

Could disease labelling have positive effects? An experimental study exploring the effect of the Chronic Fatigue Syndrome label on social support

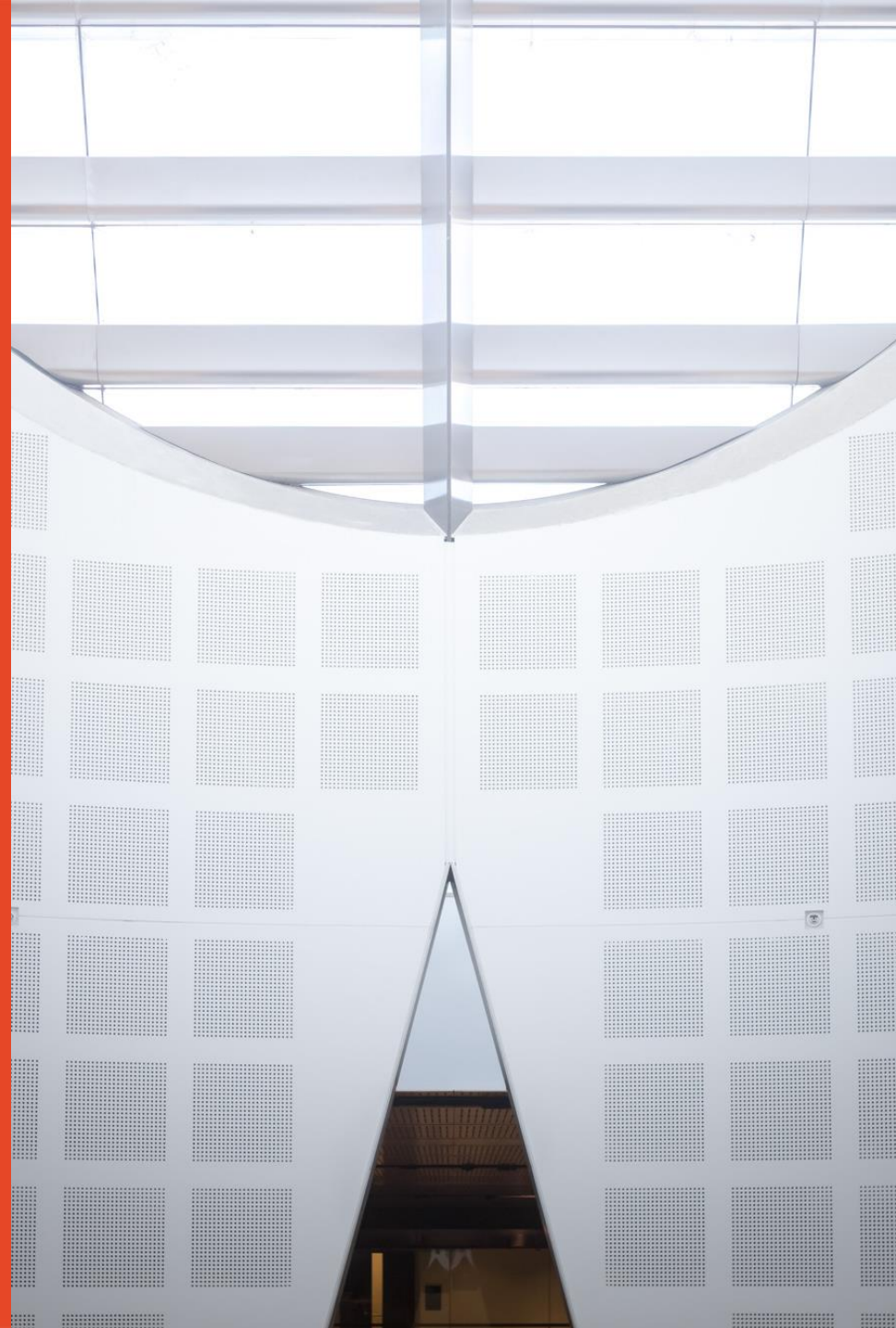
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Disease labelling

- Terminology is important.
- Current labelling literature focusses on the harmful effects disease labels can have (Nickel et al., 2017).
- A label can legitimise a patient's experience or be a source of stigma (Anderson et al., 2012; Woodward et al., 1995).
- The meaning conveyed by a label is shaped by the social context in which it is used (Ward & Horrocks, 2015).

Chronic Fatigue Syndrome (CFS)

- Persistent fatigue, post-exertional malaise, muscle pain, somatic and cognitive symptoms
- Patients report that the label validates their experience and gives them a sense of identity (Moss-Morris & Petrie, 2001).
- Clinicians have reported a reluctance to use the CFS label (Jason et al., 2001; Twisk, 2015)

Social support

- It is important to consider the effect of a label on social support.
- Social support was identified as a major need by CFS patients (de Lourdes Drachler et al., 2009)
- Patients perceive a lack of recognition, leading to social rejection (Dickson et al., 2007; Prins et al., 2004)
- Lack of social support can increase depression and anxiety, and lead to social isolation (DiMatteo, 2004).

Gap in the current literature

Current literature perspectives: patients, clinicians, spouses

How do *FRIENDS* respond to the CFS label?

Current study

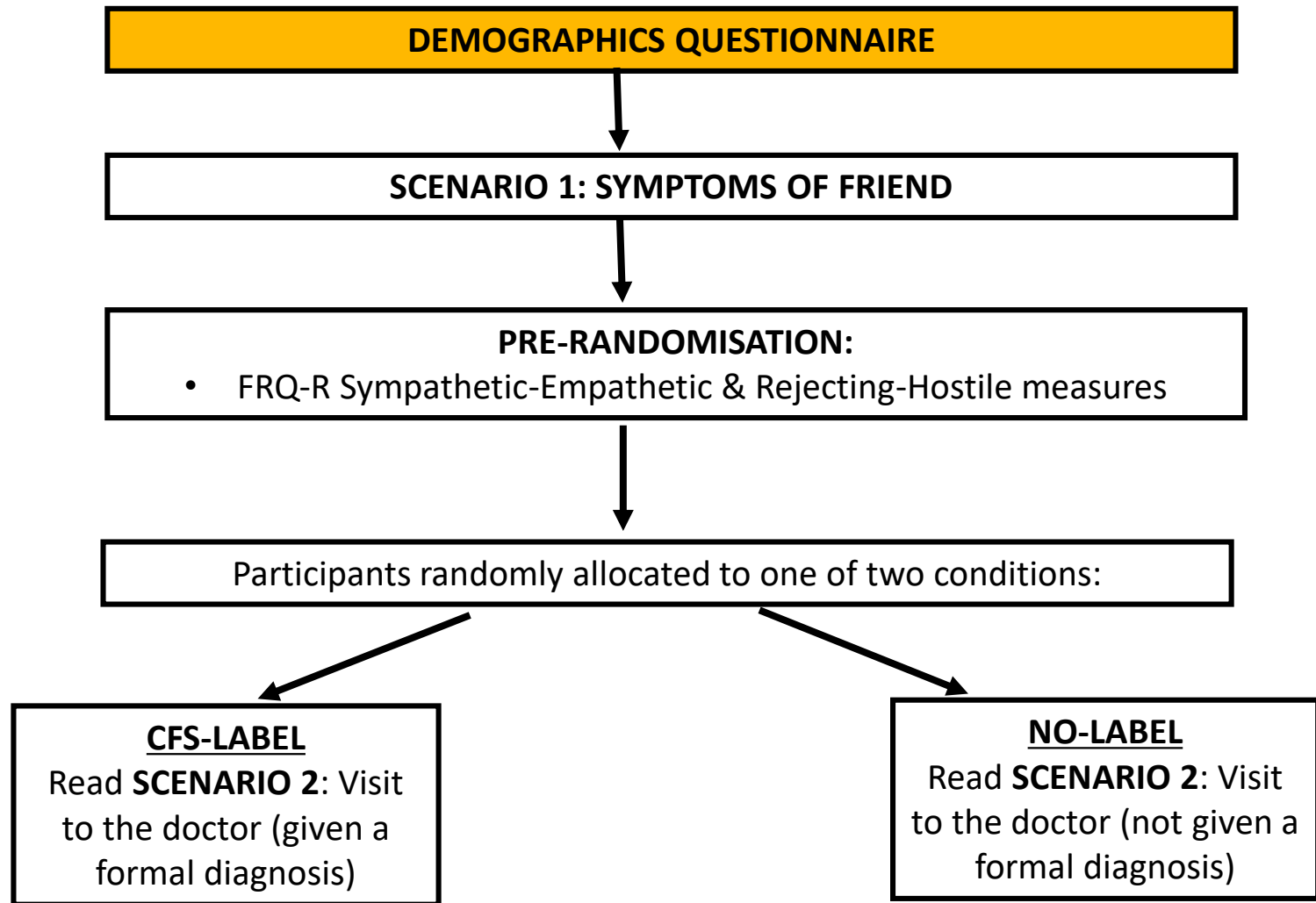
Aim

To examine whether the CFS label elicits more or less social support from friends compared with no label being used.

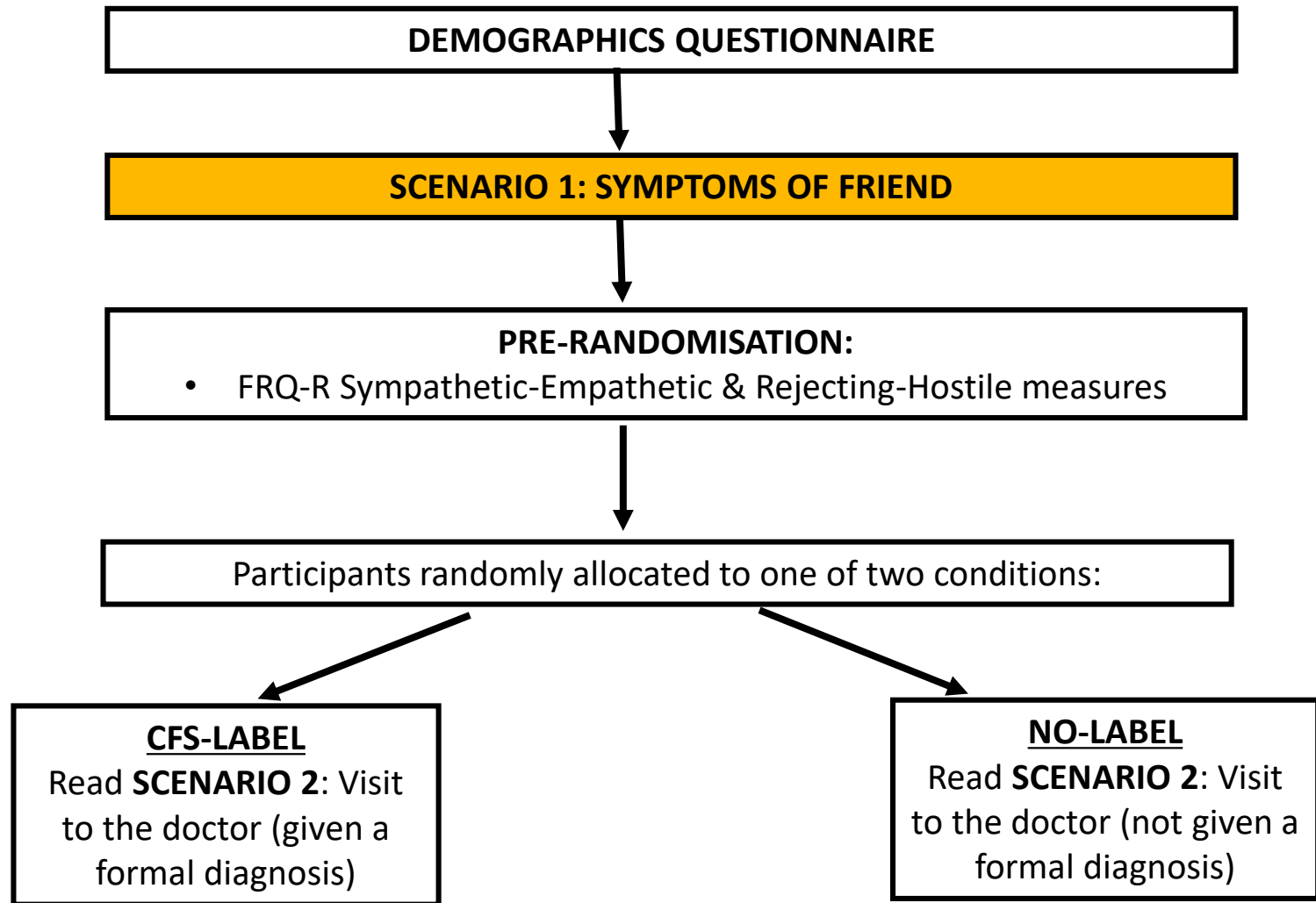
Participants

- 207 first year psychology students.
- No exclusion criteria.
- Exposure to CFS was measured and controlled for.

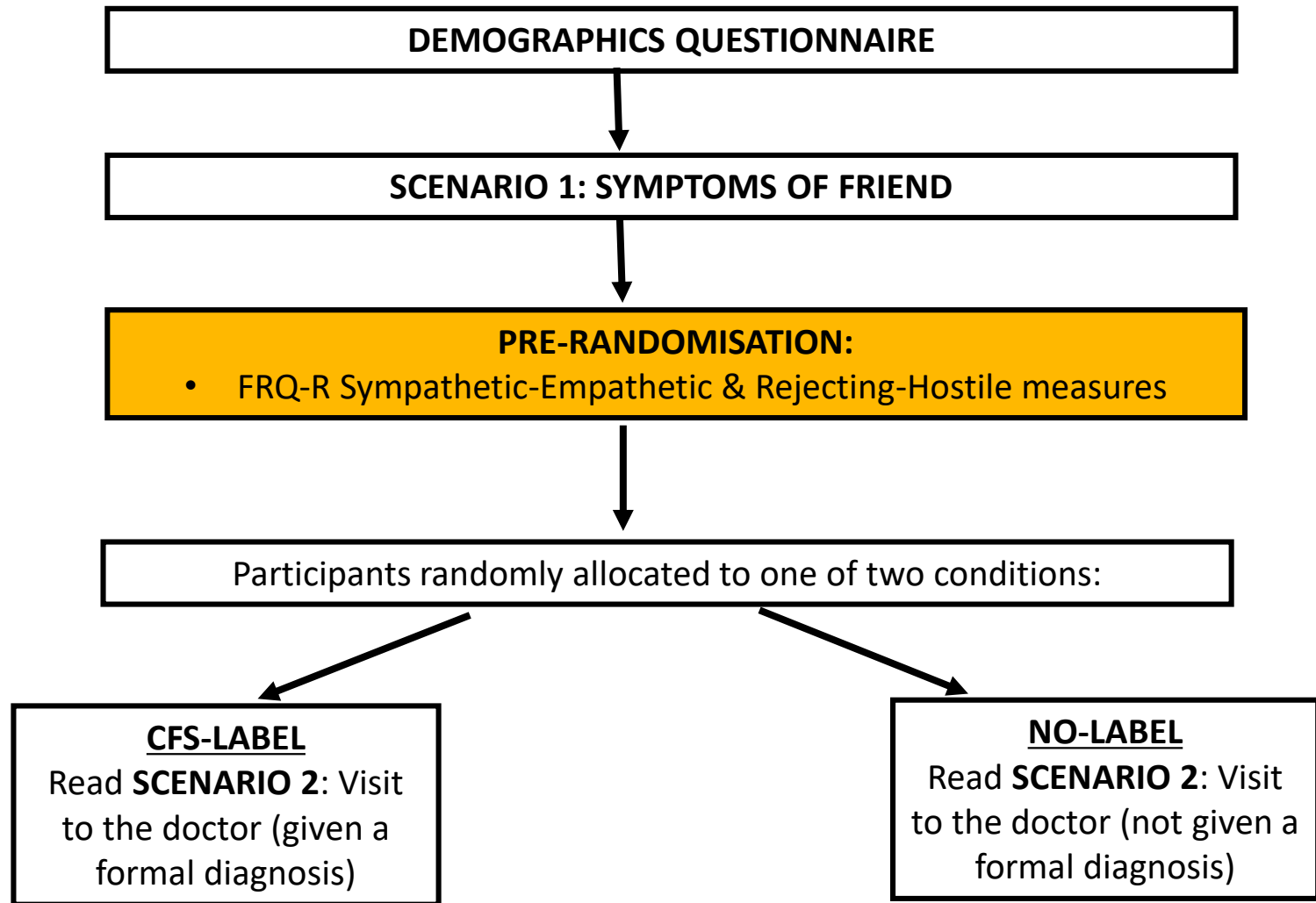
Study design



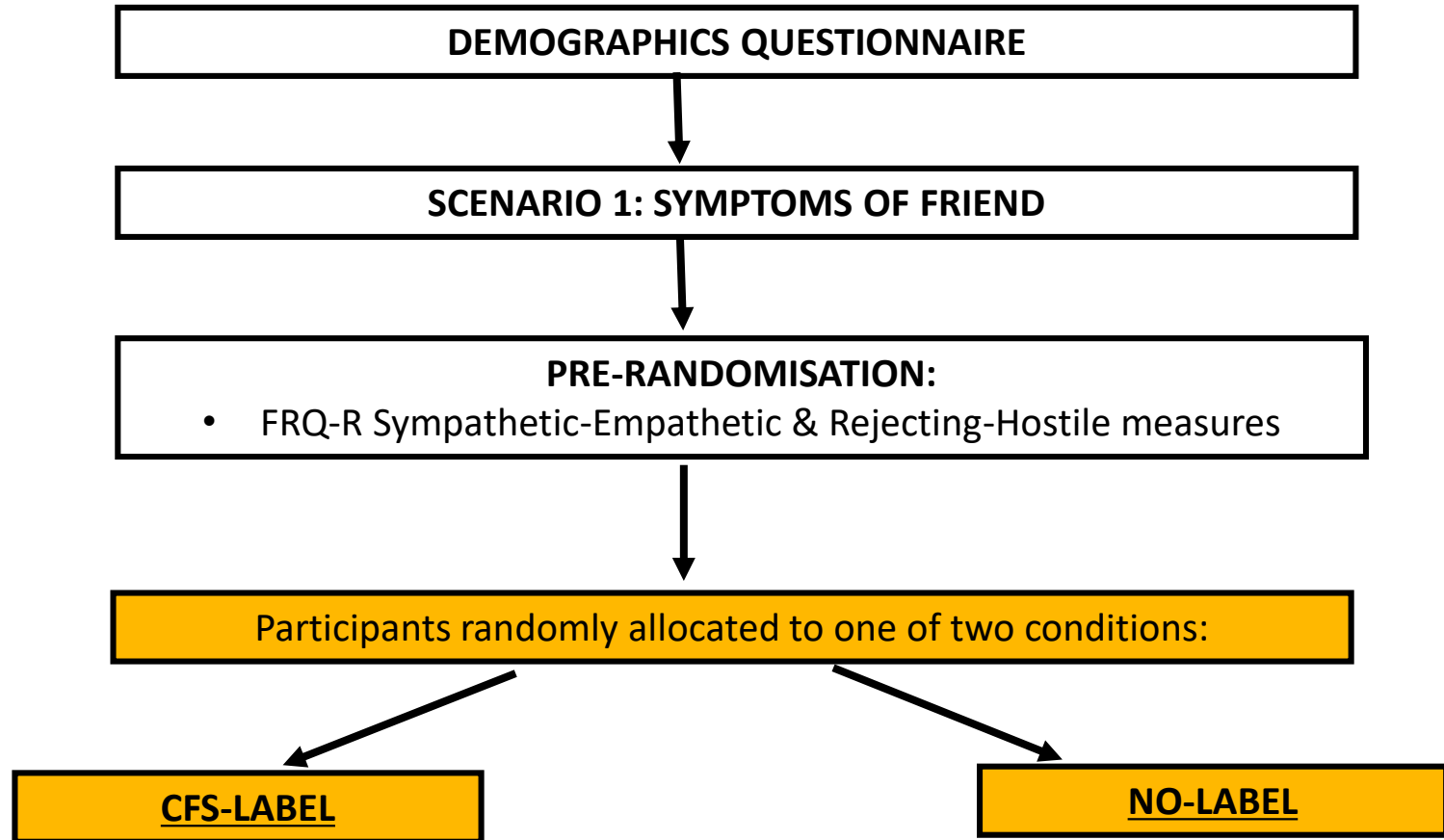
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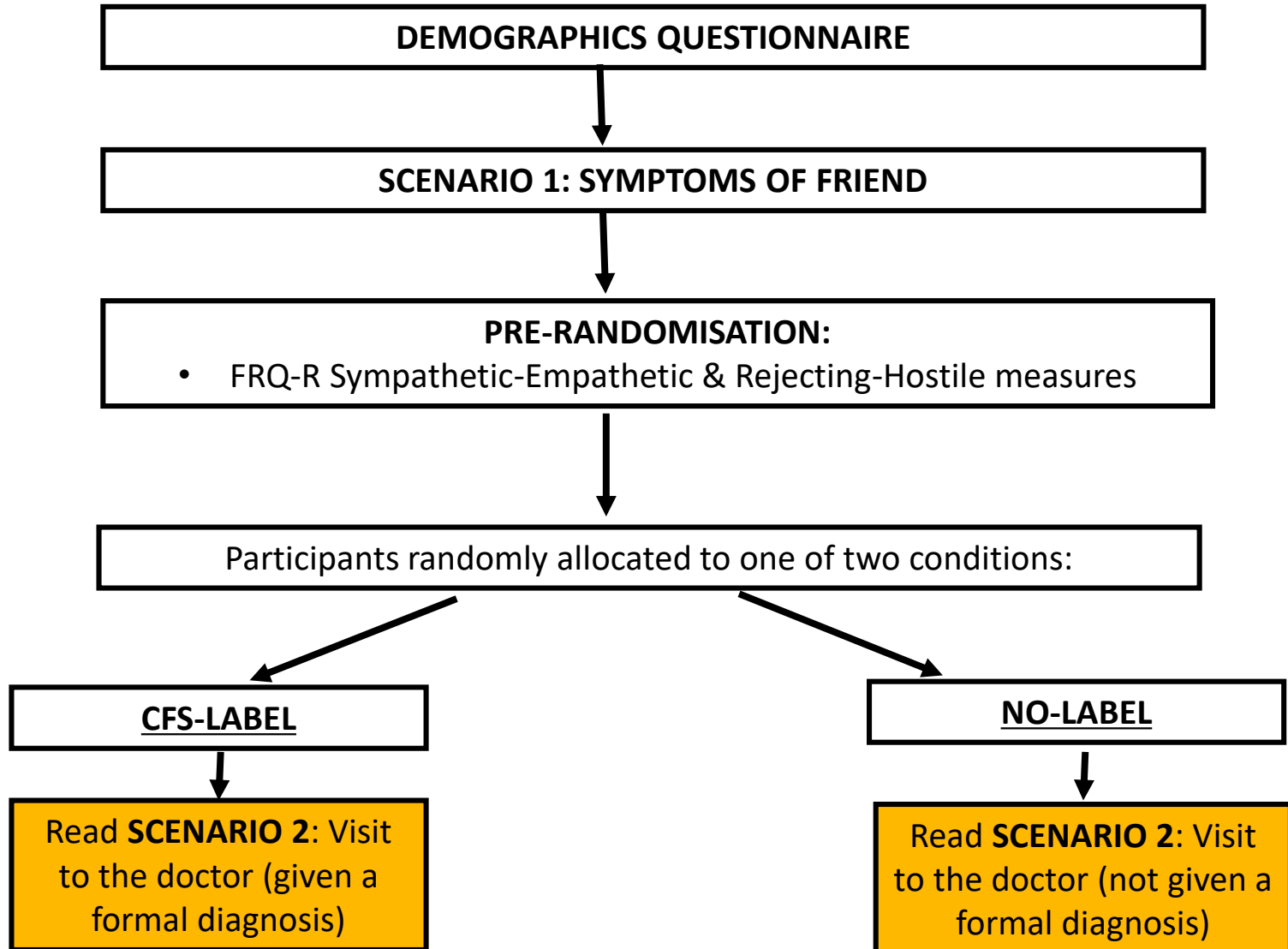
Study design



Study design



Study design



Scenario 2

CFS Label

Your friend then tells you that the doctor, after considering these symptoms and the test results, diagnosed her with Chronic Fatigue Syndrome.

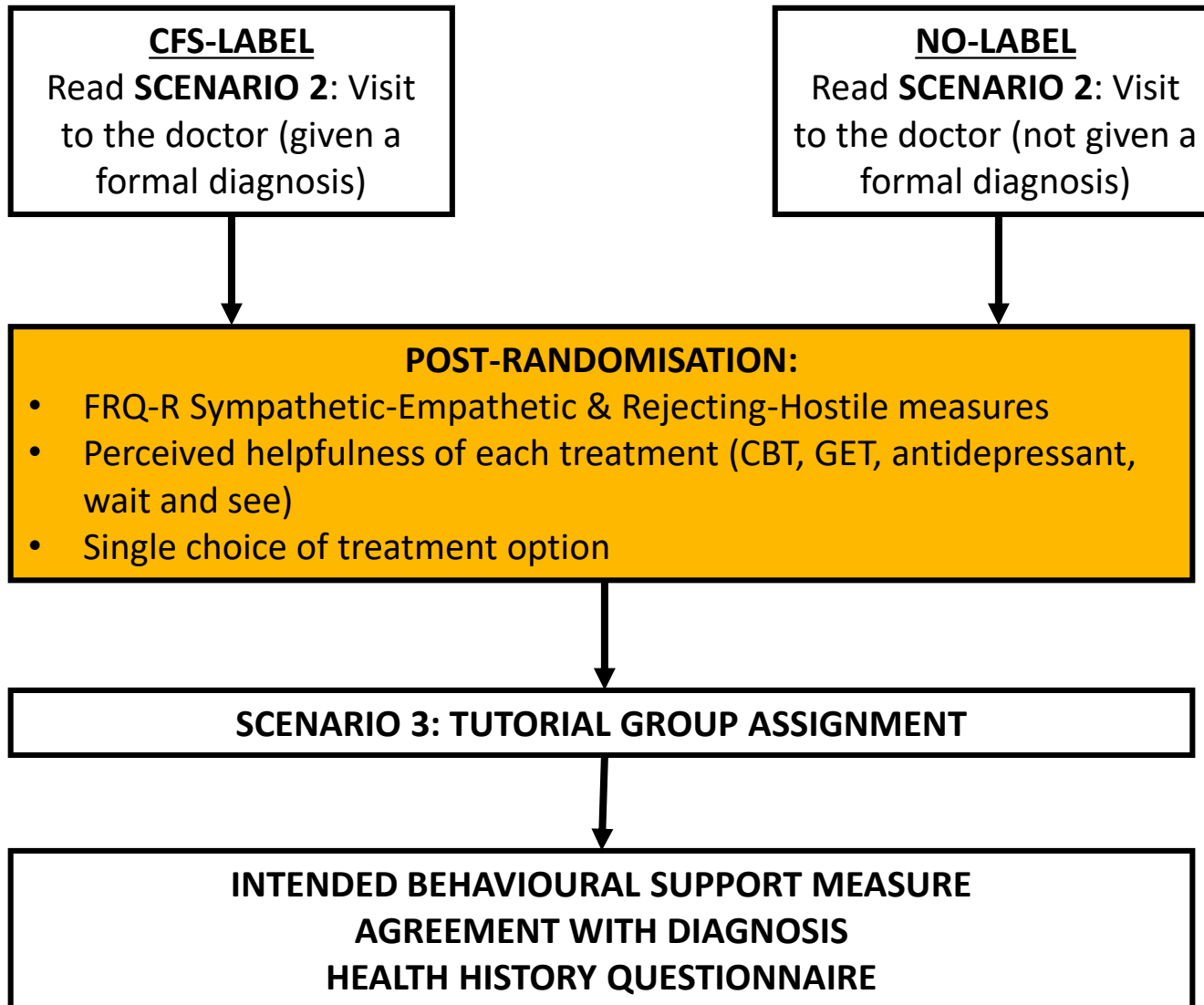
She tells you that the doctor outlined some treatment options for how to manage Chronic Fatigue Syndrome.

No Label

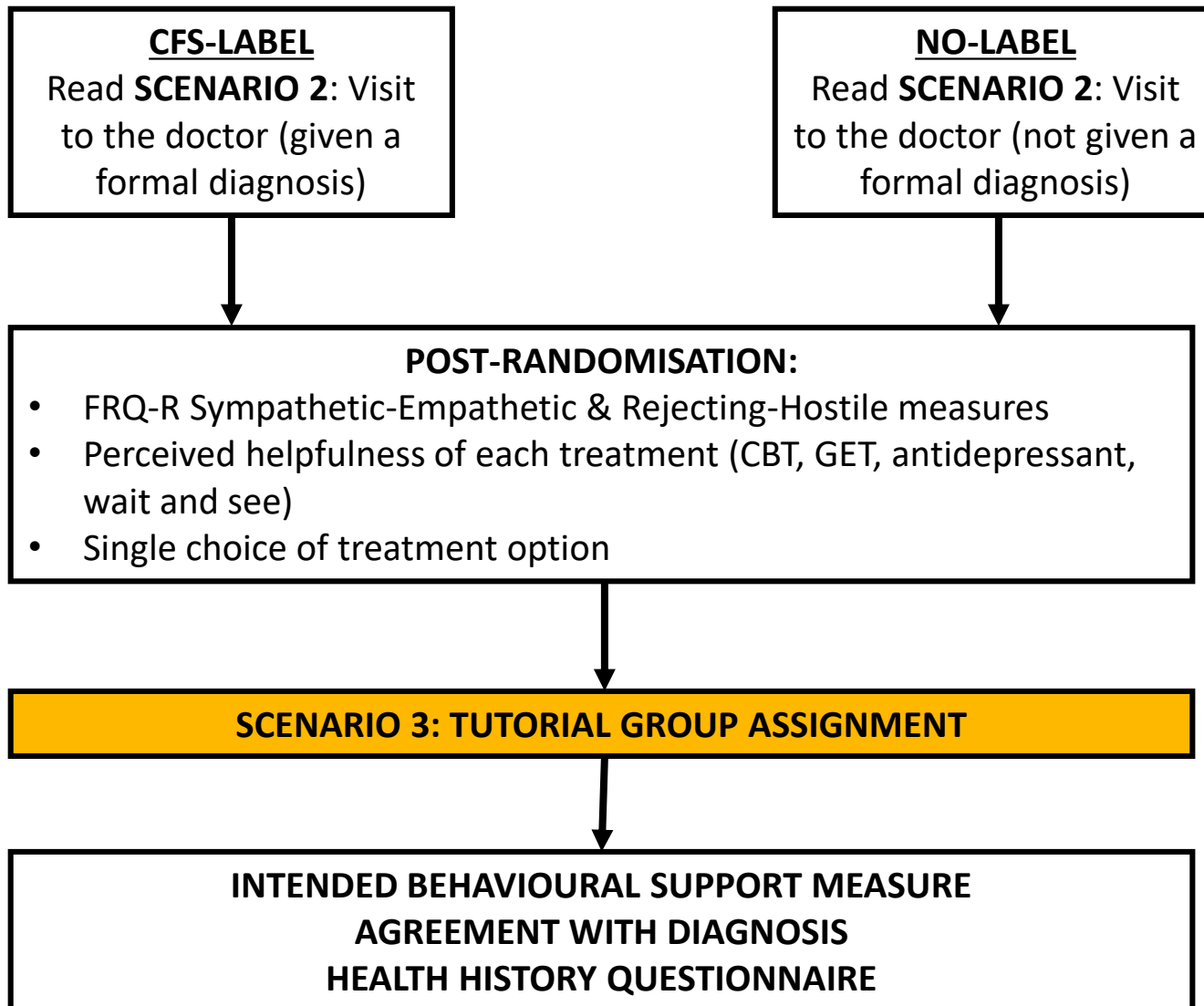
Your friend then tells you that the doctor, after considering these symptoms and the test results, concluded that she is probably recovering from a virus.

She tells you that the doctor outlined some treatment options for how to manage these symptoms.

Study design cont.



Study design cont.



Scenario 3

“You and your friend (from the previous scenarios) are in the same group for a group assignment this semester that requires a tutorial presentation. However, your friend rarely makes it to your group meetings because she does not have enough energy. She never gets her sections of the assignment to the group on time. On the day of the tutorial presentation, your friend says she is feeling too tired and sore to come to class.

One of the other members of your group makes a complaint to your tutor about your friend. Your tutor emails you asking for your feedback about your friend’s contribution to the group.”

Intended Behavioural Support

How likely are you to endorse the complaint, saying that your friend did not fairly contribute?

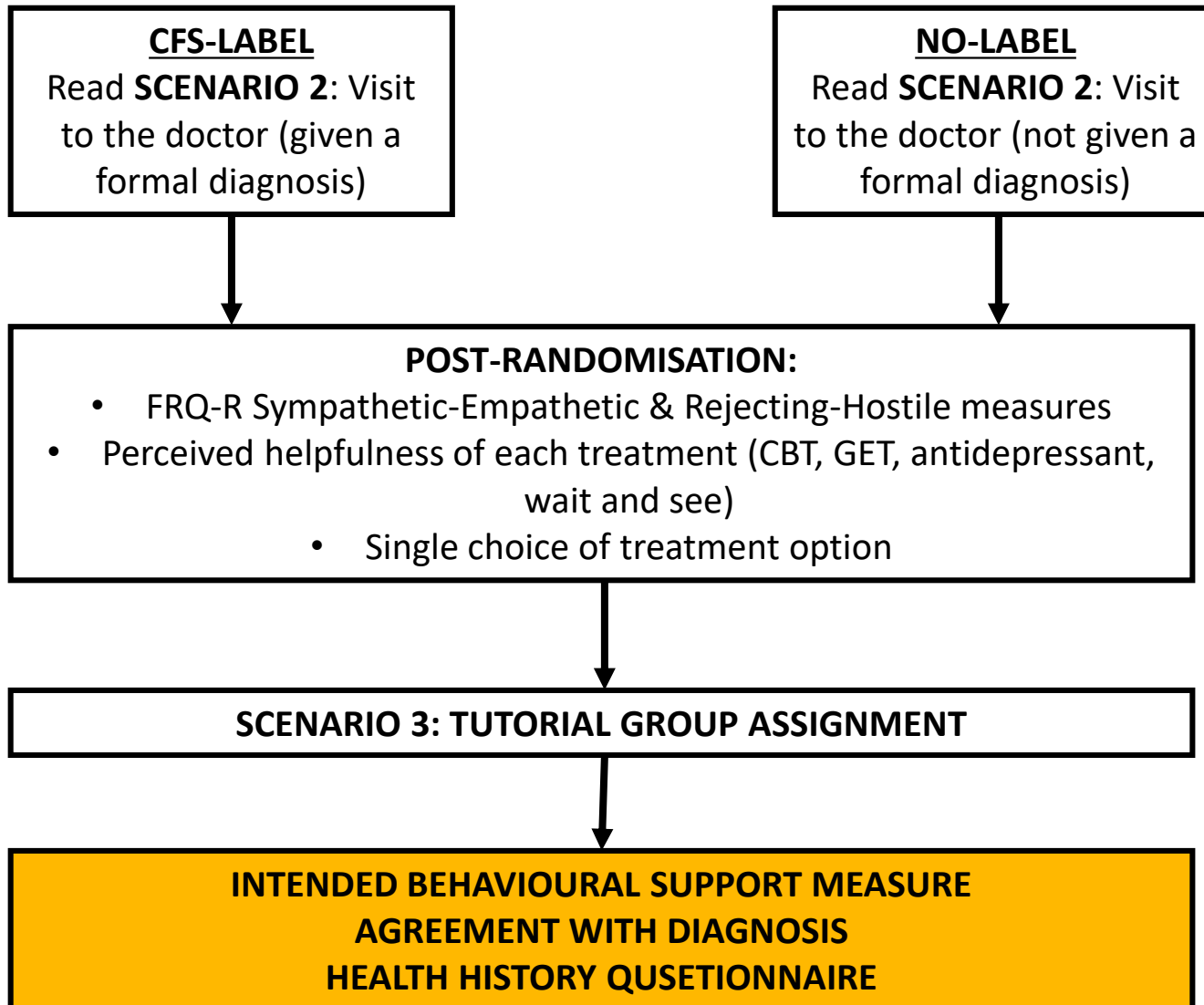
1. Definitely will not
2. Unlikely to
3. Unsure

SUPPORTIVE

4. Likely to
5. Definitely will

UNSUPPORTIVE

Study design cont.



Current study

Method

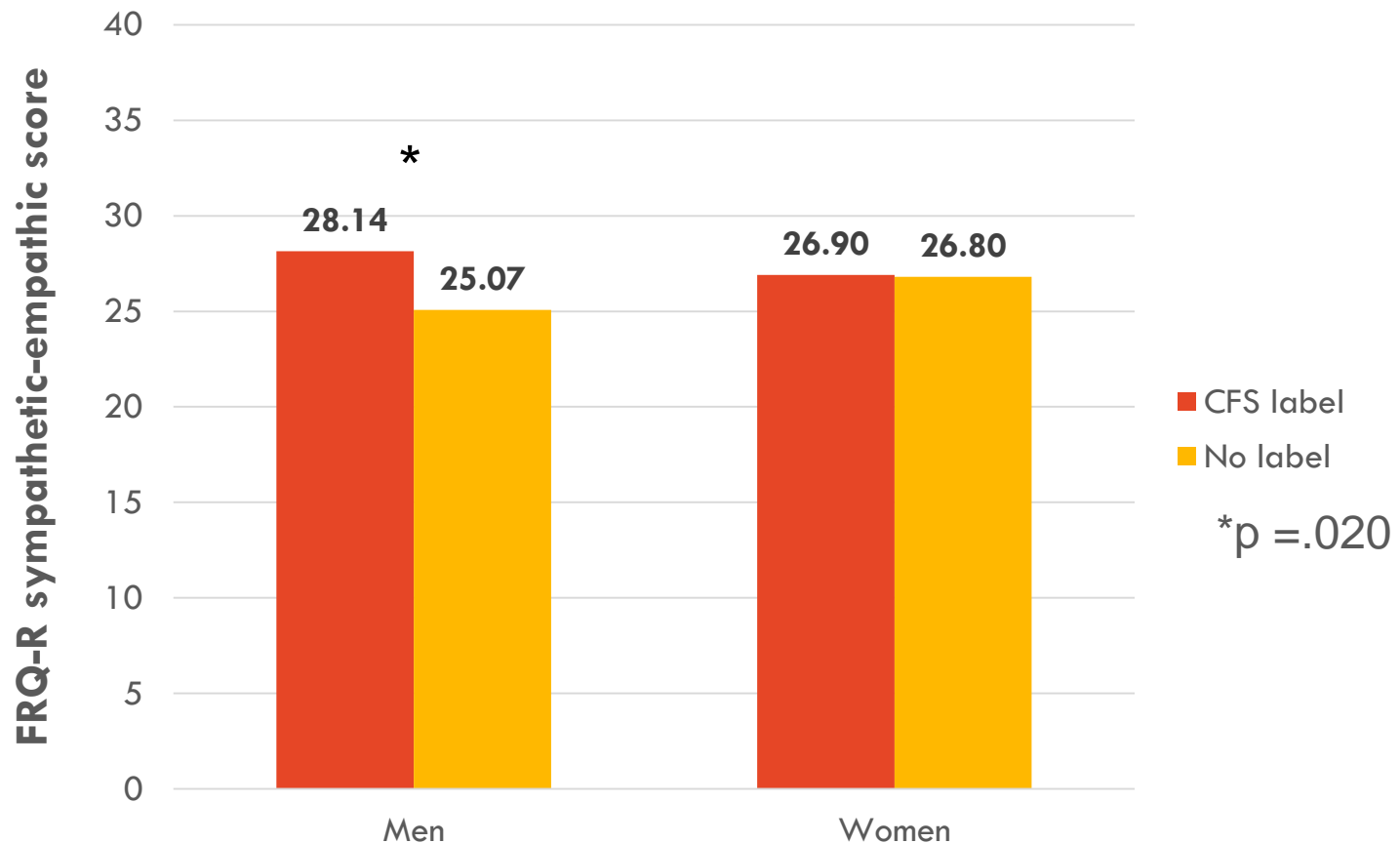
- Design: between-subjects randomised experiment

	CFS-label group	No-label group
Male	Male friend given CFS label	Male friend not given an illness label
Female	Female friend given CFS label	Female friend not given an illness label

- Outcome measures of social support:
 - Sympathy/empathy (indicating support), rejecting/hostile (indicating lack of support), active treatment support, intended behavioural support

Results: Sympathy-Empathy scores

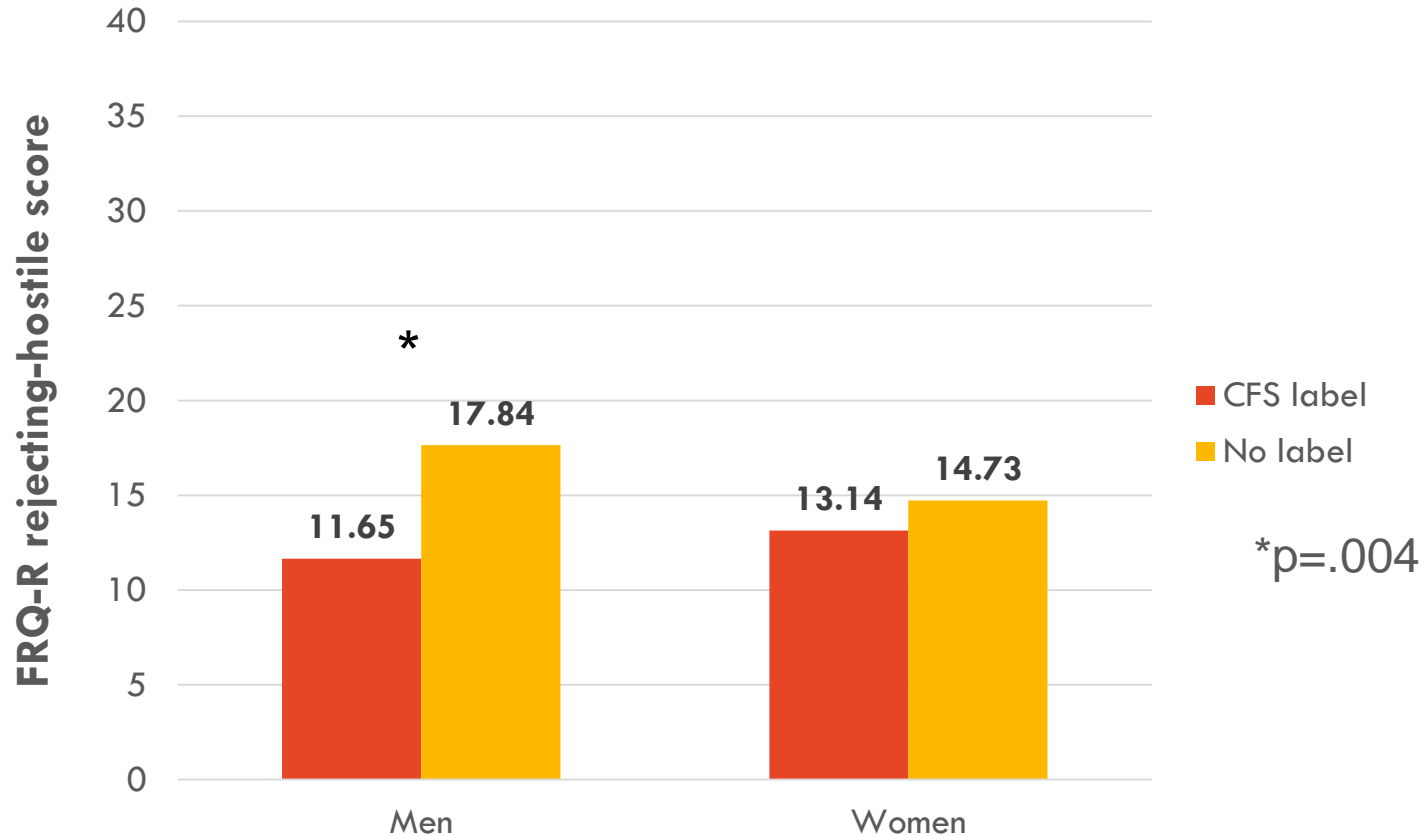
Higher sympathy-empathy scores indicate greater social support.



Adjusted means for post-randomisation sympathetic-empathic scale by label group and gender, controlling for CFS experience and pre-randomisation sympathy-empathy scores ($N=207$).

Results: Rejecting-Hostile scores

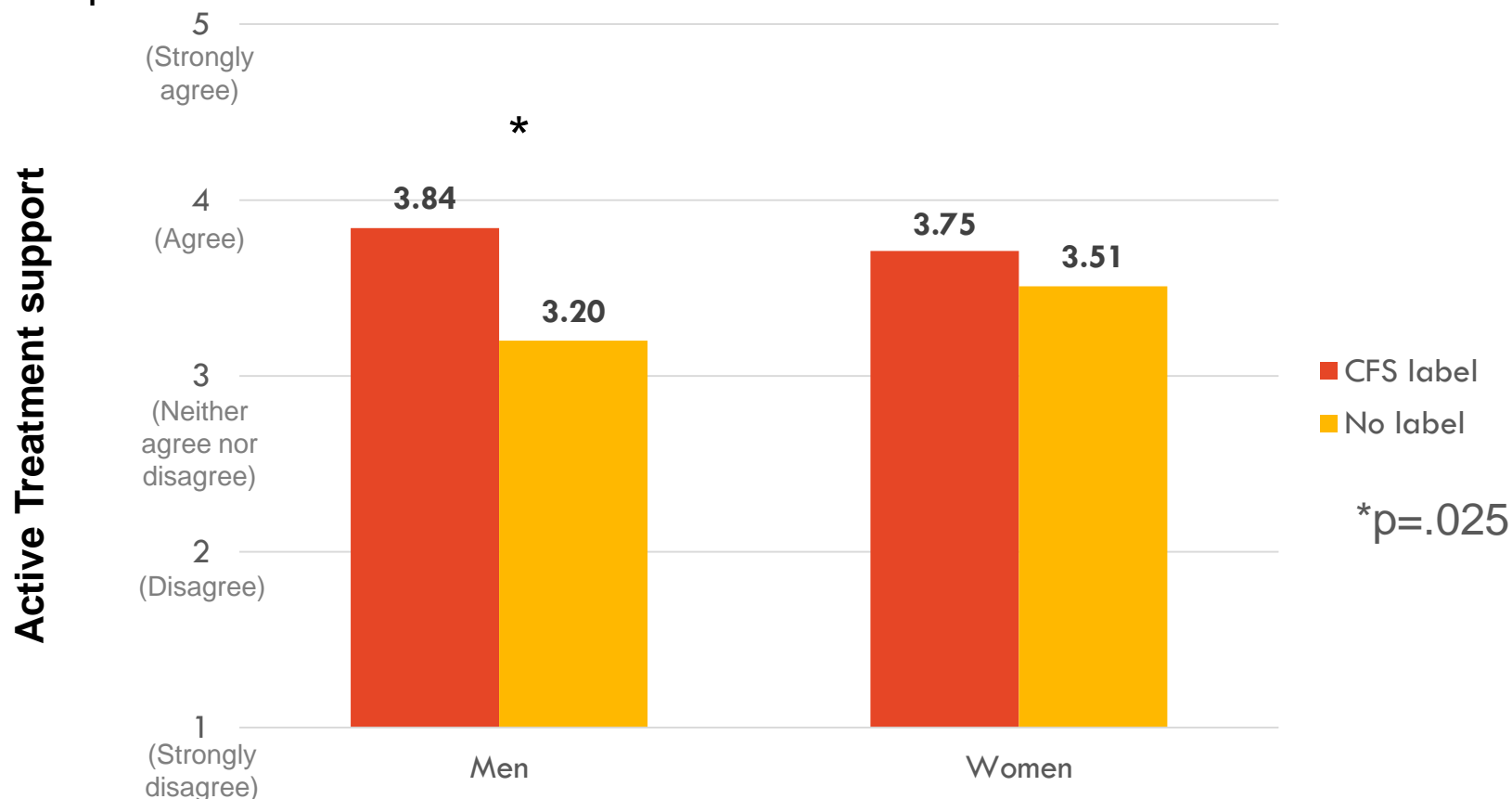
Higher rejecting-hostile scores indicate lower social support.



Adjusted means for post-randomisation rejecting-hostile scale by label group and gender, controlling for CFS experience and pre-randomisation rejecting-hostile scores ($N=207$).

Results: Active Treatment Support

Higher active treatment scores indicate greater agreement that active treatment is helpful



Adjusted means for active treatment support by label group and gender, controlling for CFS experience ($N=207$).

Results: Intended Behavioural Support

Variable	B (S.E.)	p	Exp(B)	95% CI for Exp(B)
<i>Intended Behavioural Support</i>				
Gender	0.33 (0.44)	.462	1.39	0.58-3.30
Label Group	-0.21 (0.36)	.556	0.81	0.40-1.64
Gender*Label interaction	-1.01 (0.69)	.145	0.36	0.09-1.42

Summary of findings

- CFS label elicited more social support in terms of:
 - More sympathy and empathy
 - Less hostility and rejection
 - Greater support for active treatment

- The CFS label had a stronger effect amongst men.

Contribution to current labelling literature

- Previous literature warns against overdiagnosis, highlighting the negative impact disease labels can have.
- This study offers a novel perspective, suggesting that disease labels can have a beneficial social effect.
- Whilst we need to prevent overdiagnosis, the positive effects of labels need to be considered before discarding certain labels.

Where to from here?

- Further research needs to explore difference in social support to various labels for the same condition:
 - CFS
 - Myalgic Encephalomyelitis (ME)
 - Systematic Exercise Intolerance Disease (SEID)

- Further research needs to explore gender differences in responses to various disease labels.

Conclusion

- Helpfulness of the CFS label has been disputed.
- The use of the CFS label, when appropriately given by a doctor, can be useful for eliciting social support amongst a patient's broader social network.

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Possible explanations for these novel findings

- May be a discrepancy between patient perceptions of social support and their friend's intention.
- Intention-behavior gap
- Doctor's authority in the scenario may have influenced these results and facilitated social support
 - 57% of participants in the CFS-label group agreed with doctor's diagnosis; only 28% in the no-label group agreed.
- Nature of the relationship (friend vs spouse) may affect the degree of social support.
- Perhaps women respond more to the symptoms and men respond more to the diagnosis

Scenario 1

“For the past six months, a close friend of yours has been experiencing a significant amount of recurrent fatigue. However, whenever you see her, she looks perfectly fine. She will often call you just before you are about to catch up to cancel because she is feeling tired. On the night of your birthday party, where she was meant to arrive early and help you set up, she didn’t come at all because she had a really bad headache and was feeling too tired. This is not the first time she has not shown up for parties due to serious headaches. The last time you went for a 30-minute jog with her, she complained for 5 days afterwards about how tired and sore she felt because of it, even though you only took a day to recover from the jog. Whenever you do catch up, she often complains of a sore throat or flu-like symptoms. A few times, she has told you that she is not sleeping very well and has lost a bit of weight.”

Scenario 2

“Yesterday, when that close friend came over, she told you she had been to the doctor about feeling constantly tired. After considering the symptoms, the doctor ran a series of physical tests including blood tests, thyroid function tests, urine tests and tests for HIV, Coeliac disease and cancer. The doctor found no abnormalities, excluding a range of possible diagnoses.

Your friend then tells you that the doctor, after considering these symptoms and the test results, diagnosed her with Chronic Fatigue Syndrome.

She tells you that the doctor outlined some treatment options for how to manage Chronic Fatigue Syndrome.

The treatment options that the doctor mentioned were:

- *Cognitive-behavioural therapy* which restructures unhelpful beliefs, sets up a sleep routine and works on a timetable for how much activity and rest to have.
- *Graded Exercise Program* which involves gradually increasing the amount of exercise you do to tolerate more and more.
- *A low dose antidepressant* (60mg/day dose of Nortriptyline) shown to reduce symptoms of fatigue.
- *Wait and see* if the symptoms will resolve on their own and the doctor will review her again in 2 months.