

# Who benefits from what?

Key survey results


TJENESTEN OG **MEG**  
- et forskningsprosjekt

A recent review of chronic fatigue syndrome (CFS)/ME patients under the public work-assessment-allowance program in Norway underscored that:

*“...the health and welfare systems lack knowledge about who will respond well to the various alternatives.”*

PROBA Samfunnsanalyse (2022) AAP-mottakeres brukerløp i helsetjenester og NAV (Rapport 2022-3 Prosjekt nr. 18016 I). Available at: <https://www.nav.no/no/nav-og-samfunn/kunnskap/forskningsrapporter-og-evalueringer-finansiert-av-nav/sykefravaer-og-arbeidsmiljo-rapportarkiv2/aap-mottakeres-brukerlop-i-helsetjenester-og-nav> (accessed 15 November 2022)



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## Do diagnostic criteria for ME matter to patient experience with services and interventions? Key results from an online RDS survey targeting fatigue patients in Norway

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[OnlineFirst](#) | <https://doi.org/10.1177/13591053231169191>

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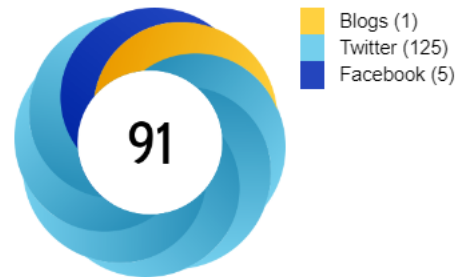
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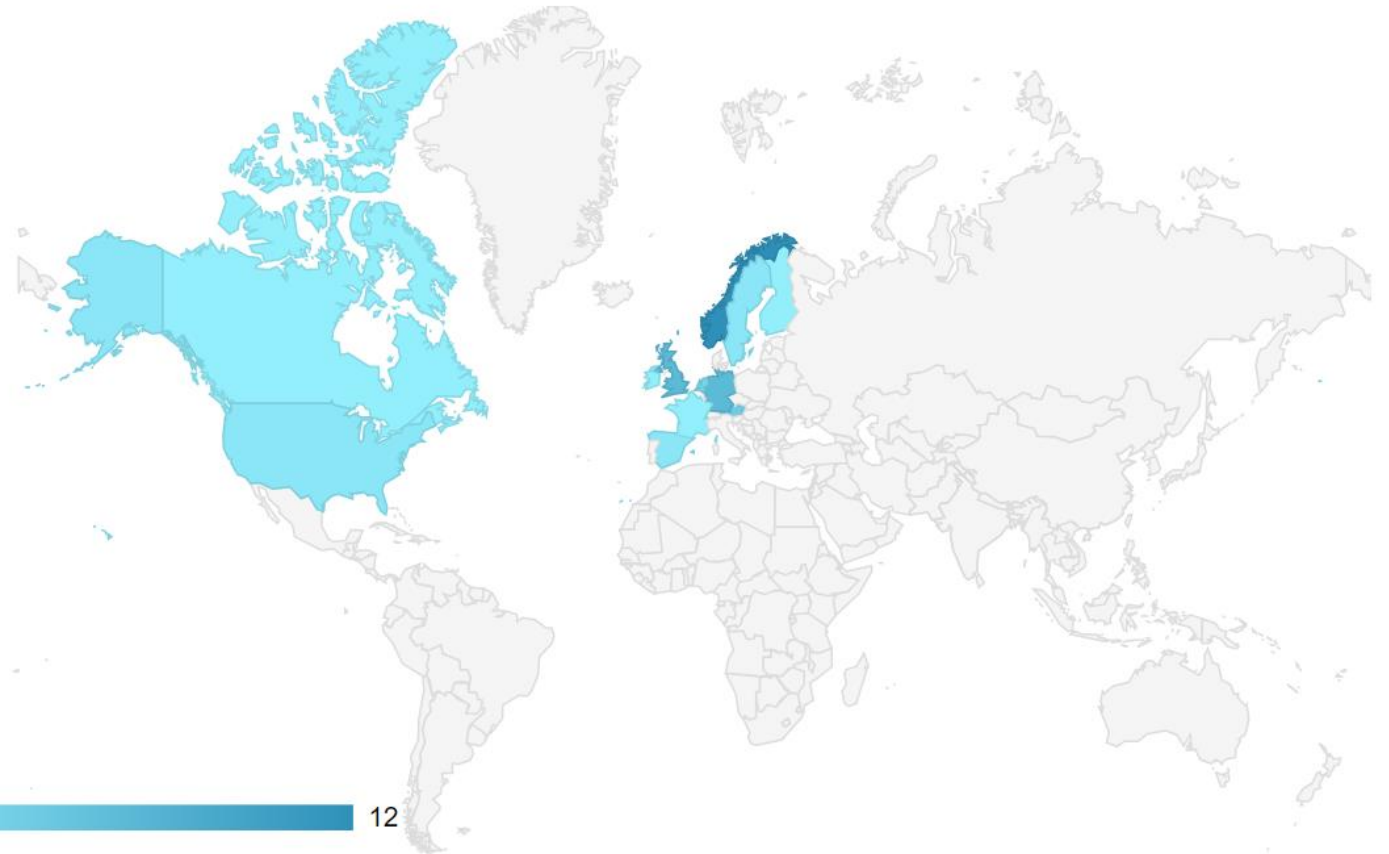
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# Three objectives

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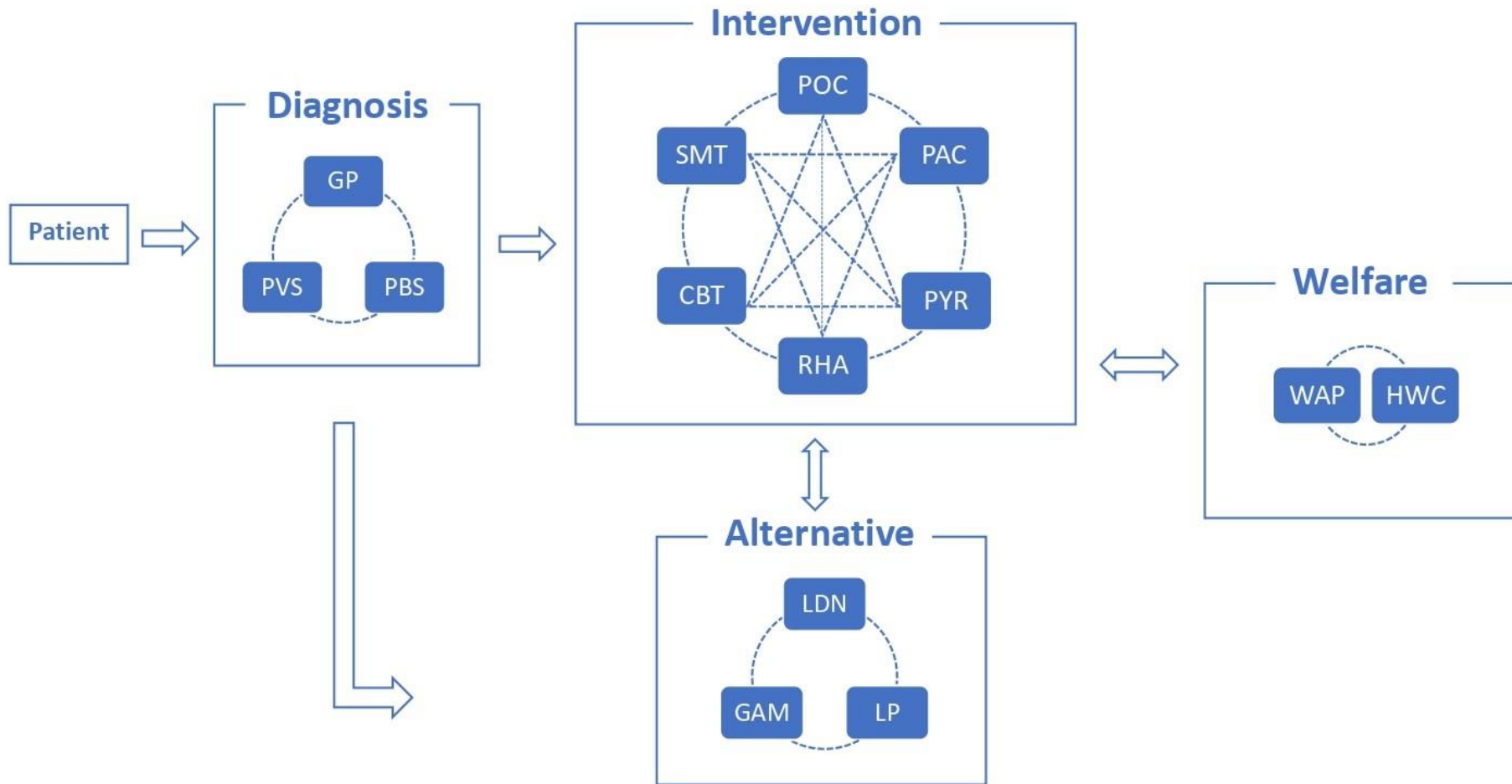
User satisfaction with services and interventions among person meeting the Canada Concensus Criteria for CFS/ME (CCC)

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Differences between CCC patients and other groups of fatigue patients

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Impact of post-exertional malaise (PEM) on user experiences among fatigue patients



### Diagnosis

- GP** General practioner
- PBS** Public specialist
- PVS** Private specialist

### Intervention

- POC** Psychologist consultation
- PAC** Psychiatrist consultation
- PYR** Physiotherapy
- RHA** Rehabilitation
- CBT** Cognitive therapy
- SMT** Symptoms management training

### Alternative

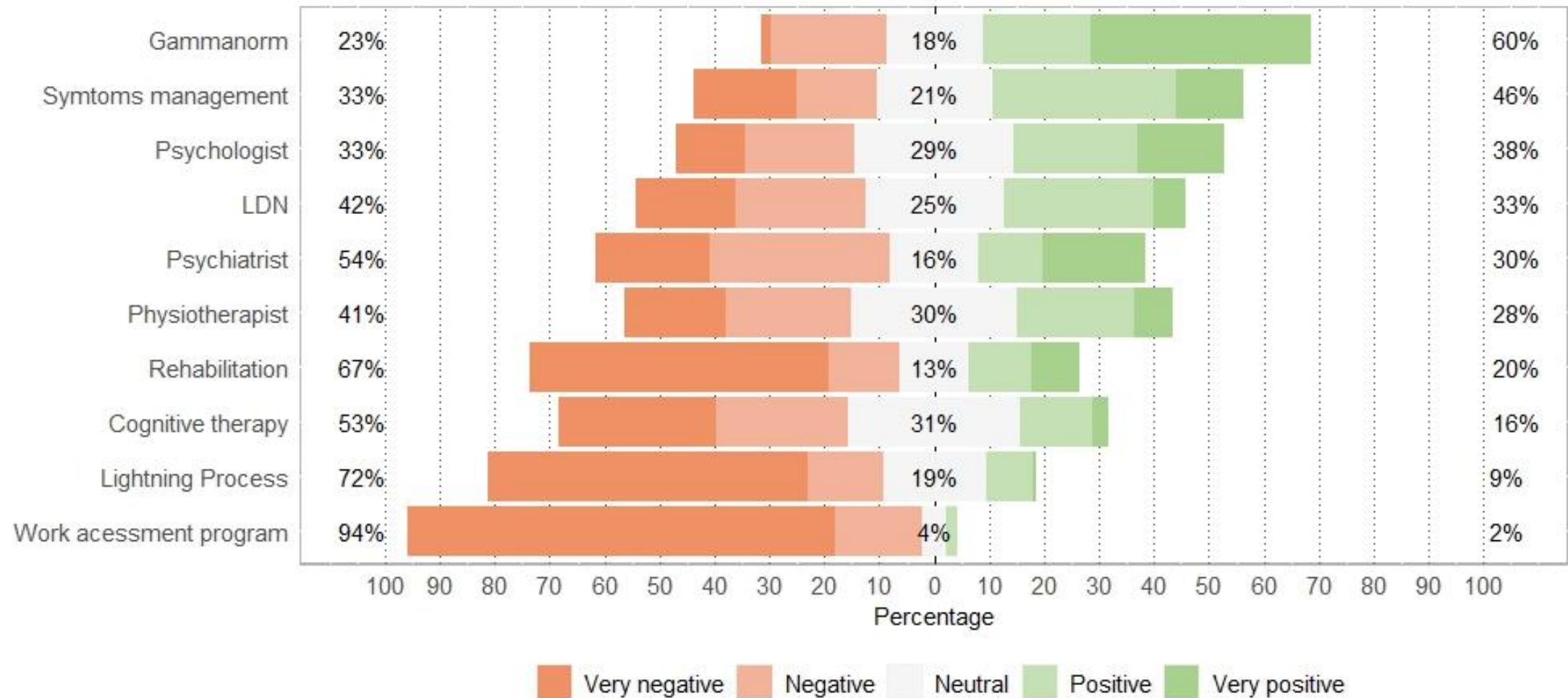
- LDN** Low-dose naltrexone
- LP** Lightning process
- GAM** Gammanorm

### Welfare

- WAP** Work assessment program
- HWC** Health and welfare coordination

# Experienced benefit to health

## Agree or disagree

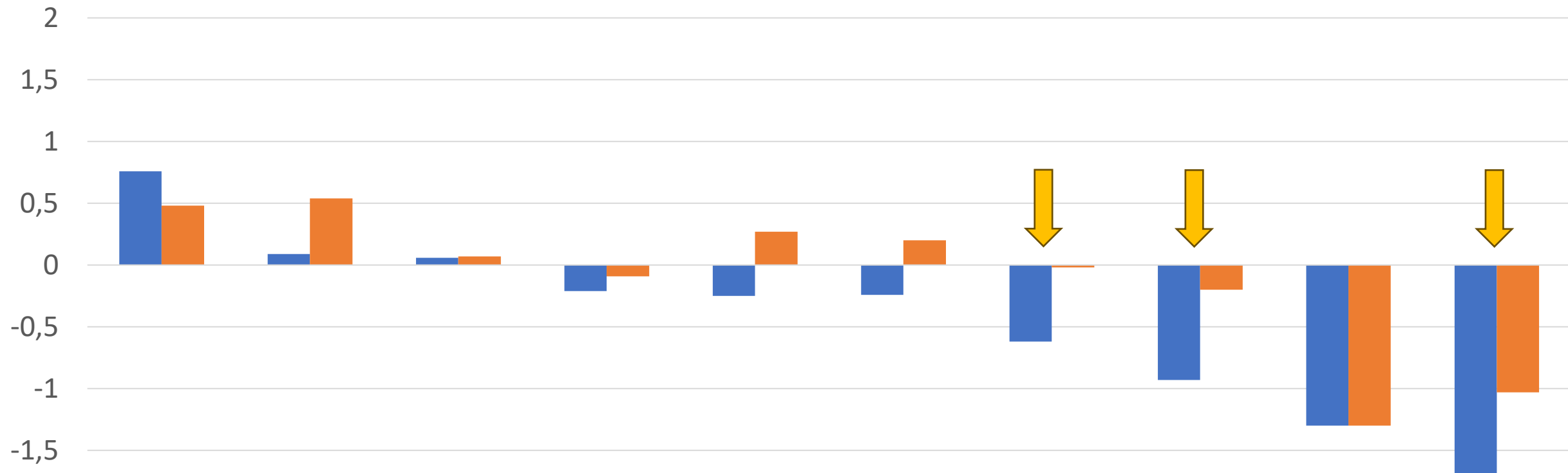


# Experience of acknowledgement; Agree seen and understood by services providers





# Mean satisfaction/helpfulness CCC Vs. Fukuda



	Gamma	Psychol.	Sympt.Man.	LDN	Psychiatr.	Physio	CBT	Rehab	LP	WA
■ CCC	0,76	0,09	0,06	-0,21	-0,25	-0,24	-0,62	-0,93	-1,30	-1,70
■ Fukuda	0,48	0,54	0,07	-0,09	0,27	0,20	-0,02	-0,20	-1,30	-1,03

The main findings are...

# User satisfaction with services and interventions

1. Less than half of patients experience benefit from the most common interventions for ME sufferers today, for rehabilitation this proportion is down to 20% and for cognitive therapy, 16%.
2. For most interventions, the average score for benefit is negative.
3. The extent of the negative health consequences reported on NAV's work assessment program (Arbeidsutprøving) appears disturbing.
4. Patients more often experience recognition than benefit from interventions/services, but the proportion of patients who do not feel that they are seen and understood in certain areas may nevertheless be regarded as unsatisfactory.

# Differences between CCC and Fukuda patients

1. The patient group that meets the Canadian criteria generally has poorer experiences with services and interventions than the group that only meets the Fukuda criteria.
2. The difference in the proportion of Canada and Fukuda patients who experienced benefit from CBT and rehabilitation was statistically significant, even in a limited sample.

# The PEM score as a potential indicator

1. The degree of PEM is related to perceived benefit in almost all aspects of most services and interventions, and the effect of PEM is largely statistically significant.
2. The degree of PEM thus appears as a possible indicator of whether a patient will experience benefit from a service or intervention or not.

# So...

1. Negative average scores in the perceived benefit of an intervention should be a reminder that the overriding principle of all health care is **“do-no-harm”** .
2. The relatively low proportion of patients who experience being seen and understood in many services and interventions should remind us of the importance of recognition to **ensure good synergies between the psychological, social, and somatic** aspects of an assessment and follow-up process.

# Read more about the article here

<https://www.fafo.no/zoo-publikasjoner/artikler-og-bokkapitler/do-diagnostic-criteria-for-me-matter-to-patient-experience-with-services-and-interventions-2>

Thanks!