

International Conference

ADVANCING HOLISTIC HEALTH THROUGH OPTIMAL NUTRITIONAL CARE

A NUTRITIONAL CARE POLICY SUMMIT

Athens 5 & 6 May 2025



LIFE

Leading Intestinal Failure Equality

Leading **I**ntestinal **F**ailure Equality (**LIFE**) Initiative

The **LIFE Survey First Results: opportunities to improve IF policies**

Stéphane Schneider, Simon Lal, Maja Kopczynska

CHRONIC INTESTINAL FAILURE

- **Intestinal failure:** reduction of gut function below the minimum necessary for the absorption of macronutrients and/or water and electrolytes, such that intravenous supplementation is required to maintain health and/or growth.
- **Chronic IF:** long-term IF in a steady-state condition
- **Main etiologies:** short bowel syndrome, dysmotility
- **Treatment:** home parenteral nutrition
- **Many unmet needs**

THE STEERING COMMITTEE

Professor Palle Bekker Jeppesen - Copenhagen University Hospital, Denmark

Professor Francisca Joly - Hospital Beaujon AP-HP, Paris, France

Valerie Joubert - President, La Vie par un Fil, Paris, France

Professor Simon Lal - Salford Royal NHS Foundation Trust, Salford, UK

Nathalie Lauwers - Clinical Nurse Specialist IF, UZ Leuven, Belgium

Marek Lichota - CEO, Appetite for Life and IF patient, Krakow, Poland

Professor Anibal Marinho - Hospital Geral de Santo Antonio, Porto, Portugal

Doctor Nada Rotovnik Kozjek - Faculty of Medicine, University of Ljubljana

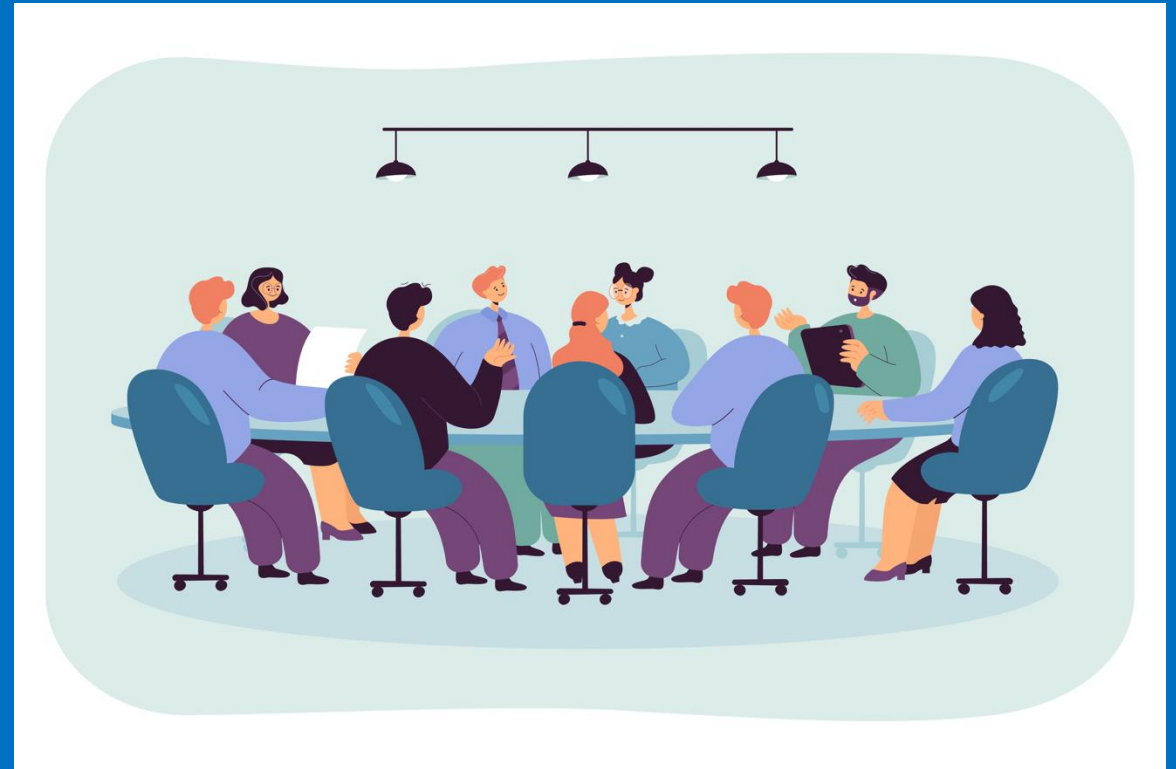
Professor Stéphane Schneider - Archet Hospital, Nice, France

Professor Tim Vanuytsel - UZ Leuven, Belgium

Rob Walton - Independent policy expert, Farnham, UK

Joost Wesseling - Executive Director, ENHA, Amsterdam, The Netherlands

Carolyn Wheatley - Chair, PINNT and IF patient, Christchurch, UK



WHAT WE AIM AT

Our objectives



We are committed to:

- **Raising awareness of IF** among healthcare professionals, patients, policymakers, and the public.
- **Advocating for IF** to be included on political agendas across Europe.
- Supporting the development of **centers of excellence** for IF care across Europe.
- Ensuring **equal access to IF treatment and care for all** patients, regardless of location.



2024-2025 PROJECTS

- 1F Day
- Manifesto
 - Speeding-up diagnosis
 - Delivering comprehensive care
 - Providing access to appropriate treatments
 - Working together to share best practice and data
- Quality-of-care standards survey



ELSEVIER

Contents lists available at [ScienceDirect](https://www.sciencedirect.com)

Clinical Nutrition ESPEN

journal homepage: <http://www.clinicalnutritionespen.com>



Opinion Paper

Quality-of-care standards in adult type 3 intestinal failure caused by benign disease: A European society of clinical nutrition and metabolism (ESPEN) position paper

S. Lal ^{a,*}, M. Soop ^b, C. Cuerda ^c, P. Jeppesen ^d, F. Joly ^e, G. Lamprecht ^f, M. Mundi ^g,
K. Szczepanek ^h, C. Van Gossum ⁱ, G. Wanten ^j, T. Vanuytsel ^k, A. Weimann ^l, L. Pironi ^{m, n}



THE EUROPEAN
SOCIETY FOR
CLINICAL
NUTRITION AND
METABOLISM

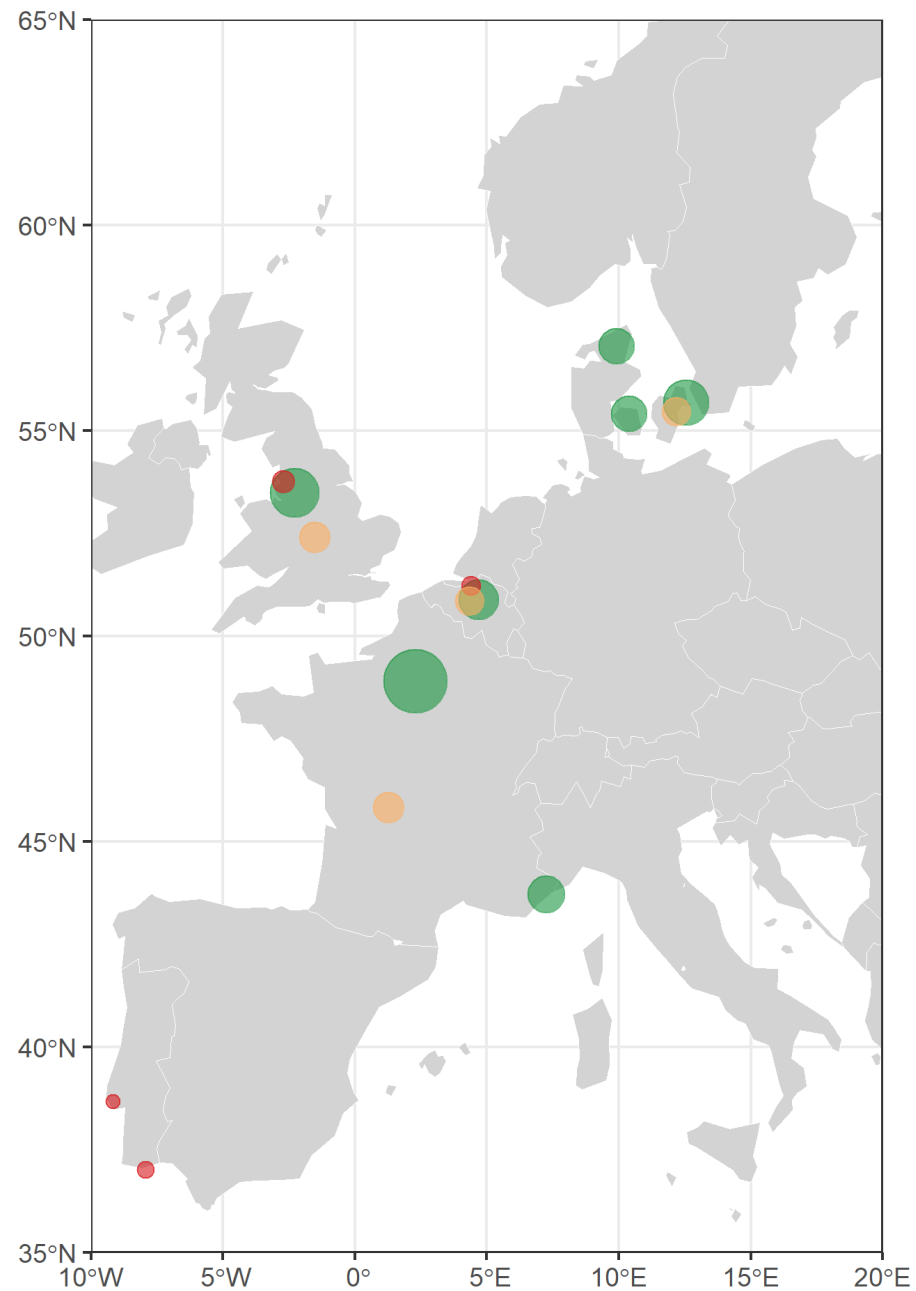
optimal

nutritional care

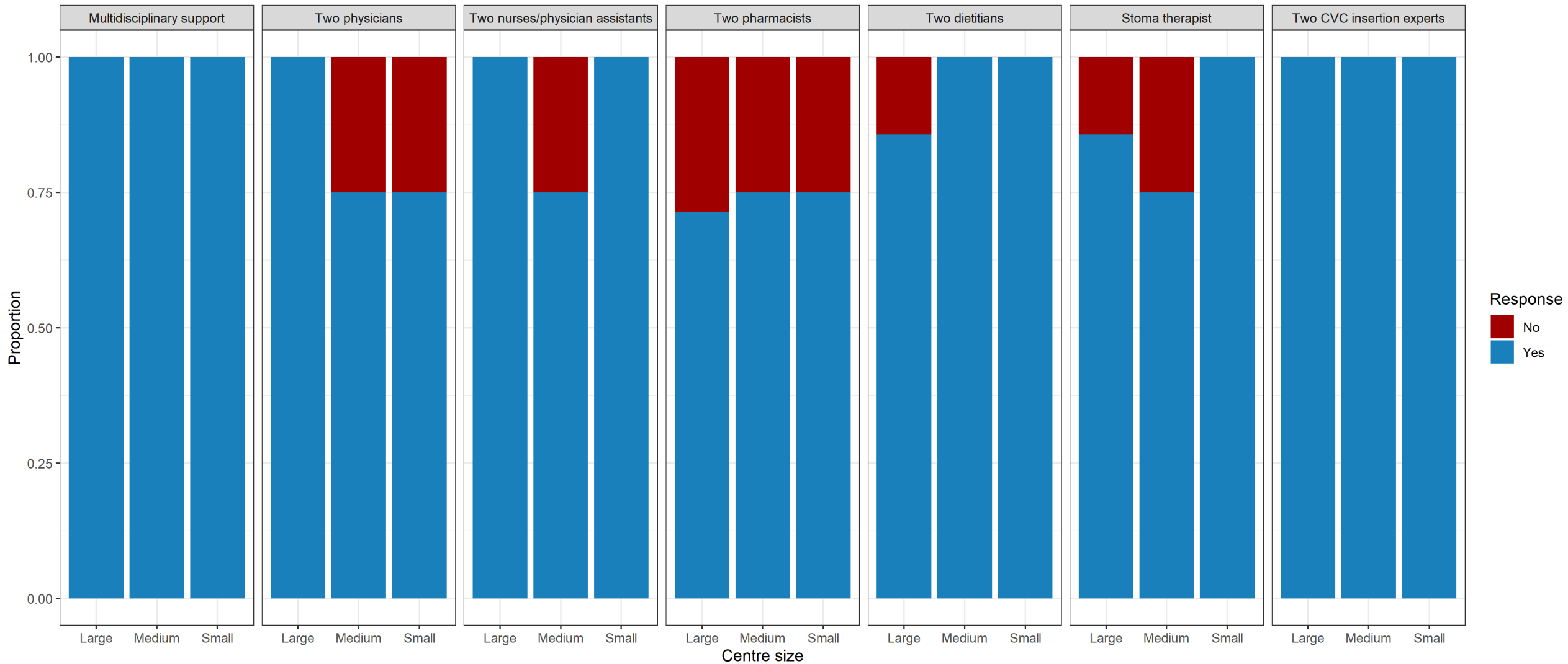
for all

PROPOSED STANDARDS

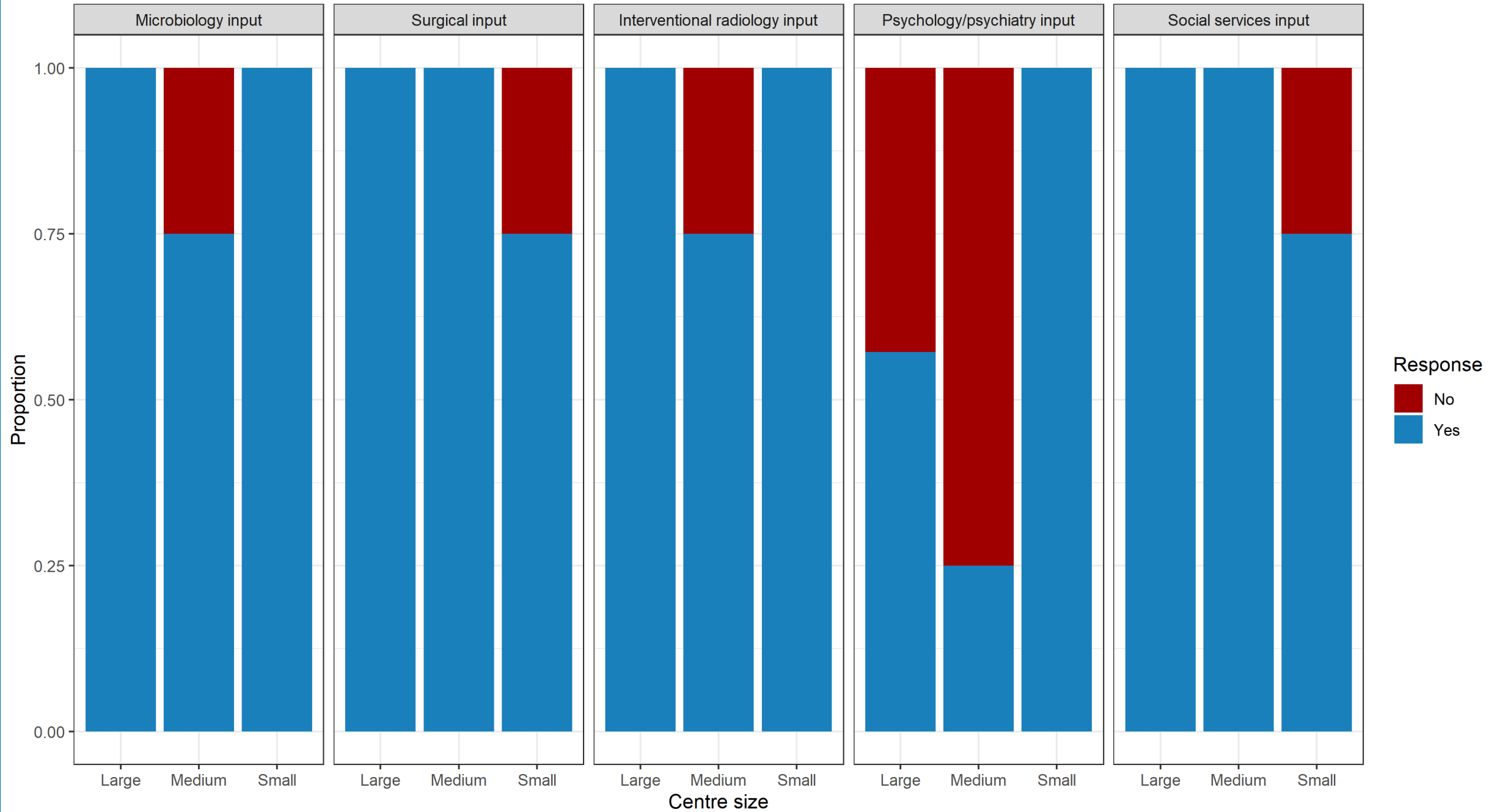
- Structure (30)
- Process (18)
- Outcome (16)
- Modified Delphi process (lack of published data)
- Does size matter??



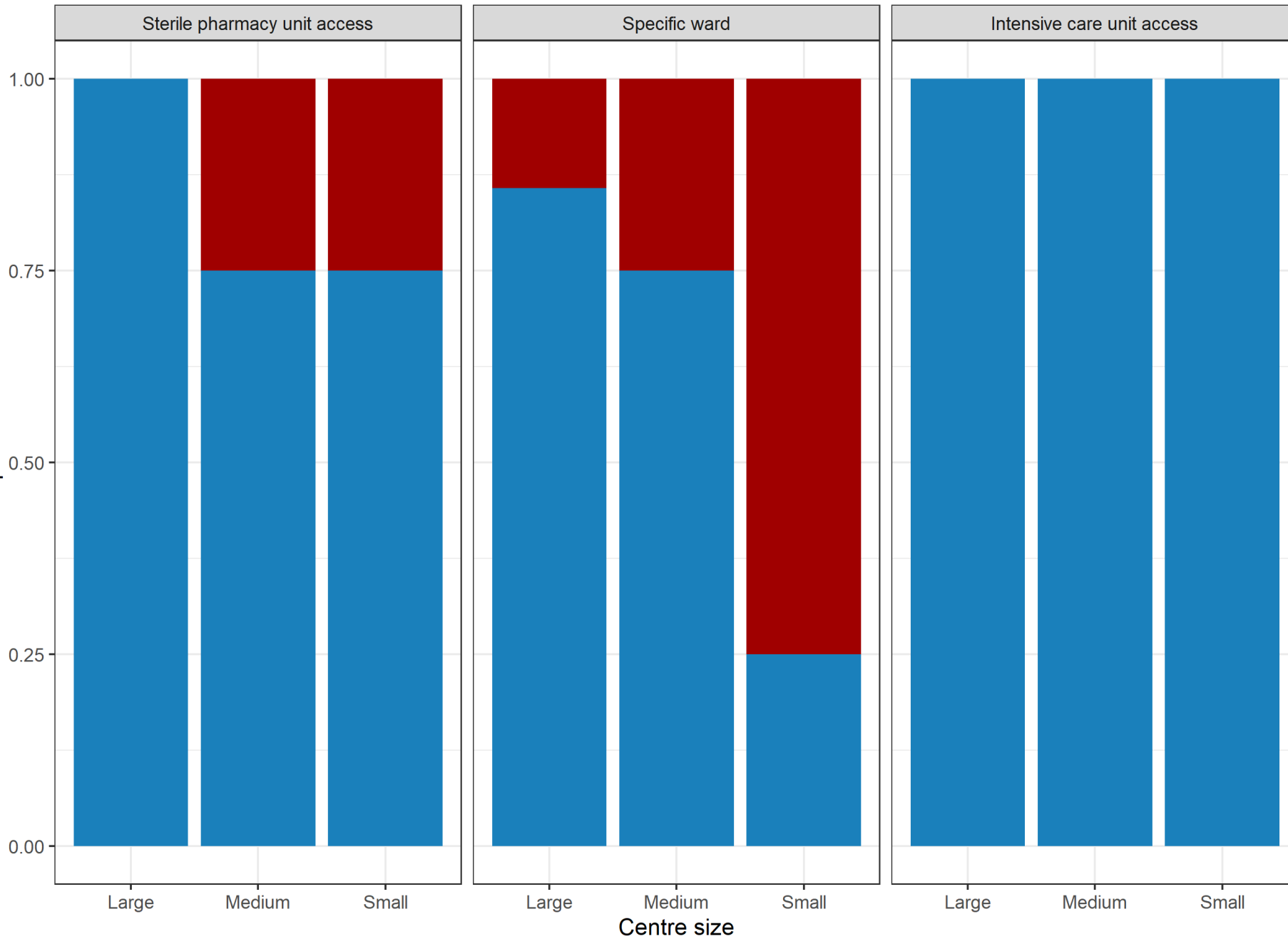
Structure: IF team



Structure: Additional teams

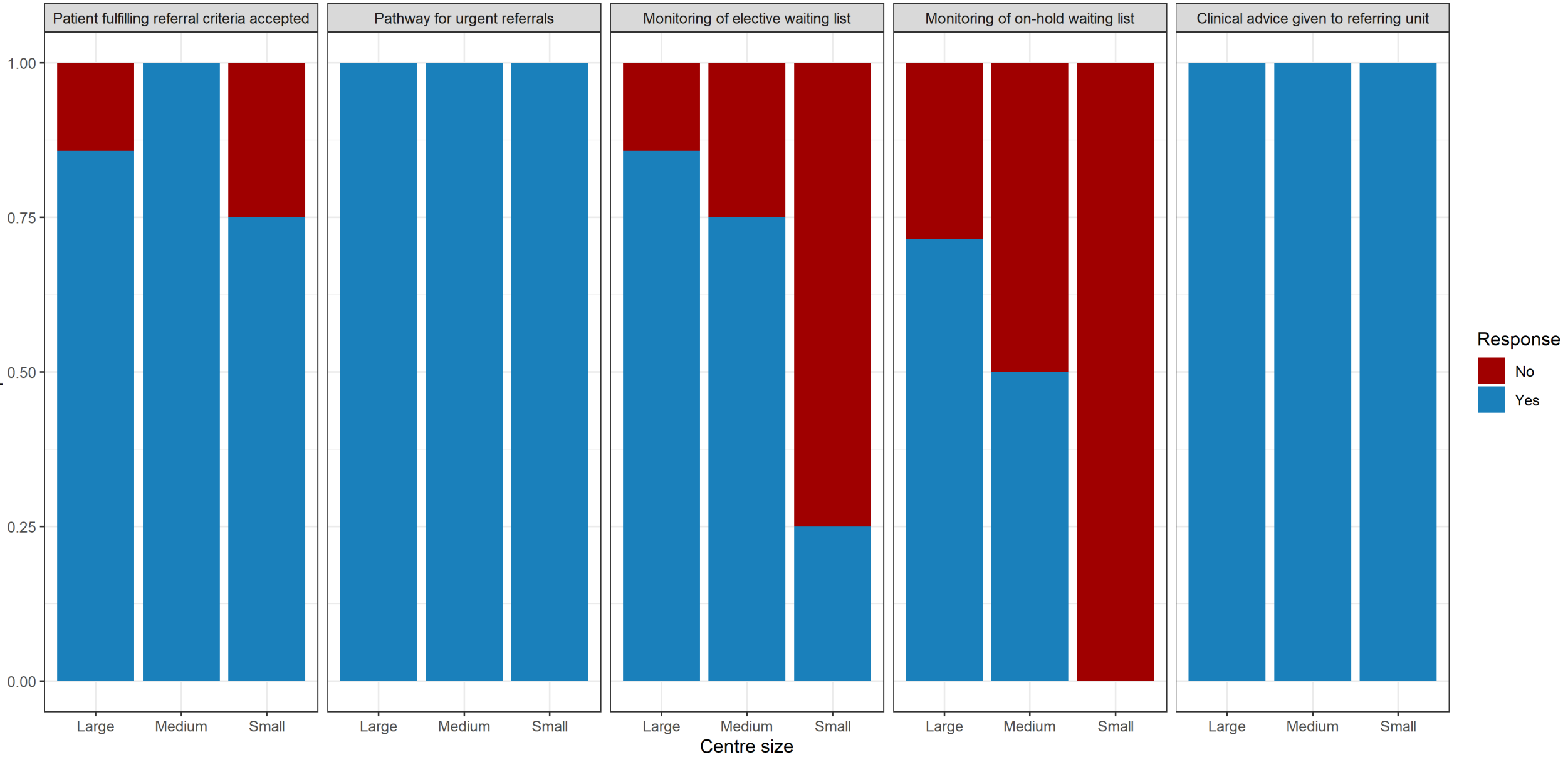


Structure: Facilities

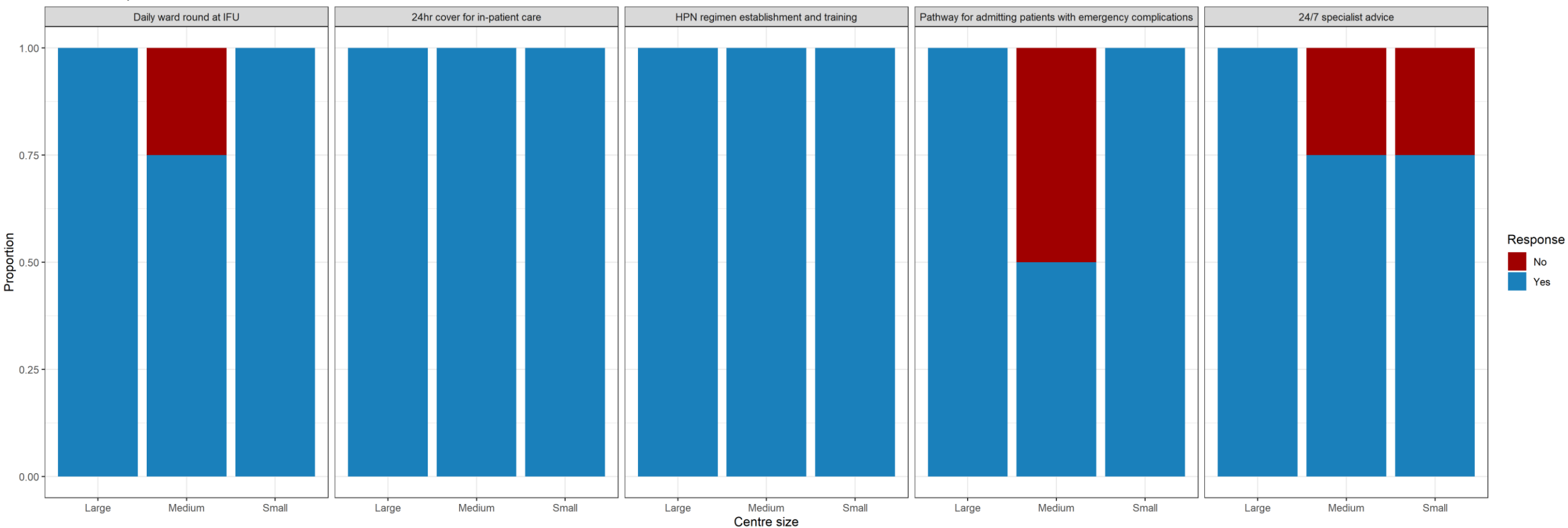


Response
No
Yes

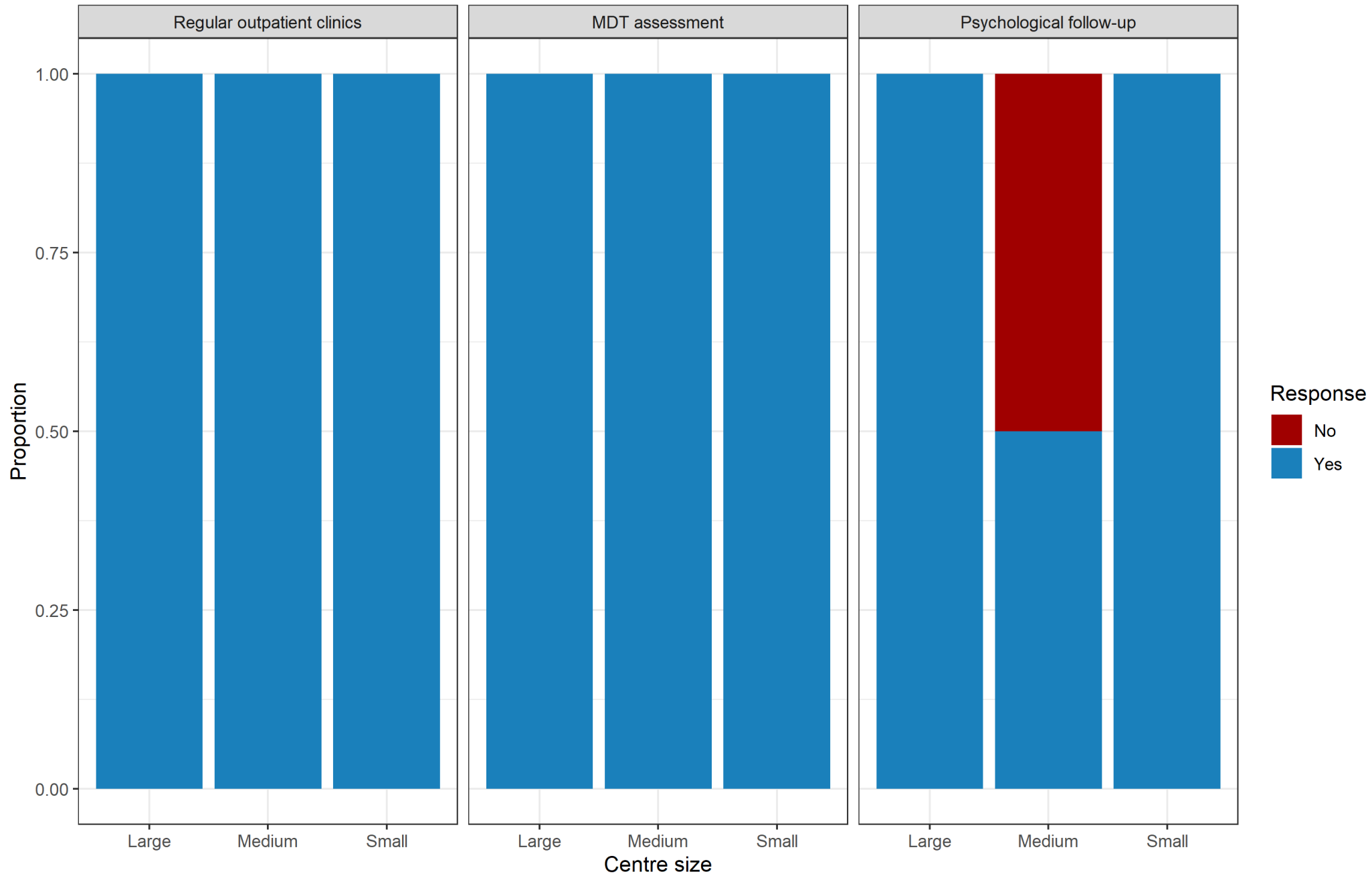
Process: Pre-admission



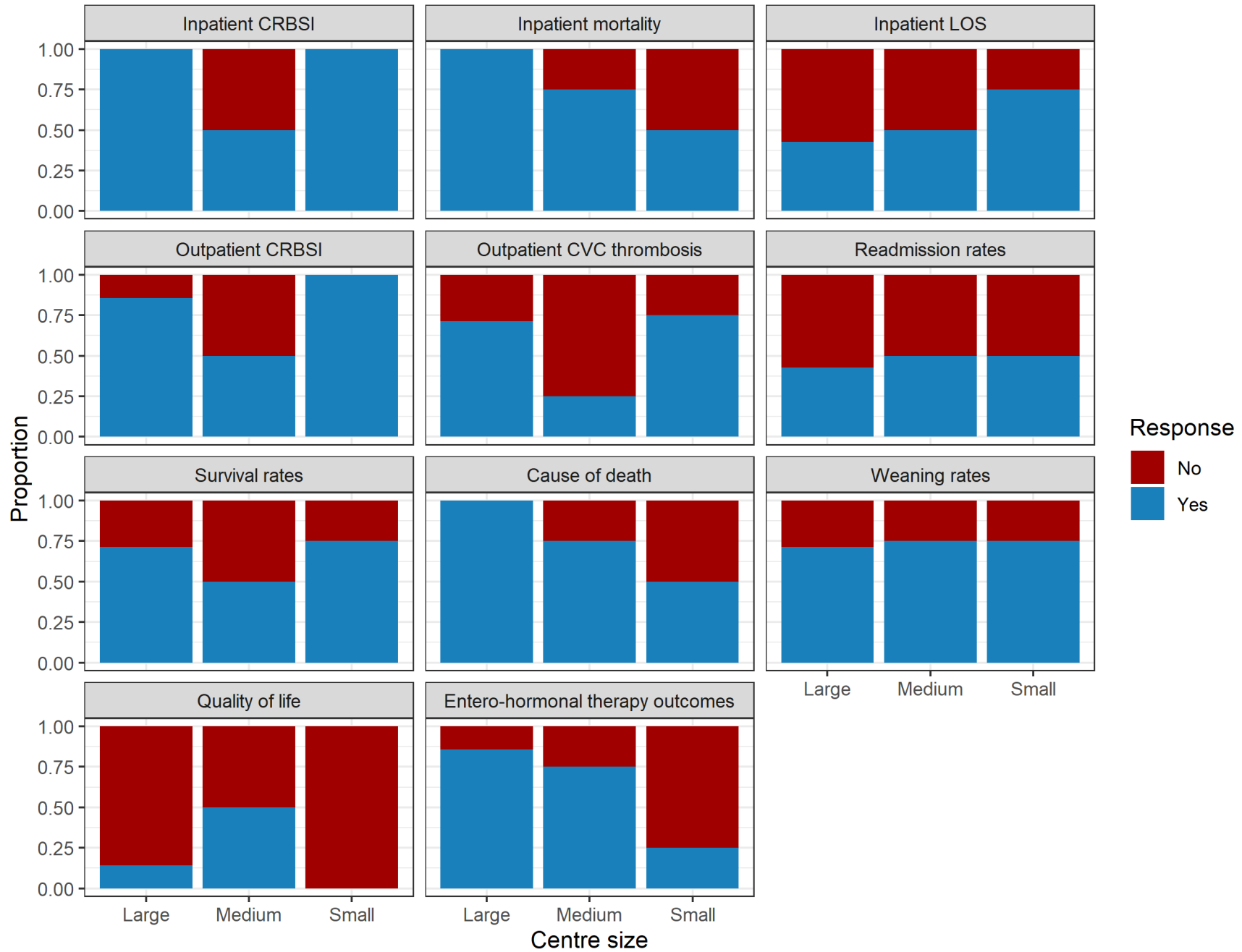
Process: In-patient



Process: Outpatient



Outcomes: Monitoring



CONCLUSIONS

- Standards largely followed
- No size effect for most standards
- Small centres: absence of specific ward and non-emergent referral procedures
- Possible reasons:
 - « Obvious » standards and ESPEN guidelines followed
 - Standards comparable to government requests for approval
 - Bias in recruitment
 - Unequal distribution of same size centres by country
 - Lack of power

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Thank you