October 2024

Ethics of Inclusion:

exploring whether people of working age with invisible illnesses and chronic conditions feel they belong in their church communities

A study led by Penny Pullan

Why?

CHURCH TIMES

Home   UK   World   Comment   Features   Faith   Books & Arts   Regulars   Audio

Health: Surely, things will get better?

15 OCTOBER 2021

How does Christian faith sit alongside chronic illness? *Penny and Malcolm Pullan* recount their stories

Penny's story

I MET Malcolm when we were postgraduate students at Cambridge, in January 1990. I was studying for a Ph.D. in engineering (nanotechnology), and his doctorate was in mathematics (operations research). We met remotely on the Cambridge University mainframe computer, and discussed life, the universe, and everything, in between working on our Ph.D.s. Within six months, Malcolm had

ME/CFS is a complex and chronic medical condition that effects multiple body systems.

Symptoms include flu-like malaise, sleep difficulties, brain fog and a profound fatigue that is unlike normal tiredness. People may also experience chronic pain, headaches, nausea, digestive problems, and sensitivity to light, sound and other stimuli.
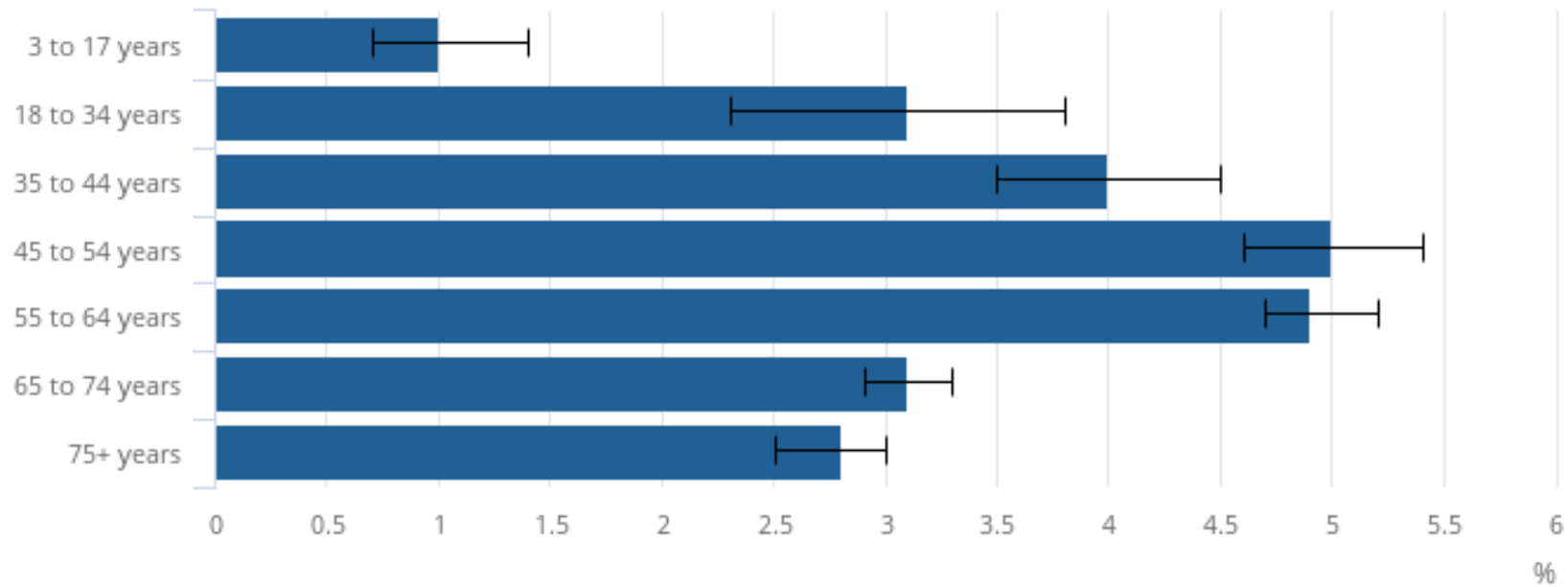
https://meassociation.org.uk/me-cfs-long-covid-overview/

Long COVID is defined as the continuation or development of new symptoms 3 months after the initial SARS-CoV-2 infection, with these symptoms lasting for at least 2 months with no other explanation.

https://www.who.int/europe/news-room/fact-sheets/item/post-covid-19-condition

Figure 2: Those aged 45 to 54 years are most likely to report long COVID

Estimated percentage of people living in private households with self-reported long COVID of any duration by age, England and Scotland, four-week period ending 7 March 2024

The Study

Study Progress 2024

Coding

Teaching needs to be accessible

Lucky to be part of this church

Over-estimating inclusion   Change to supportive leader

Hybrid for meetings   Feeling grief and loss   Inclusion means LGBTQI+++

Gifts/ministry not used   Non supportive church leader

PCC member   "I have disappeared/been forgotten"

Church Worker   Supportive church leader   Mitigations lacking for COVID

"You look well!"   Costs of church involvement

Churchwarden   Healing (or not)   Inclusion looks like...   Disabled is not their idea of priest/minister

'I'm unreliable'   how affected?   COVID deterioration

Reader/LLM

Sound/Tech   Fluctuating condition   How Valued   Need more flexibility and understanding

Seen

Unseen   What else?   Can't attend in person church

Pain

Noise   Notes   Stigma

Next step   Great Quotes

Church is tiring

Leading music   Pacing   Exclusion   Lament/suffering - talking about it openly

Lay Role   Frustration   How Included

Isolated   Online is valuable

Ordained   Rotas are bad   Valued for what I do/my role

'I have to say no'   Gifts/ministry used   Value other illnesses more

Sit or stand, that's fine   Disability Theology   Stand - no allowances made

Secular alternative better   Belonged when well   Church services that work for ill people

Decisions made for me   No or less online provision

Leader - lived experience

Teacher in church school   Valued for who I am, rather than what I do

The Results: Themes

Themes

The Challenging Ones

I'm valued for what I do, not who I am

Rotas are a nightmare

Church harms…

I'm treated differently from others

'I have disappeared'

I'm valued for what I do, not who I am

"**There's a lot of pressure. You only seem valued if you do stuff.**"
— **Participant P30**

"**[I'm] of no value to the church as I am not well enough to volunteer**"
— **Participant S14**

Rotas are a nightmare

"I never know whether I'm going to feel ok or not so don't like commit to things. Hence, I don't get as involved as I might otherwise, and therefore feel less included."

– Participant S07

People say: 'We won't bother because she's unreliable. She's a bit all over the place.'

– Participant P30

Church harms…

physically, mentally and spiritually

"All I want to do is cry all the way through the service because I'm in so much pain."

– Participant P05

"There is no safe inclusion for people with chronic illnesses" [speaking of COVID infections in church]

– Participant P35

"People disbelieving and continually praying for my healing and telling me to repent. It affected me so much emotionally… I really believed God hated me."**– Participant S28**

I'm treated differently from others

"People find it easier to cope with when they can see some outward sign or something."

– Participant P30

"When they try to include me, I feel different as it's always a special effort that feels a trouble."

– Participant S36

"They've been good with them, but terrible with me!" [comparing her treatment to those with visible disabilities]

– Participant P20

'I have disappeared'

"Out of sight and out of mind. I feel I've been abandoned."

– Participant P35

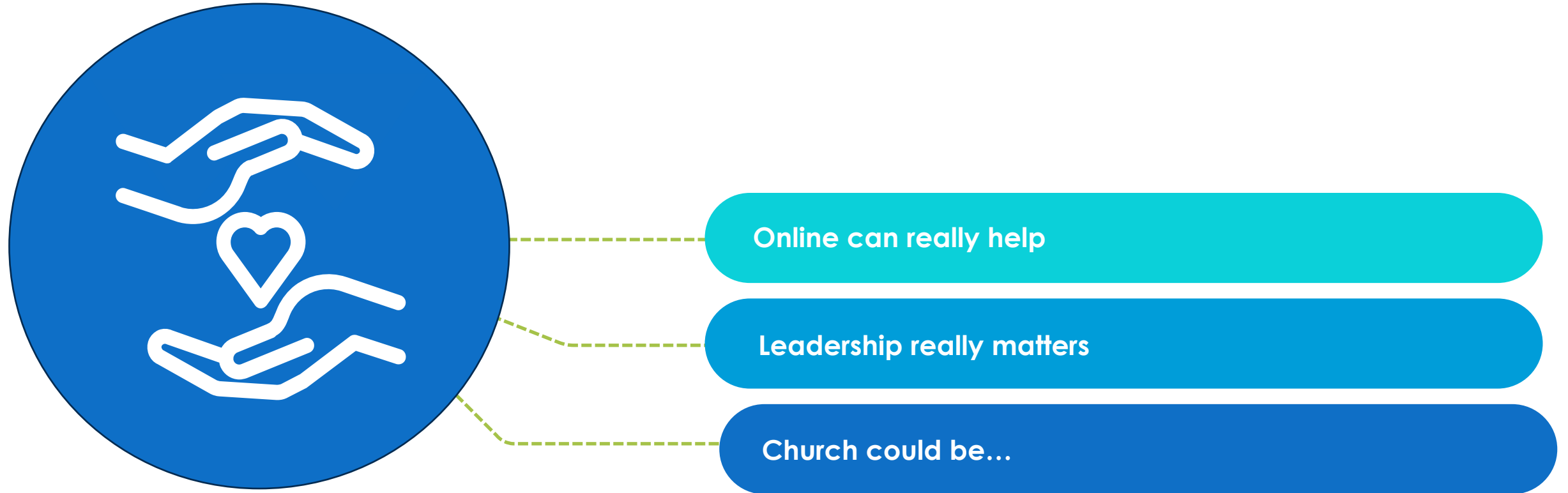"Live-streaming [was] taken away"

– Participant S33

"I was told I can't go on the [home communion] list because they're too busy looking after all the older people who need it."

– Participant P34

Themes

The Positive Ones

Online can really help

Leadership really matters

Church could be…

Online can really help

"Suddenly there was a level playing field. Everything was on Zoom and I could take part!" (March 2020)

– Participant P35

"We do art, we do Bible studies, we pray. It's just lovely. Lots of online chatting. It seems to really bless people."

– Participant P34

Leadership really matters

"

"It makes such a difference! My vicar tells me: 'If you want to sit down, just sit down.'"

– **Participant P17**

"Stand if you can - God doesn't mind if you don't."

– **Participant S46's vicar**

"

Church could be…

"more welcoming, more joyful, more like Jesus"

– Participant P24

'strength in weakness, beauty from brokenness, growth from suffering, great capacity from incapacity and so on. The upside-down kingdom'

– Participant S55

Analysis Framework

Combining theology, social psychology, leadership and anthropology.

1. Culture
Typically individualistic, valuing doing over being.

2. Social Identity Theory
Looking at in-groups and out—groups, stereotyping and stigma

3. Exclusion
Moving from exclusion to embrace, following Volf.

4. Imago Dei
What does it mean to be a person made in the image of God?

5. Inclusion/Belonging
True belonging as a disabled person, beyond inclusion

6. The Body of Christ
Equal across difference in Christ

Invisible Illness Framework

6 5 1 4 2 3

"To be included, you just need to belong. To belong you need to be missed."

John Swinton
'From Inclusion to Belonging: A Practical Theology of Community, Disability and Humanness' in '*Journal of Religion, Disability and Health,* 16(2) 2012, pp. 172-190 p. 177

Theology: The Body of Christ

1 Cor 12

Why everyone should belong
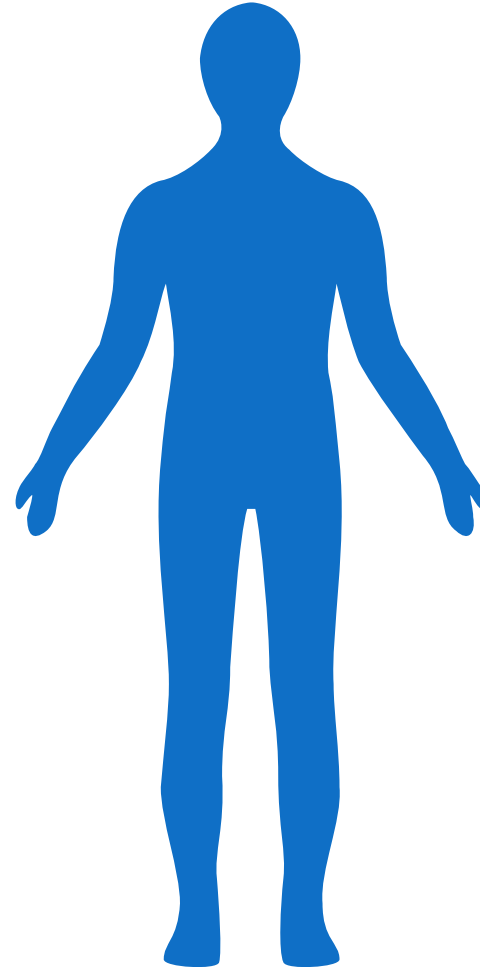
✓ **No hierarchy**

All organs are just as important as all the others

✓ **Weaker**

Are indispensable!
(but weaker doesn't necessarily mean disabled, which could be someone with less will power to resist temptation)

✓ **All are conduits**

Of divine love. Disabled people need to play their full part in ministry.

✓ **One suffers…**

All suffer, together. No concept of abandonment/surgical removal.

What can Churches do?

Some Ideas for Churches

Based on the themes...

Model
The Body of Christ from 1 Corinthians 12

Stop the harm
Physical, mental, spiritual and emotional

Transform Culture
from
-individualistic
- doing over being

Rotas
Make rotas flexible so more can serve.

The Same
Treat people well, whether they have cancer or ME.

Online
Use interactive online sessions to engage those stuck at home.

Explore
What church could be...

Listen
Listen to people and their unique set of needs.

Check
Who has disappeared? Did they want to leave?

Stop being indifferent!

"The havoc wreaked by indifference may be even "greater than that brought by felt, lived, practiced hatred.""

Miroslav Volf
Exclusion and Embrace p. 67

What can we do?

EthicsofInclusion.study

Email
penny@makingprojectswork.co.uk

Thank You!

Extras

Some Demographic and Ratings Results

Dedoose

dedoose
Great Research Made Easy

MA Study

Project: MA Study

Users:	1
Media:	62
Descriptors:	61
Excerpts:	329
Codes:	35
Code Application:	329

Import Data — Spreadsheets, Documents, Audio, Video, Projects, etc.

Export Data — Excerpts, Media, Codes, Descriptors, Project, etc.

Codes

- Belonged when well
- Can't attend in person church
- Great Quotes
- ▼ How do others see me?
  - Valued for what I did for others/role
- ▼ Leader impact
  - Leader not supportive now
  - Non supportive church leader
  - Supportive Church Leader
- ▼ Negative Experience of Church In-Person
  - Can't take part
  - Distant from God
  - Giving too much
  - Lonely

Media

Type	Title	Added	User	# Ex
	Participant: 10	02/17/202	pennypullan	6
	Participant: 11	02/17/202	pennypullan	4
	Participant: 12	02/17/202	pennypullan	8
	Participant: 13	02/17/202	pennypullan	4
	Participant: 14	02/17/202	pennypullan	5
	Participant: 15	02/17/202	pennypullan	6
	Participant: 16	02/17/202	pennypullan	5
	Participant: 17	02/17/202	pennypullan	6
	Participant: 18	02/17/202	pennypullan	6
	Participant: 19	02/17/202	pennypullan	7
	Participant: 20	02/17/202	pennypullan	6

Excerpts: 329

Resource	**Participant: 61**	Added	**04/09/2024**	Username	**pennypullan**	# Codes	1

I am unable to physically attend church. I have not been able to attend for 22 years.

Resource	**Participant: 60**	Added	**04/09/2024**	Username	**pennypullan**	# Codes	1

because I've been ill for so long, no one ever visits me, and never has done. Even our vicar who has since left never came to see me.

Resource	**Participant: 60**	Added	**04/09/2024**	Username	**pennypullan**	# Codes	1

I rarely attend services, as most are in the morning and therefore I am unable to wake in time to go.

Resource	**Participant: 58**	Added	**04/09/2024**	Username	**pennypullan**	# Codes	1

Codes x Descriptor

Hit/Miss ☐   Sub-code Count ☐   Normalize ☐   % ☐

Field:
Set: Default
Field: Age

Belonged when well

18-25	0.0%
26-35	0.0%
36-45	0.0%
46-55	100.0%
56-65	0.0%

100.0%

Can't attend in person church

18-25	22.9%
26-35	22.9%

Descriptor Ratios Multi Chart

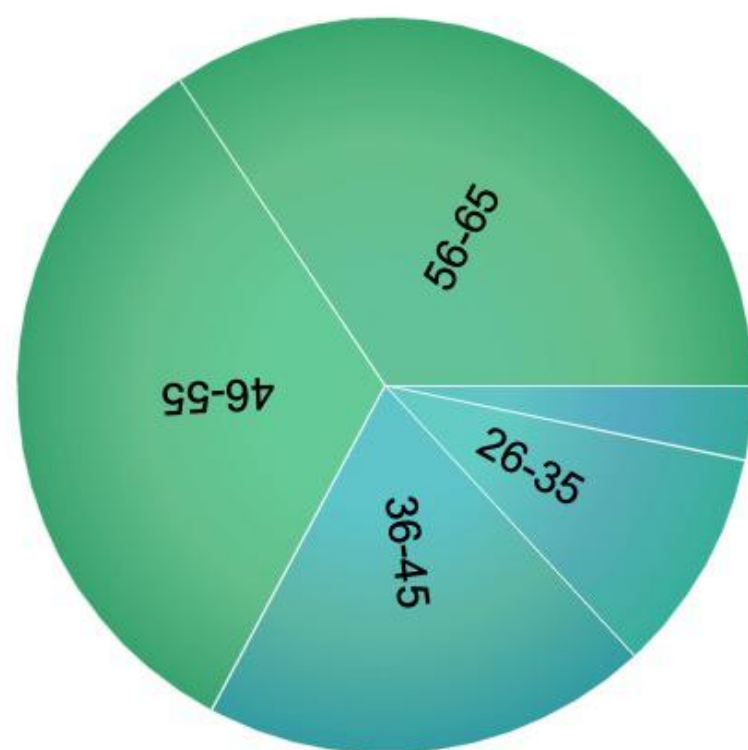Set: Default, Field: Age
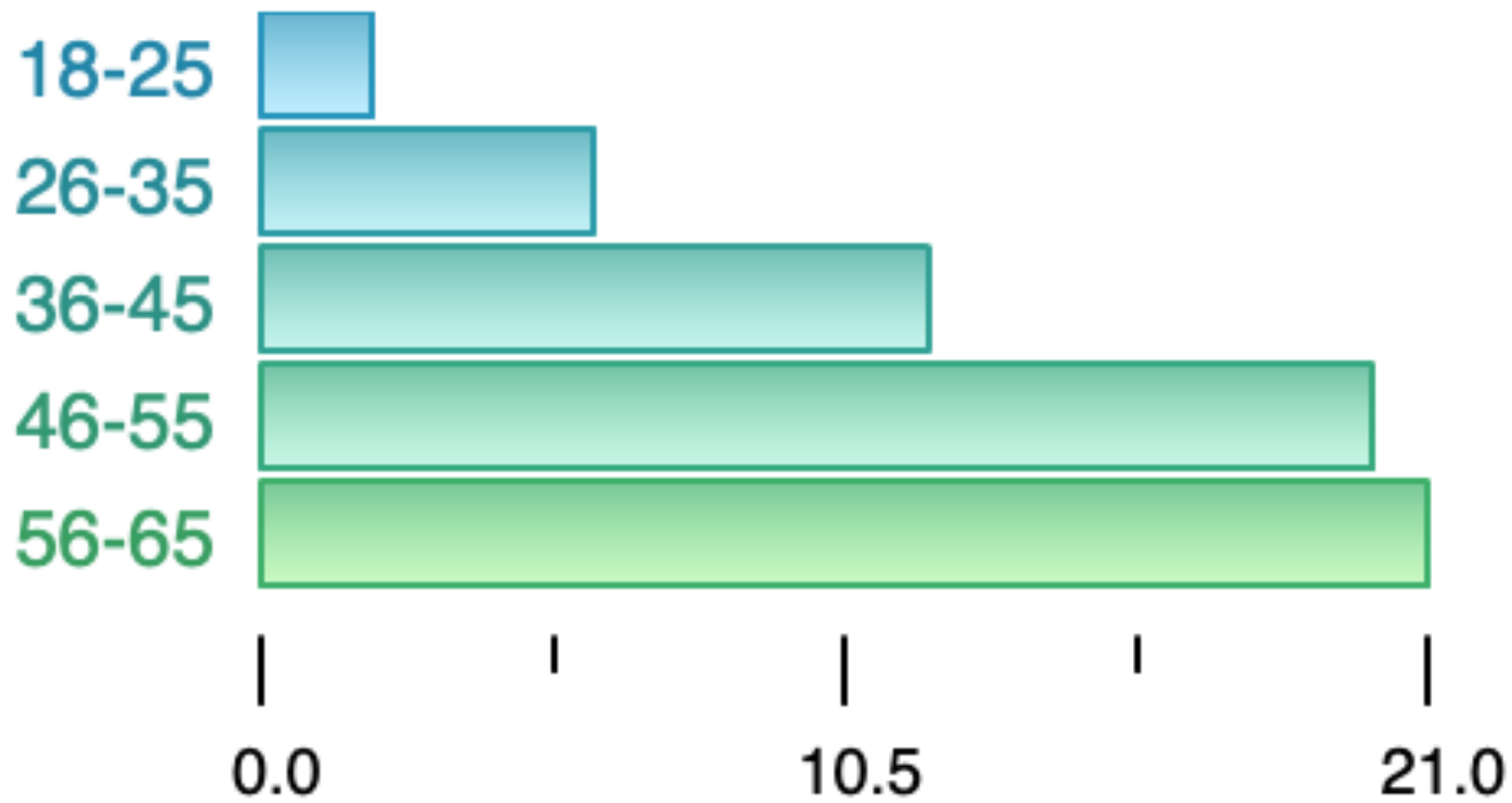
56-65
46-55
26-35
36-45

Set: Default, Field: Gender

Female
Male
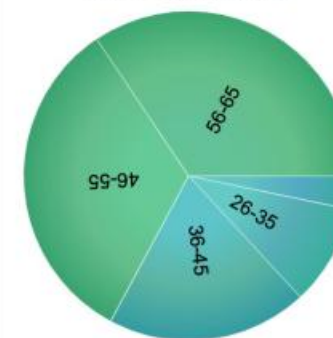
Set: Default, Field: Illness
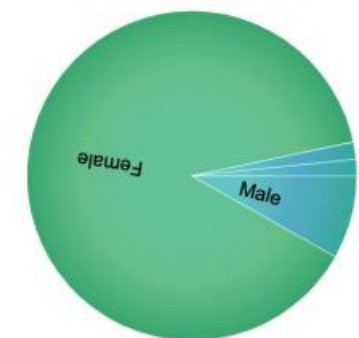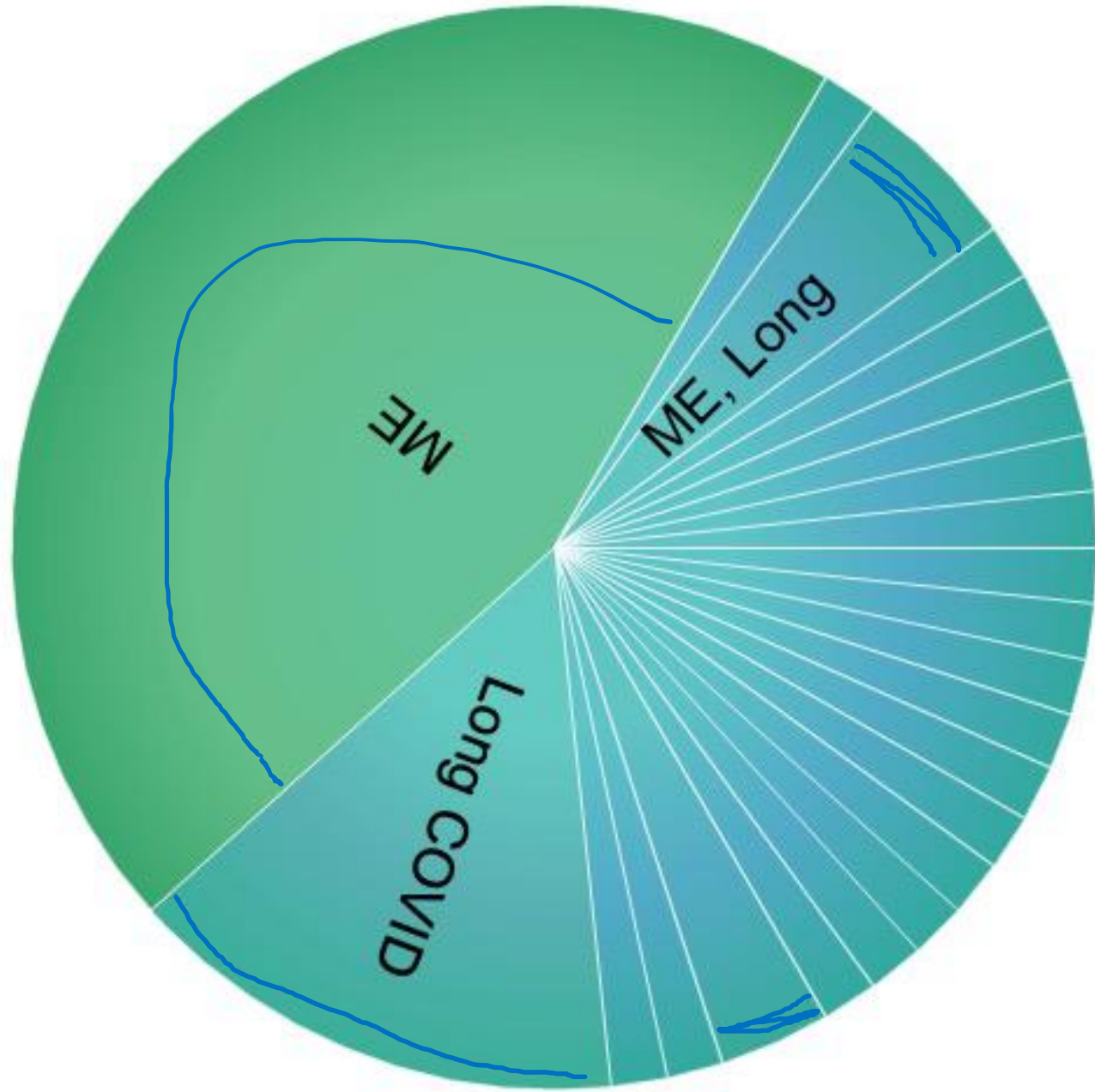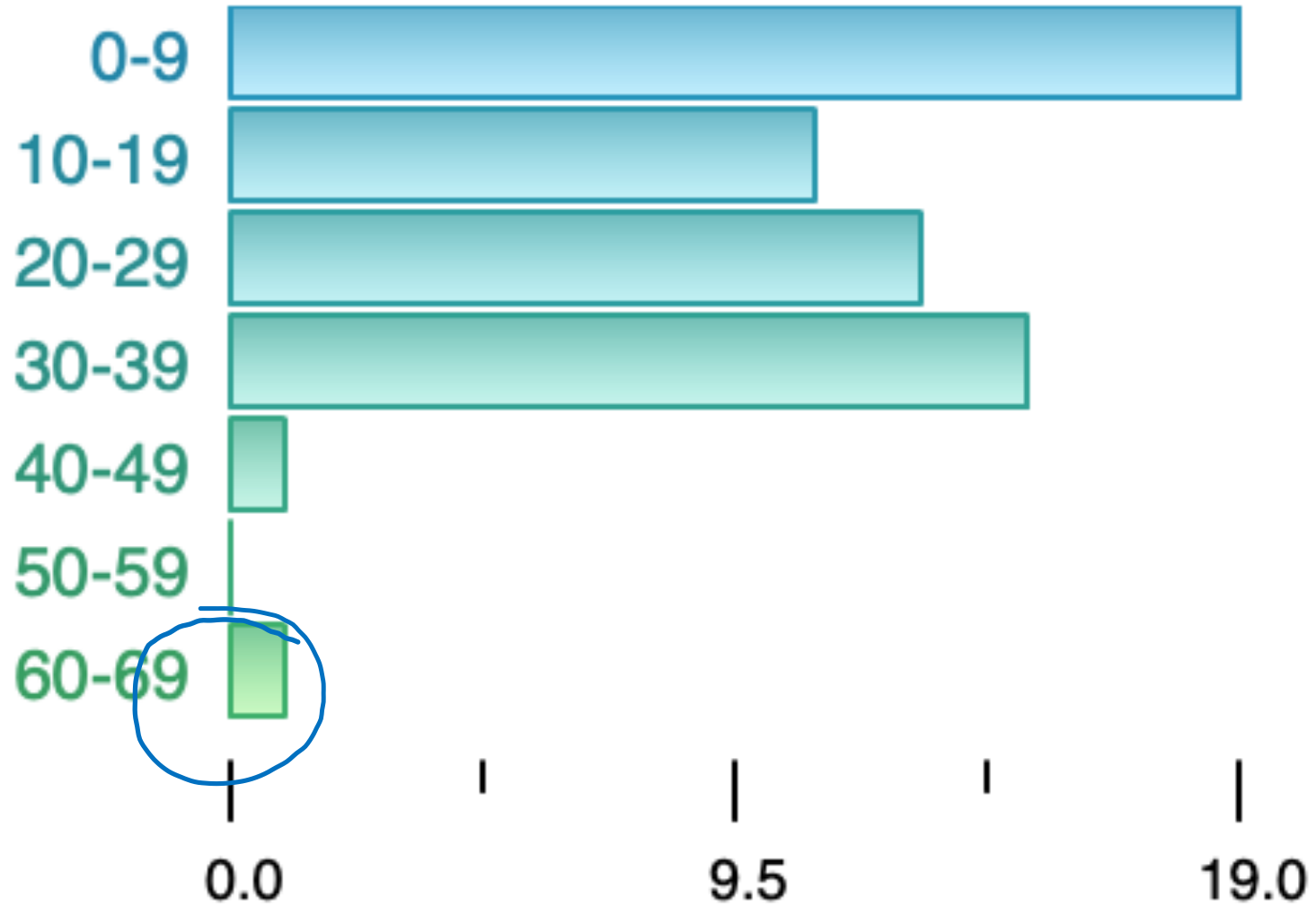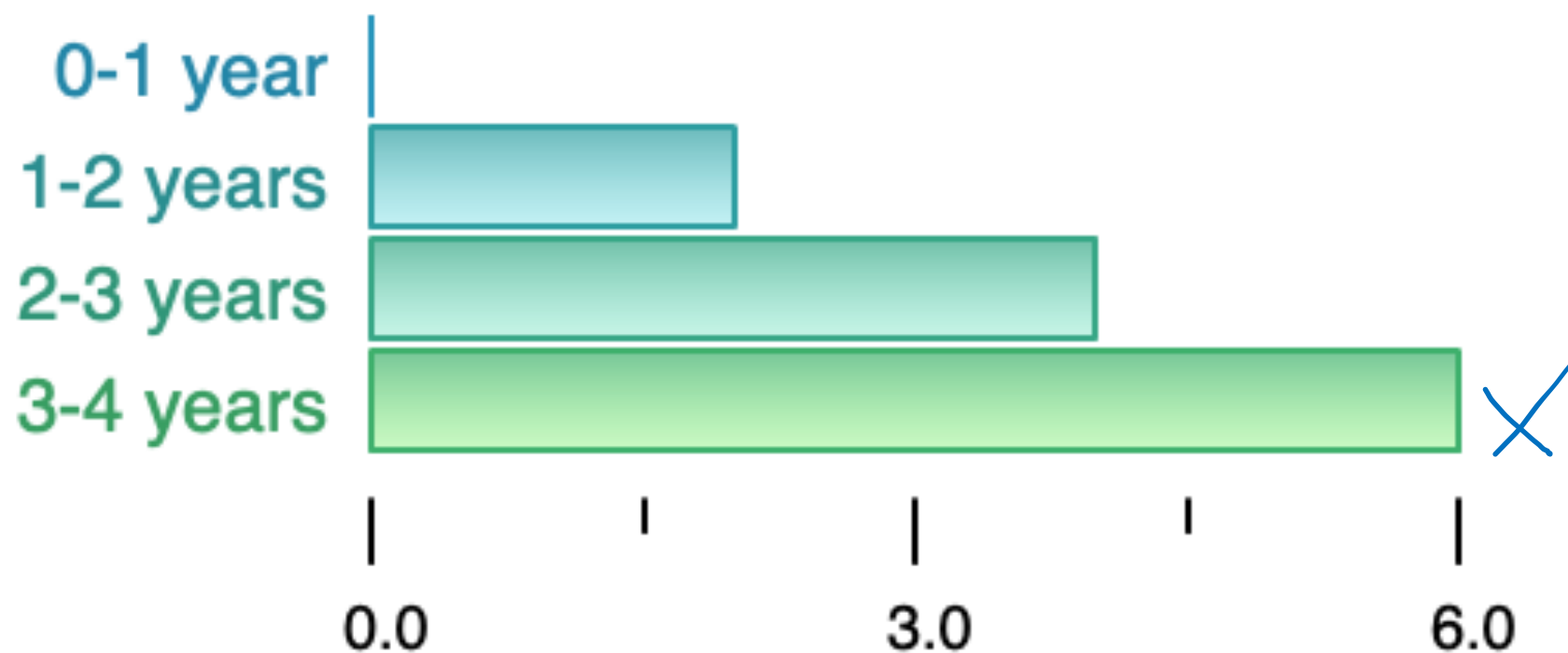
Set: Default, Field: ME

Gender

Female

Male
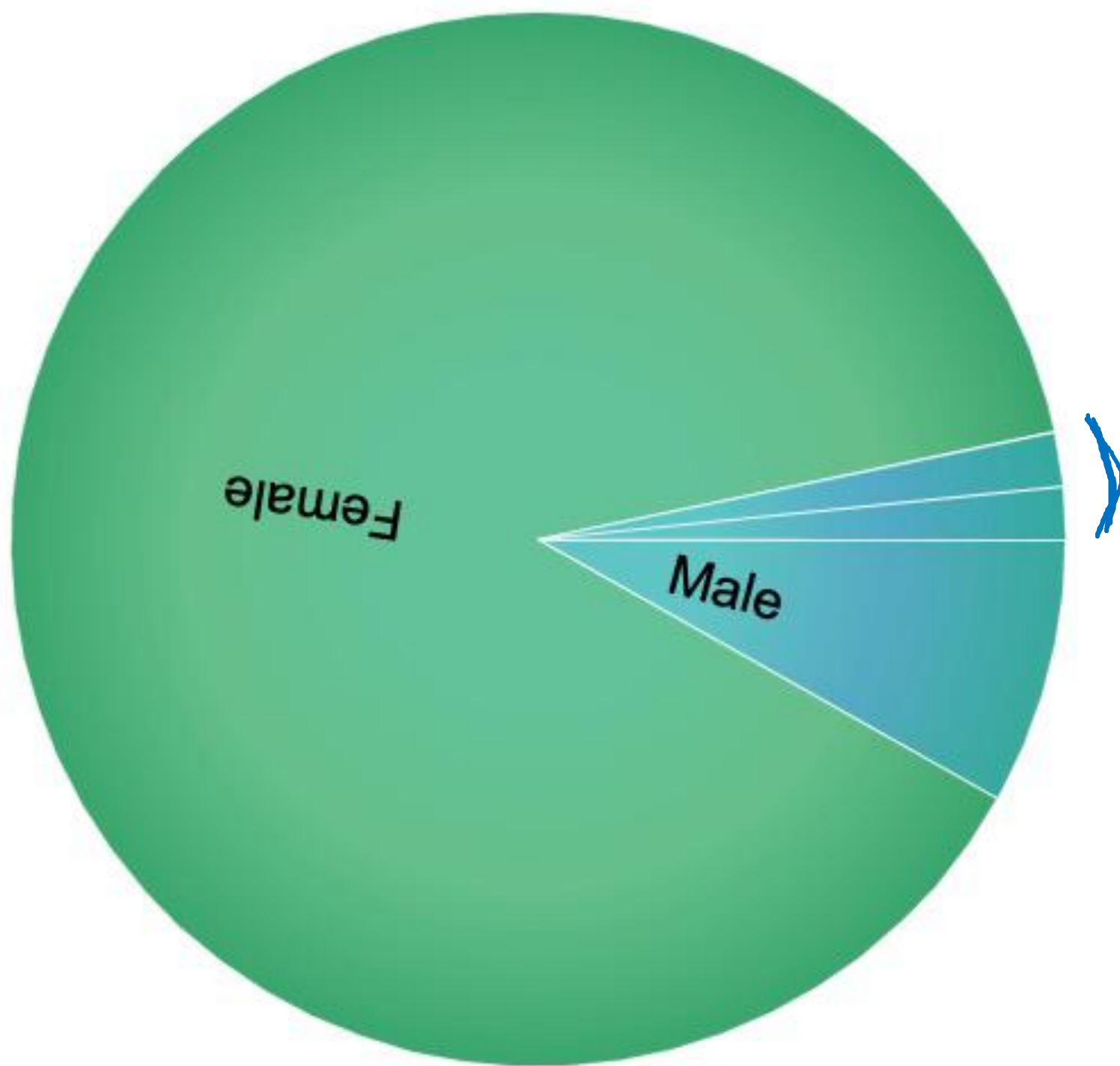
Invisible Illness or Unseen Condition

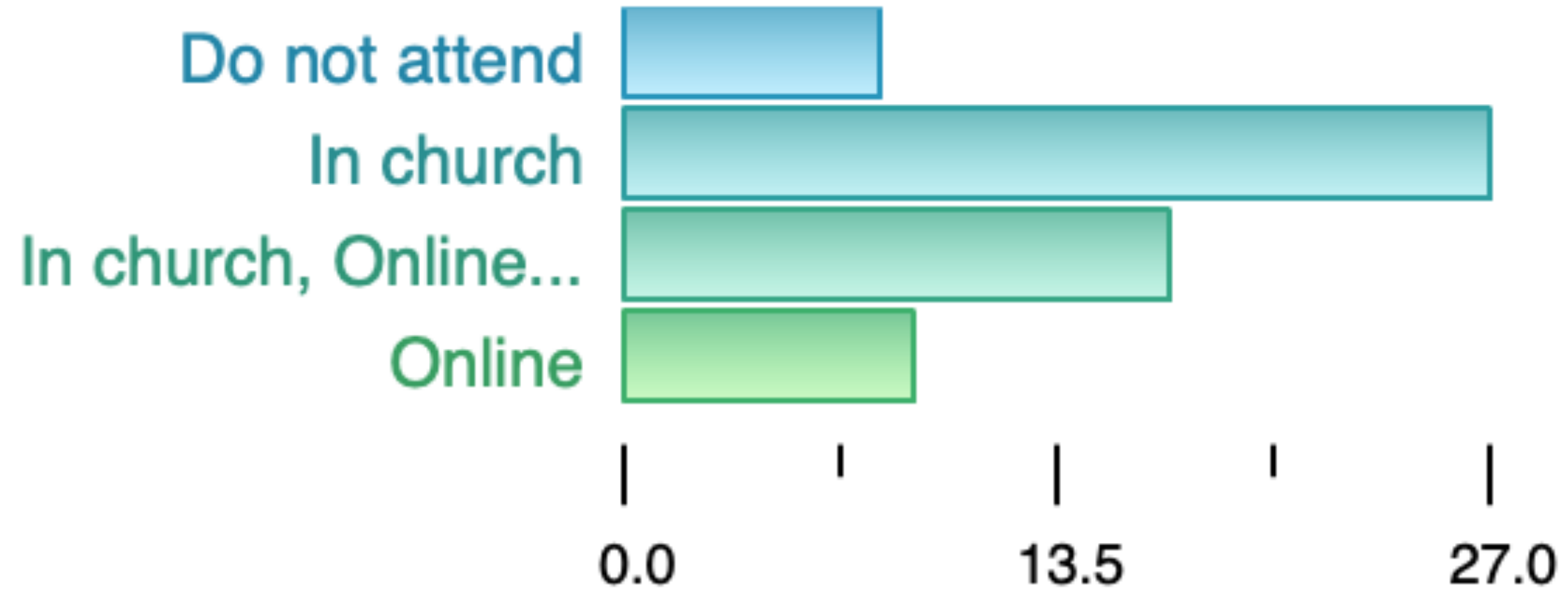# Length of Illness

Length of illness for those with Long COVID

On a scale of 1-5, how included do you feel in your church community, where 1 is 'not at all' and 5 is 'I am included wholeheartedly by everyone in my church community, despite my invisible illness'
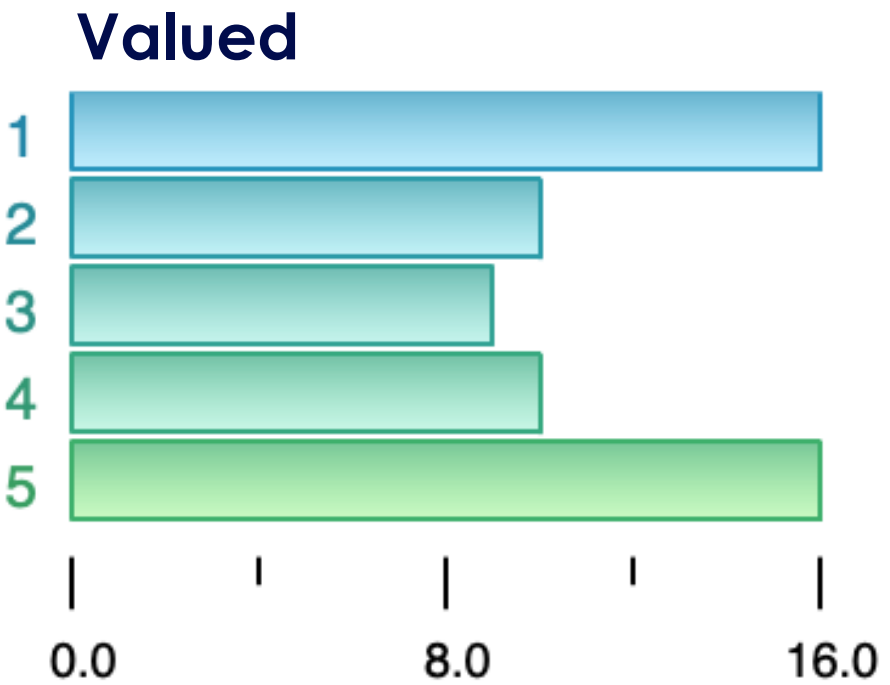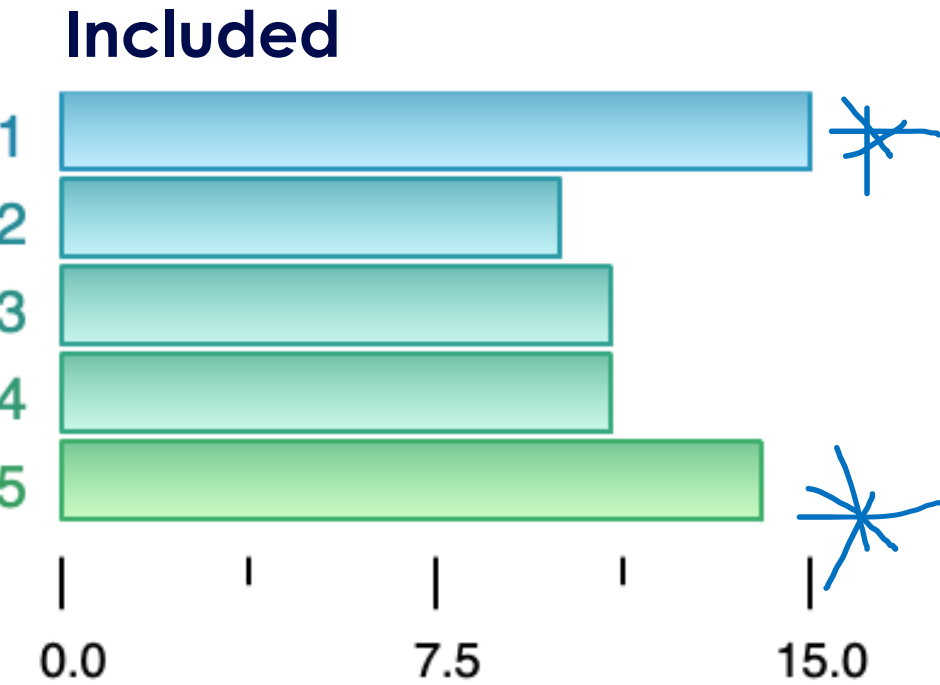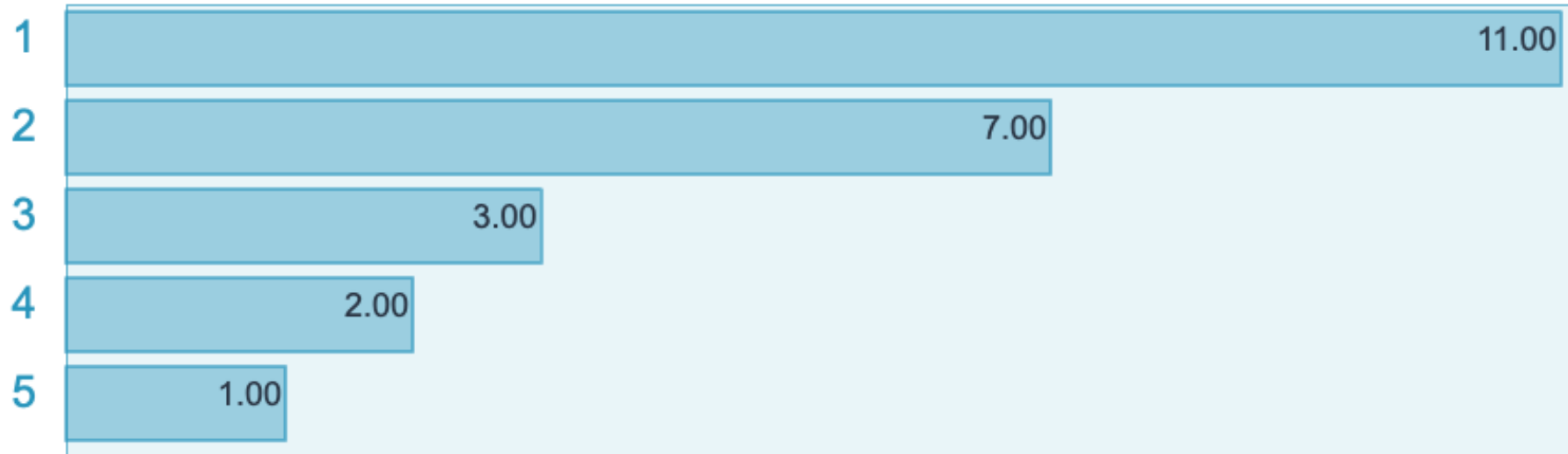
	1	2	3	4	5	
Not at all	○	○	○	○	○	I am included wholeheartedly

Included

Valued

Included?

Can't attend in person church

ME

Score	Value
1	10.00
2	8.00
3	5.00
4	7.00
5	3.00

33.0

Long COVID

Score	Value
1	6.00
2	2.00
3	2.00
4	1.00
5	2.00

13.0

Chemo

Score	Value
5	2.00

2.0
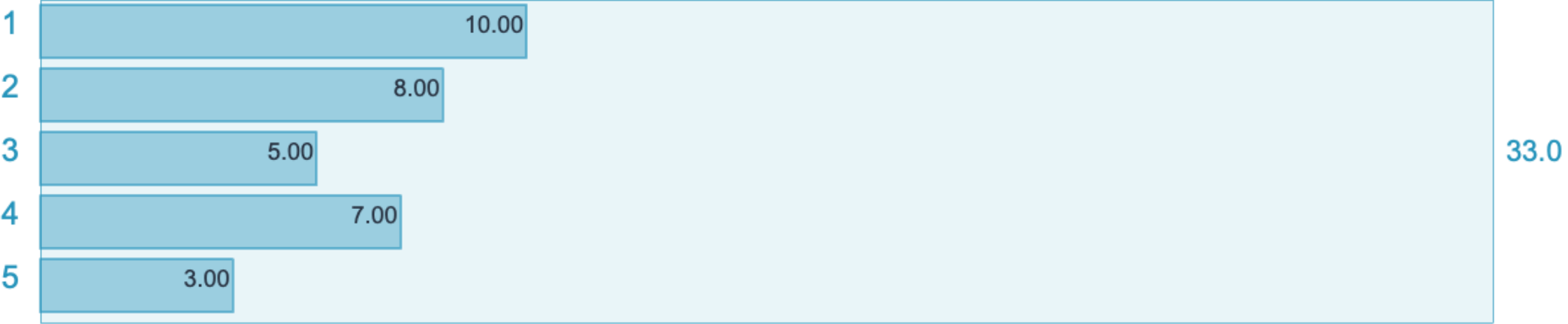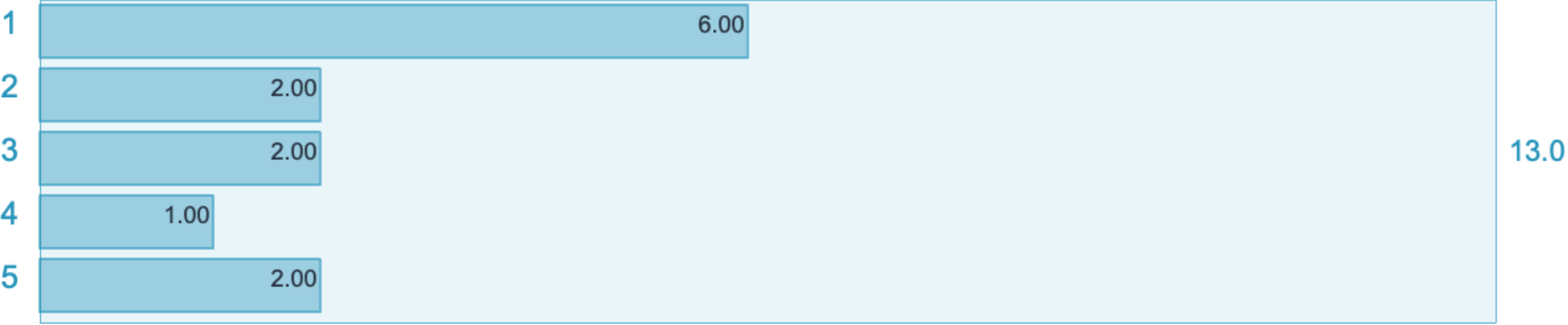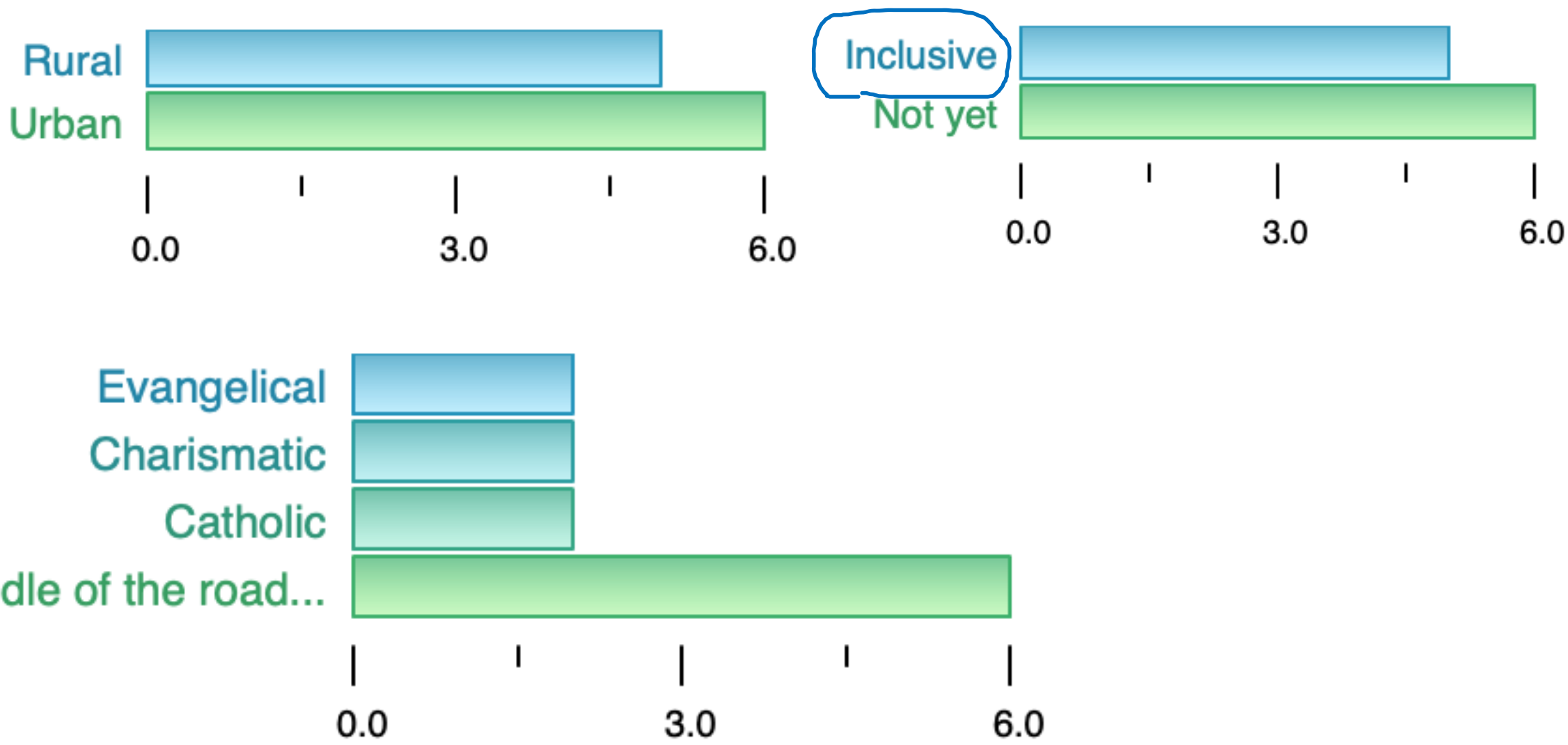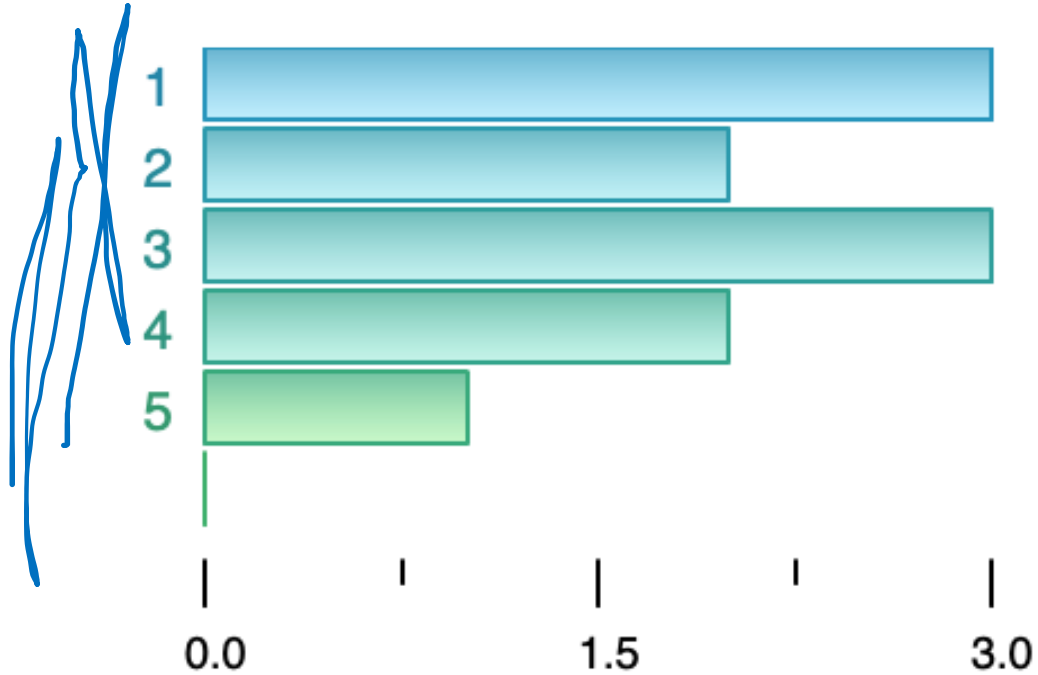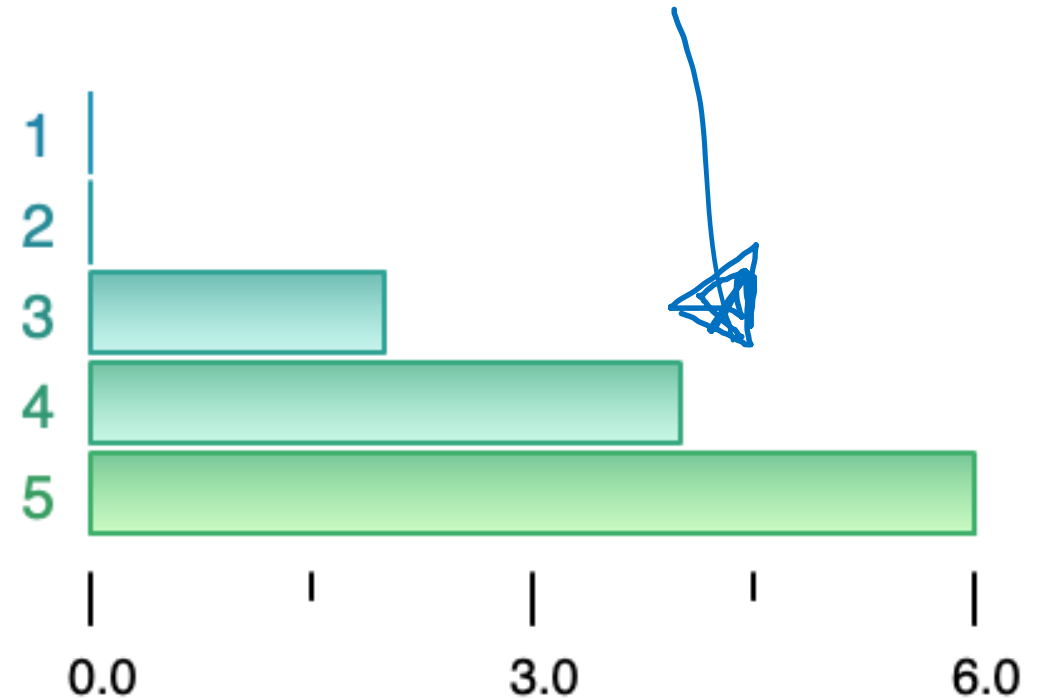
How did interviewees describe their church?

How welcoming is your church?

My experience of welcome as someone with an invisible illness

How my church would rate themselves on their welcome of disabled people

Gathering Participants

John Beauchamp

Diocesan Disability Ministry Enabler

ME Association ✓

9 January · 🌐

Ethics of Inclusion Study - We have been asked to share this link with our followers and we would be very happy to help any religious group with a similar type of survey.

"The study seeks to explore whether people of working age with invisible illnesses are included in their church communities in the Church of England.

"I'm focusing on people with chronic conditions that are not immediately obvious, including ME, Long Covid or people immunocompromised due to chemotherapy. Their church communities might include in-person, hybrid and/or online churches.

"I wonder how much do these people feel they really matter and belong?"

https://www.ethicsofinclusion.study/

#pwME #MECFS #MyalgicE #MyalgicEncephalomyelits #LongCovid #PostCovid #CofE #ChurchofEngland

ETHICSOFINCLUSION.STUDY
Ethics of Inclusion
The study seeks to explore whether people of working age with invisible disabilities are included in their church communities in the Church of England.

Penny A Pullan Yes thanks it was very ME friendly and I've completed it. I have also put myself down for a video interview if required. Coming from a non-inclusive to an inclusive church has been a very interesting journey, the change is remarkable, from individual attitudes to systemic ones.

action for m·e

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Our community

Membership

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A A A | Text size

Our projects and PhDs

DecodeME

Priority Setting Partnership

UK ME Research Collaborative

Advice for M.E. Researchers

Get involved in research

The Ethics of Inclusion: exploring whether people of working age with invisible illnesses and chronic conditions feel they belong in their church communities

Research question and details: How are people of working age with invisible illnesses and chronic conditions (particularly those with ME, Long COVID or the immunocompromised (due to chemotherapy treatment) included in their C of E church communities, whether in-person, hybrid and/or online, and how much do they feel they really matter and belong?

What's involved: To take part, people need to answer a questionnaire online, which has been described by participants as "short" and "very ME friendly". Please visit: **www.ethicsofinclusion.study**

If participants wish to take part further, they can put themselves forward to be one of the ten people interviewed over Zoom to gather deeper insights. This second step is purely voluntary.

Participant eligibility criteria: Participants must be of working age (defined as 18 - 65 inclusive for this study), members of a Church of England church (to some extent) and living with an invisible illness or chronic condition, such as ME or Long COVID.

Ethical approval: This project has received ethics approval from Yorkshire Theological Education Partnership (YTEP) and St Hild College, as part of my Durham University MA research.

Contact details: To take part in the survey, please visit: **www.ethicsofinclusion.study**

The researcher's email is **penny@pennypullan.com**

Deadline for taking part: The survey will close in March 2024.