



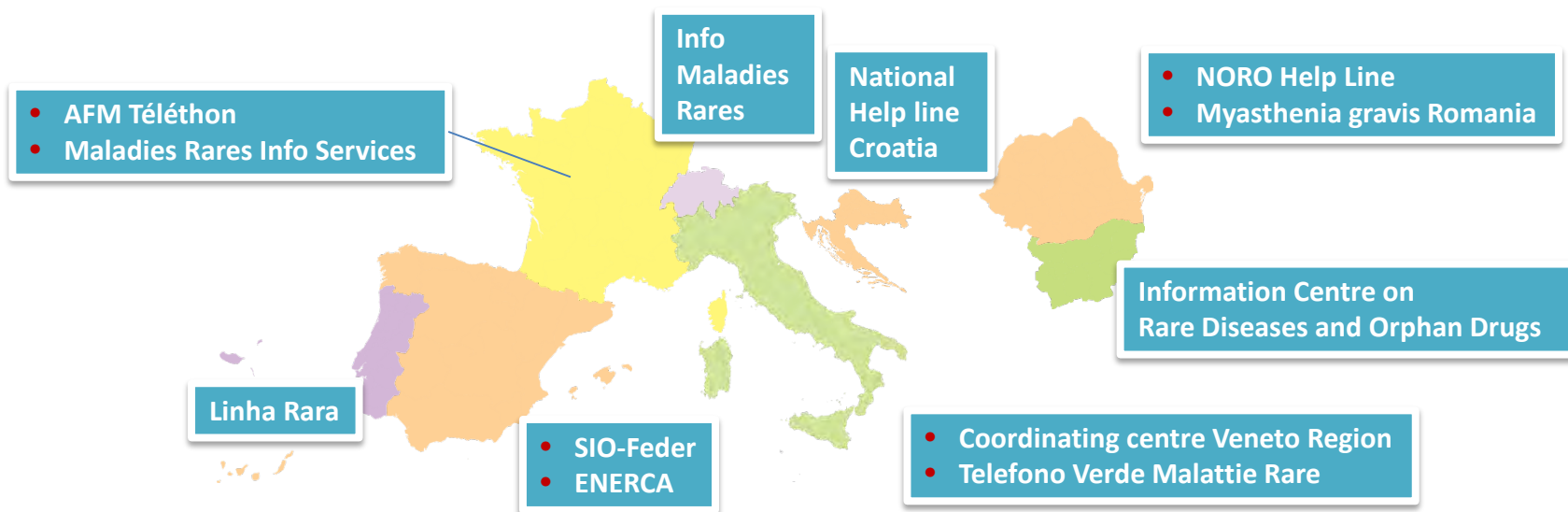
**European Network of Help Lines
for Rare Diseases**

Caller Profile Analysis 2015



Help Lines
for Rare
Diseases

ENRDHL in 2015





Help Lines
for Rare
Diseases

« a given month » study type

- ① Descriptive approach
 - Cross-sectional survey “snapshot”
 - Transversal analysis of help lines’ activity
- ① To participate is one of the commitments for network membership
- ① All enquiries received from 1 to 30 October 2015



Help Lines
for Rare
Diseases

CPA 2015

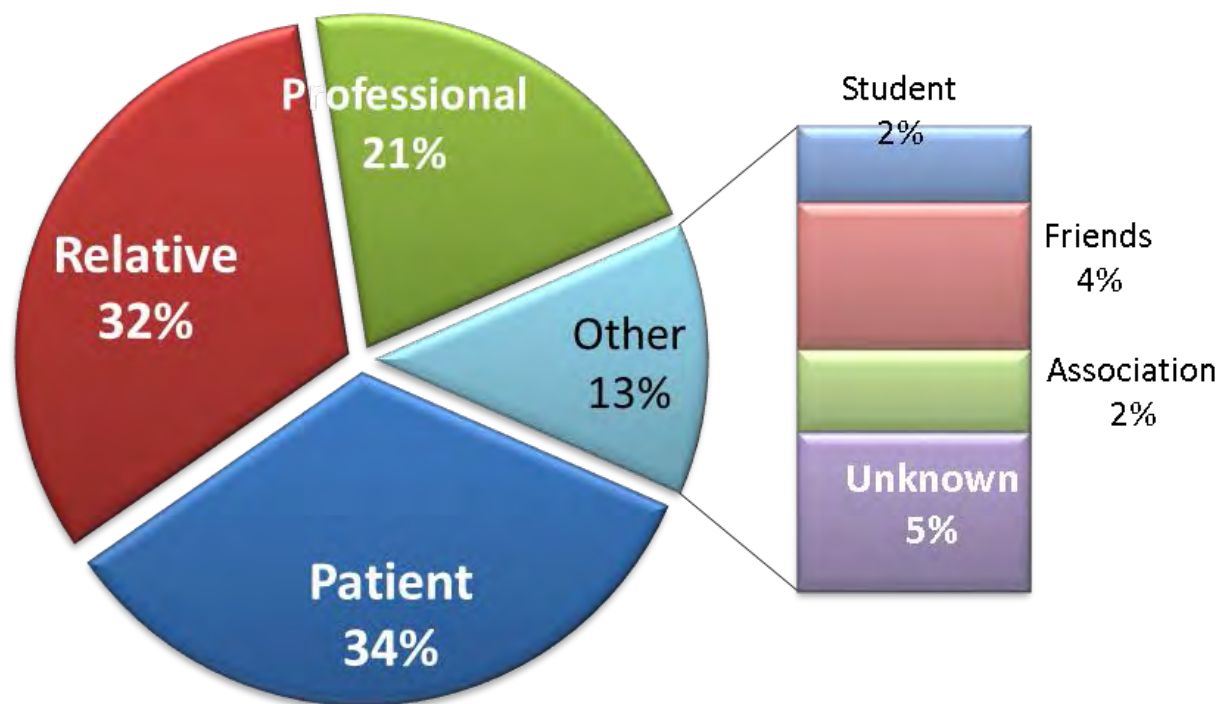
	Nov. 2011	Nov. 2012	Oct. 2013	Oct. 2014	Oct. 2015
Number of help lines	11	12	11	12	12
Number of respondents	51	51	53		68
# calls, emails...	1739	1676	1672	1850	1714
Average # of enquiries per respondent	34.1	32.9	31.5		25.2
Average # of enquiries per help line	165.3	163.8	152.0		142.8
Help lines using ORPHA codes	7/11	10/12	10/11	11/12	11/12



Help Lines
for Rare
Diseases

Who's enquiring?

Category of enquirer
n= 1,850

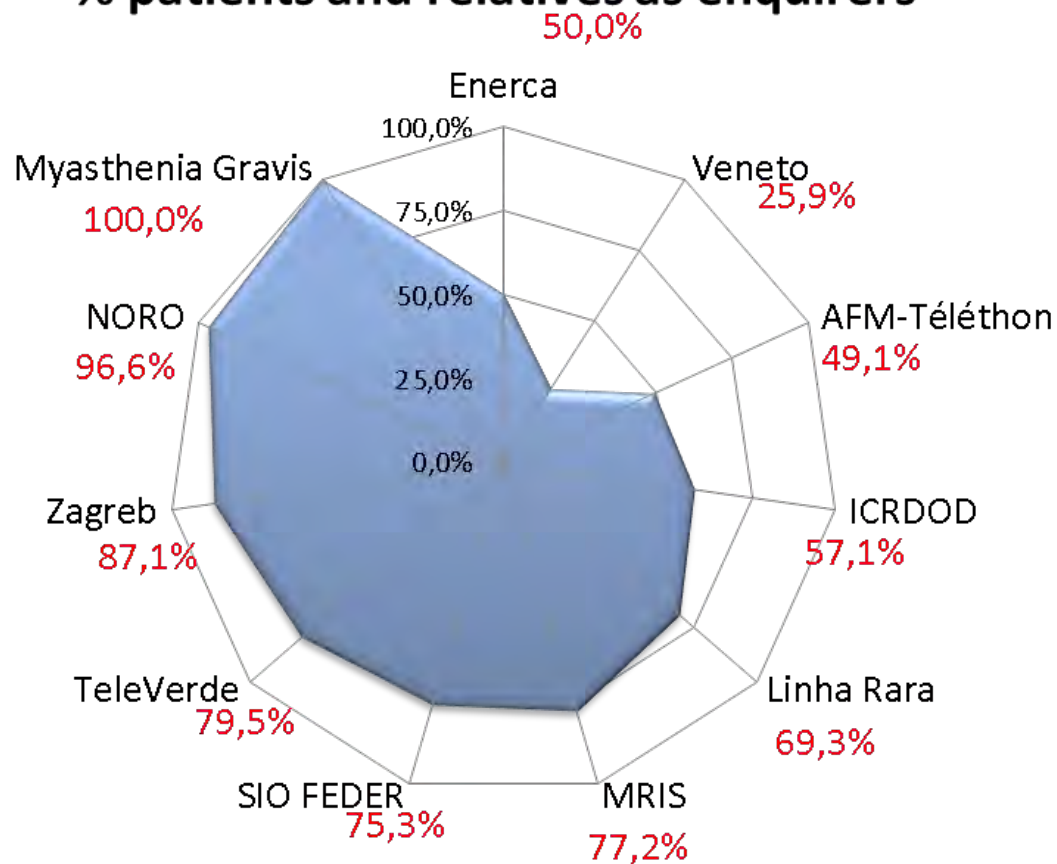




Help Lines
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Diseases

Different publics

% patients and relatives as enquirers

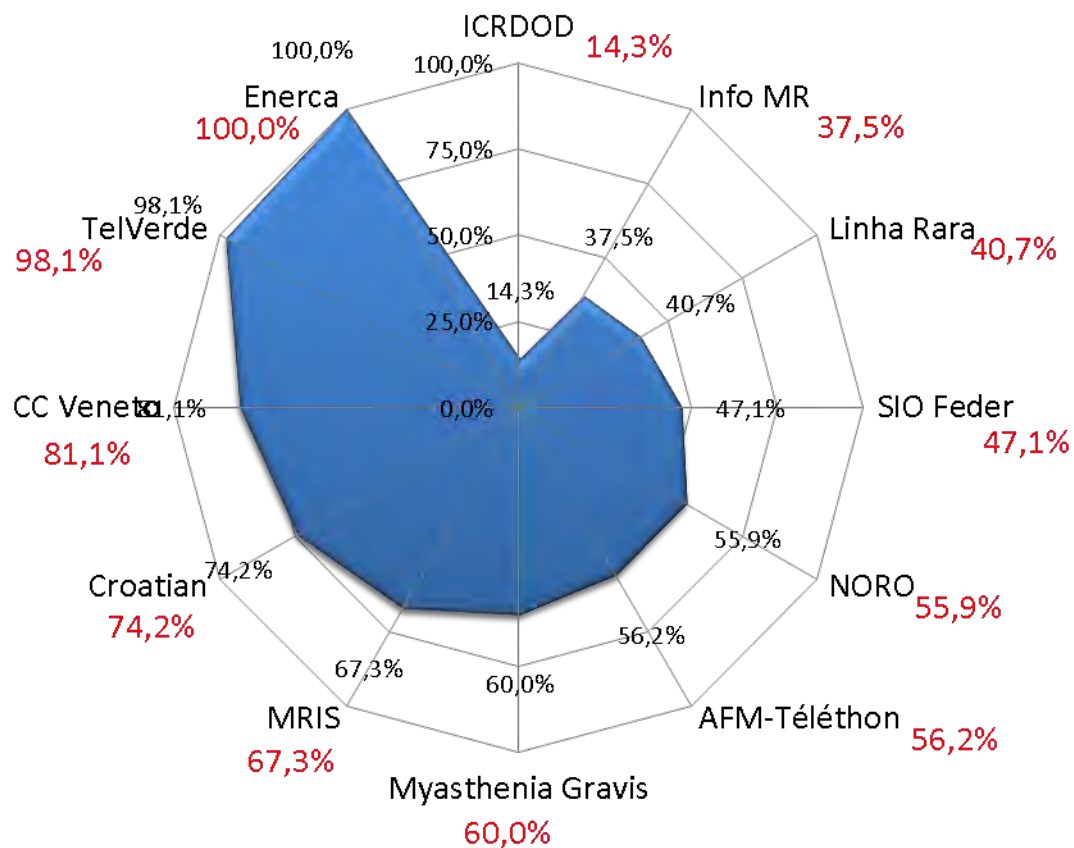




Help Lines
for Rare
Diseases

How?

Proportion of enquiries made by phone
by help line

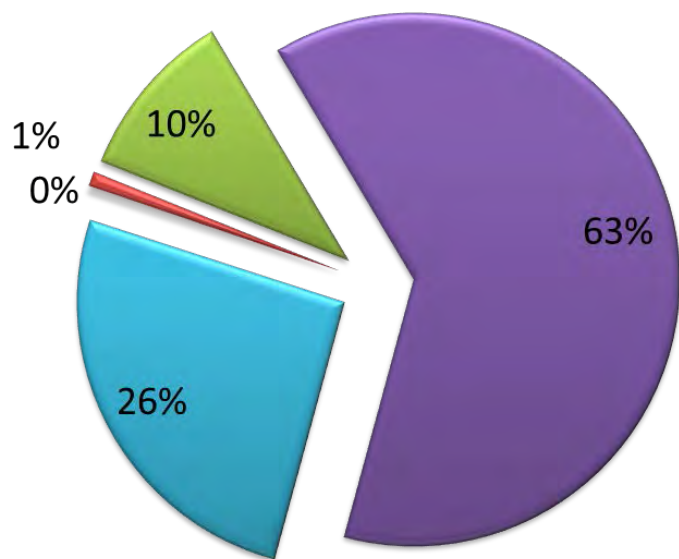




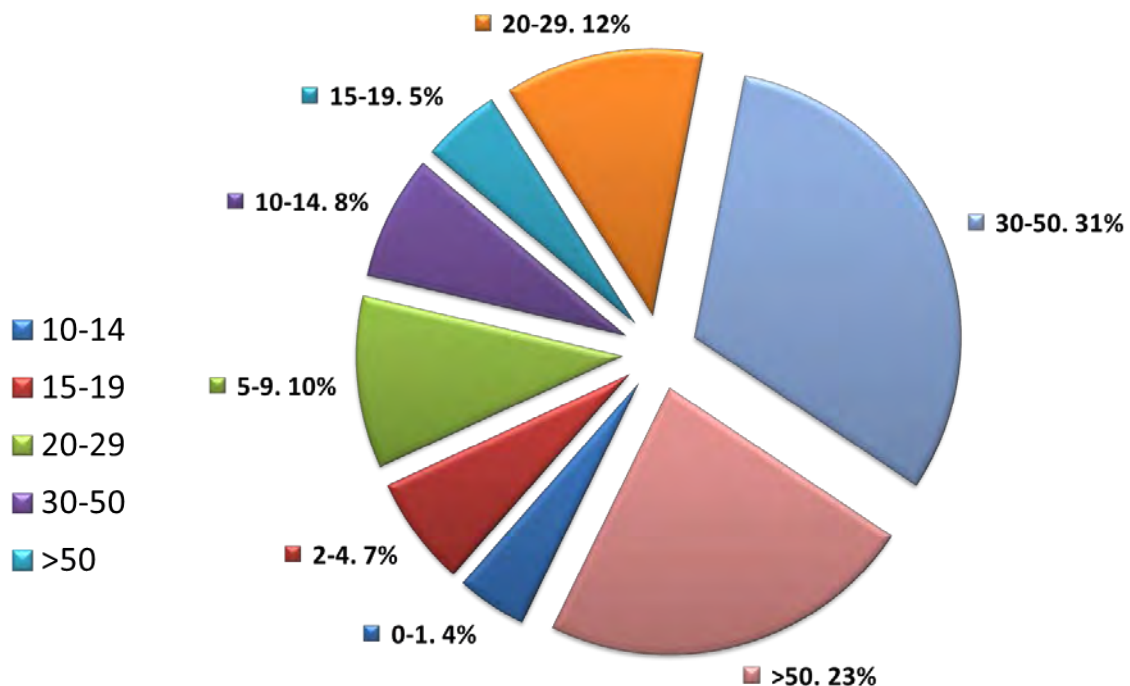
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Age of the enquirers and patients

Age of enquirers
(when known, n=1,1178)



Age of patients
(when known, n=1,335)

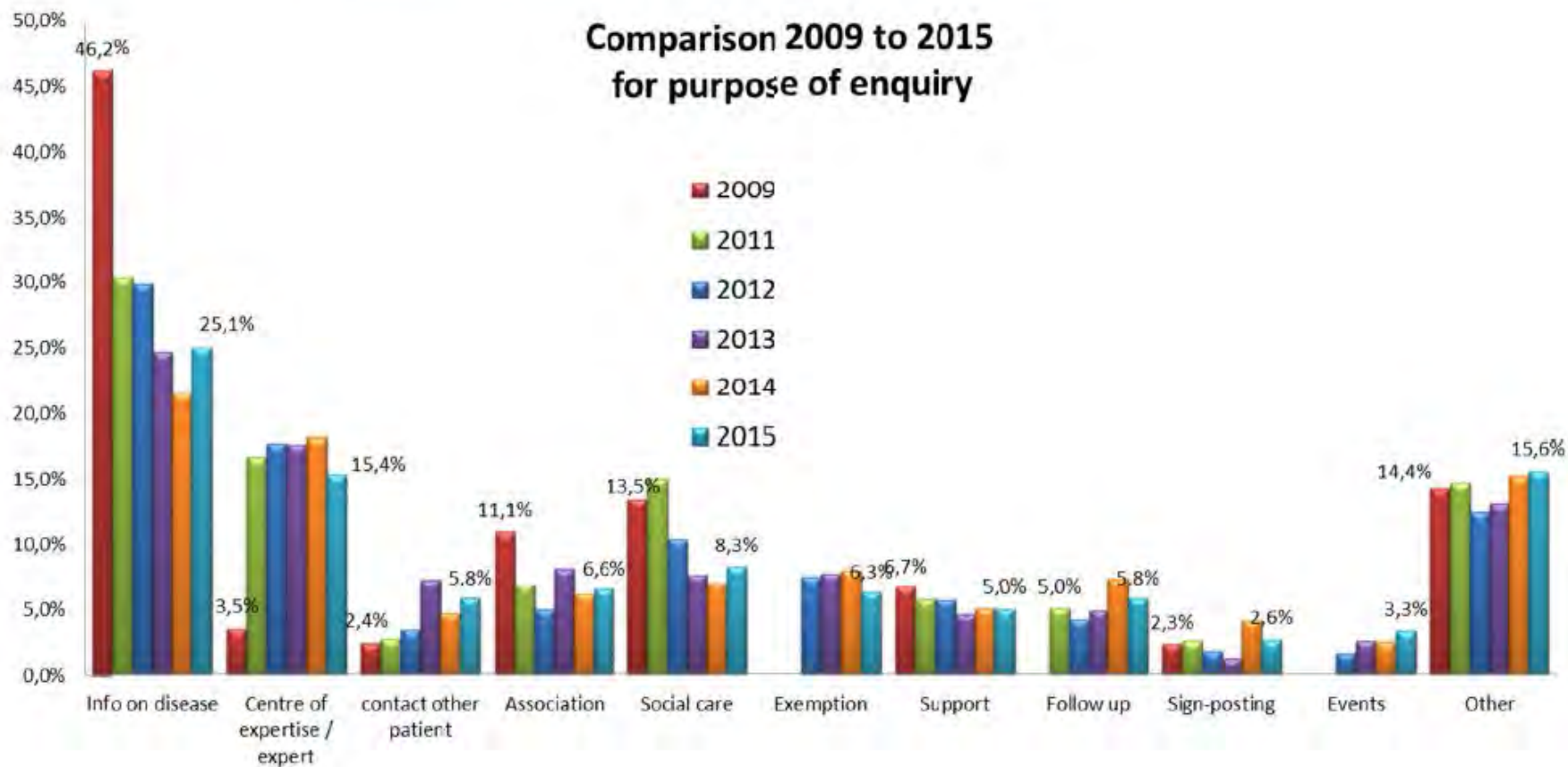




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Purpose of the enquiry

Figure 12: purpose of contact by phone or email from 2009 to 2015



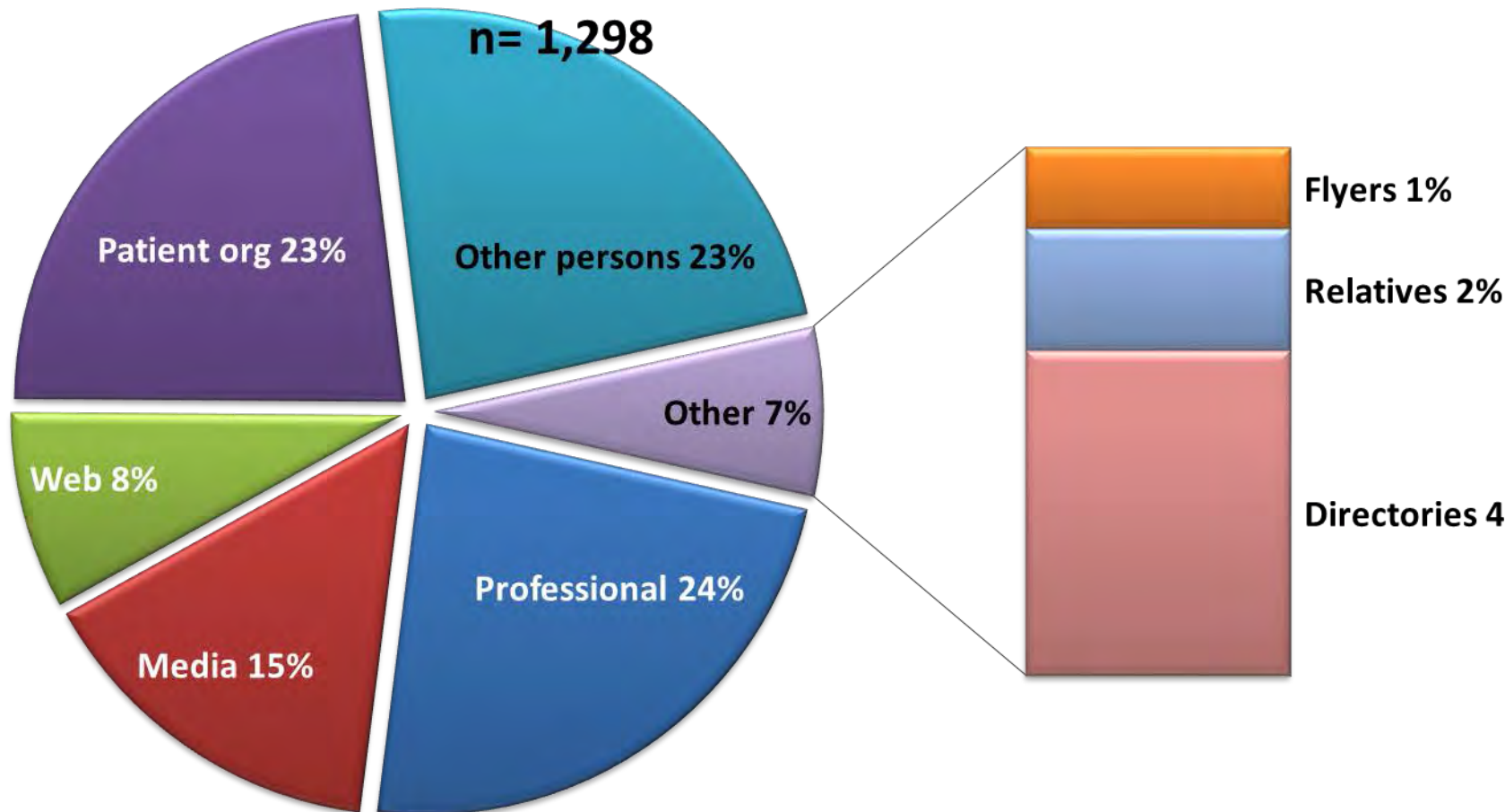
All help lines



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Help lines' awareness

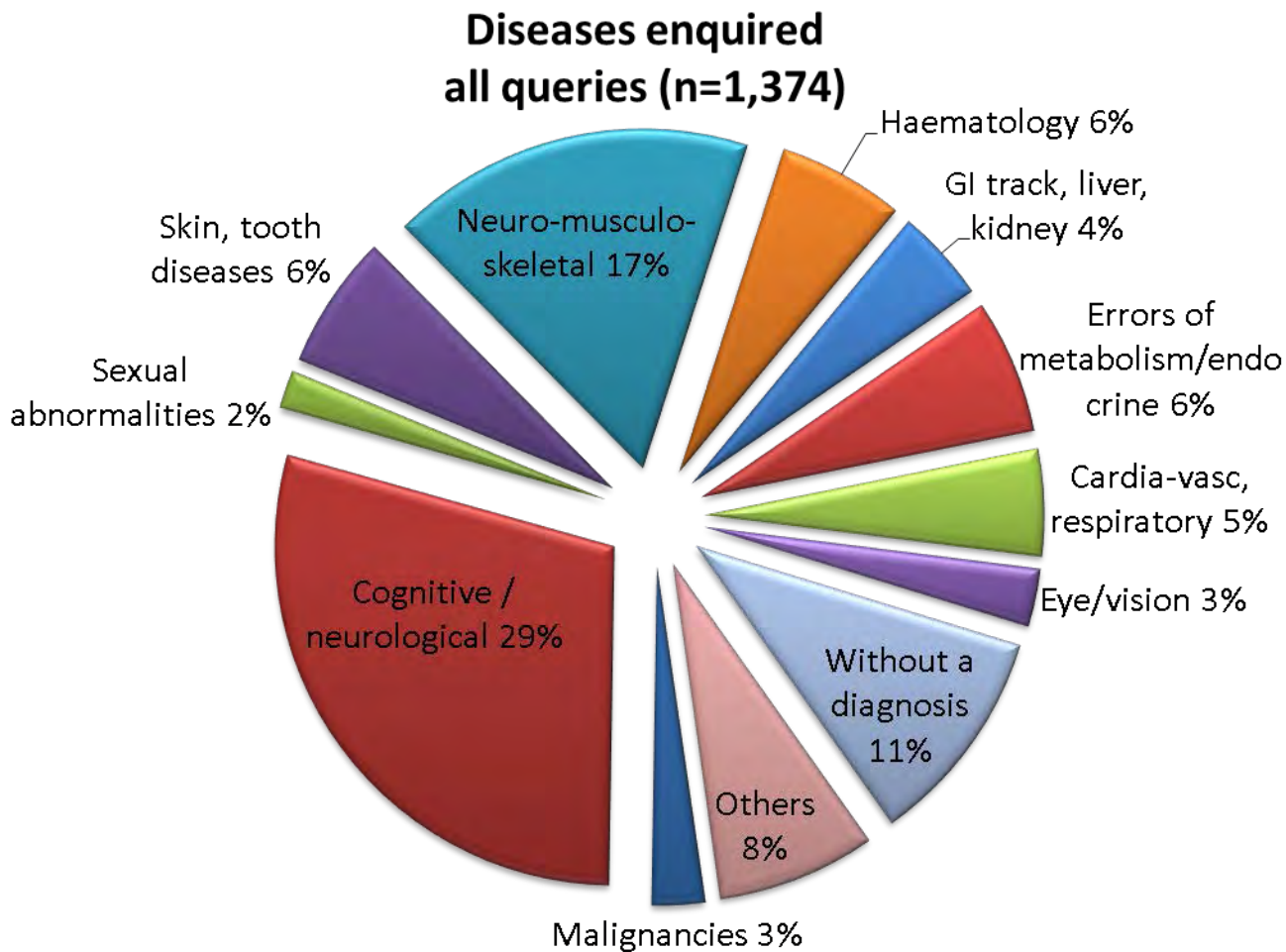
How did you hear about help line?





Help Lines
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Which diseases?

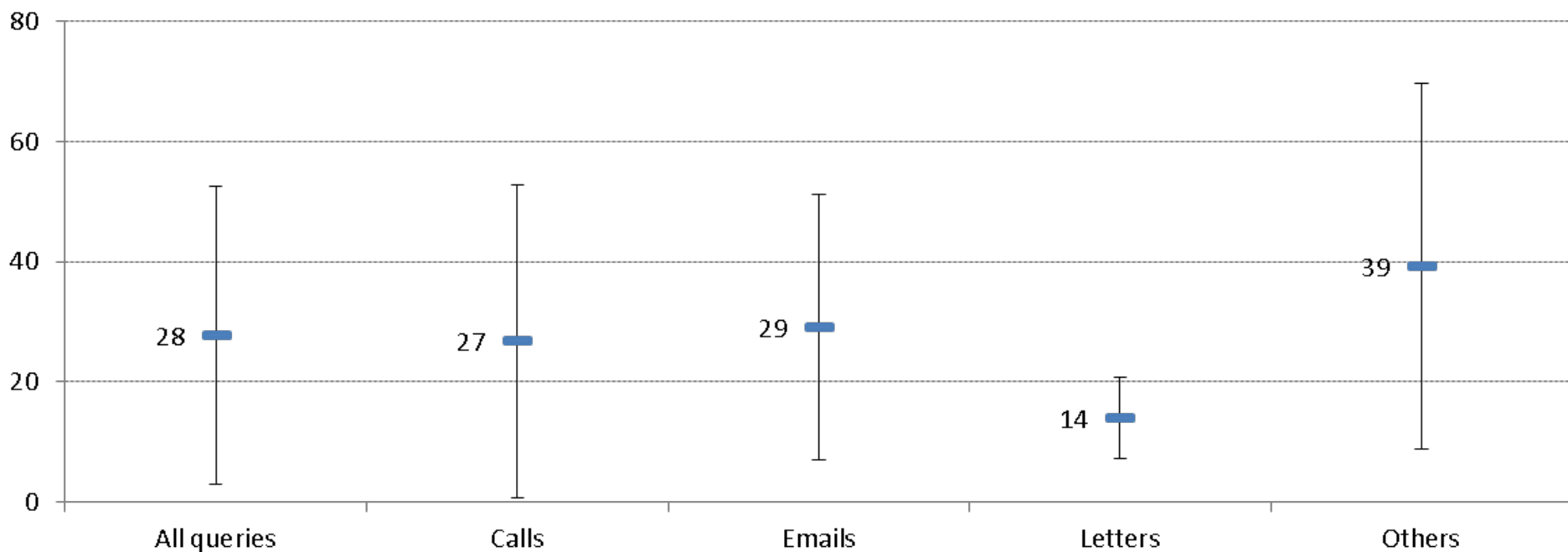




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Average duration (n=1,712)

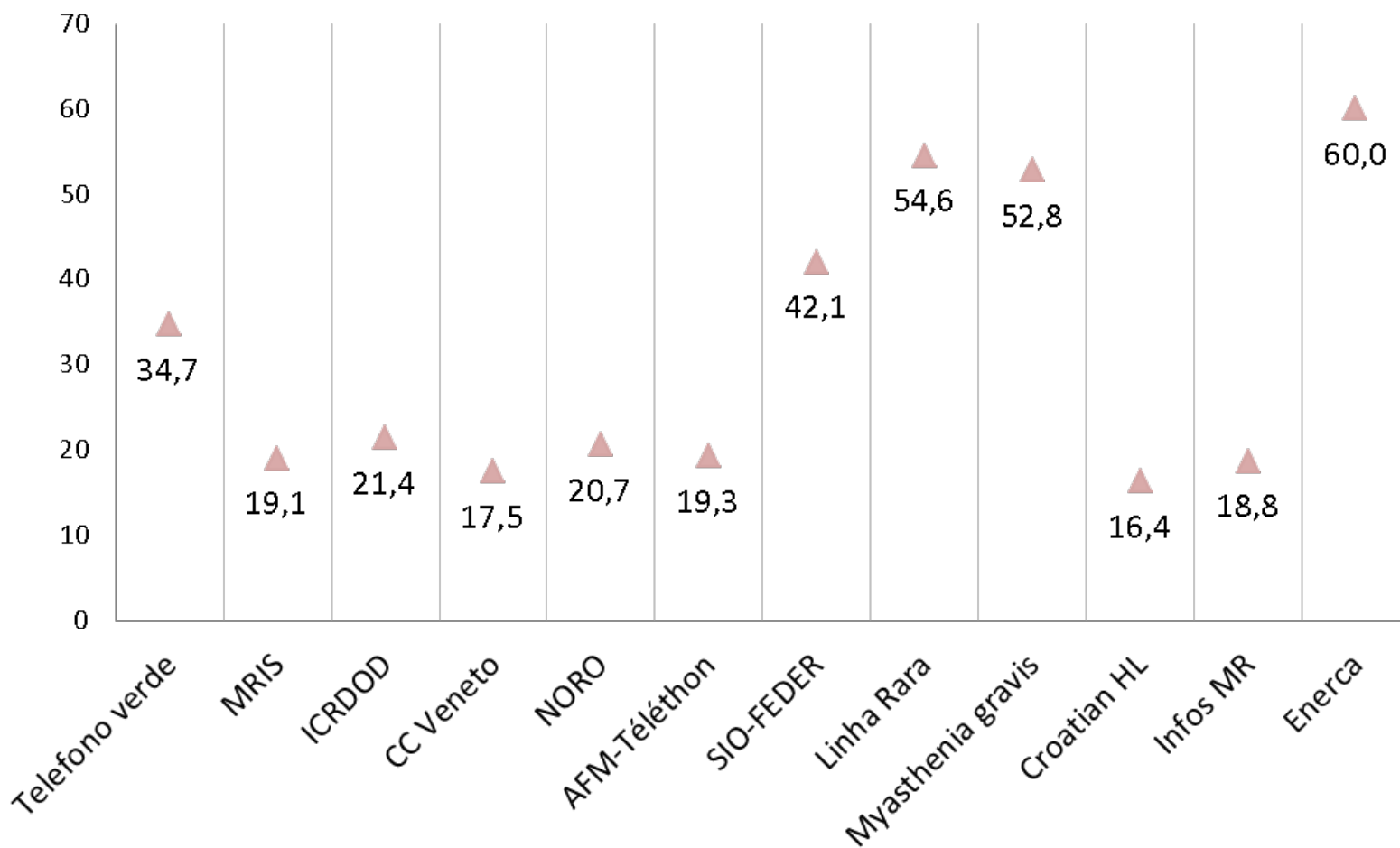
Average enquiry duration by type of contact





Help Lines
for Rare
Diseases

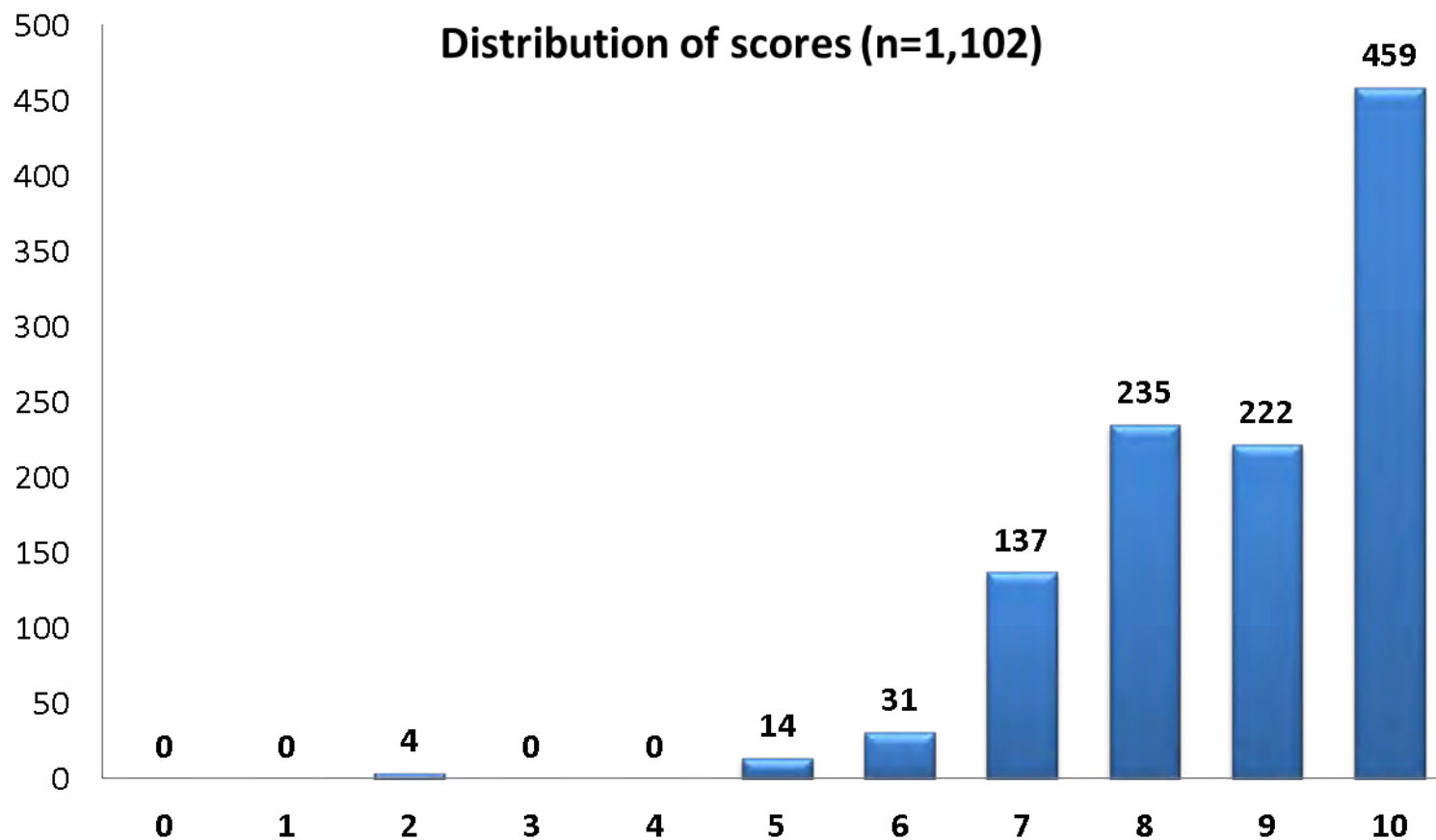
Average duration by help line





Help Lines
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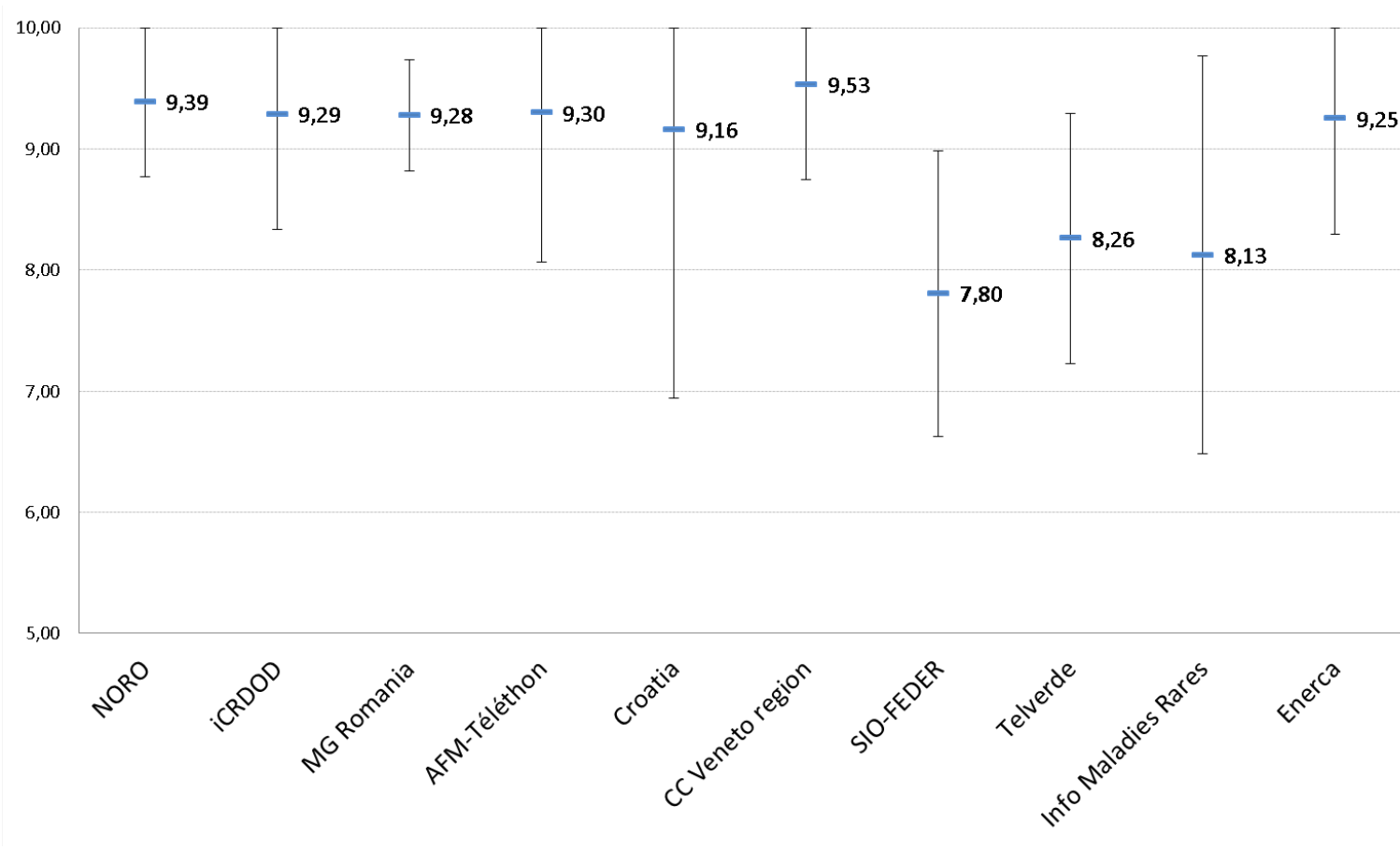
Satisfaction





Help Lines
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Diseases

Satisfaction

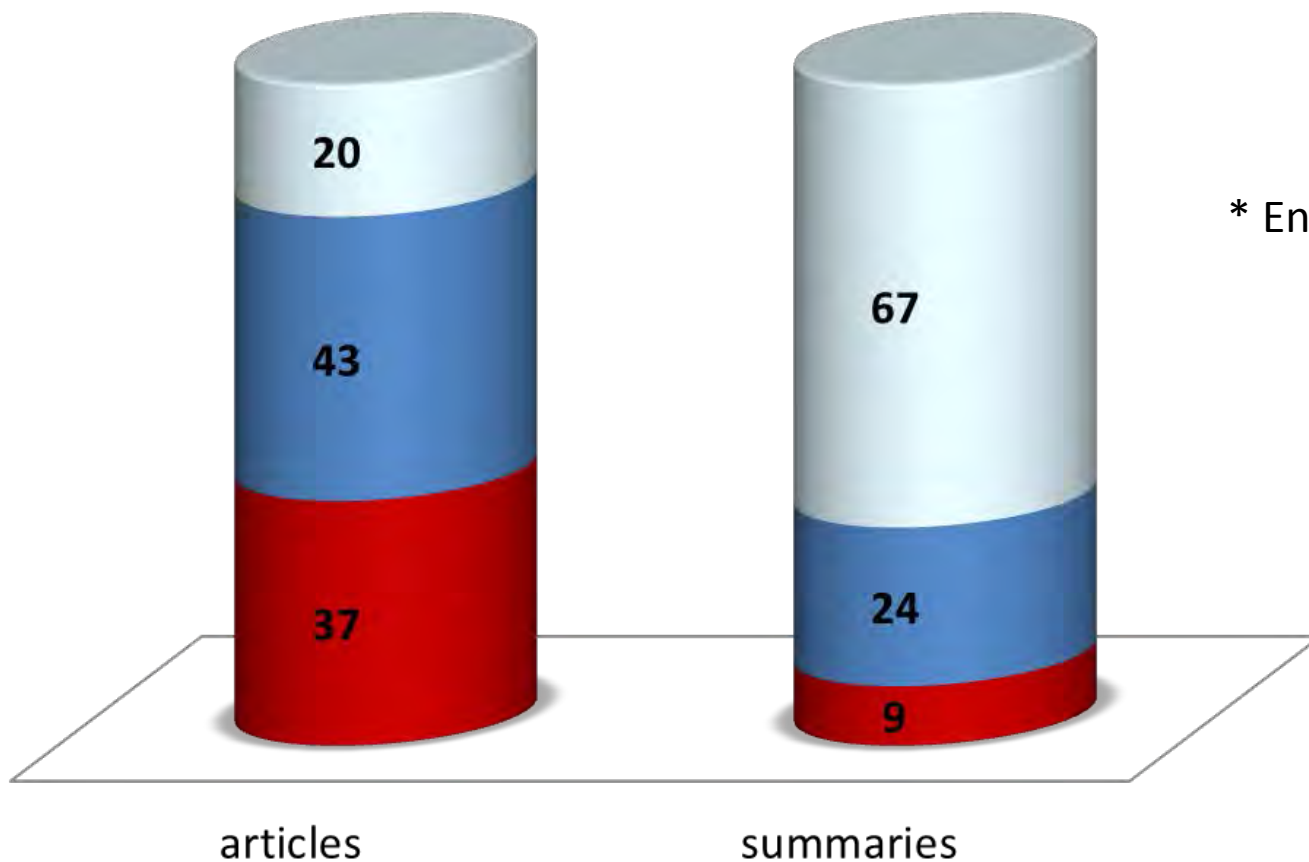




Help Lines
for Rare
Diseases

2013: Orpha.net and/or Wikipedia as a source of information* for respondents

■ none ■ only one ■ both



* English only



Help Lines
for Rare
Diseases

Distribution Orphanet / Wikipedia

	Orphanet	Wikipedia
Summaries	79	86
Articles	22*	59

* Other documents exist (clinical practice guidelines, review genetic testing...)

100 diseases randomly selected among 165 that correspond to 509 enquiries requesting information on the disease, 9 services included, 1-31/10/2013: Coordinating Centre Veneto Region, ICRDOD, AFM-Téléthon, SIO-FEDER, MG Romania, Croatian HL, Linha Rara, Enerca.

Note: Maladies Rares Info Services was not included as it is not using ORPHA codes



Help Lines
for Rare
Diseases

To learn more

Mr François Houÿez, Ms Rosa Sanchez de Vega, Dr Tuy Nga Brignol, MD, Dr Monica Mazzucato, Dr Agata Polizzi MD.

A European network of email and telephone help lines providing information and support on rare diseases - results of a 1-month activity survey.

Interact J Med Res (forthcoming).

doi:10.2196/ijmr.2867



Help Lines
for Rare
Diseases

Research objectives

- ① To analyse whether it makes a difference when:
 - A help line is driven by a patients' organisation or by a healthcare professionals'/governmental organisation (nature)
 - A help line is composed of paid staff, or volunteers, or a mix (composition)
 - A help line addresses all rare diseases or specific ones (scope)
 - A help line operates mostly by telephone, or by email (mode)
- ① On:
 - Category of enquirer, purpose of the enquiry, responses given, duration of the enquiry...



Help Lines
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Diseases

Duration of enquiries by help lines' characteristics (CPA 2012)

Nature		
	Patient driven	Healthcare professionals or governmental
Average minutes (95% CI)	23.7 (22.2 – 25.3)	19.7 (17.8 – 21.6)
Nb of enquiries	969	469
Scope		
	All rare diseases	Specific diseases
Average minutes (95% CI)	24 (22.6 – 25.4)	17.9 (15.5 – 20.3)
Nb of enquiries	1172	283
Composition		
	Paid staff only	Paid staff/volunteers
Average minutes (95% CI)	24.7 (23.1 – 26.2)	16.3 (14.9 – 17.7)
Nb of enquiries	1052	386

* One help line does not provide information on the duration of enquiries (MRIS)



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Purpose of the enquiry by nature of the help lines (CPA 2012)

Purpose of enquiry	Patient driven (%)	Healthcare professionals or governmental (%)
Information on disease	32.7%	25.7%
Specialist/centre	17.0%	19.9%
Contact with other patient	4.5%	1.1%
Support	6.5%	4.2%
Social care	11.7%	8.1%
Exemption (reimbursement)	0.9%	22.1%
Patients' organisation	6.9%	1.2%
Follow-up	5.0%	2.8%
Sign-posting	1.7%	1.5%
Events	1.8%	1.2%
Other	11.3%	15.3%



Help Lines
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Responses given by nature of the help lines (CPA 2012)

Responses given	Patient driven (%)	Healthcare professionals or governmental (%)
Provide contact with relevant organisation	18.3%	15.2%
Provide info on disease and care	22.8%	17.3%
Orientation to expert	8.9%	19.1%
Provide information on access to treatment and regulatory affairs	1.4%	23.1%
Psychological support	5.3%	0.6%
Provide info on disability/social rights	6.3%	14.9%
Contact with other patient	3.0%	0.0%
Provide information on respite care	0.5%	0.1%
Link to Orphanet or other sites	10.2%	0.6%



Help Lines
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Credits and funding

This Caller Profile Analysis is one of the outcomes of the RAPSODY project supported by the European Commission, conducted by Eurordis and its partners:



Funding

European Commission, Public Health Programme 2008-2013,
DG Health and Consumer Protection
Programme of Community action in the field of public health
Executive Agency for Health and Consumers

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