



# SURVEY ON COMPLEMENTARY AND ALTERNATIVE THERAPIES

## Preliminary results

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Sandra Courbier, Surveys and Social Studies Manager, Rare  
Barometer Leader

[EURORDIS.ORG](http://EURORDIS.ORG)

# Survey methodology

*Sandra Courbier, EURORDIS*

# Rare Barometer Voices framework

## 1900 respondents



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Group of people living with a rare diseases who participate in EURORDIS surveys and studies

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Rare Barometer Voices members received an invitation to participate in the survey/New participants had to register first (social media, patient organisations, etc.)

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High level of data protection (data storage in France, de-identified data, approved by French data protection authority)

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Covers 48 countries

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Survey translated in 23 languages

# Question

- Movement therapies (yoga, Tai Chi, Qigong, Healing Touch, Pilates, Feldenkrais Method etc.)
- Chiropractic or osteopathic manipulation
- Aromatherapy or herbal therapies
- Phage therapy
- Supplements (vitamins, minerals, probiotics, etc.)
- Homeopathy
- Traditional medicines (Chinese, Ayurvedic)
- Special diets (gluten-free, ketogenic diet, etc.)
- Physiotherapy and massage
- Energy therapies (acupuncture, acupressure, Shiatsu, Reiki, magnetic therapies etc.)
- Relaxation techniques (meditation, guided imagery, sophrology, biofeedback, etc.)
- Psychological therapies (cognitive behavioural therapy, group therapy, equitherapy etc.)
- Art therapies
- Spiritual therapies (spirit release therapies, shamanism, druidism, etc.)

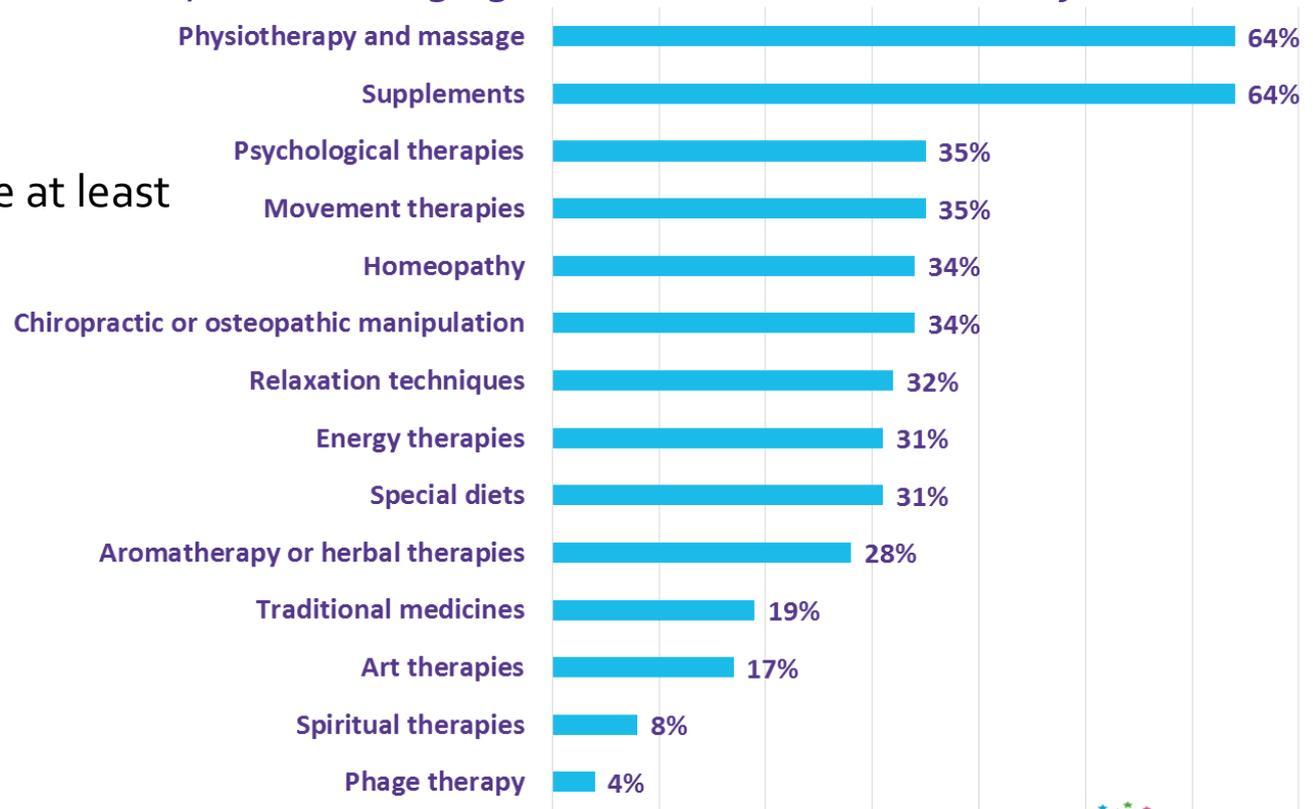
**Do you have any experience of the following medicines or therapies in managing the rare disease?**

- ✓ No, but I am interested in such therapies
- ✓ No, I don't have a need for such therapies
- ✓ No, because I don't know enough about these therapies
- ✓ Yes, instead of conventional therapies or medicines
- ✓ Yes, to complement conventional therapies or medicines
- ✓ Yes, for prevention and/or general well-being purposes
- ✓ Don't know/Not applicable

# Use of alternative and complementary therapies

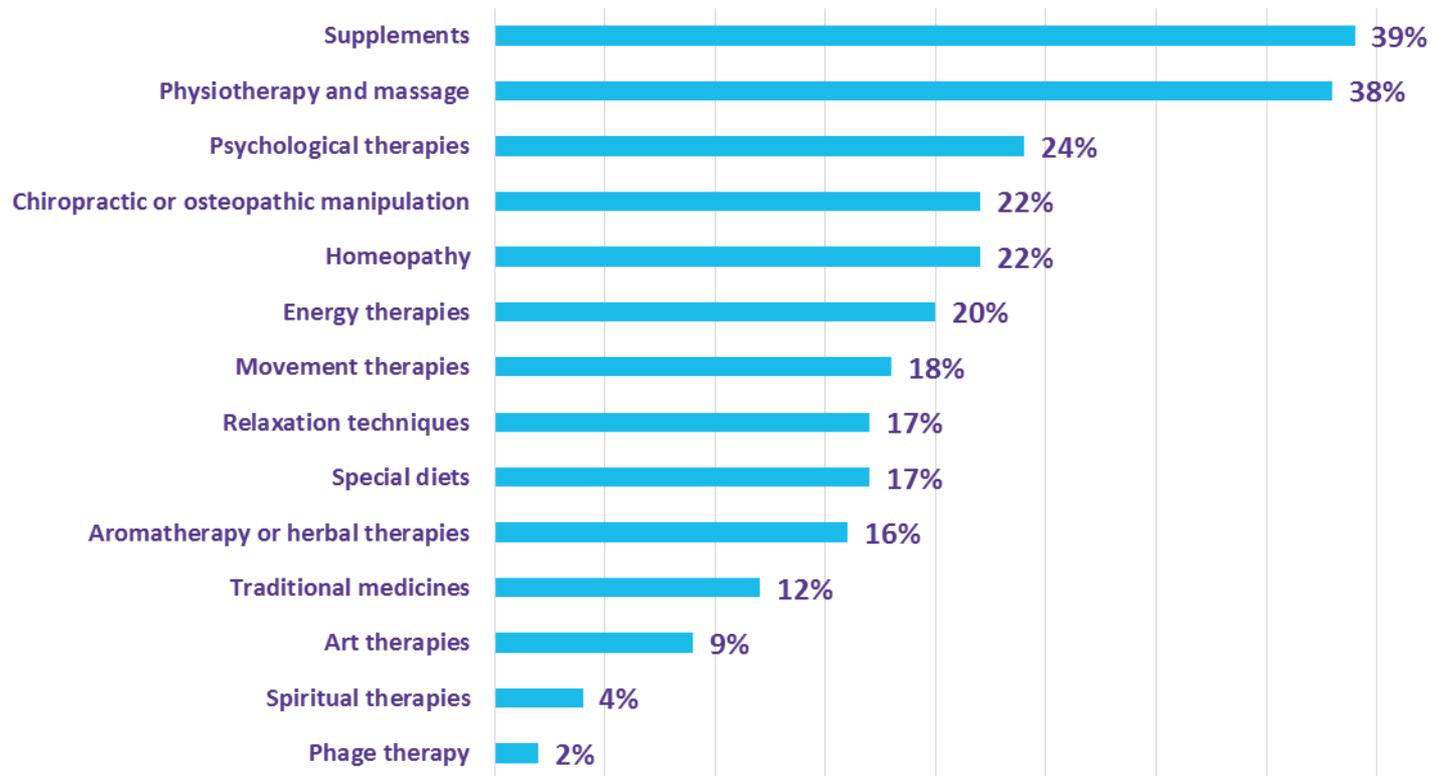
*Do you have any experience of the following medicines or therapies in managing the rare disease? (Answer = yes)*

Almost 9/10 quote at least 1 therapy



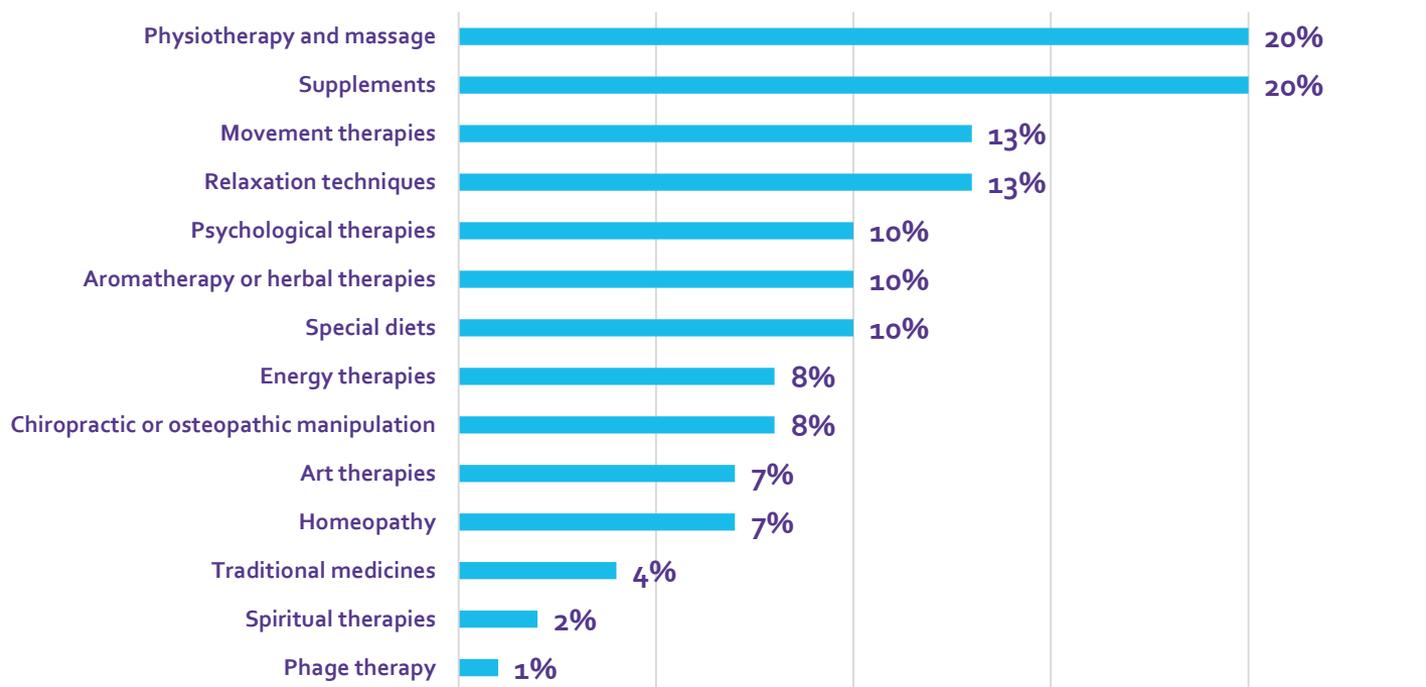
# The first use is to complement conventional therapies

Yes, to complement conventional therapies or medicines



# 2nd use is for prevention and well-being

## Yes, for prevention or general well being purposes



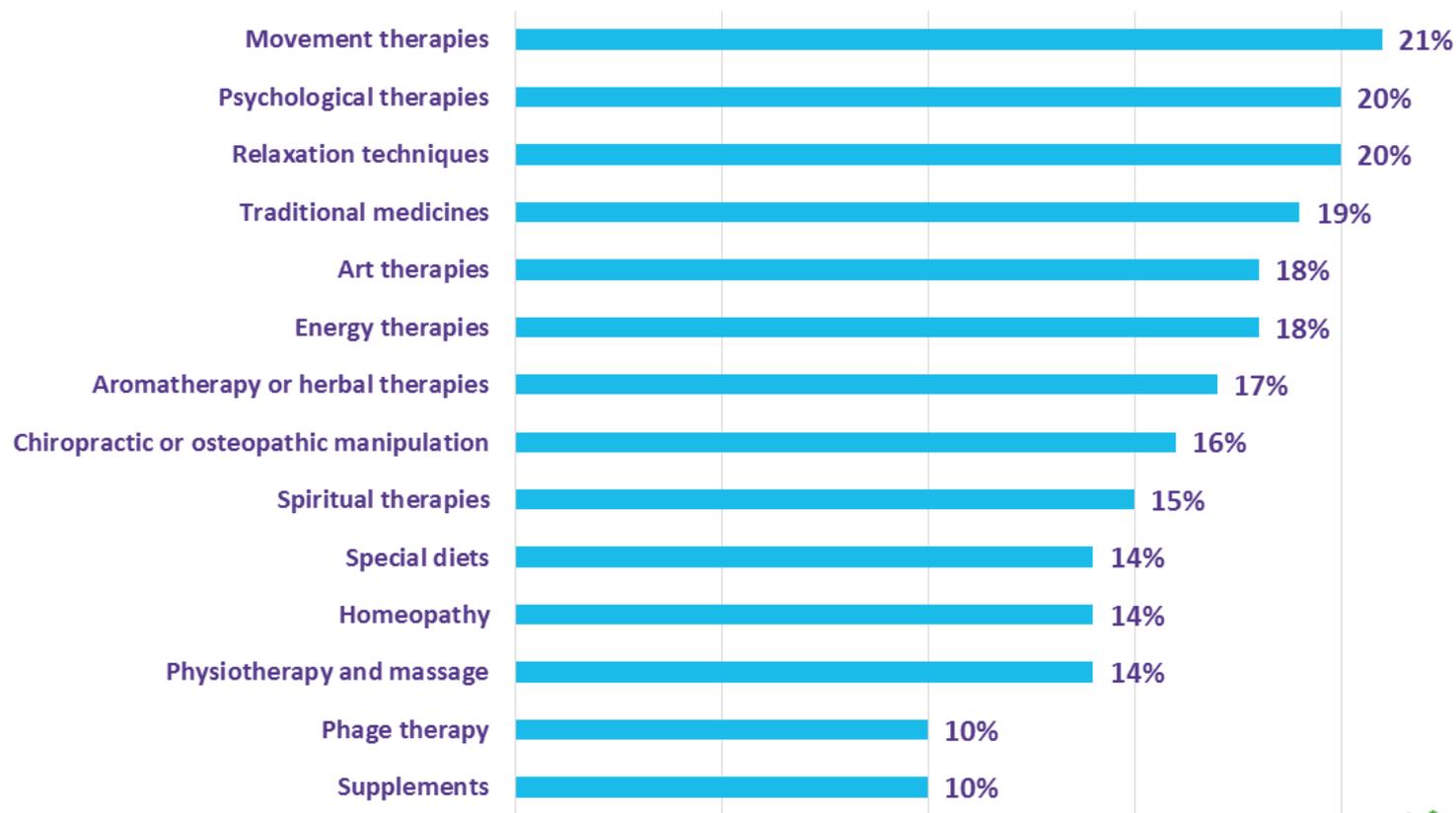
# Improve the general well-being (1/4)

“Feldenkrais is the one that has helped me most. Regular physical therapy does not work at all but degrades rather. I was told about Feldenkrais through a pain relic where I found myself and got my diagnosis. With Feldenkrais, I have learned a new way of thinking. Instead of the conventional way of physiotherapy, I have started listening to my body, finding ways to relax, relieve pain, etc. Even gluten-free diets have improved my intestinal problems a lot, even though I do not have celiac disease.

**Female, Sweden**

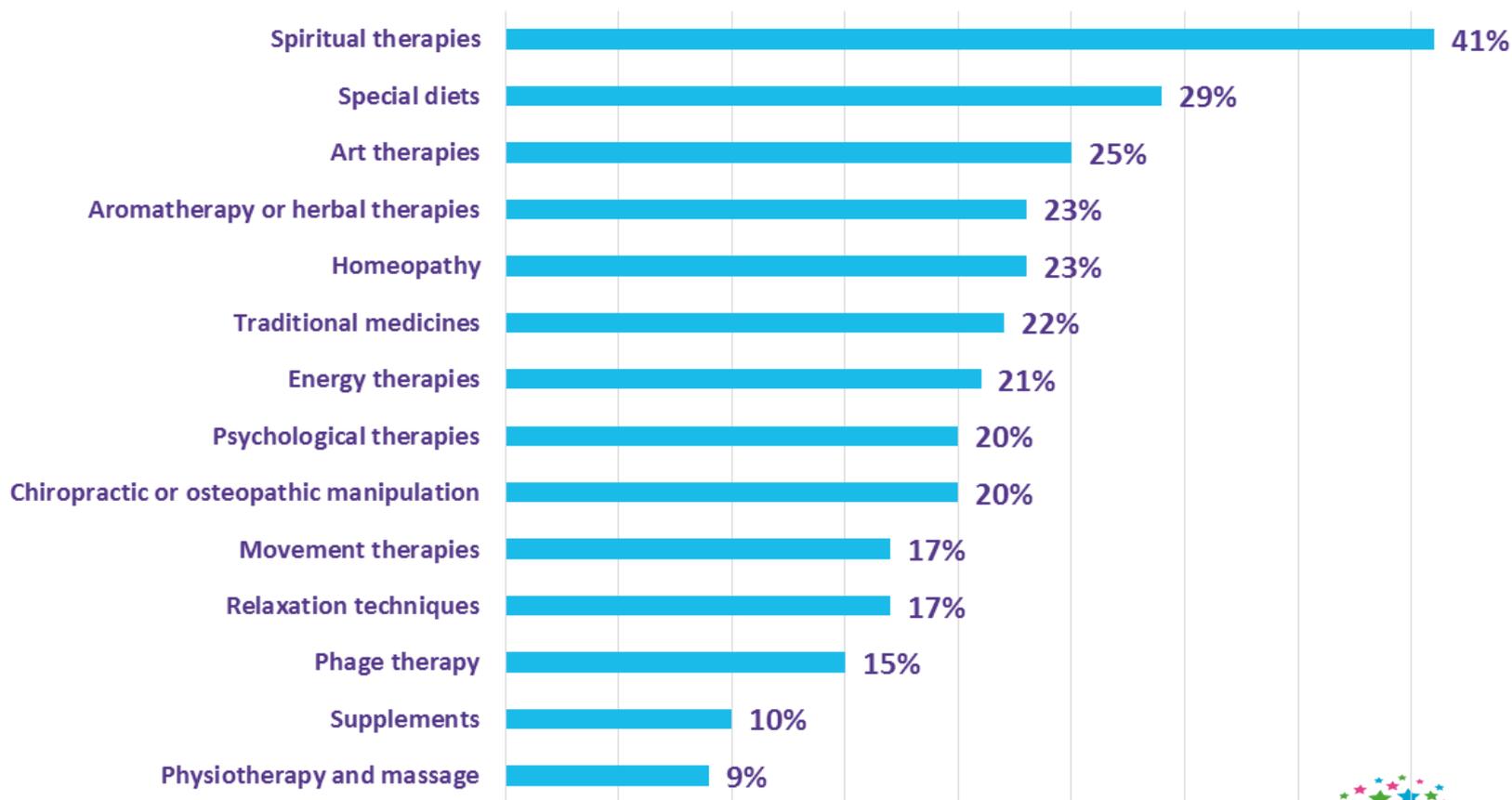
# A significant interest for complementary and alternative therapies

No, but I am interested in such therapies



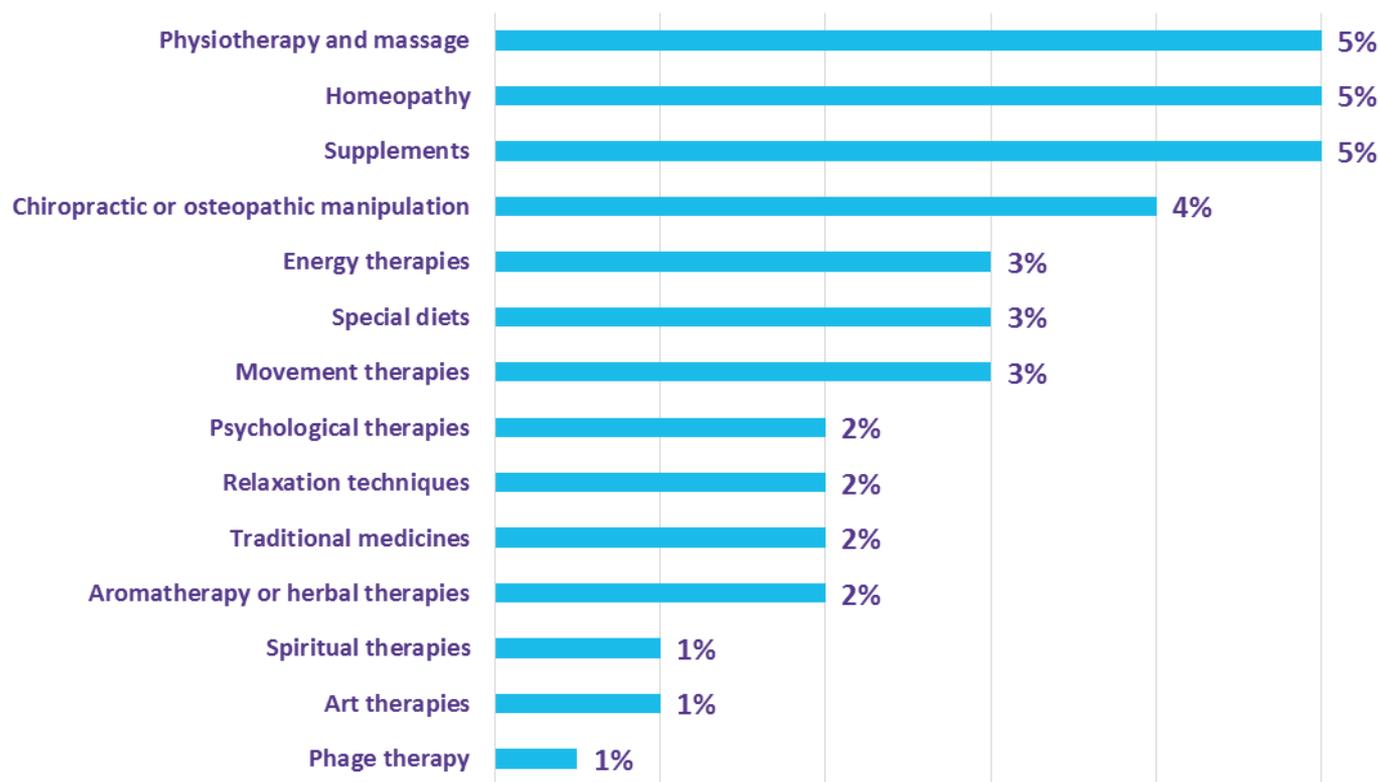
# Less needed therapies

## No, I don't have a need for such therapies



# A few experiences of using CAT instead of conventional therapies

Yes, instead of conventional therapies or medicines



# Experiences of use instead of conventional treatment

“ I can report positive experiences with homeopathy. One of them is related to my boy. He had been treated with antibiotics for an ear infection five times in a year, and it did not work. A friend from the family in Germany recommended homeopathic remedies for us, which are not available in Hungary. They brought them to us and we used them. The ear infections became increasingly rare and after ten months, they were gone. It is a great help because ear infections come back every few months and with this, we can fix it

Female, Hungary

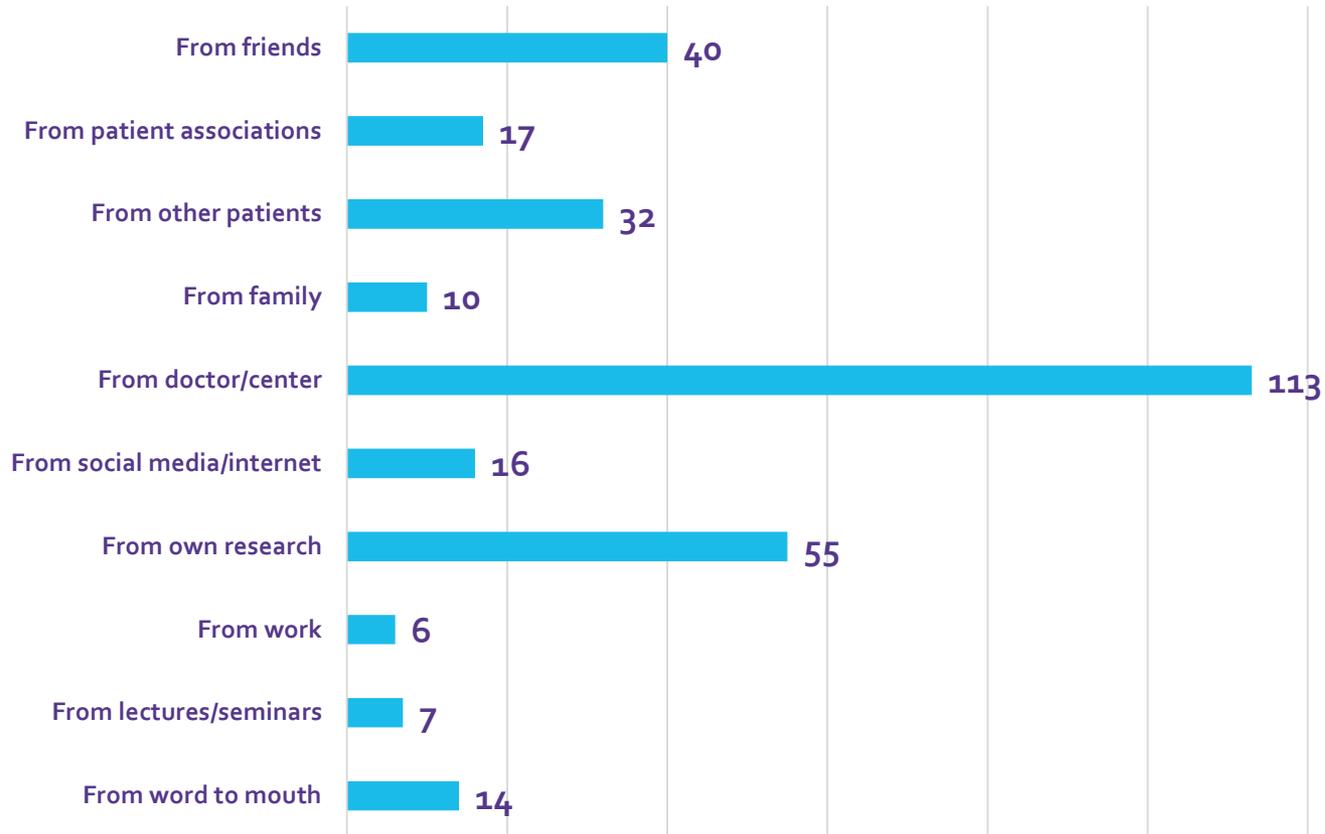
“ Traditional Chinese medicine has given us the first positive results out of alternative therapies. Because of it, our child began to walk again.

Female, Ukraine

“ With neuromuscular diseases, the only « medicine » that can be applied is physiotherapy and it is fundamental to keep the body the most stable and to avoid muscular pain. Psychological help is also very important to be able to cope with this type of disease.”

Male, Spain

# Medical centers are the first sources of information



# How patient seek for information

“ I learned about acupuncture from my rheumatologist. Acupuncture has helped me in dealing with the pain and massage and physiotherapy helps me keep my mobility.

Female, Croatia

“ I go on my own and read about things, even foreign literature. When I find something reliable, I try to see if my doctor recommends it. There is a need to find something that can keep a person that lives with a rare disease healthy, or at least somewhat better. I could write about my own experience with ATs for long, but what is really important is that even though I find a treatment for my mitochondrial disease (nutritional supplements), I never get any discounts and it is hard.

Female, Hungary

# Specific therapies mentioned

Aqua therapy

Incense capsules

Padovan method

Autopathy

Lecba energy

Socio esthétique

Bioenergy

Lymph drainage therapy

Speech therapy

DBT therapy

Mindfulness

Thermal therapy

Dévény gymnastics method  
(DGSM)

Myofacial stress release

Tibetain medicine

Chopra's teaching

Nadi healing

Fasciatherapie

Ergotherapy

Napratherapy

Cuevas Medek Exercises

Hypnosis

Ortho-molecular therapy

Ozono therapy

# Main hurdles (1/2)

- Lack of information available
  - Skepticism because lack of scientific background
- ➔ Strong request for receiving more information

“ The information I have on them is very small, which is why I cannot describe my experience- However, I do believe they can be beneficial and there should be more information on them so that people can see when it is a fraud and when it is serious

Female, Spain

## Main hurdles (2/2)

- The location of the therapy: not available in countries and rural area

“ My mother is very sick. Most of the therapies discussed in the survey are not available in the small town where my parents live. The problem is that, even if we find something, it is very expensive.

Female, Poland

- The condition itself, difficulty to travel etc.
- Lack of specialist

“ I was treated during 13 years with the Dévényi Gymnastics method (Movement therapy). This is why I live a happier, livelier life. It was an excellent treatment. However, I am no longer treated with it because there are few professionals that know this method in my country, and I need the treatment.

Female, Hungary

# Most of the therapies are reported to have a very positive impact

**How would you rate the effect of the following medicines or therapies in managing the rare disease?**

	Positive		No impact		Negative		Don't know/Not applicable	
	N	% cit.	N	% cit.	N	% cit.	N	% cit.
Movement therapies	538	82%	57	9%	11	2%	47	7%
Chiropractic or osteopathic manipulation	518	81%	73	11%	14	2%	37	6%
Aromatherapy or herbal therapies	365	70%	110	21%	4	0.8%	42	8%
Phage therapy	44	57%	11	14%	3	4%	19	25%
Supplements	930	77%	211	17%	2	0.2%	64	5%
Homeopathy	393	61%	183	29%	9	1%	55	9%
Traditional medicines	220	61%	76	21%	4	1%	59	16%
Special diets	429	74%	94	16%	11	2%	45	8%
Physiotherapy and massage	1080	91%	80	7%	10	0.8%	22	2%
Energy therapies	419	71%	102	17%	11	2%	60	10%
Relaxation techniques	496	82%	68	11%	3	0.5%	35	6%
Psychological therapies	562	85%	60	9%	11	2%	30	5%
Art therapies	245	79%	35	11%	3	1%	28	9%
Spiritual therapies	96	67%	27	19%	0	0%	20	14%

Some modalities have been grouped

# Negative experiences (less than 20%) (1/2)

- No impact on the disease (1/3 of the negative experience)
- Time consuming

“ Some alternative therapists would order the discontinuation of our treatment without any reason. Some of them accused us of having the illness because of our negative thinking, which was daunting. Sometimes I felt as if we were paying for nothing.”

*Male, Czech Republic*

# Negative experiences (less than 20%) (2/2)

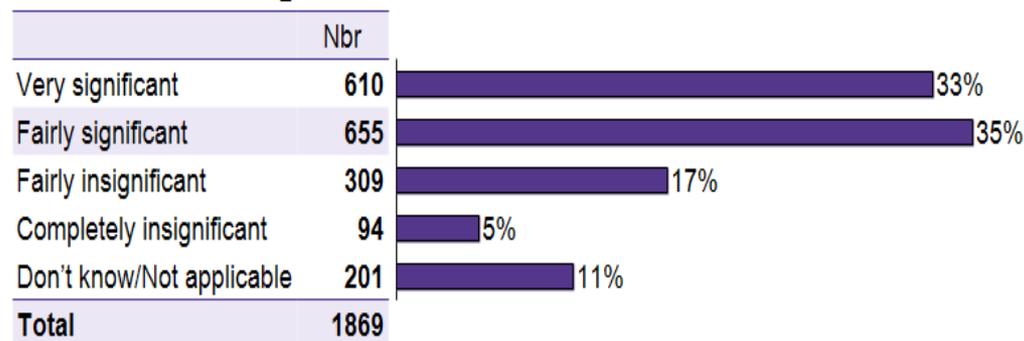
- Lack of scientific background/empathy from therapists towards them
- Fraud (1/10)
- Has made the situation worse

“The Alternative Therapy we did made her really sore. The manipulation treatment we were receiving would have been life-threatening because of her joint problems, so we stopped.”

**Female, Czech Republic**

# High impact on the household budget

**How would you qualify the impact of the cost of complementary and/or alternative therapies on your household budget?**



“ My son practices yoga for children with special education needs. Overall, it is a positive experience for him, but to do this, we must commute 100km, and the insurance company does not cover it.

Female, Czech Republic

# The impact varies according to countries

**How would you qualify the impact of the cost of complementary and/or alternative therapies on your household budget?**

