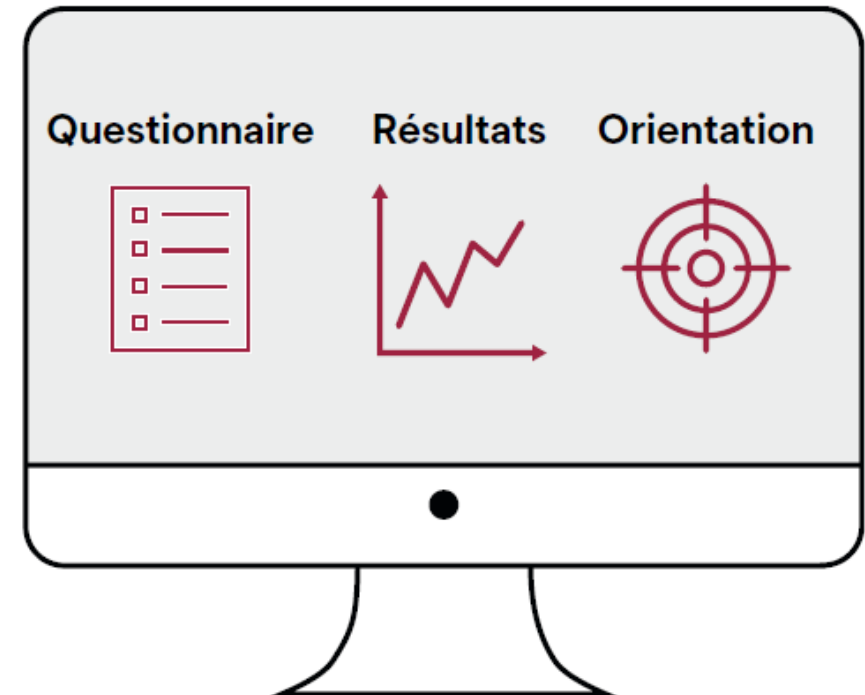Hochschule für Gesundheit Freiburg

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

Questionnaire   Résultats   Orientation

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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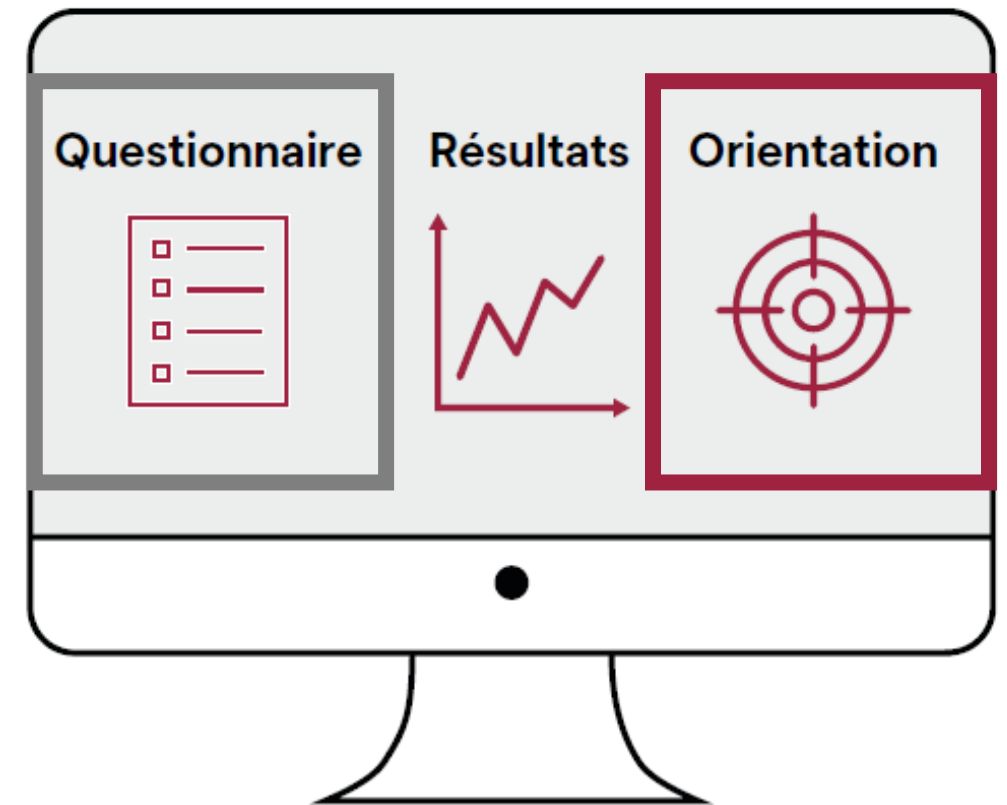Shortage of healthcare professionals and family caregivers (PePA)

Questions

How to assess the many and diverse needs of IDC?

How to refer IDC to the most relevant support services?

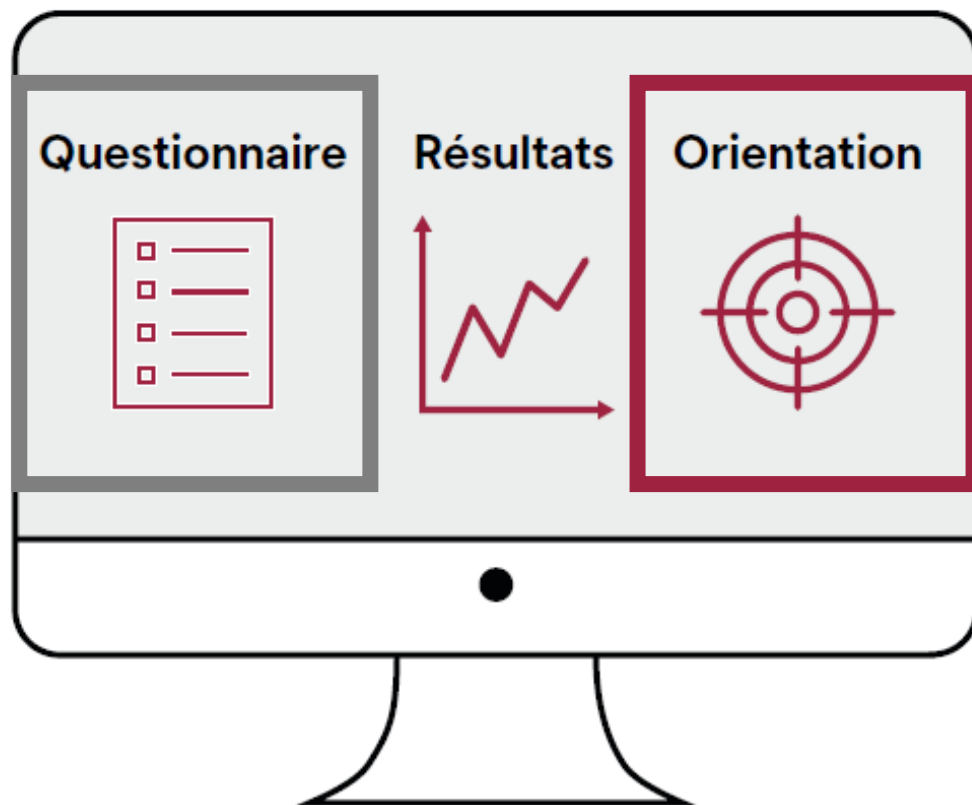**What are the preferences for an online platform ?**

Plateforme en ligne

Questionnaire   Résultats   Orientation

Methods

Plateforme en ligne

Questionnaire

Résultats

Orientation

## 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

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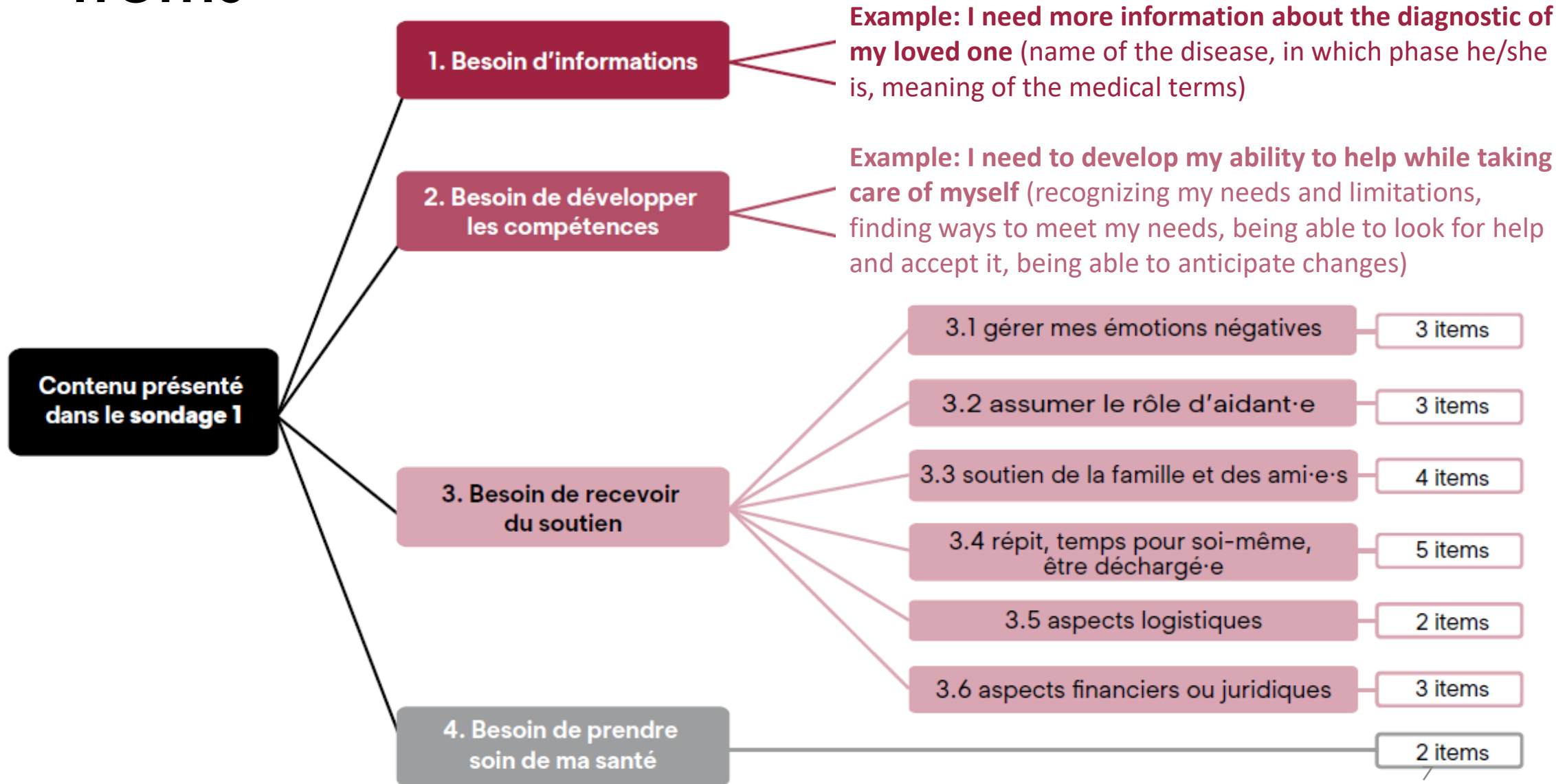
Support providers

- 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 councellor	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)
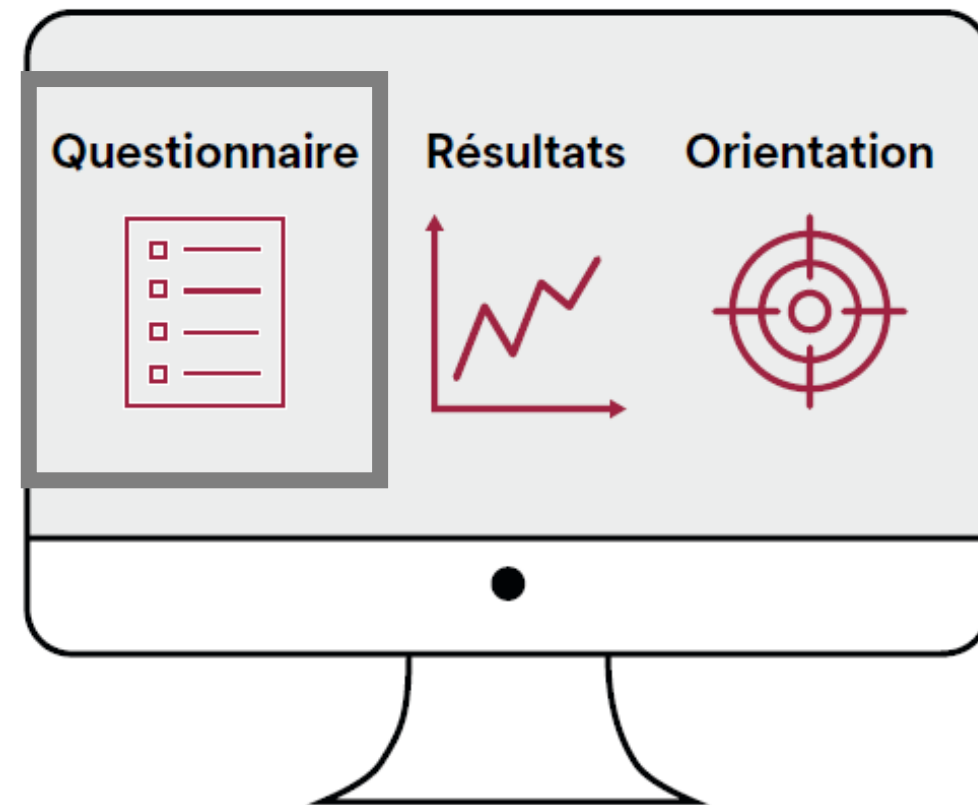
- IDC from 1-168 hours/week (Med=40)

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

- 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

Questionnaire Résultats Orientation

Results

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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

Results

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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

Questionnaire   Résultats   Orientation
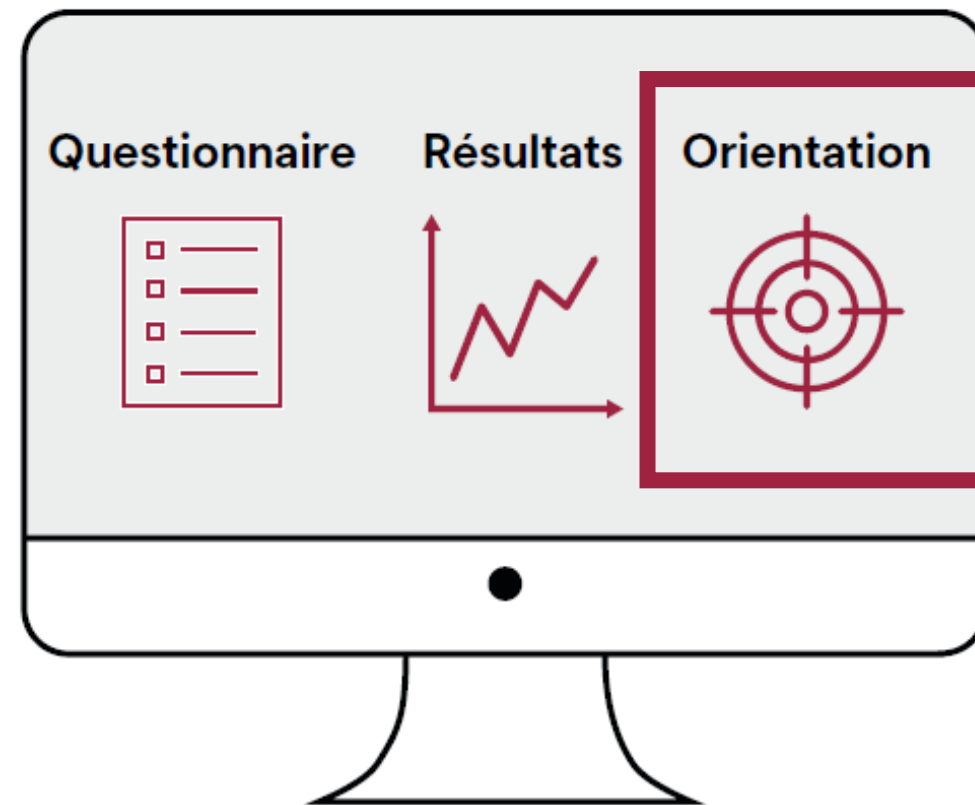
Results

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?

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 (%)
Échelles de réponses			
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)
Organisation des items			
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)

Results

Graph presenting participant's needs

Find balance between sobriety and cheerfulness
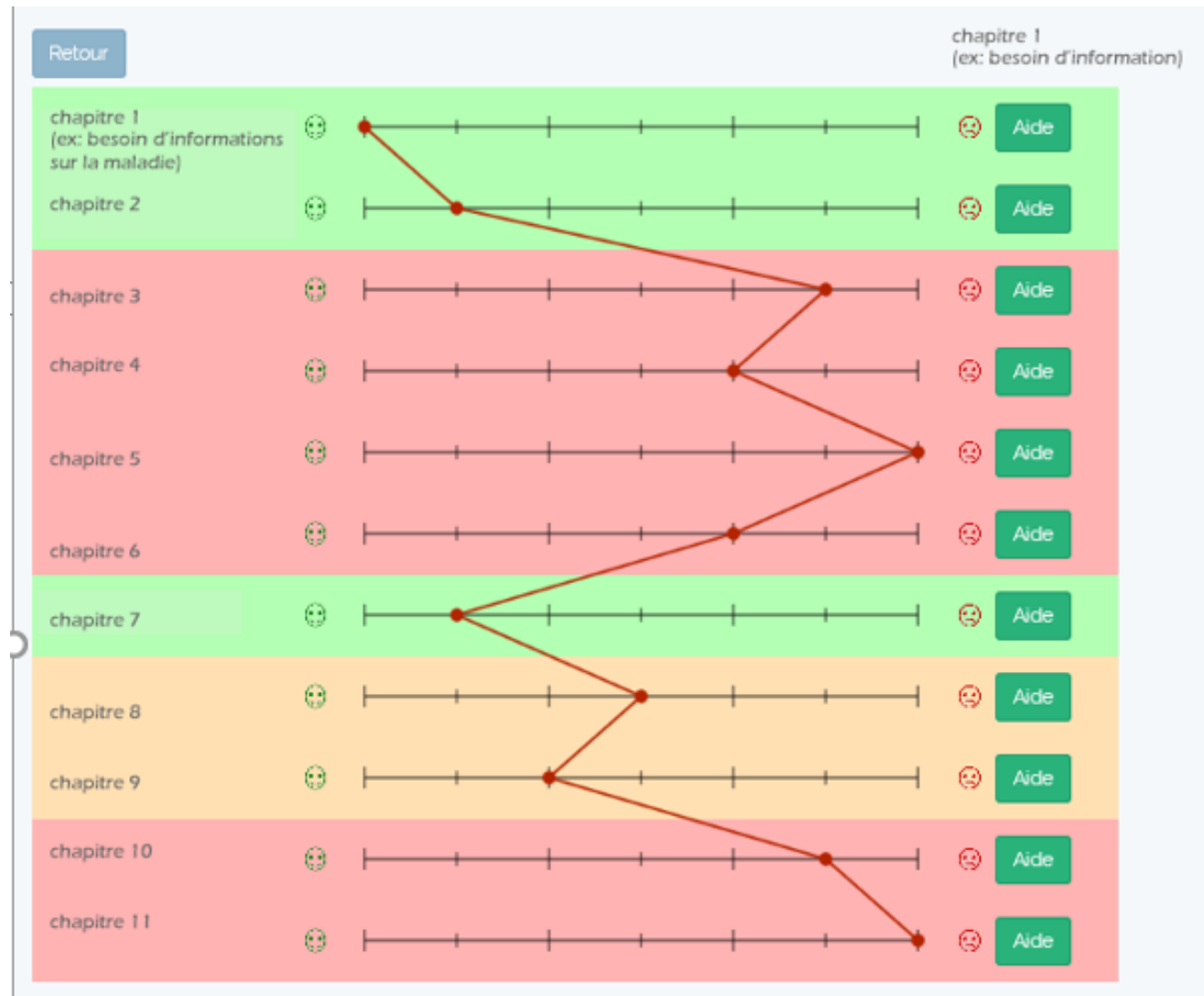
Discussion

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

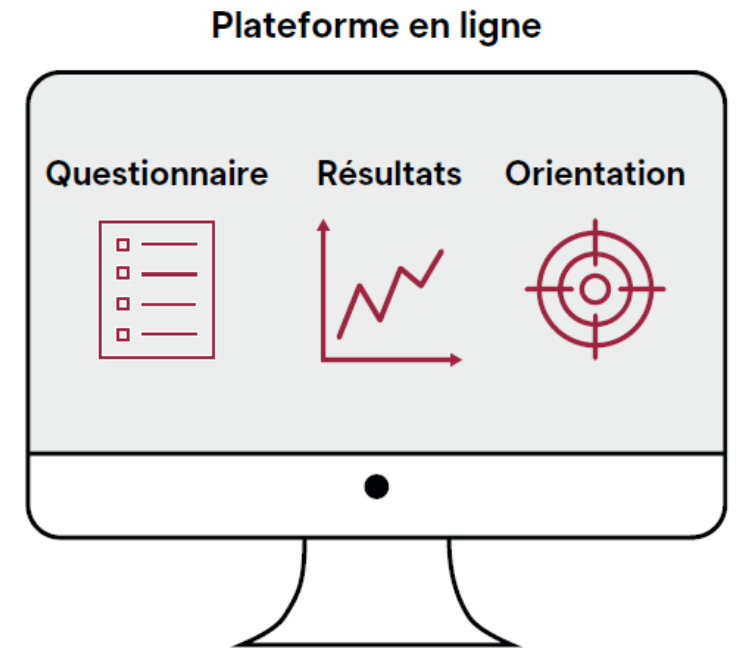Platform available **only for IDC**, not for other informal caregivers

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

Plateforme en ligne

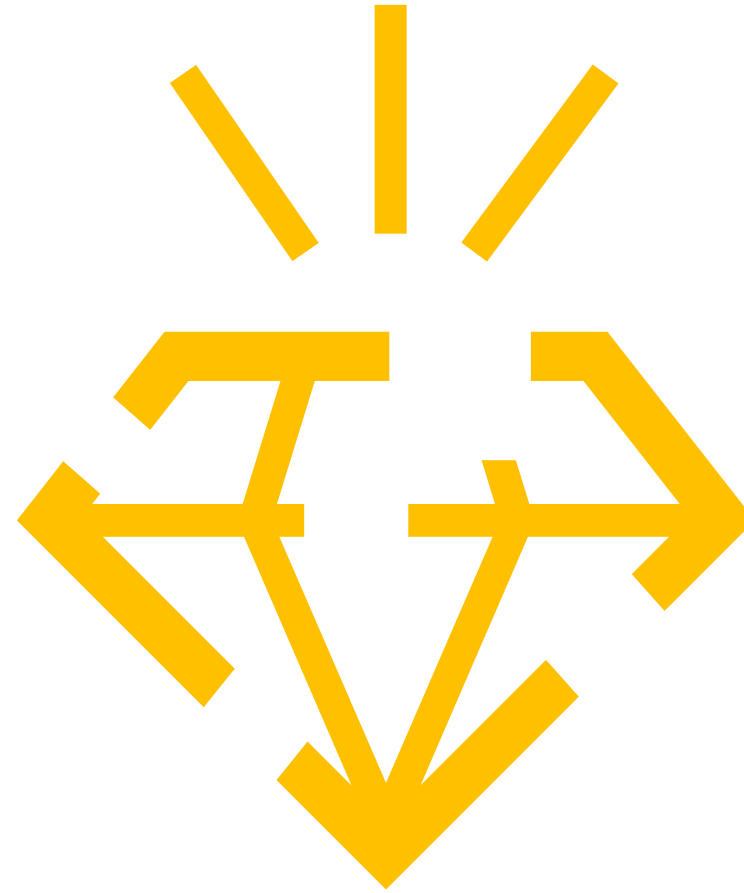Questionnaire   Résultats   Orientation

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Merci pour votre attention!
Avez-vous des questions?