

Swiss COhort of Healthcare Professionals and Informal Caregivers



SCOHPICA Informal caregivers: First results of the pilot study

23.01.2025

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Plan

General information on SCOHPICA

SCOHPICA – Informal caregivers: Pilot study

- Aims & design
- Questionnaire
- Acceptability and feasibility
- Recruitment

Results

- Acceptability and feasibility
- Sample characteristics & burnout scale

Discussion

Conclusion

General information on SCOHPICA

Background

Health professionals (HP) and **informal caregivers (IC)** play a central role in the healthcare system and health services

Concerns and challenges

- Shortage of HPs in Switzerland
- Increased expectations and ongoing adaptations required of HPs and ICs
- Scarce data on HPs and ICs (i.e., trajectories, well-being, etc.)

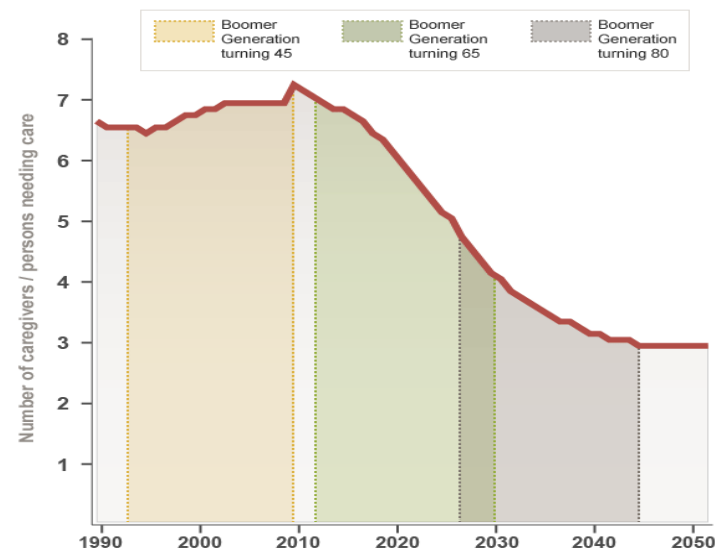


Longitudinal data on informal caregivers and health professionals is essential for **public policy planning** and **management** of the health workforce and informal caregivers in Switzerland, and for ensuring **high-quality healthcare**.

You Take Care of Mom, But Who Will Take Care of You?

Family caregivers provide the majority of long-term services and supports (LTSS). But the supply of family caregivers is unlikely to keep pace with future demand. The Caregiver Support Ratio is defined as the number of potential family caregivers (mostly adult children) aged 45-64 for each person aged 80 and older—those most likely to need LTSS. The caregiver support ratio is used to estimate the availability of family caregivers during the next few decades.

Caregiver Support Ratio



In **2010**, the caregiver support ratio was **more than 7 potential caregivers** for every person in the high-risk years of 80-plus.



In **2030**, the ratio is projected to decline sharply to **4 to 1**; and it is expected to further fall to less than **3 to 1** in **2050**.

POLICY ACTION: Rising demand and shrinking families to provide LTSS call for new solutions to the financing and delivery of LTSS and family support.

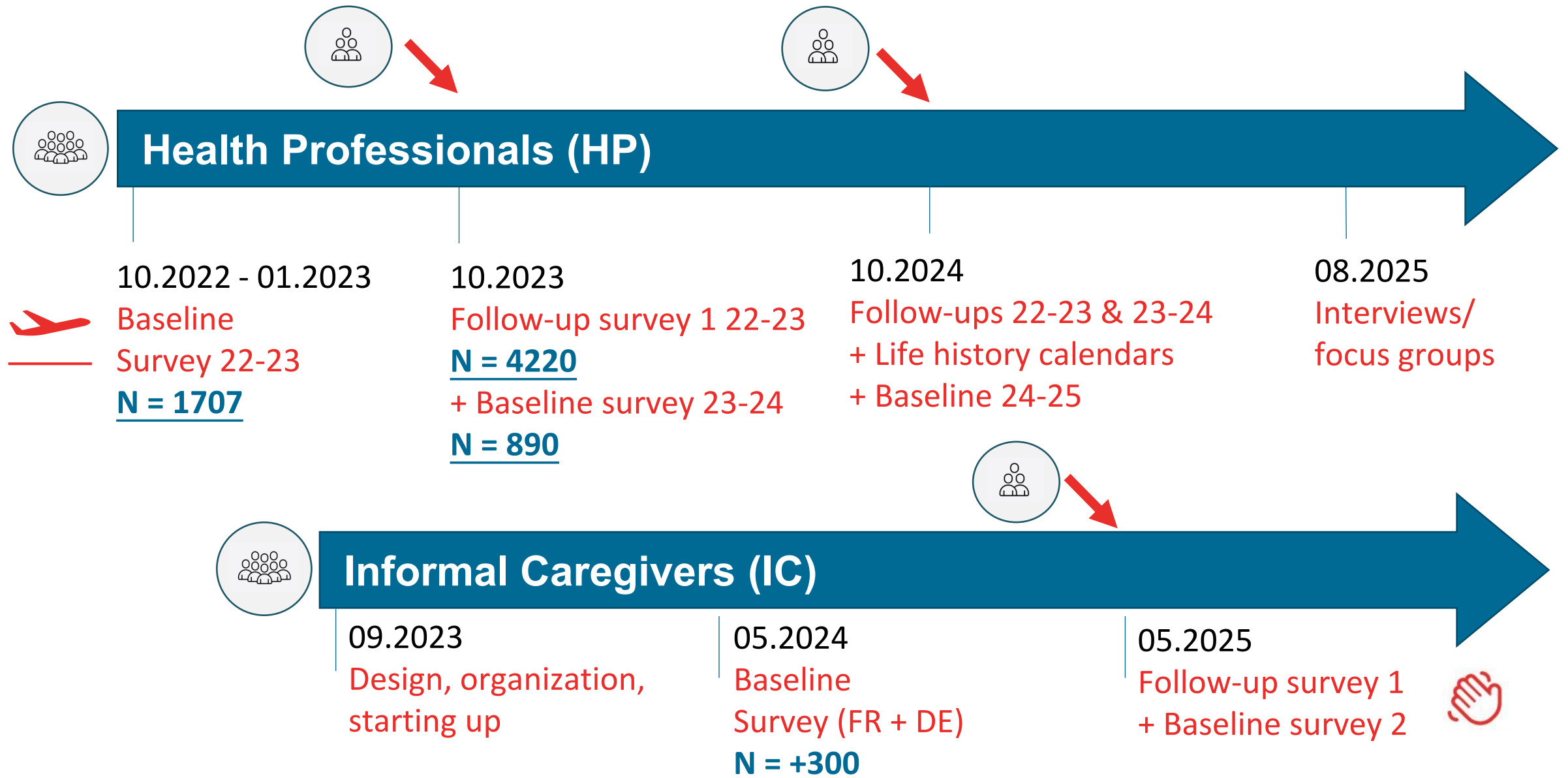
Source: D. Redfoot, L. Feinberg, and A. Houser, *The Aging of the Baby Boom and the Growing Care Gap: A Look at Future Declines in the Availability of Family Caregivers* (Washington, D.C.: AARP Public Policy Institute, August 2013). www.aarp.org/research/ppi

SCOHPICA: Global aim

To describe and understand,
over time, **HPs** and **ICs**
trajectories and well-being



Open prospective cohort



GROUP OF SCIENTIFIC EXPERTS Healthcare professionals

National experts :

- Dr Thomas BUCHER : ZHAW
- Dr Christophe GOLZ : BFH
- Laurence ROBATTO : HES-SO
- Dr Tiziana SALA DEFILIPIS : SUPSI
- Prof. Michael SIMON : UNIBAS
- Prof. Matthias STUDER : UNIGE
- Prof. André BERCHTOLD, Prof. Nicky LE FEUVRE et Prof. Manuela EICHER : UNIL

International experts :

- Prof. Anne-Marie RAFFERTY et Dr Andreas XYRICHIS : King's College, London (KCL)
- Prof. Sally THORNE : University of British Columbia (UBC)
- Prof. André CÔTÉ : University Laval (ULaval)
- Prof. Ivy BOURGEAULT : University of Ottawa (UOttawa)
- Prof. Erin P. Fraher: University of North Carolina

SUPPORT PANEL Healthcare professionals

- ARTISET
- Association suisse des infirmières et infirmiers (ASI)
- Competence Network Healthcare Workforce (CNHW)
- Conférence des directrices et directeurs cantonaux de la santé (CDS)
- Fédération de médecins suisses (FMH)
- Médecins de famille et de l'enfance Suisse (mfe)
- Observatoire suisse de la santé (Obsan)
- Office Fédéral de la Santé Publique (OFSP), Division professionnels de la santé, Plateforme Professions Santé
- Pharmasuisse
- SPITEX Suisse
- Swiss Nurse Leaders
- Unisanté, Département santé, travail et environnement (DSTE)
- Université de Lausanne (UNIL), Faculté Sciences Sociales Politiques (SSP)

STRATEGIC COMMITTEE

Prof. Isabelle PEYTREMANN-BRIDEVAUX
Principal investigator

Dre Ingrid GILLES
Co-investigator

Prof. Annie OULEVEY BACHMANN
Co-investigator

Marcel WIDMER
Director of Obsan

Dr Stefan SPYCHER
Director of Careum

OPERATIONAL MANAGEMENT

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Principal investigator

Dre Ingrid GILLES
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Prof. Annie OULEVEY BACHMANN
Co-investigator

Dr Jonathan JUBIN
Head of Healthcare pro. cohort

Dr Emeric OFFENSTEIN
Head of Caregivers cohort

Admin support and coordination
Yasumi KATANISHI
Maura SOUPPER

COHORT HEALTHCARE PROFESSIONALS

Responsable
Dr Jonathan JUBIN

Researchers

Post-docs

Doctoral students

GENERAL SERVICES

Finance

Communication

IT

COHORT INFORMAL CAREGIVERS

Responsable
Dr Emeric OFFENSTEIN

Researchers

Post-docs

Doctoral students

GROUP OF SCIENTIFIC EXPERTS Informal Caregivers

National experts :

- Dr Mauricio AVENDANO PABON : Unisanté
- Dr Karin VAN HOLTEN : BFH
- Christine COHEN : Haute école de santé La Source
- Dr André FRINGER : ZHAW
- Pia COPPEX : Sene Suisse
- Dr Björn UHLMANN : OFSP
- Prof Jacques-Antoine GAUTHIER : UNIL
- Dr Barbara MASOTTI : SUPSI
- Marc-Antoine BERTHOD: HETSL
- Prof Heidrun GATTINGER and Prof Manuel STADTMANN : OST
- Prof Marco PEDROTTI: HE-ARC

International experts :

- Dr Pierre GÉRAIN : Université libre de Bruxelles
- Dr Ludovico CARRINO : Université of Trieste & King's College, London (KCL)
- Prof Marjolein BROESE VAN GROENOU : Vrije Universiteit Amsterdam

SUPPORT PANEL Informal Caregivers

- Swisscarers
- Association Vaudoise des proches aidants
- Espace Proches
- Pro Infirmis, CIPA
- CIPA, Solicare
- Solicare
- Canton de Vaud
- Fondation SILO
- Canton du Tessin
- Pro-XY
- Pro Senectute
- Informal caregiver and former informal caregiver

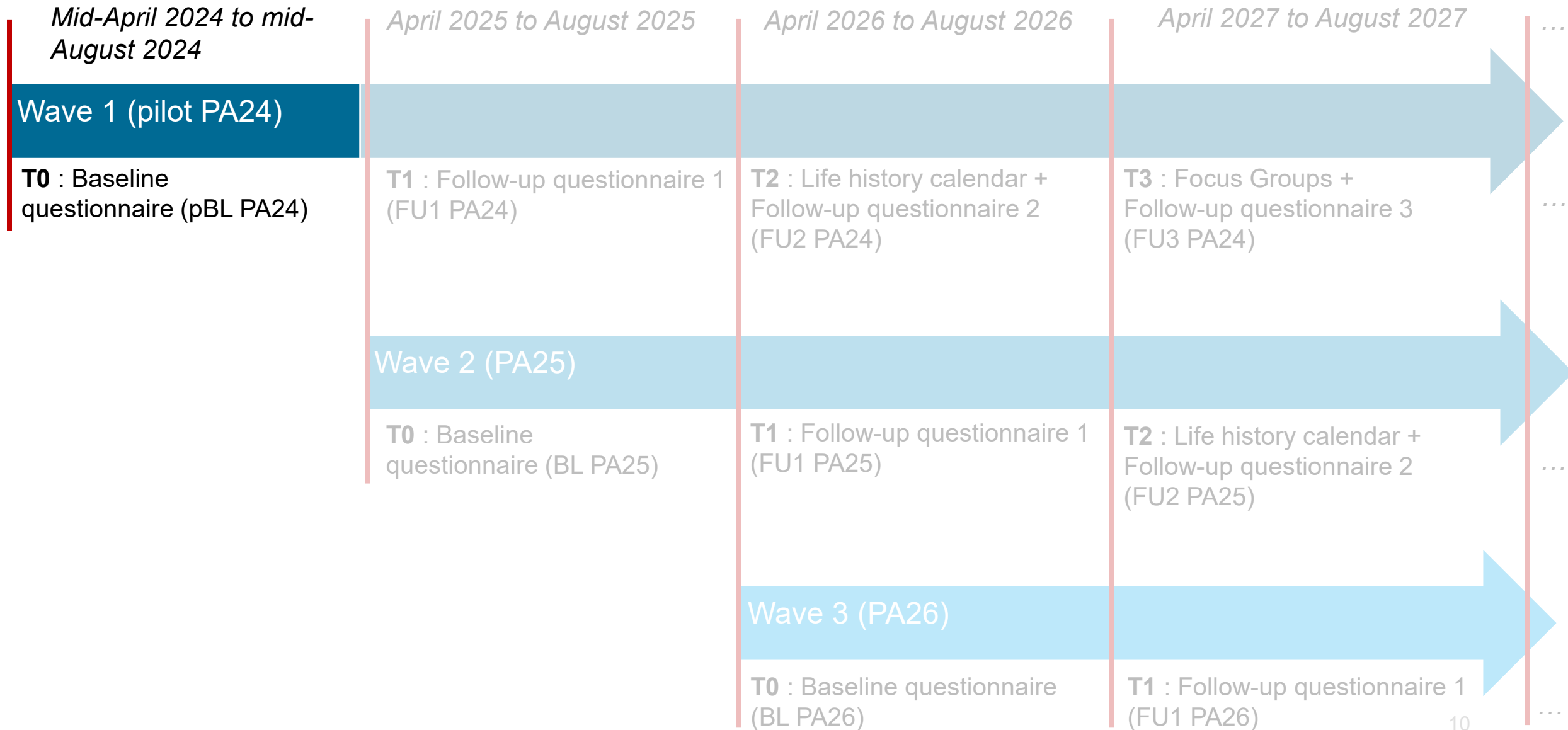
SCOHPICA-IC pilot study

SCOHPICA-IC aims – pBL2024

- 1) To examine the accuracy of the ICIM concepts and their operationalization
- 2) To validate the translation of different scales and describe their psychometric properties
- 3) To assess the acceptability and feasibility of SCOHPICA IC



Design: open prospective cohort



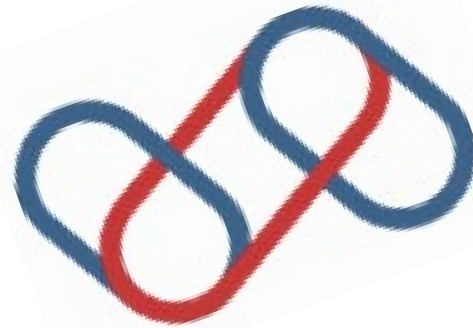
Populations



Health professionals 5-10'000 in the long term

Physicians, nurses, pharmacists, psychologists, physiotherapists, paramedics, dieticians, assistants (of physicians, pharmacists, nurses, ...) and other health professionals.

... in direct contact with patients ...



Switzerland:
German-,
French-, and
Italian-speaking
regions

≥ 18 years old
currently ICs

Informal Caregivers 1-2'000 in the long term

“...persons who aid a relative or friend with **daily living activities** when s/he is no longer able to perform them. This dependence can be caused by a physical or psychological disease, disability, or fragility. ICs provide this support on a **long-term basis** and are involved to a large extent”

(adapted and translated from Promotion Santé Suisse, 2019)

SCOHPICA IC pilot questionnaire



Literature review (Escasain et al, 2022)

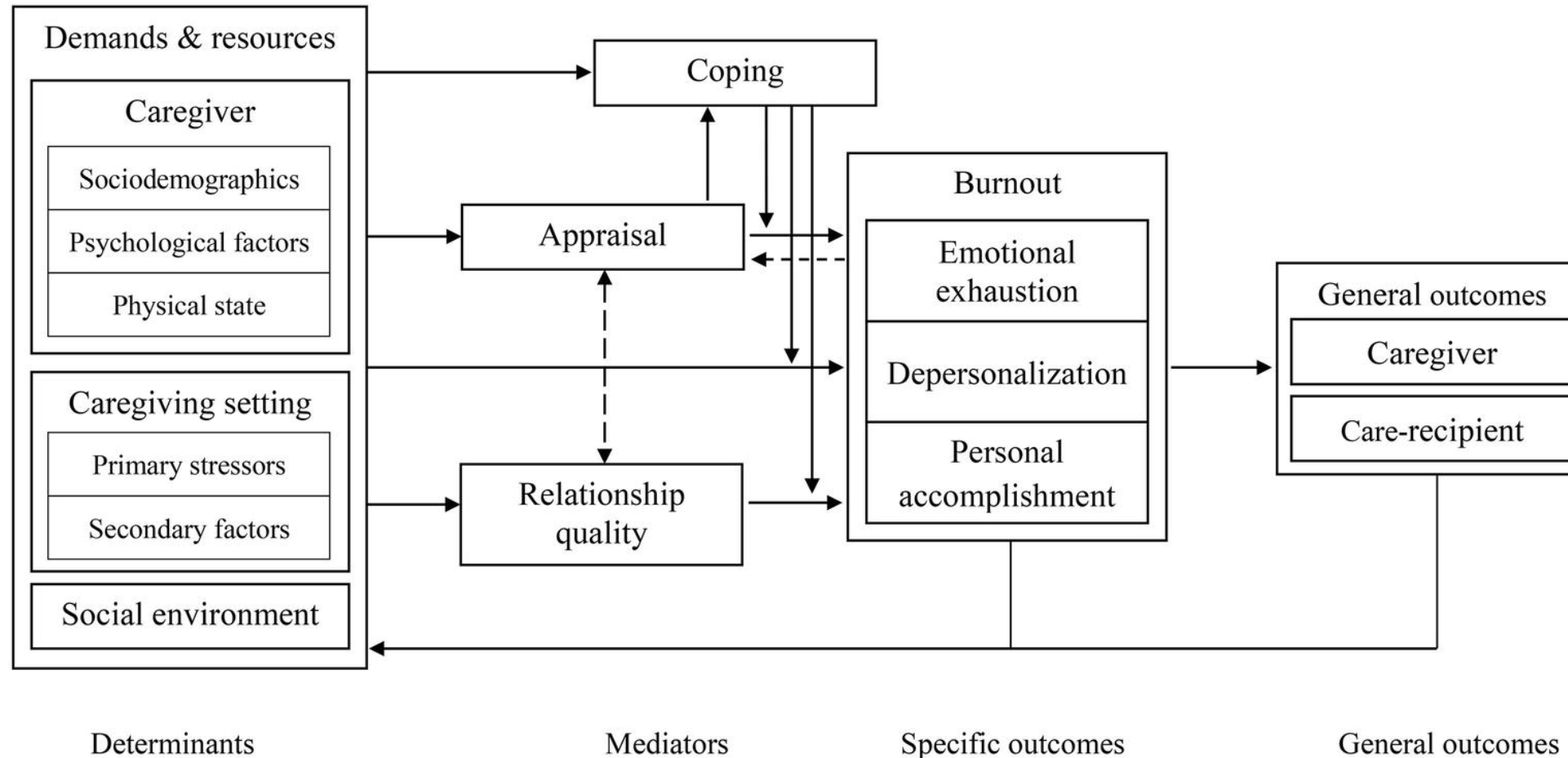
What are the determinants of well-being, quality of life, and subjective and objective burden of informal caregivers?

Determinants

- Sociodemographics
- Care recipient (CR) and evolution of their condition
- Physical and mental health of ICs
- Protective factors
 - Psychosocial factors
 - Relationship with CR
 - Contextual factors

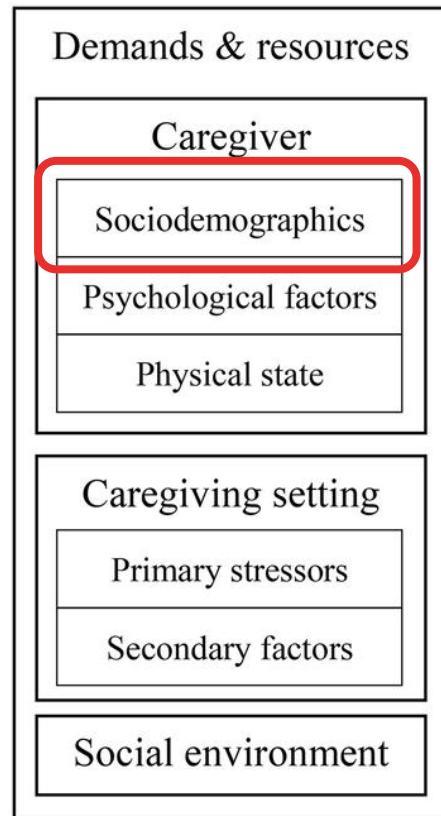


Theoretical framework



[The Informal Caregiving Integrative Model \(ICIM\)](#) (ICIM). Gérain, P., & Zech, E. (2019). Informal caregiver burnout? Development of a theoretical framework to understand the impact of caregiving. *Frontiers in psychology*, 10, 466359.

Determinants – Sociodemographics

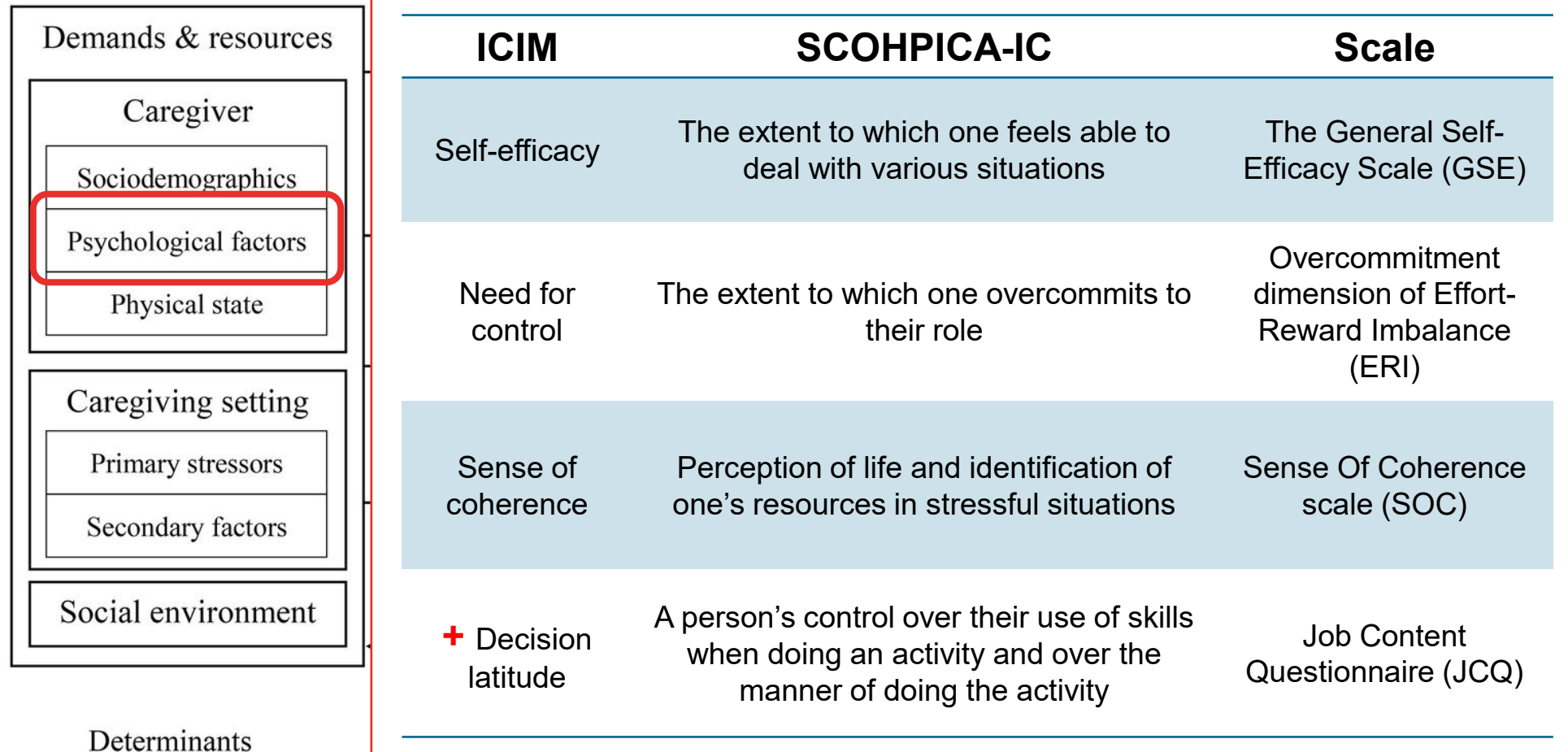


Determinants

ICIM	SCOHPICA-IC
Gender	/
Age	/
Type of relationship	The nature of the relationship between IC and CR
Professional status	Working status, activity rate and variations
Double duty caregiving	Professional activity in the health or social domain
Financial strain	Satisfaction with financial situation

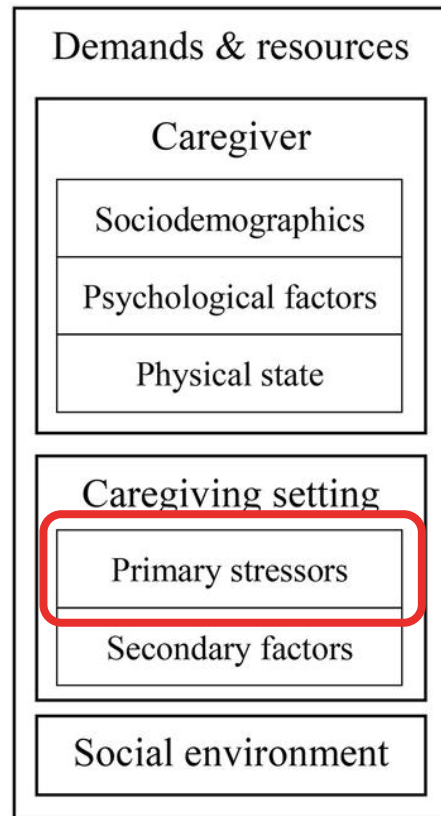
[The Informal Caregiving Integrative Model](#) (ICIM). Gérain, P., & Zech, E. (2019). Informal caregiver burnout? Development of a theoretical framework to understand the impact of caregiving. *Frontiers in psychology*, 10, 466359.

Determinants – Psychological



The Informal Caregiving Integrative Model (ICIM). Gérain, P., & Zech, E. (2019). Informal caregiver burnout? Development of a theoretical framework to understand the impact of caregiving. *Frontiers in psychology*, 10, 466359.

Determinants – Primary stressors

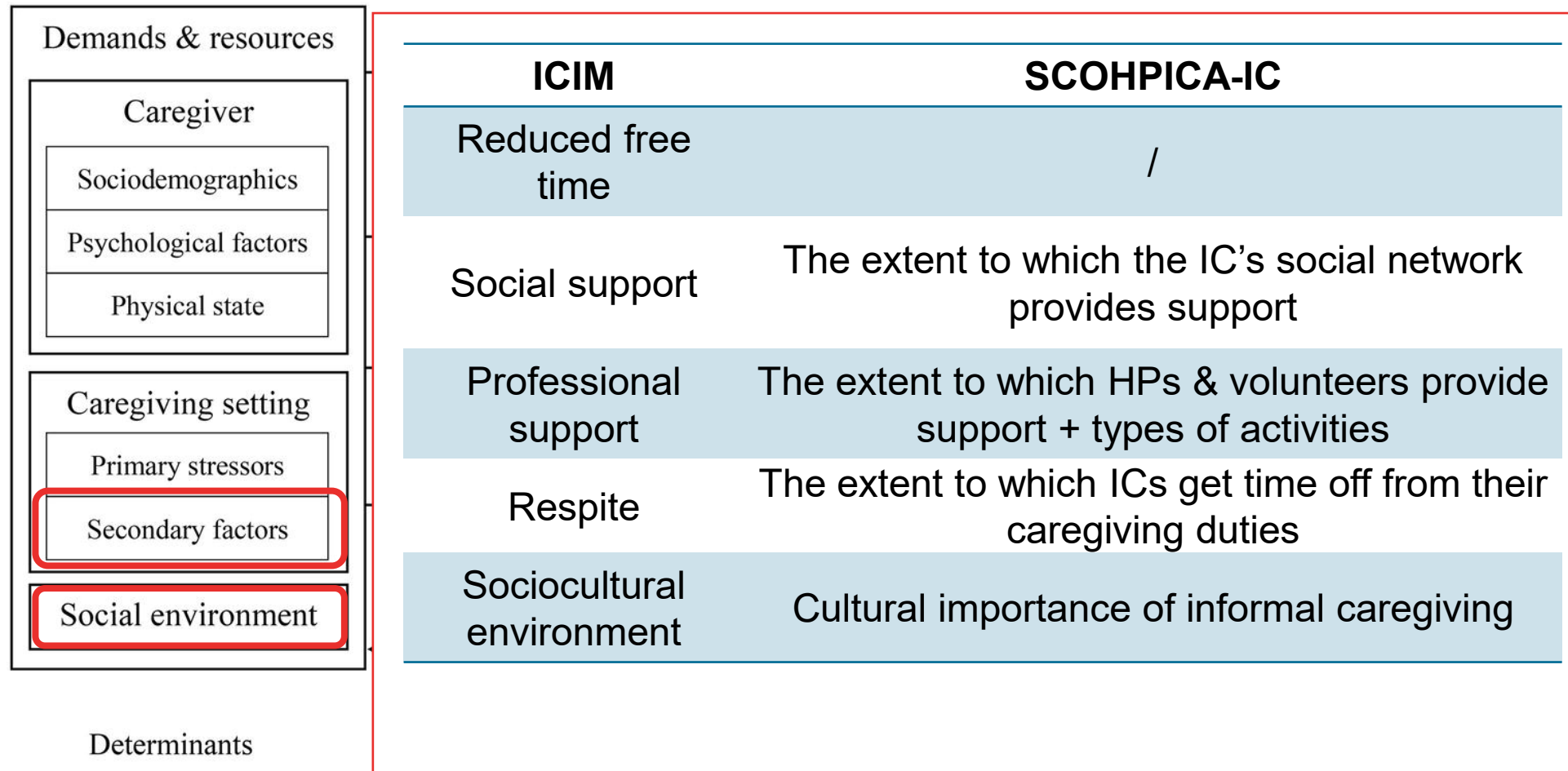


Determinants

ICIM	SCOHPICA-IC
Duration	Time since the start of informal caregiving
Intensity/Autonomy	Quantification of help provided by IC (in hours)
+ number of CR(s)	/
Cohabitation	Living situation of IC and CR (together, CR in institution, CR abroad)
Health condition of CR	/
Choice	The (forced) decision to care for the CR

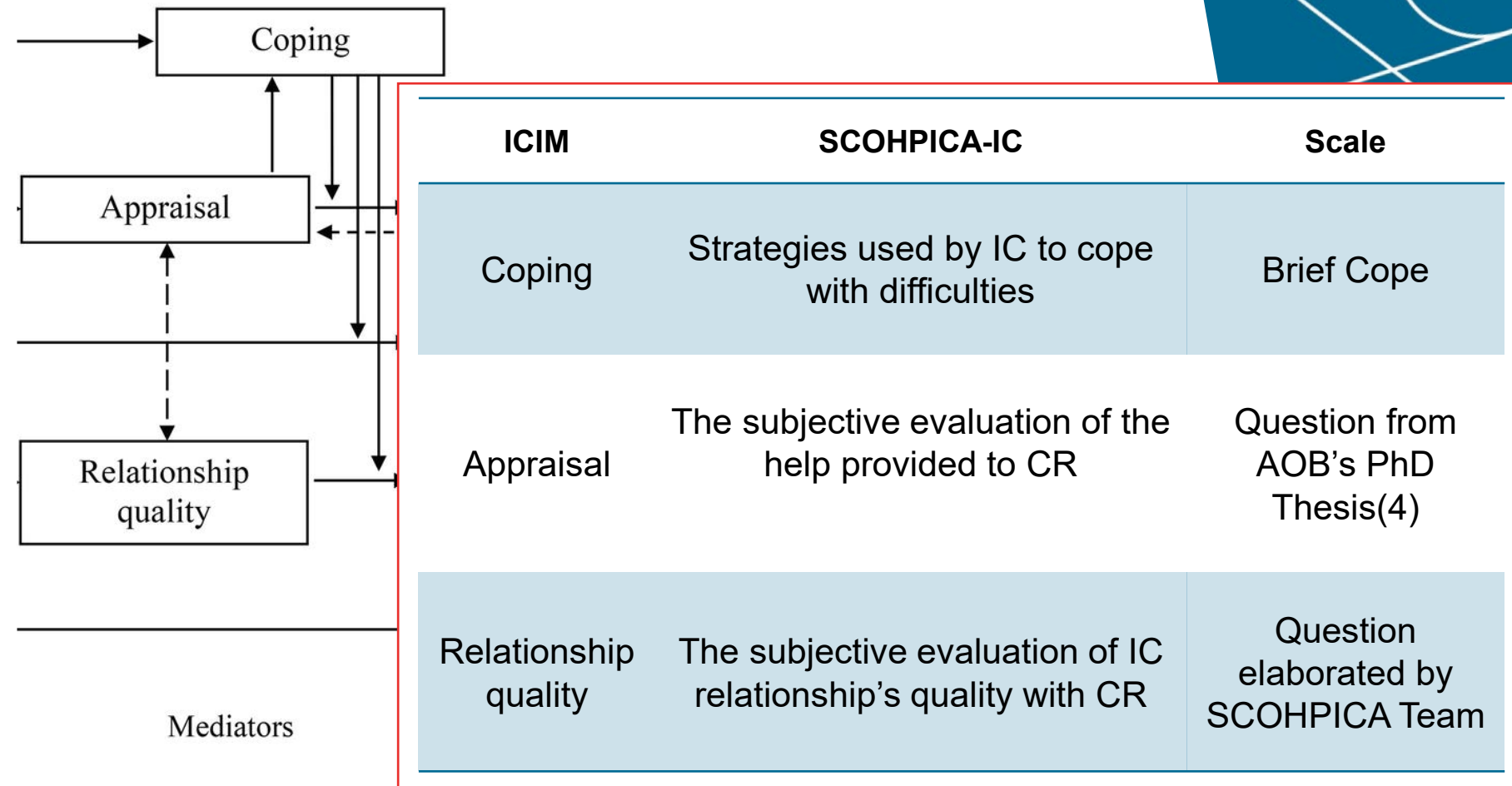
[The Informal Caregiving Integrative Model](#) (ICIM). Gérain, P., & Zech, E. (2019). Informal caregiver burnout? Development of a theoretical framework to understand the impact of caregiving. *Frontiers in psychology*, 10, 466359.

Determinants – Secondary factors + social environment



The Informal Caregiving Integrative Model (ICIM). Gérain, P., & Zech, E. (2019). Informal caregiver burnout? Development of a theoretical framework to understand the impact of caregiving. *Frontiers in psychology*, 10, 466359.

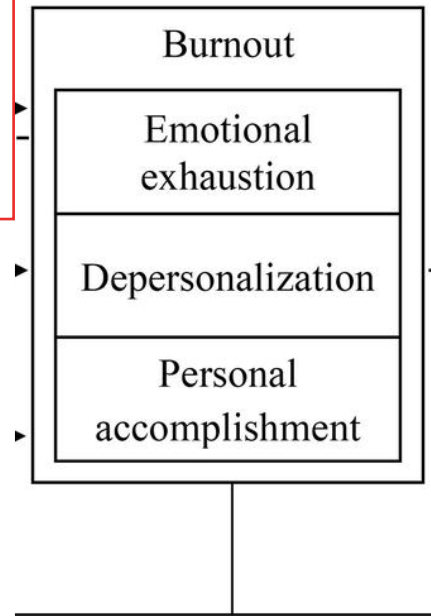
Mediators



The Informal Caregiving Integrative Model (ICIM). Gérain, P., & Zech, E. (2019). Informal caregiver burnout? Development of a theoretical framework to understand the impact of caregiving. *Frontiers in psychology*, 10, 466359.

Specific outcomes

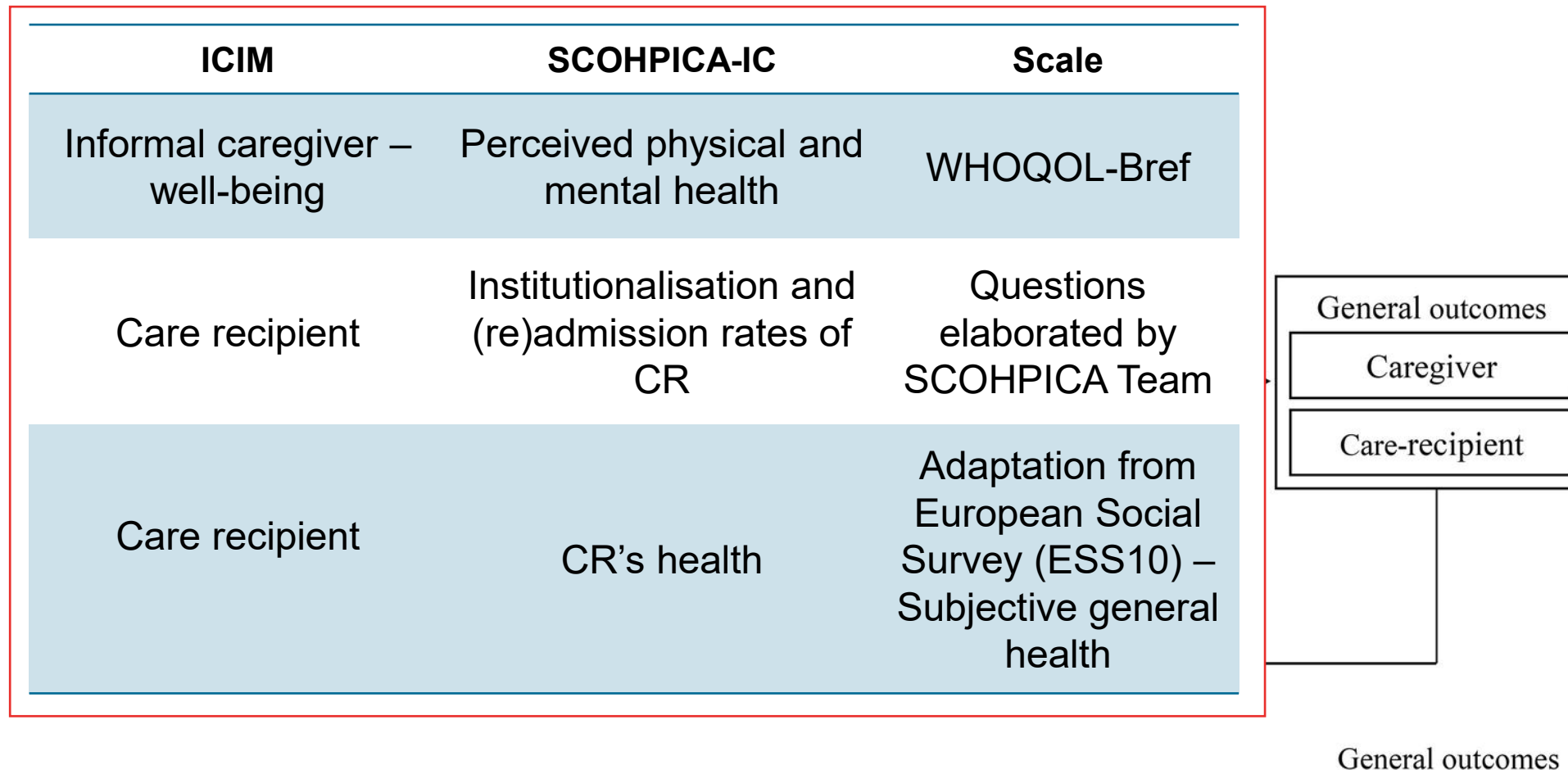
ICIM	Scale
Burnout	Adapted BAT-12 (emotional exhaustion, depersonalisation) + Revised caregiving Appraisal Scale (personal accomplishment)



Specific outcomes

[The Informal Caregiving Integrative Model \(ICIM\)](#). Gérain, P., & Zech, E. (2019). Informal caregiver burnout? Development of a theoretical framework to understand the impact of caregiving. *Frontiers in psychology*, 10, 466359.

General outcomes – IC and CR



[The Informal Caregiving Integrative Model](#) (ICIM). Gérain, P., & Zech, E. (2019). Informal caregiver burnout? Development of a theoretical framework to understand the impact of caregiving. *Frontiers in psychology*, 10, 466359.

SCOHPICA-IC:

Acceptability

	IC'S PILOT BASELINE QUESTIONNAIRE	ANALYSIS
	ACCEPTABILITY	
Emotional impact	What emotions did you feel when you completed this questionnaire? Please explain in a few words.	QUAL
Effort required	If you had to rate the effort required to complete this questionnaire, how would you rate it? (0 no effort at all - 10 an inordinate effort)	QUANT
Adequation with their values	Did any of the questions offend you? (Yes/No) If so, which ones? Please explain in a few words.	QUANT QUAL
Coherence	If you had to explain in a few words how the data collected by SCOHPICA IC will be used, what would you say? Please explain in a few words.	QUAL
Opportunity costs	What advantages do you see in taking part in SCOHPICA IC? Please explain in a few words	QUAL
Efficacy of the recruitment	How did you hear about SCOHPICA IC? What suggestions would you make to increase participation in SCOHPICA IC?	QUAL QUAL
Open question	Overall, are there any themes that the questionnaire did not address? (Yes/No) If so, which ones? Please explain in a few words	QUANT QUAL
Open question	Would you encourage other ICs to participate in SCOHPICA IC? (Yes/No) If no, why?	QUANT QUAL

Assessment of **recruitment strategy**, **retention** and **adherence rates**:

- Initial data (gender, age, total workload, etc...)→ description of participants and types of ICs who would be missing
- Free comments : a space for free expression
- Logbook kept throughout the first data collection (channels of dissemination, number of reminders sent, open remarks by partners in the field)
- Discussions with the group of scientific experts and members of the support panel

Questionnaire

Pilot Baseline web and paper questionnaire

- French and German
- 189 questions
 - ICIM : determinants, mediators, outcomes
 - Acceptability & Feasibility (11 questions)
- ~ 30-40 minutes

SCOHPICA IC pilot recruitment



Data collection

Article in
preparation



Ethics committee

- Protocol approved for the 1st year of SCOHPICA IC (pilot study)

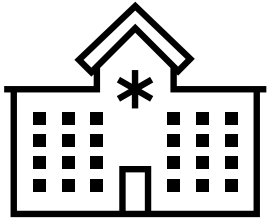
Data collection

- OST : actively involved in the recruitment (German speaking part of Switzerland)
- Data collection from mid-April to mid-September 2024 with electronic and paper questionnaire (French & German)

**The pilot baseline survey of IC has been launched
in late April to the beginning of September 2024**

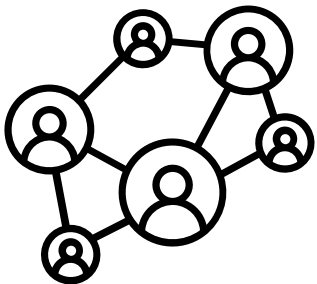


SCOHPICA ICs' partners and recruitment



Thanks to a lot of supporting partners

- Associations of patients, other organisations
- Hospitals, clinics, nursing homes, home care
- HR associations
- Protestant and Catholic parishes
- Cantons



How?

- Conferences
- Websites/Newsletters
- Social media and press contacts
- Word of mouth...

Data collection with students

- Bachelor Thesis in Nursing VAE
 - 3 students collected 10 questionnaires each
 - Elaboration of an observational grid and lived observation of participants completing the questionnaire
 - Analysis of the observations and recommendations based on their conclusions
- Bachelor Thesis in Nursing 2024
 - 9 students
 - Contribution to qualitative analysis of the 2024 questions on feasibility and acceptability
 - Each students will collect 10 questionnaires in 2025
- Bachelor Thesis in Occupational Therapy 2024
 - 3 students
 - Preparation of the structure of Life History Calendar 2026
- PAuSES programm (Nursing and Occupational therapy students offering respite to ICs) by 2025

Qualitative analysis: acceptability and feasibility

Qualitative analysis: questions on acceptability and feasibility

Question 2: What emotions did you feel when you completed this questionnaire? Please explain in a few words.

Number of answers: 178

Themes :

- Awareness of their role as an informal caregiver
- Sadness
 - At the care recipient situation's
 - Lack of recognition for their effort and work
- Angry
 - At the unfairness of the system that does not support them enough
- Joy
 - At the idea of being able to speak out and being heard
 - For the interest shown

Qualitative analysis: questions on acceptability and feasibility

Question 3: If you had to explain in a few words what the data collected by SCOHPICA-IC will be used for, what would you say? Please explain in a few words.

Number of answers : 139

Themes :

- Improving the situation of informal caregivers
- Recognizing and valuing informal caregivers
- Impact on policy at national level
- Learn about the experiences of informal caregivers

Qualitative analysis: questions on acceptability and feasibility

Question 4: What advantage(s) do you see in participating in SCOHPICA-IC? Please explain in a few words.

Number of answers : 155

Themes :

- Contribution to the study and feeling of usefulness
- Recognition and appreciation of informal caregivers
- Improvement in quality of life and conditions for caregivers
- Expression and introspection
- No personal benefit

Qualitative analysis: questions on acceptability and feasibility

Question 5: How did you hear about SCOHPICA-PA?

Number of answers : 176

Themes:

- Entourage
 - family, friends
- Organizations:
 - home care services, temporary care centre, nursing homes, hospitals, medical practices
- At work: colleagues
- Associations:
 - patients and IC's, parishes, Connaissance 3
- Communications:
 - via e-mails, social networks (Instagram, LinkedIn, Facebook), professional journal...

Qualitative analysis: questions on acceptability and feasibility

Question 6: Overall, are there any topics relating to helping a loved one that you would have liked to see addressed in the questionnaire but didn't? If so, which ones?

Number of answers : 75

Themes :

- Administrative procedures
- More emotional aspects
- Relationships and family dynamics
- Organization with professional life
- Resources

Qualitative analysis: questions on acceptability and feasibility

Question 7: What suggestions would you make to increase the participation of informal caregivers to SCOHPICA-PA project?

Number of answers : 99

Themes:

- Increase the support
 - healthcare organizations; patient and IC associations; medical practices...
- Increase publicity:
 - flyers; newspapers, standard media, social networks (Facebook)...
- Snowball recruitment
- A shorter questionnaire

Qualitative analysis: questions on acceptability and feasibility

Question 8: Do you have any other comments or suggestions about SCOHPICA-IC? If so, which ones?

8 participants had other comments

Themes :

- Questionnaire structure
 - Types and place of questions
- Messages of thanks and acknowledgement

Qualitative analysis: questions on acceptability and feasibility

Question 9 : Would you encourage other informal caregivers to take part in the SCOHPICA-IC project? If not, why not?

6 participants said “No”

Themes :

- Length
- Emotionally heavy
- Don't know any other informal caregiver

Qualitative analysis: questions on acceptability and feasibility

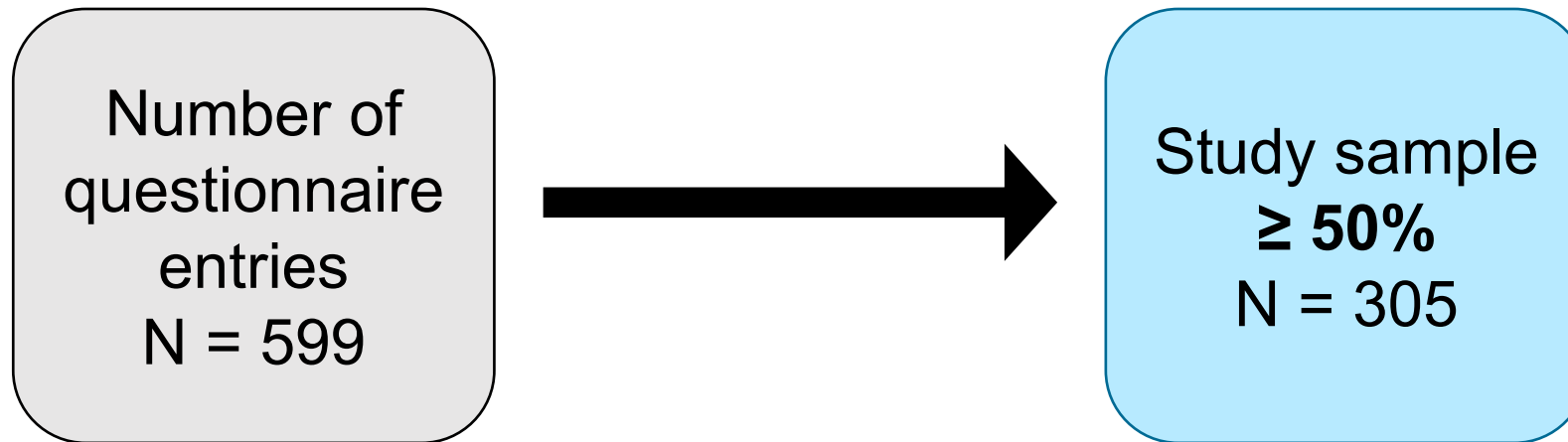
Question 10: Were there any questions that offended you? If so, which ones? Please explain in a few words.

7 participants said “Yes”

Themes:

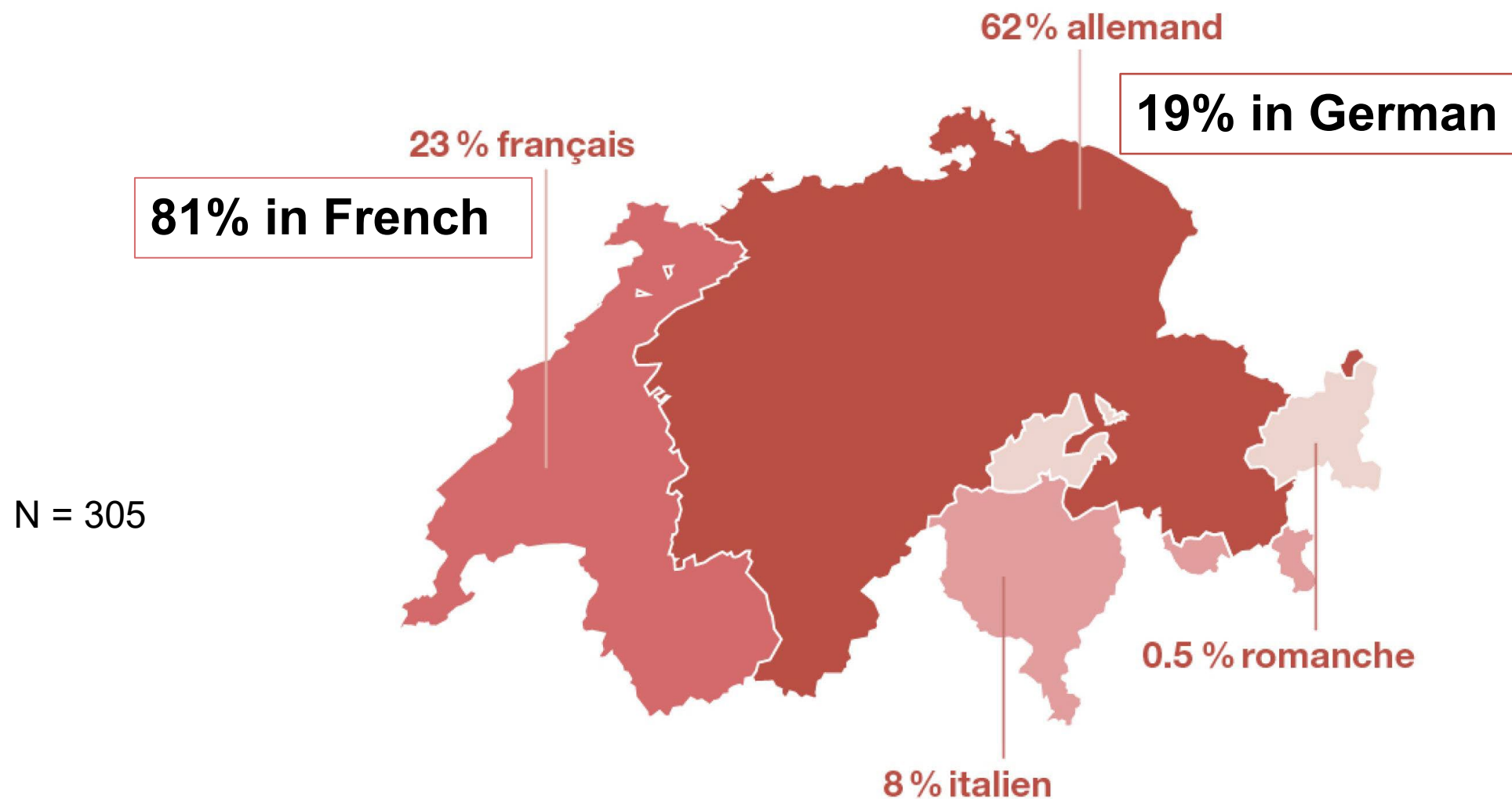
- Some questions are :
 - too intrusive
 - unclear
- Emotional burden when filling in the questionnaire

Descriptive statistics of pilot Baseline (pBL2024) questionnaire



Results are presented for
participants who completed
≥ 50%

pBL2024 – Sample



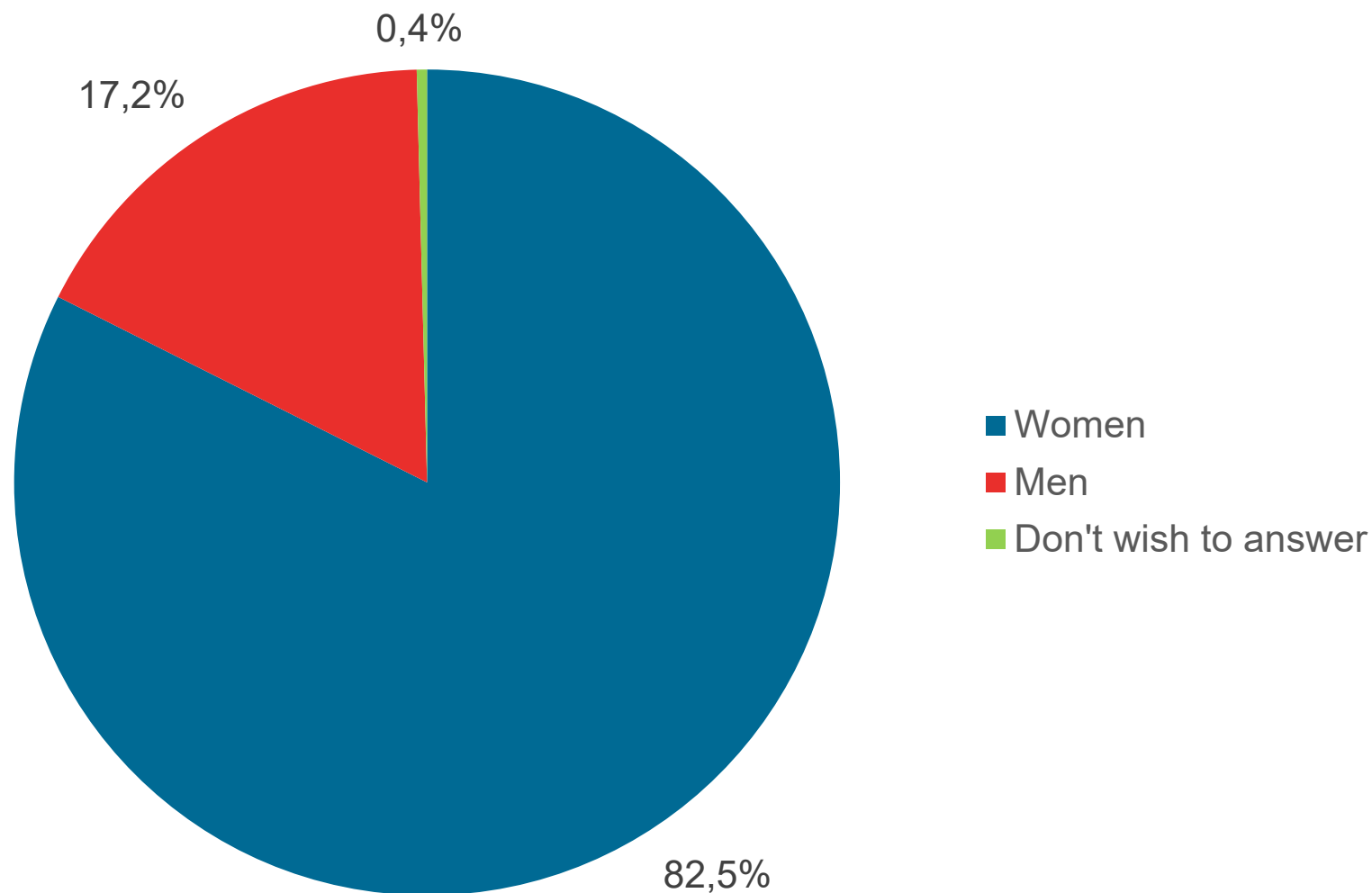
Results are presented for participants who completed $\geq 50\%$

pBL2024 – Gender



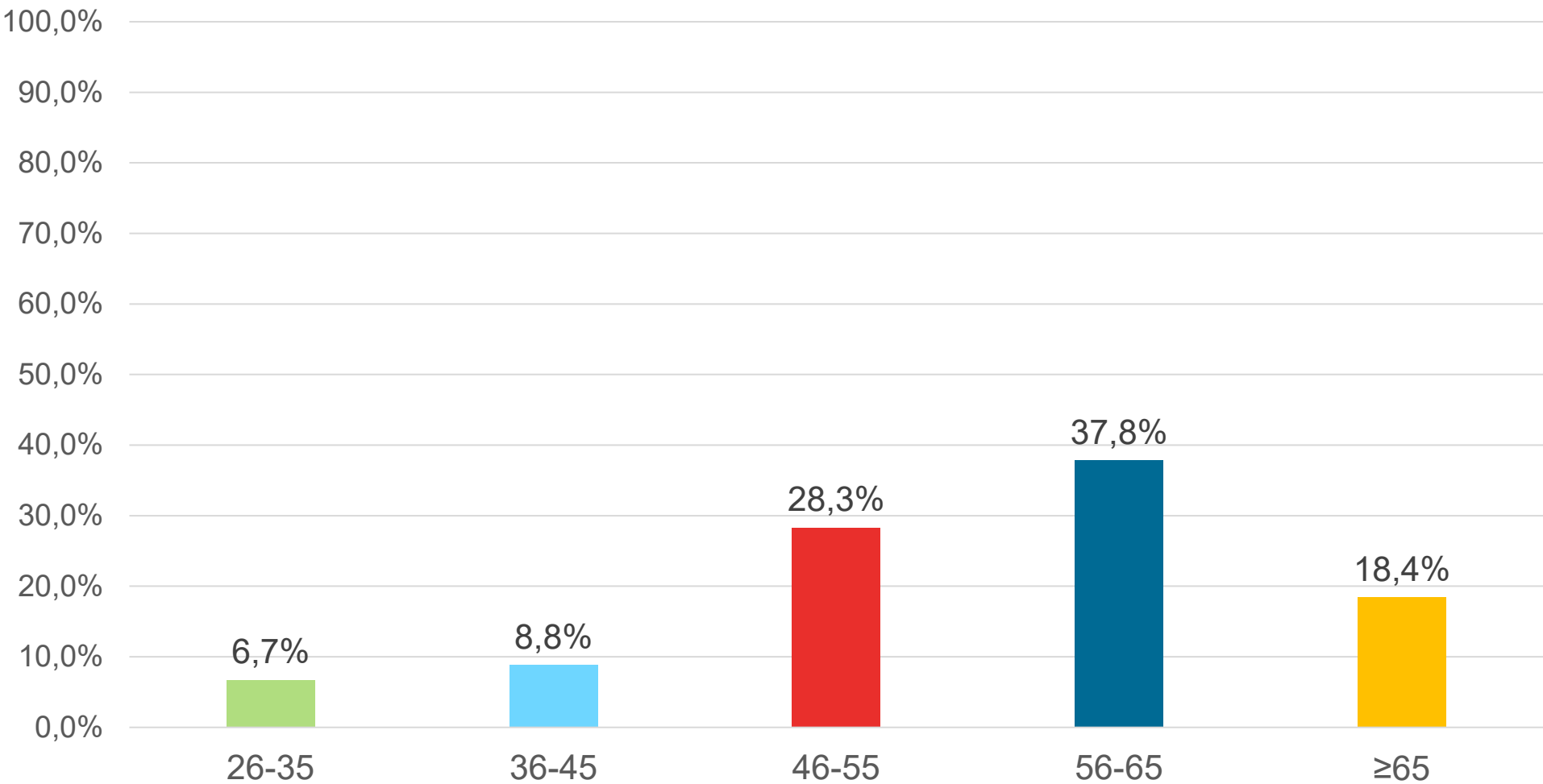
Which of the following best describes you? I am...

N = 285



Results are presented for participants who completed $\geq 50\%$

pBL2024 – Age



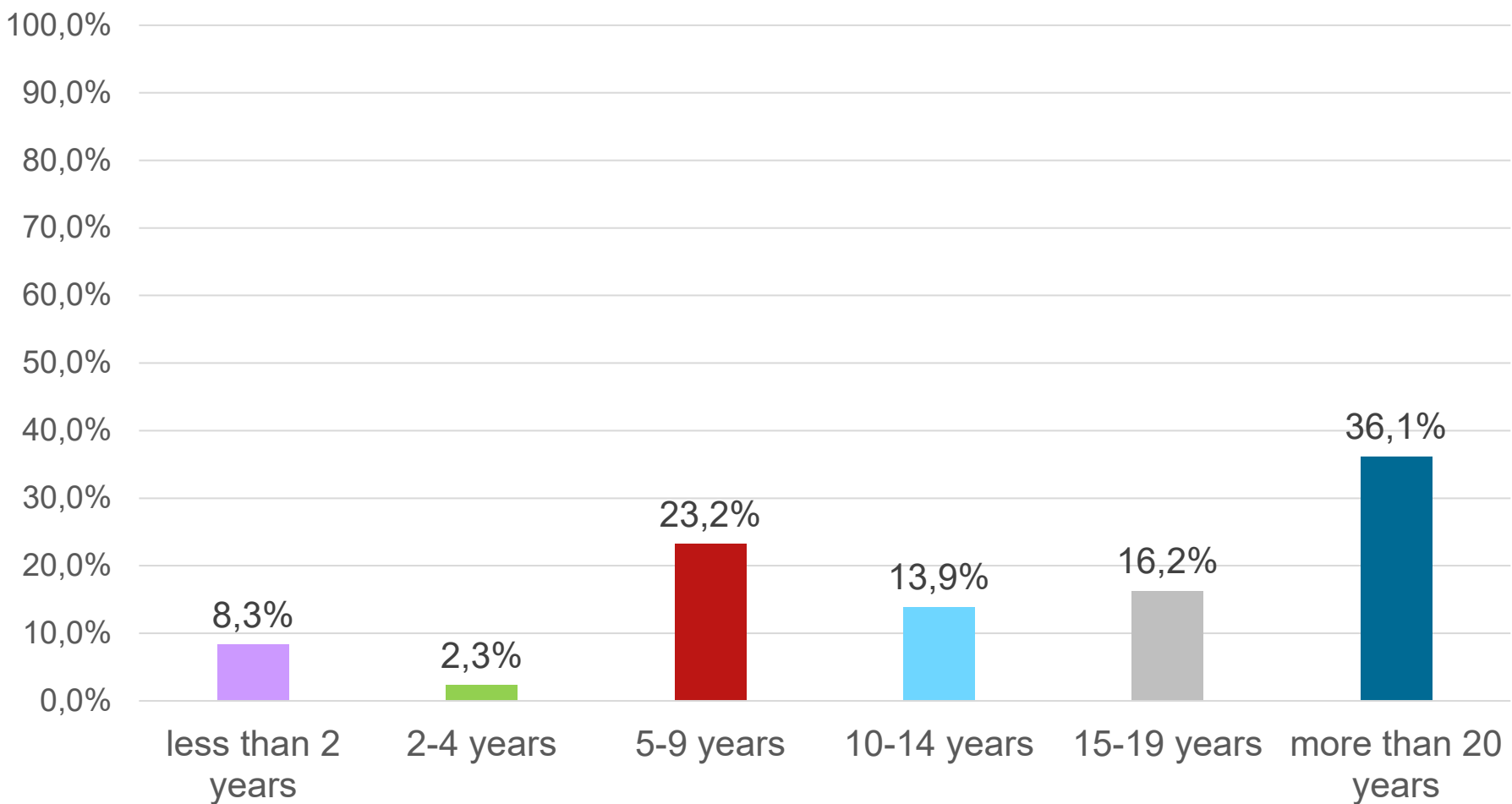
N = 283

Results are presented for participants who completed ≥ 50%

pBL2024 – Duration of informal caregiving



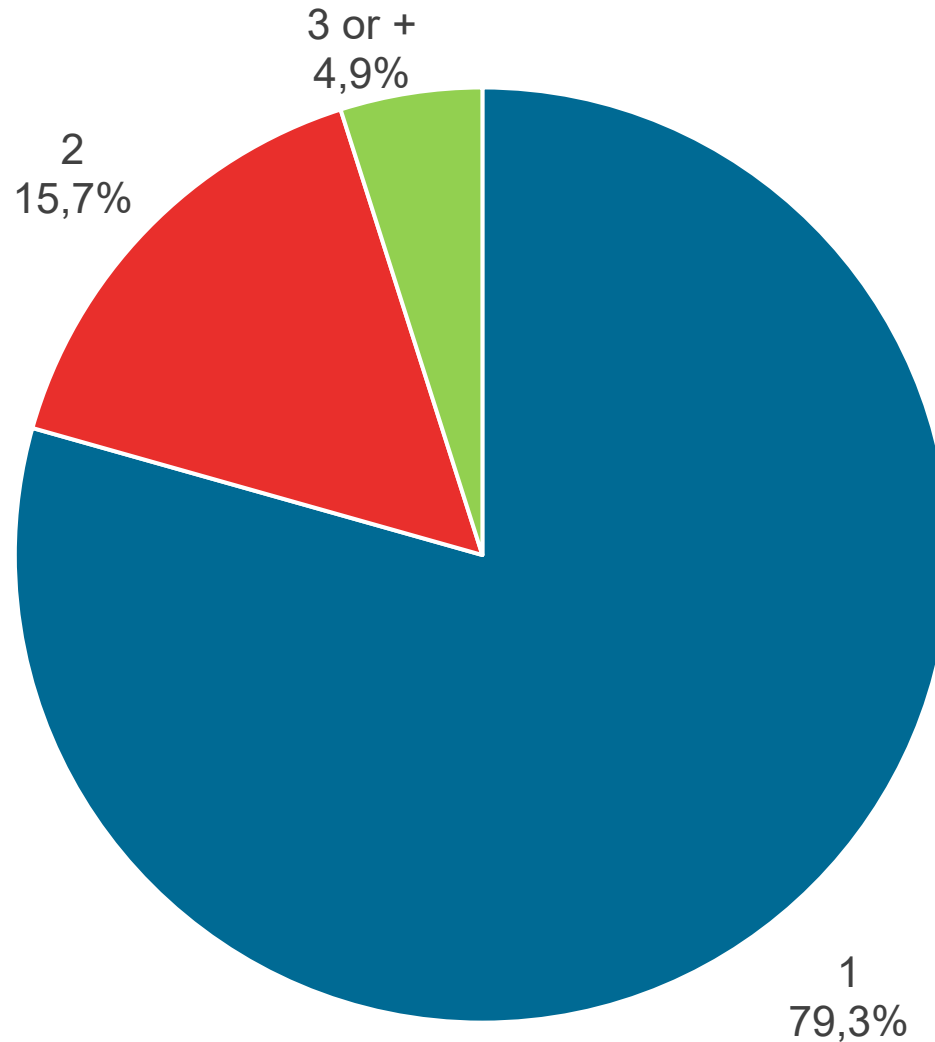
How long have you been helping this person (please indicate the year)?



N = 302

Results are presented for participants who completed ≥ 50%

pBL2024 – Number of care recipients



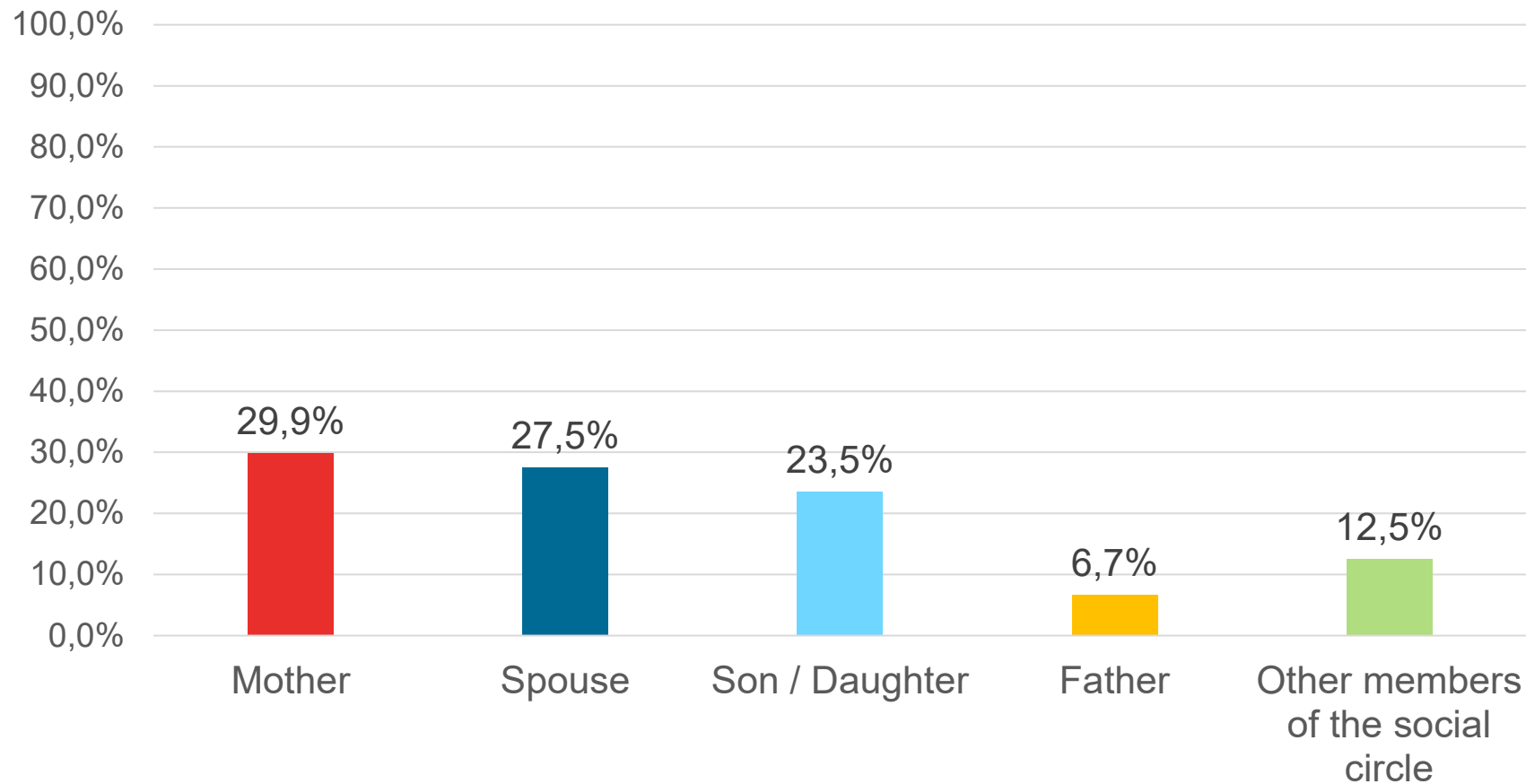
N = 305

Results are presented for participants who completed $\geq 50\%$

pBL2024 – Who is the care recipient ?



Who is the person you help most?

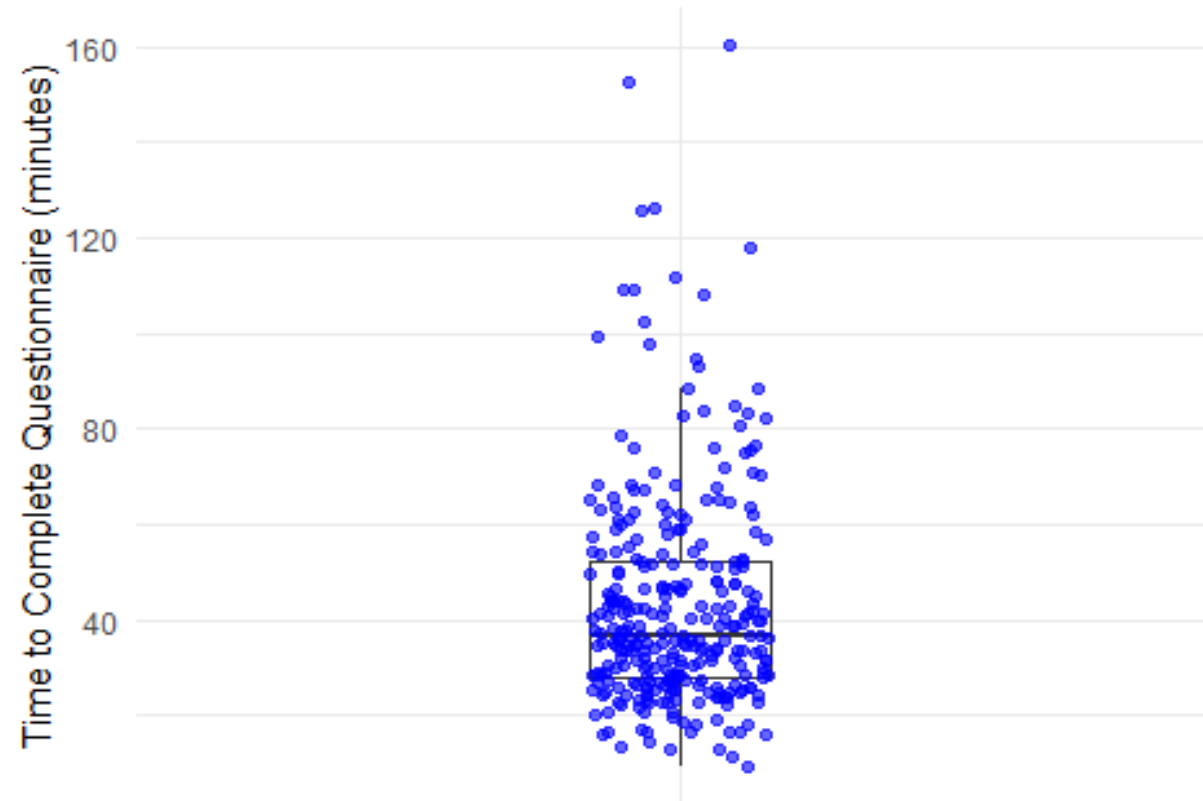


N = 298

Results are presented for participants who completed $\geq 50\%$

pBL2024 – Time to completion

Time to Complete Questionnaire - Participants Answered > 50%

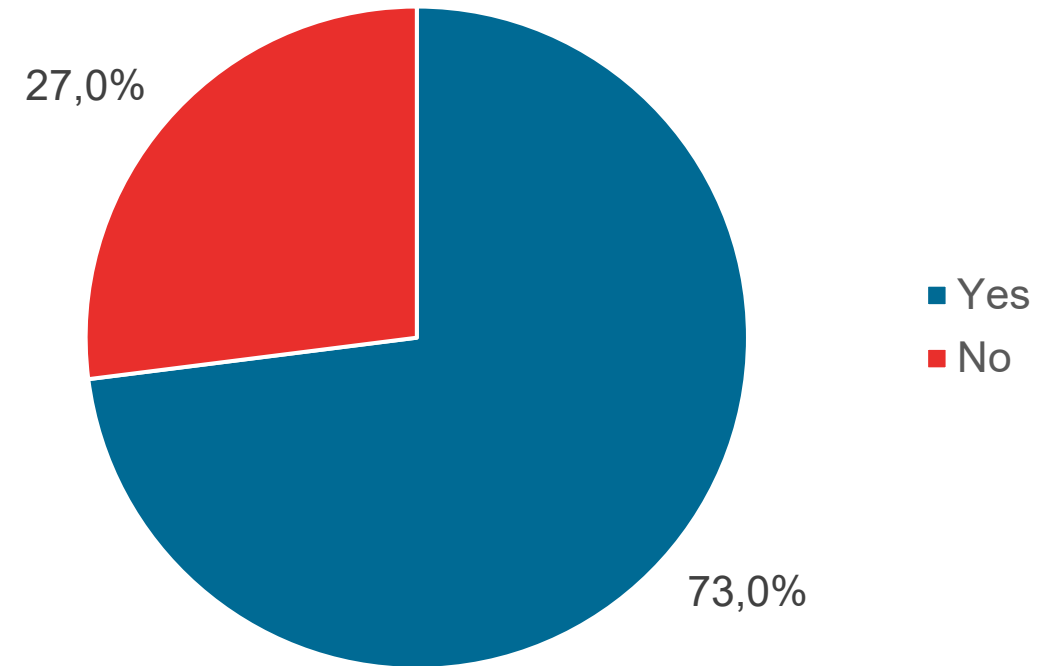


pBL2024 – Agreement to 2nd contact



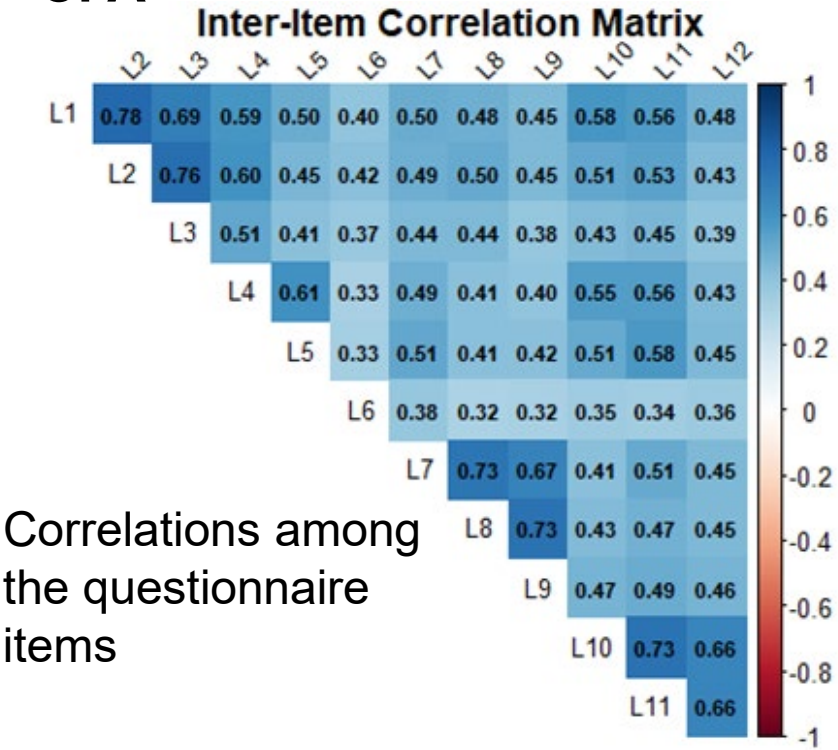
Are you willing to be contacted next year to complete this questionnaire again to see how your situation has changed?

N = 281



Results are presented for participants who completed $\geq 50\%$

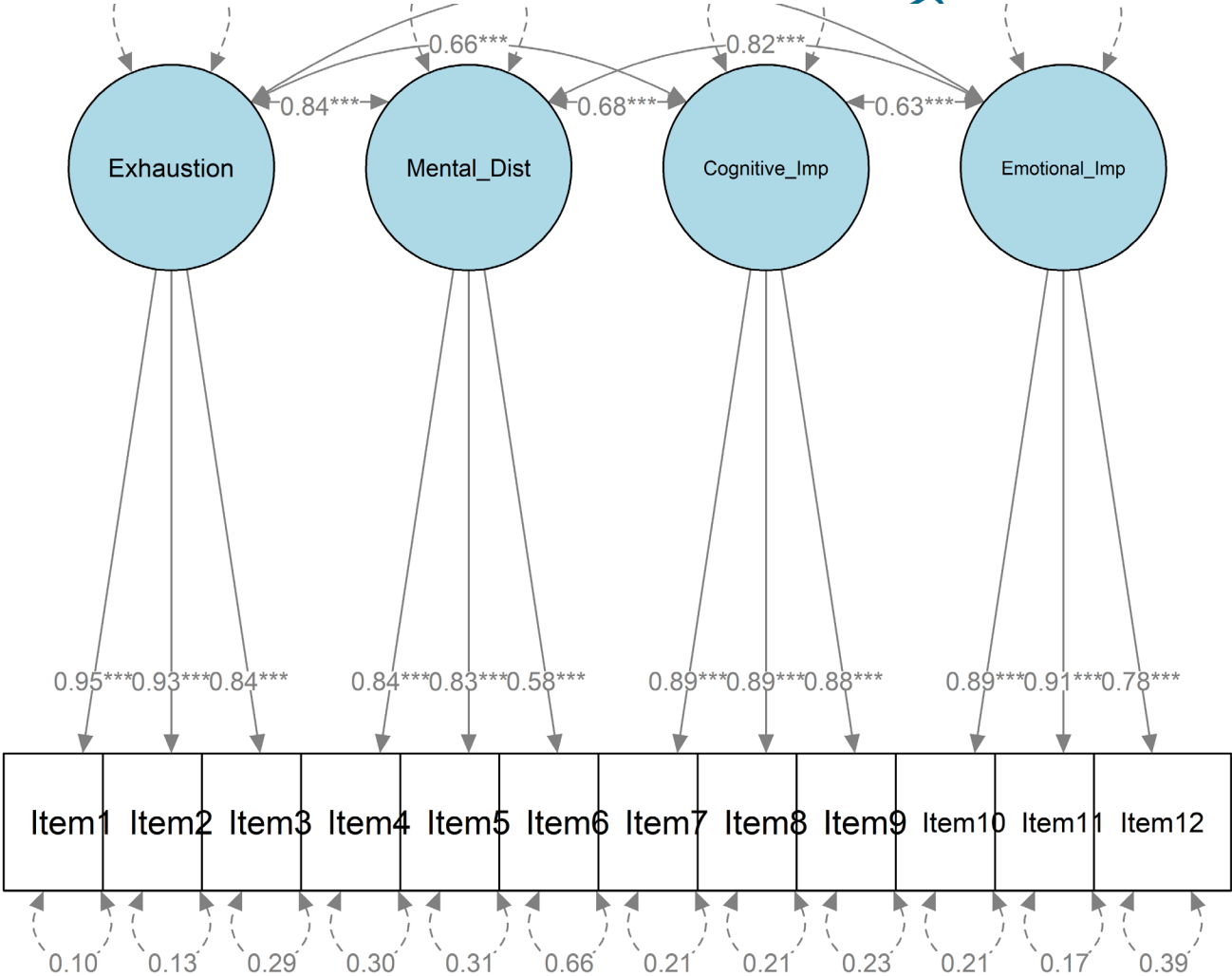
Validation of the Burnout Questionnaire (PA-BAT 12) N=260: Internal consistency and CFA



Correlations among the questionnaire items

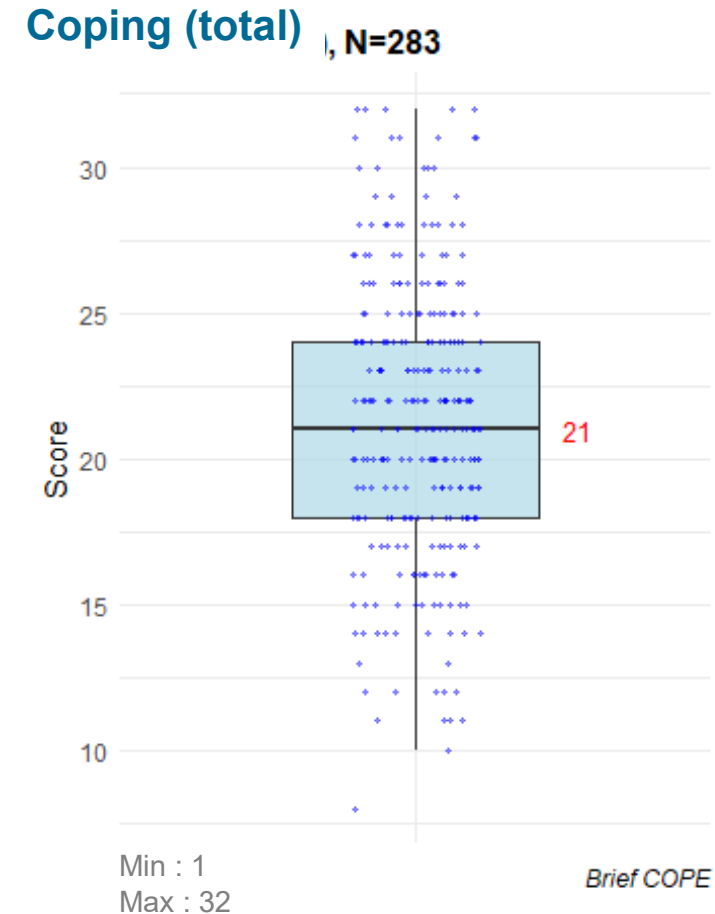
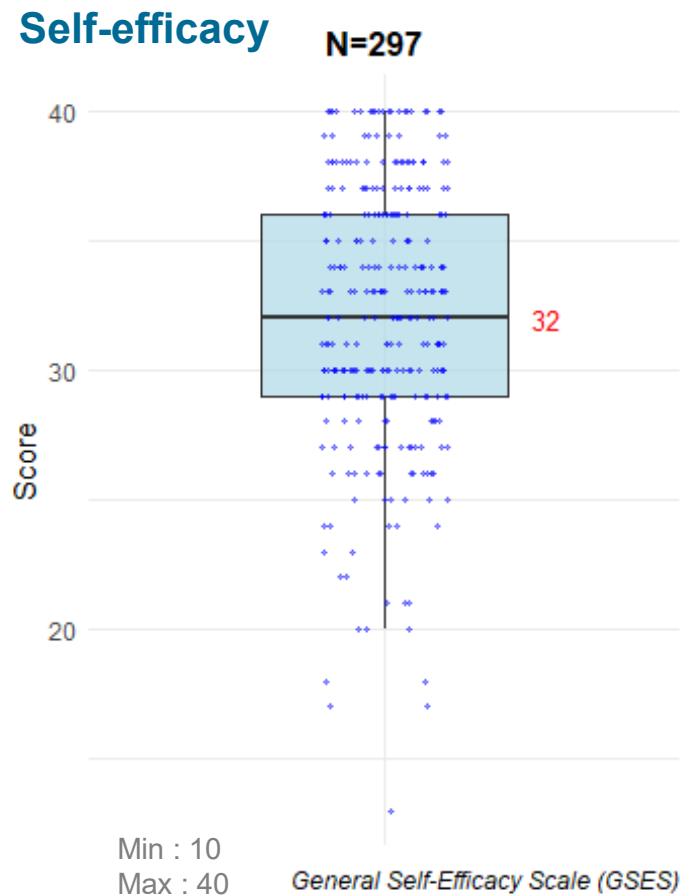
Index	Estimate	CI_Lower	CI_Upper
Cronbach's Alpha	0.92	0.91	0.93
McDonald's Omega	0.92	0.91	0.93

Internal consistency reliability coefficients. Alpha (α) and omega (ω) both indicating acceptable reliability when values exceed 0.70.



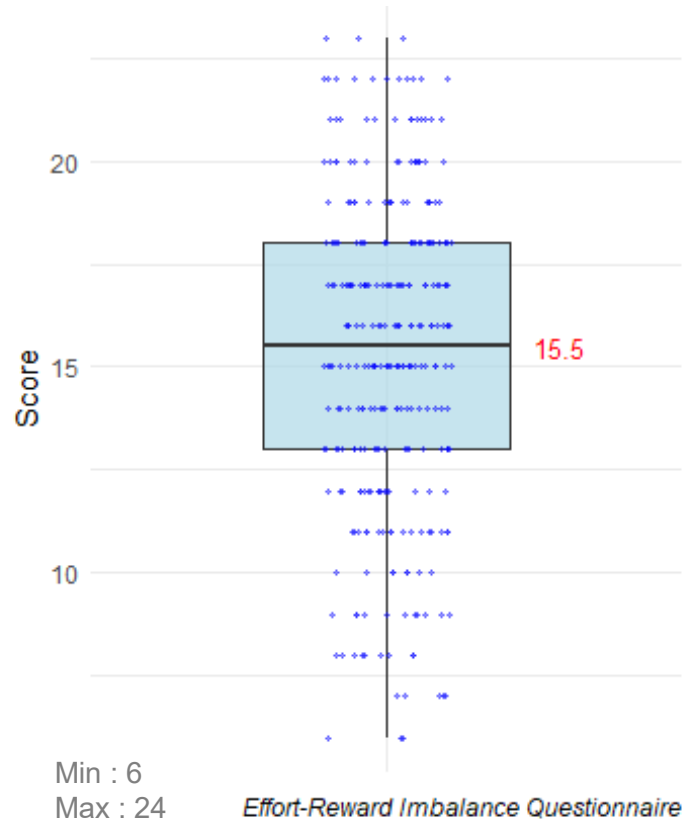
Confirmatory factor analysis (CFA) results for the adapted BAT-12 questionnaire. The model supports the expected item loadings onto the four subscales (latent variables), confirming that the adapted version retains the factorial structure of the original BAT-12.

pBL2024 – Global scores: Psychological factors

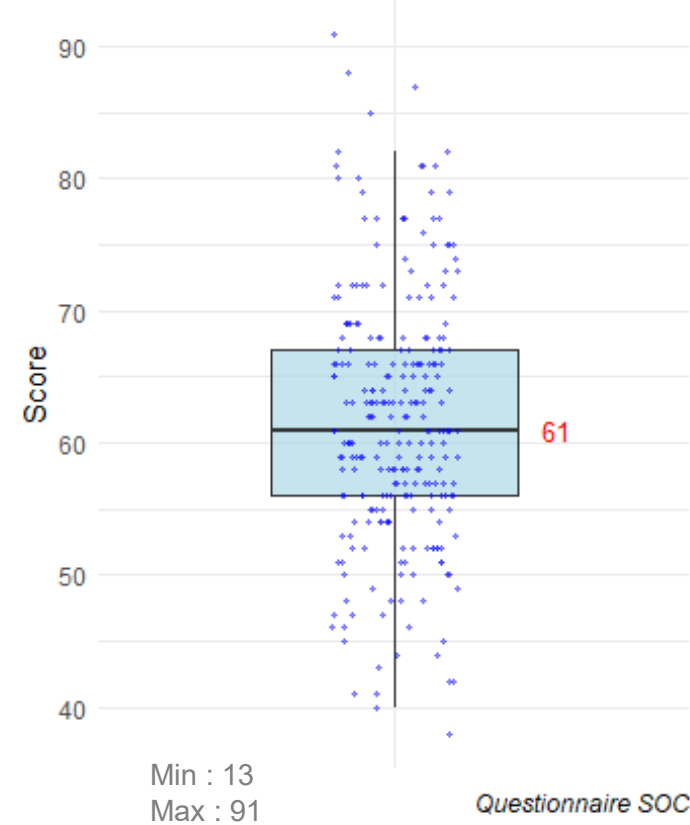


pBL2024 – Global scores: Psychological factors

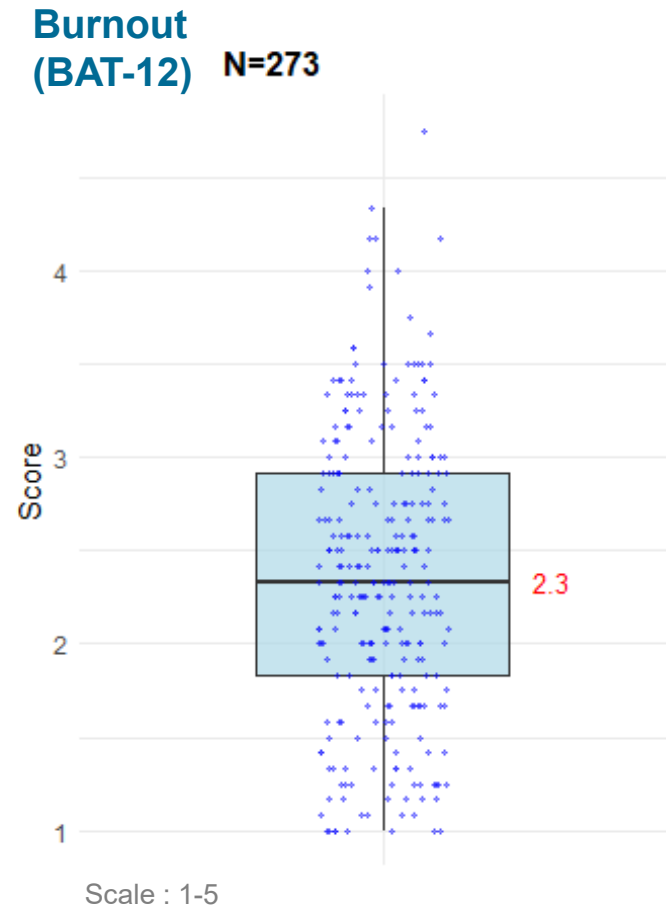
Overcommitment N=294



Sense of coherence, N=261



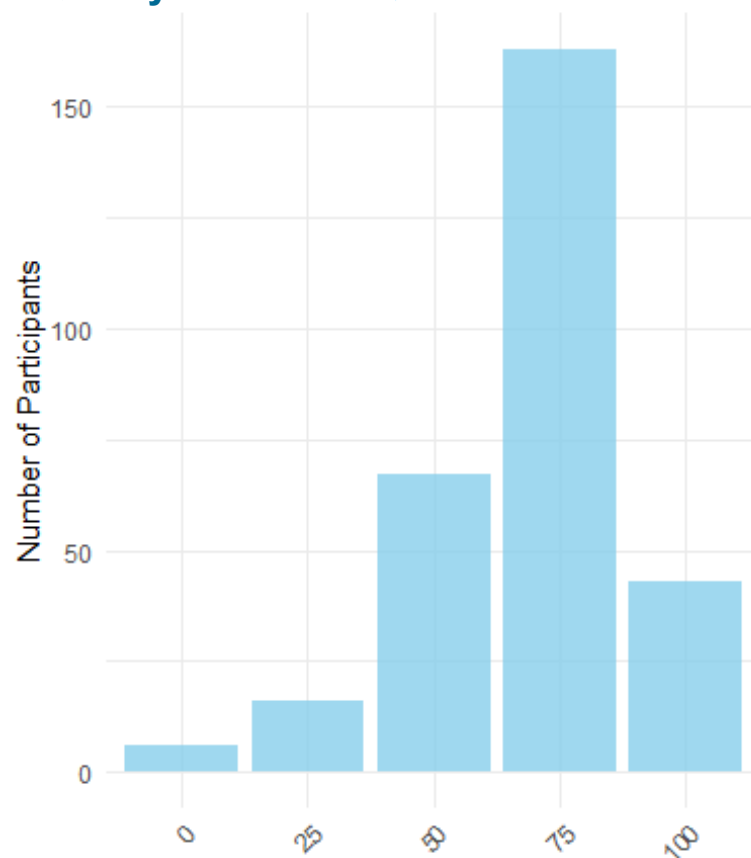
pBL2024 – Global scores : Burnout



pBL2024 – Global scores : IC's health

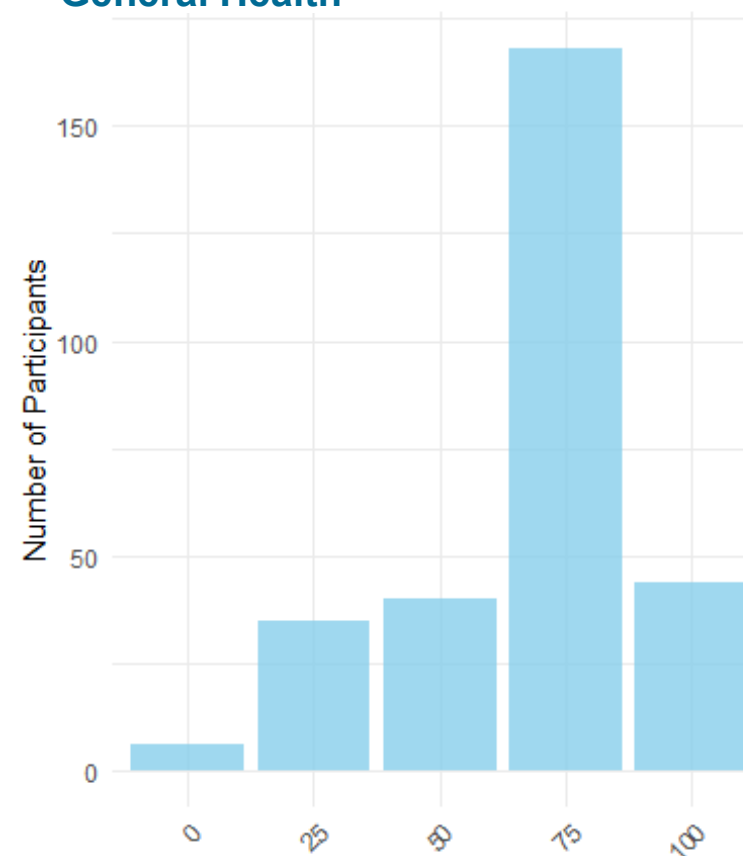
**WHOQOL –
Quality of life**

N=295



**WHOQOL –
General Health**

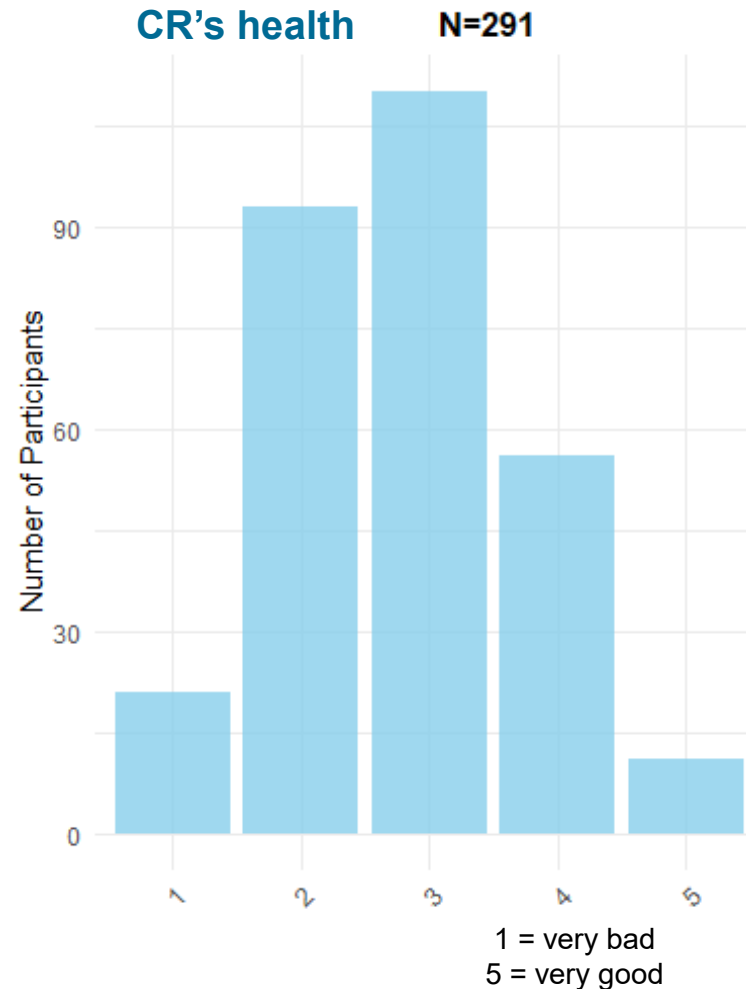
N=293



pBL2024 – Global score: CR's health

Statistical analyses in progress

→ Advanced results to be presented early summer



Qualitative analysis: open-ended comments

Qualitative analysis: standard open-ended comments

Question 1: Would you still like to comment on the help you provide for the care recipient and/or add an important aspect that was not covered by the questionnaire?

Number of answers = 113

Number of occurrences = 143

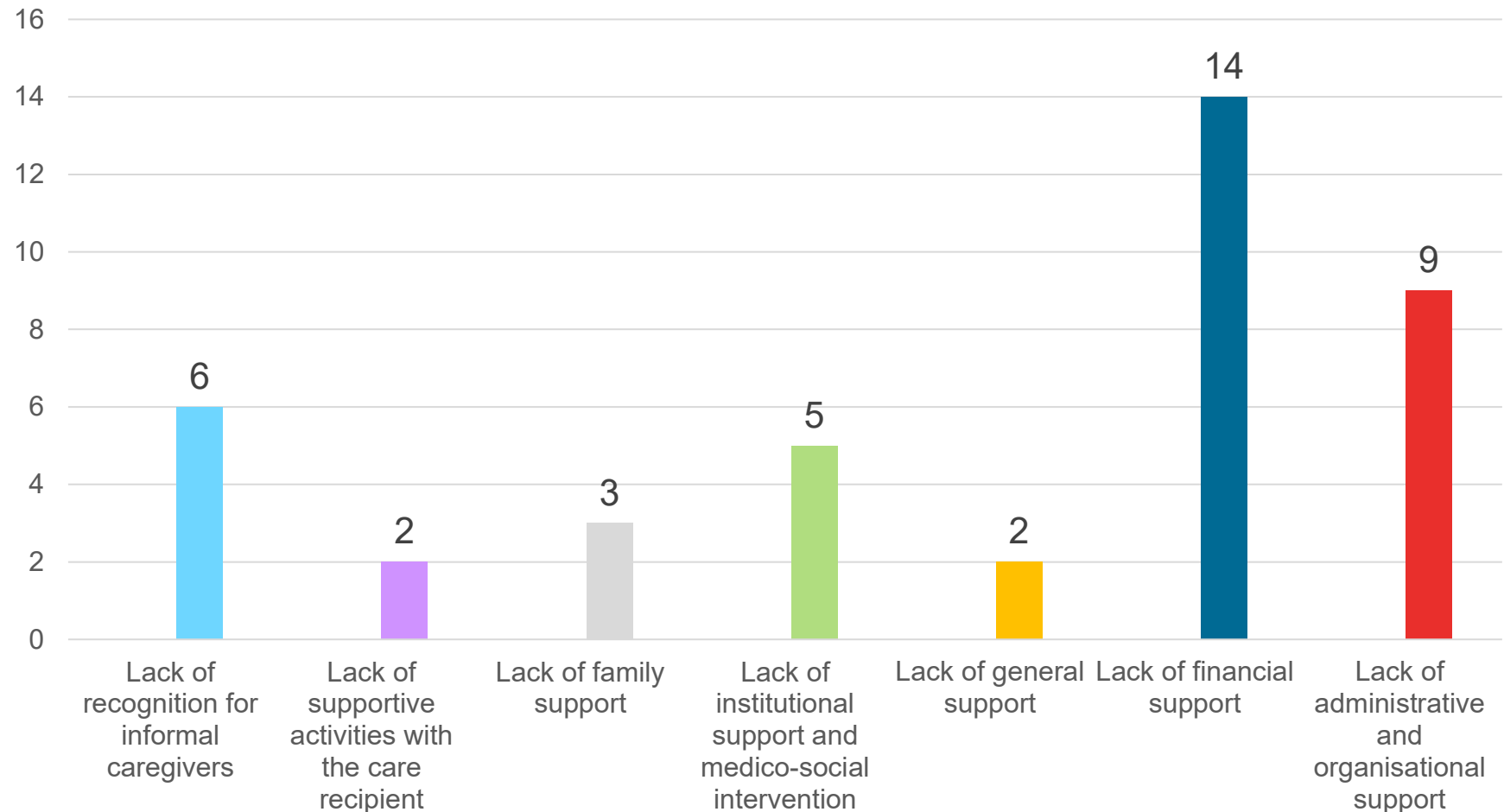
Themes:

- | | |
|---|----|
| • Lack of support and recognition | 47 |
| • Description of the help provided | 22 |
| • Relationship with the care recipient | 20 |
| • Psychological and cognitive burden | 13 |
| • Informal caregiver for CR with mental disorders | 12 |
| • Difficult coordination between care and work | 11 |

Qualitative analysis: standard open-ended comments

Lack of support and recognition

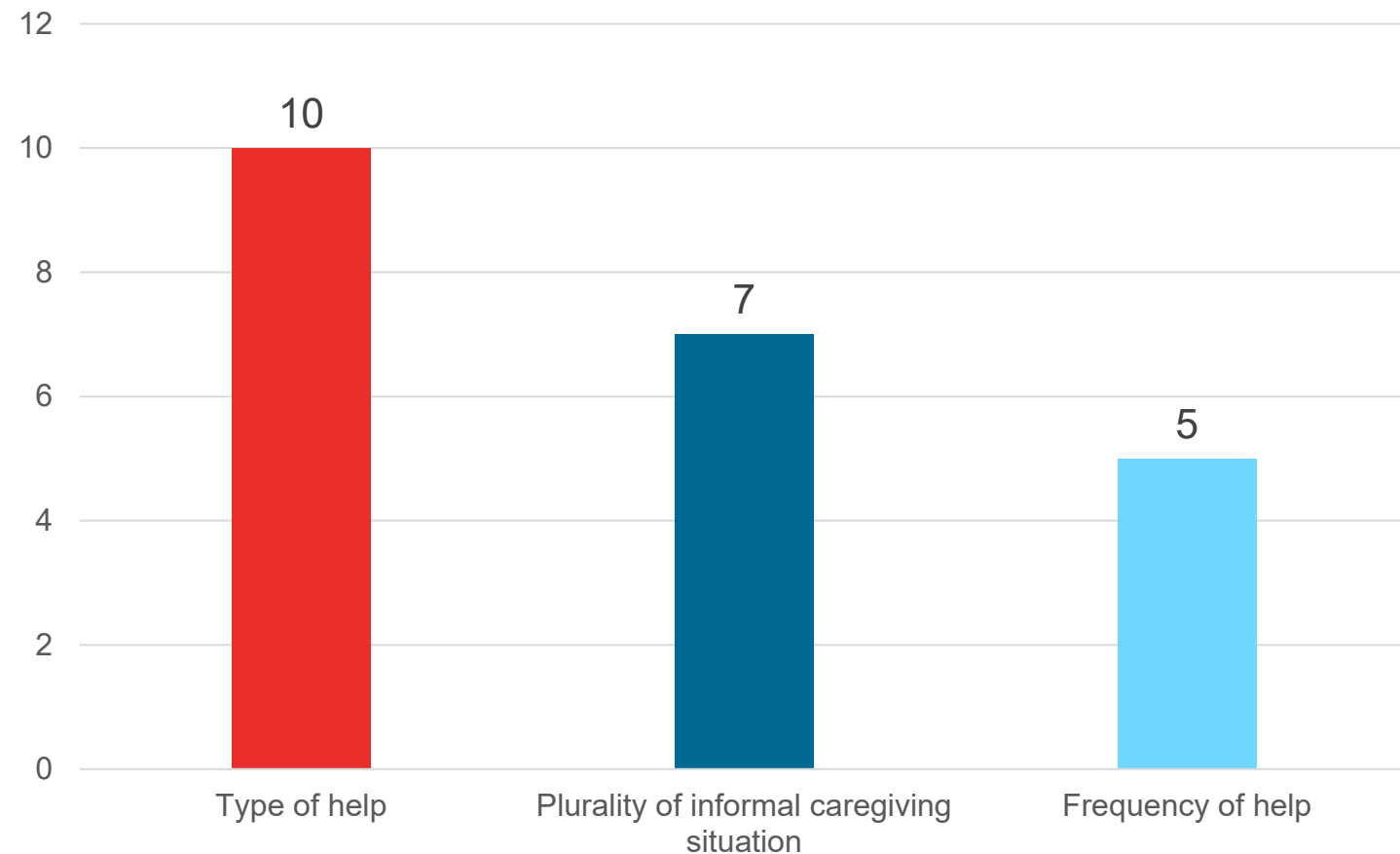
Number of occurrences = 47



Qualitative analysis: standard open-ended comments

Description of the help provided

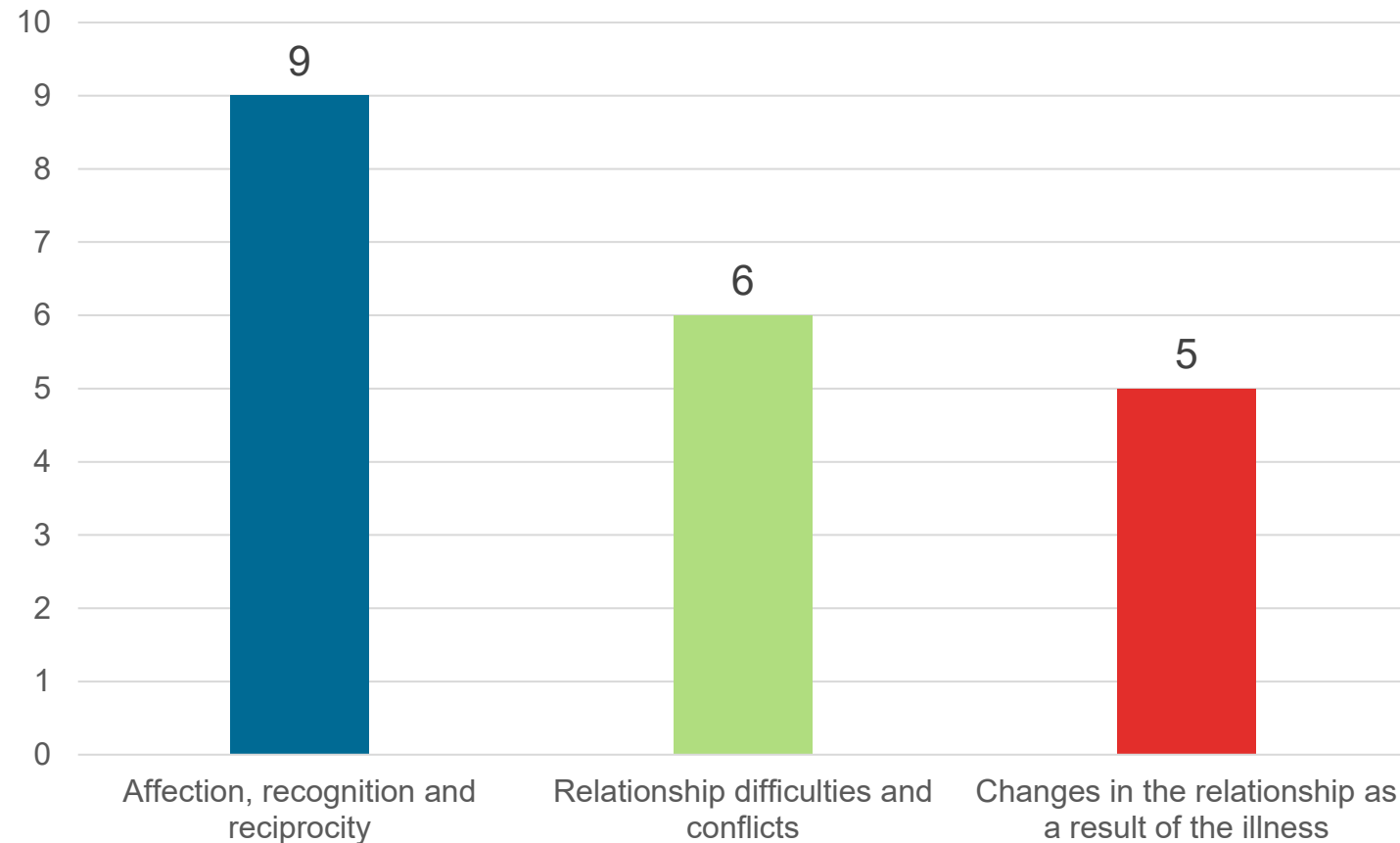
Number of
occurrences = 22



Qualitative analysis: standard open-ended comments

Relationship with the care recipient

Number of
occurrences = 20




Discussion

Strengths and limitations

Successful pilot

- Baseline and Follow-ups will benefit from acceptability and feasibility analyses
- ICIM
- Validation of the Burnout Assessment Tool (BAT) adaptation to informal caregiving

A red speech bubble with a tail pointing towards the third bullet point.

Article in preparation

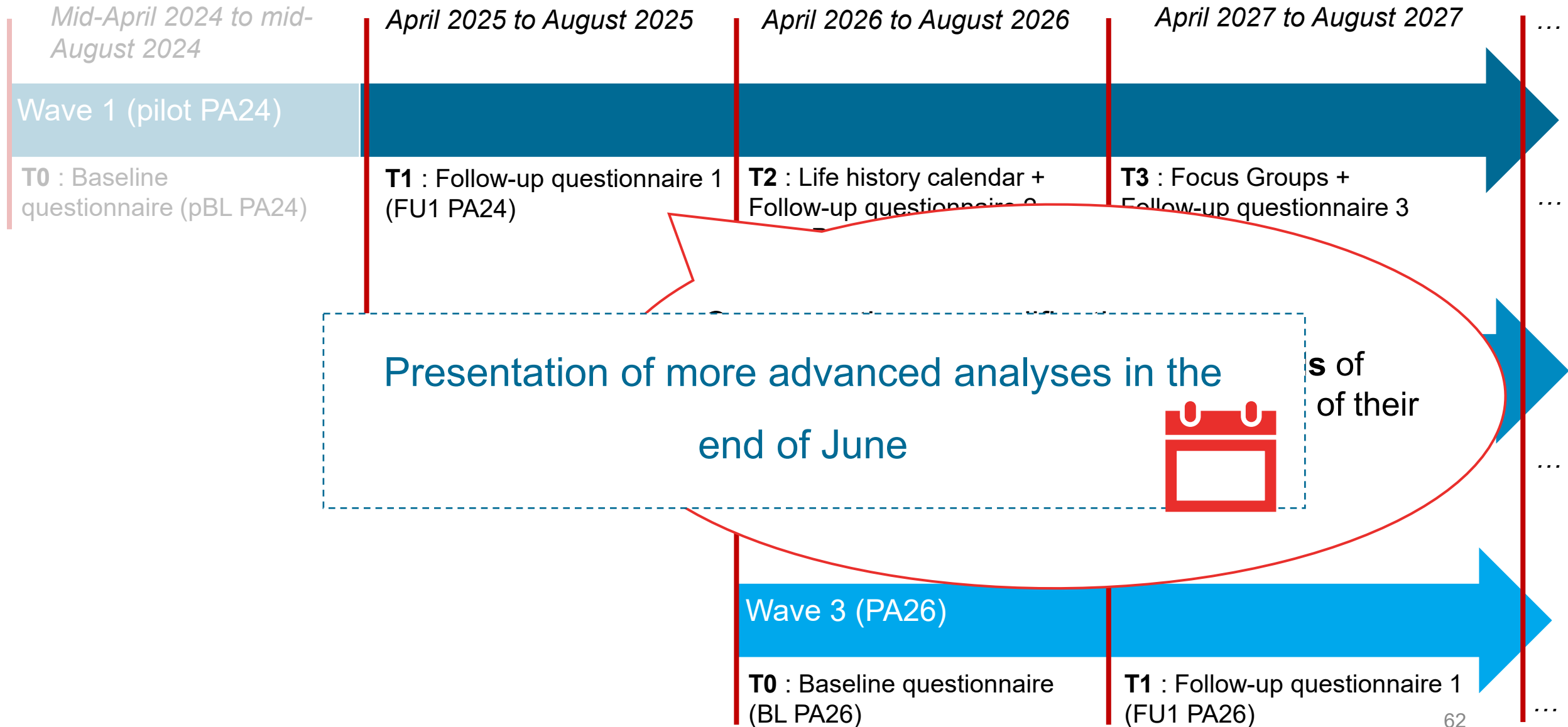
Effective recruitment strategies and strengthened partnerships

→ solid foundation for future data collection 😊

Two articles in preparation

Open research or open data : possibility to join the research team or to re-use data for secondary analyses

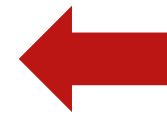
What's next??



Conclusion

SCOHPICA IC: Next steps

The baseline survey of IC will be open from
mid-April to mid-August 2025



Results of 2024 available on the
new Dashboard in April 2025 in **F**
& **G**

SCOHPICA Healthcare professionals:

Next steps



SCOHPICA PROFESSIONNEL-LES DE SANTÉ EST OUVERT!

Merci pour votre engagement dans l'étude SCOHPICA.

Cliquez ici pour participer en tant que professionnel-le de la santé

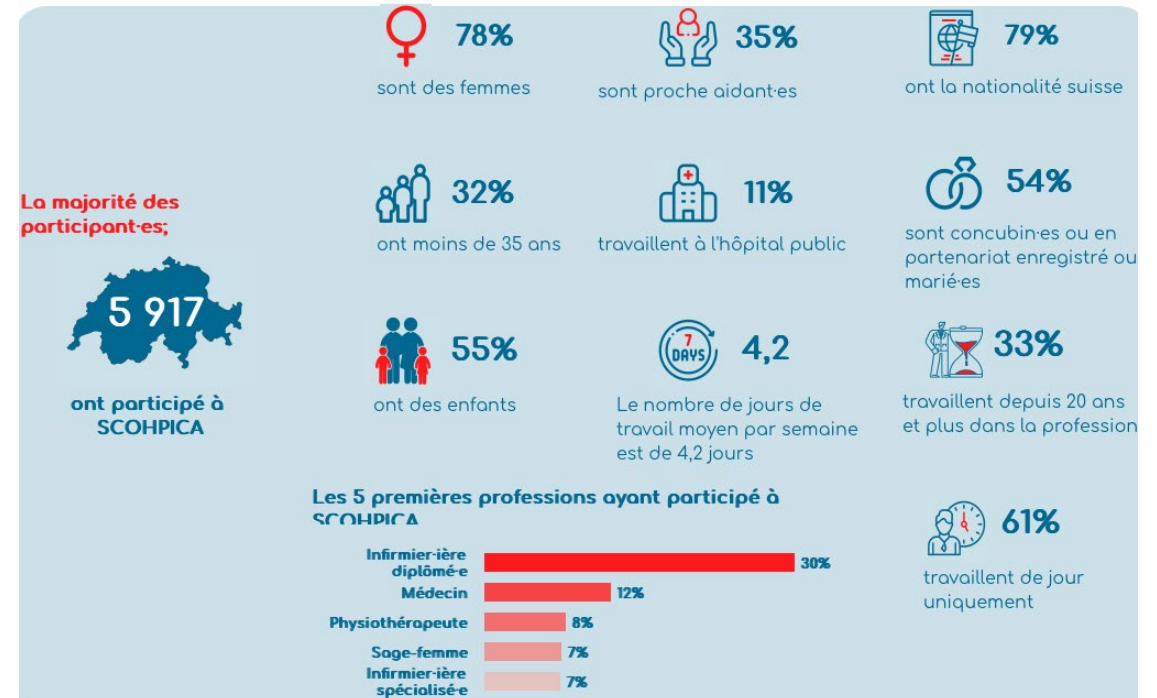


⚠ Si vous avez répondu à l'enquête l'année passée et que vous aviez donné votre adresse email à la fin du questionnaire, merci de ne PAS cliquer sur le lien ci-dessus mais de cliquer sur le lien qui vous a été transmis par email et qui permettra à l'équipe de recherche de lier vos nouvelles réponses avec celles que vous avez données l'année passée (la confidentialité des données reste garantie). Ceci est très important afin de comprendre les parcours des participants et leur évolution professionnelle.

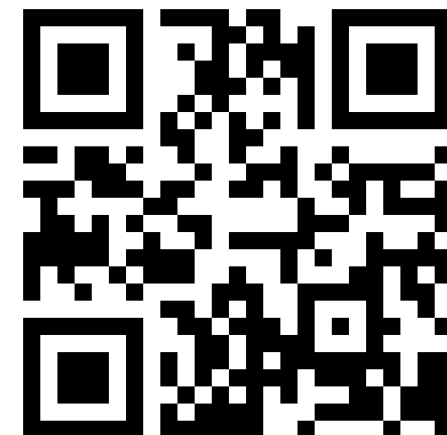
Questionnaire is **open** until the end of January 2025

Results (2022-2023)
available on the new
Dashboard
(www.scohpica.ch)

Socio-démographique et Socio-professionnelle



Thank you for your collaboration





Thank you for your attention and **contribution**



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