

Is Albinism a Pain in the Neck? The Pain in Albinism Pilot Study

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Sydney AUSTRALIA**

2EDA Valencia

April 5-6 2014

**Images thanks to Positive Exposure and the amazing
Rick Guidotti, Australia 2010**



Today's talk

- **A bit about me**
- **Headache / neck pain in people with low vision**
- **The Pain in Albinism Study**
- **Rehabilitative approaches for pain in albinism**

Sydney, Australia



Me and my sister



Dr Shari



University of NSW





Australasian Faculty of Rehabilitation Medicine





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ALBINISM
FELLOWSHIP
OF
AUSTRALIA



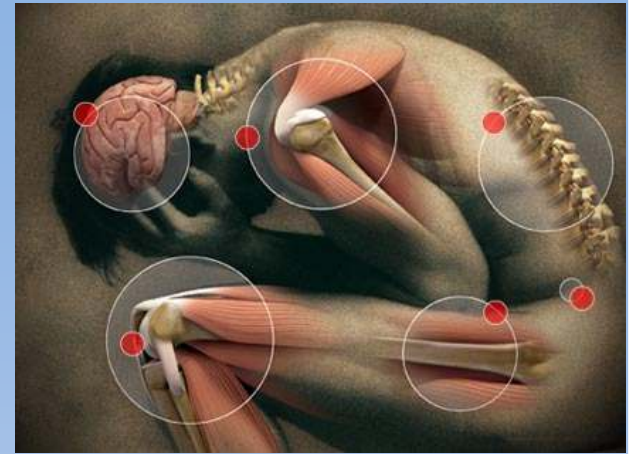
16 to 18 October 2015
New Zealand
Massey University



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Background – The nature of the Problem



- Anecdotally, neck pain and headache common in PWA
- Research on pain in low vision?
- Research on pain in albinism?

Significance of the problem

Associations with chronic pain

- **Poor Quality of life**
- **Psychological wellbeing**
- **Insomnia**
- **Functional, Social, Employment issues**
- **Mortality**
- **Cost – healthcare, society**



Aims of Pain in Albinism Pilot Study

- 1. How common is pain in people with albinism (PWA)?**
- 2. What impact does pain have?**
 - a) Severity**
 - b) Quality of life**
 - c) Health use**
 - d) Work / absenteeism**

Aims Continued

- 3. How do people with albinism manage their pain?**
- 4. What factors are associated with pain in PWA?**
 - Photophobia**
 - Lighting**
 - Using vision aids**
 - Daily activities eg sleep, exercise**



Method

- **Voluntary completion of paper questionnaire**
- **People attending albinism conferences in Australia, USA, Malaysia**
- **Being converted to electronic version**
- **Ethics approval St Vincent's Hospital**



Results



Disclaimer

- **Low numbers**
- **Non random sample**
- **People with pain more likely to respond – greater interest**
- **Difficult to make generalisations**
- **** indicates statistically significant difference**



44 respondents

Gender

■ Male 41% ■ Female 59%

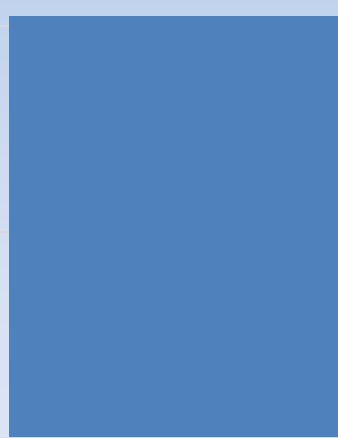
80

60

40

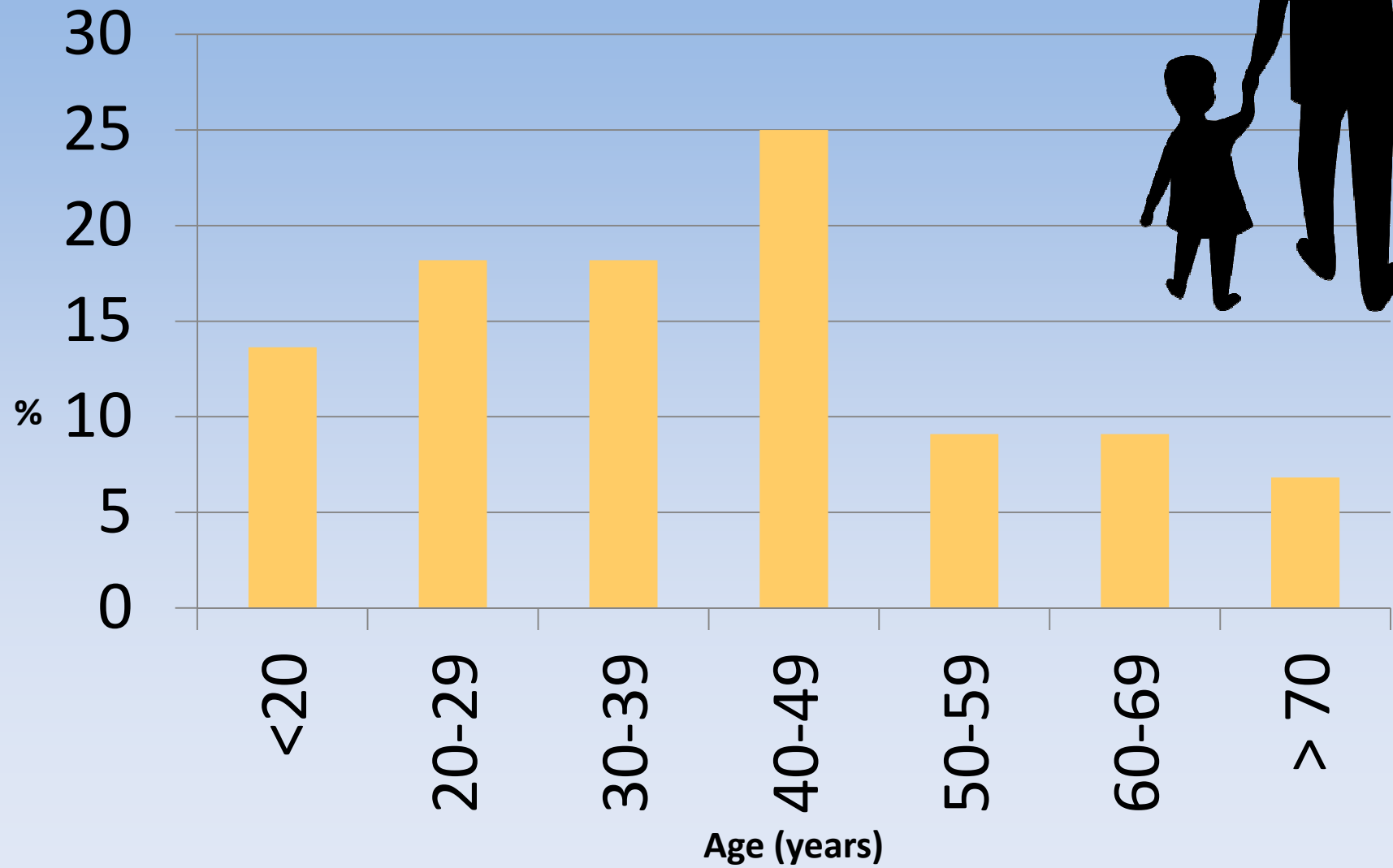
20

0



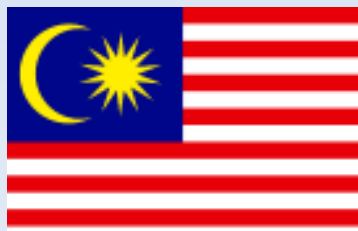
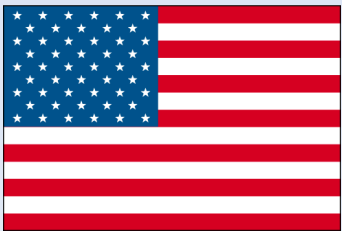
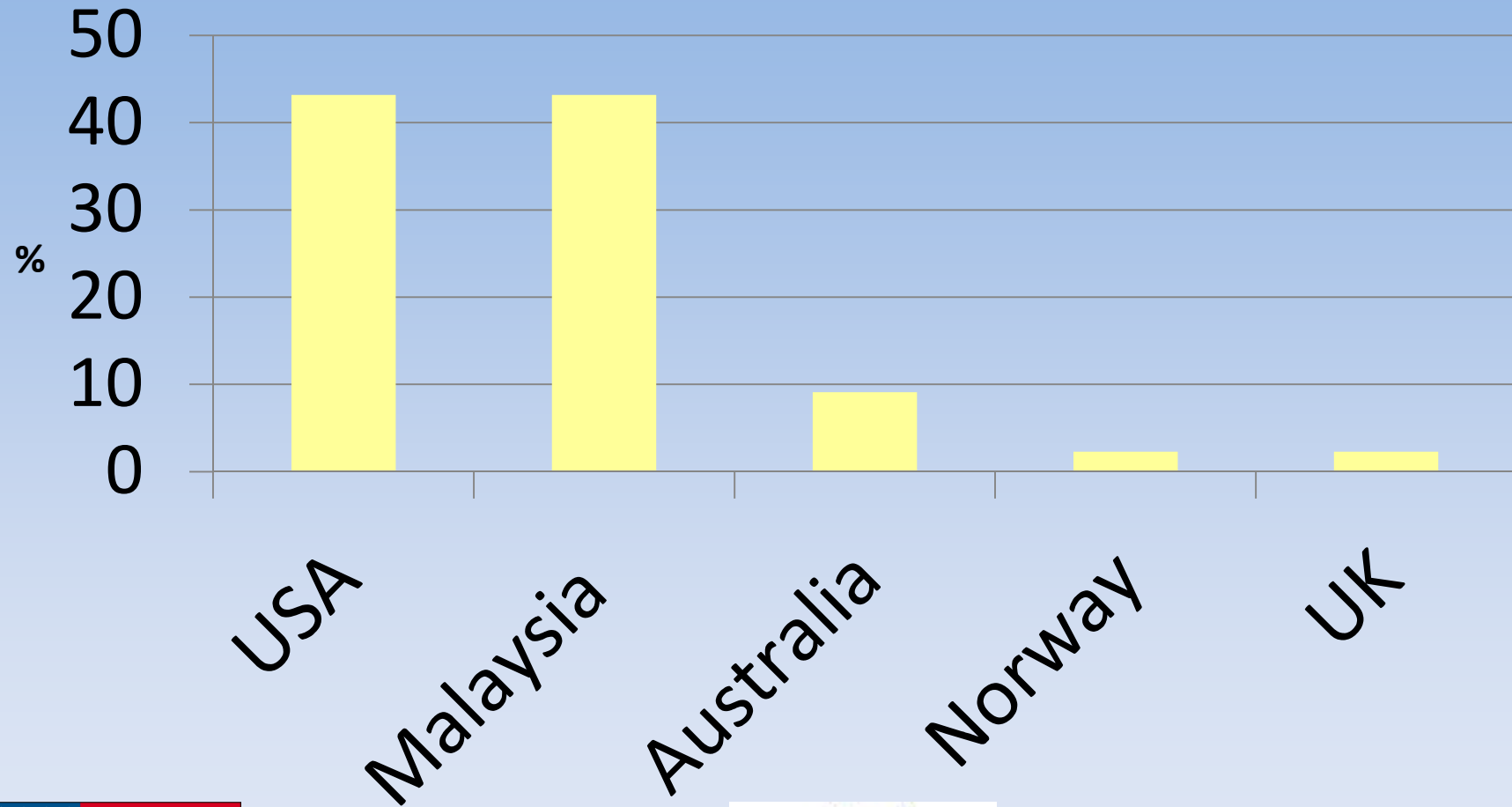
Gender

Age



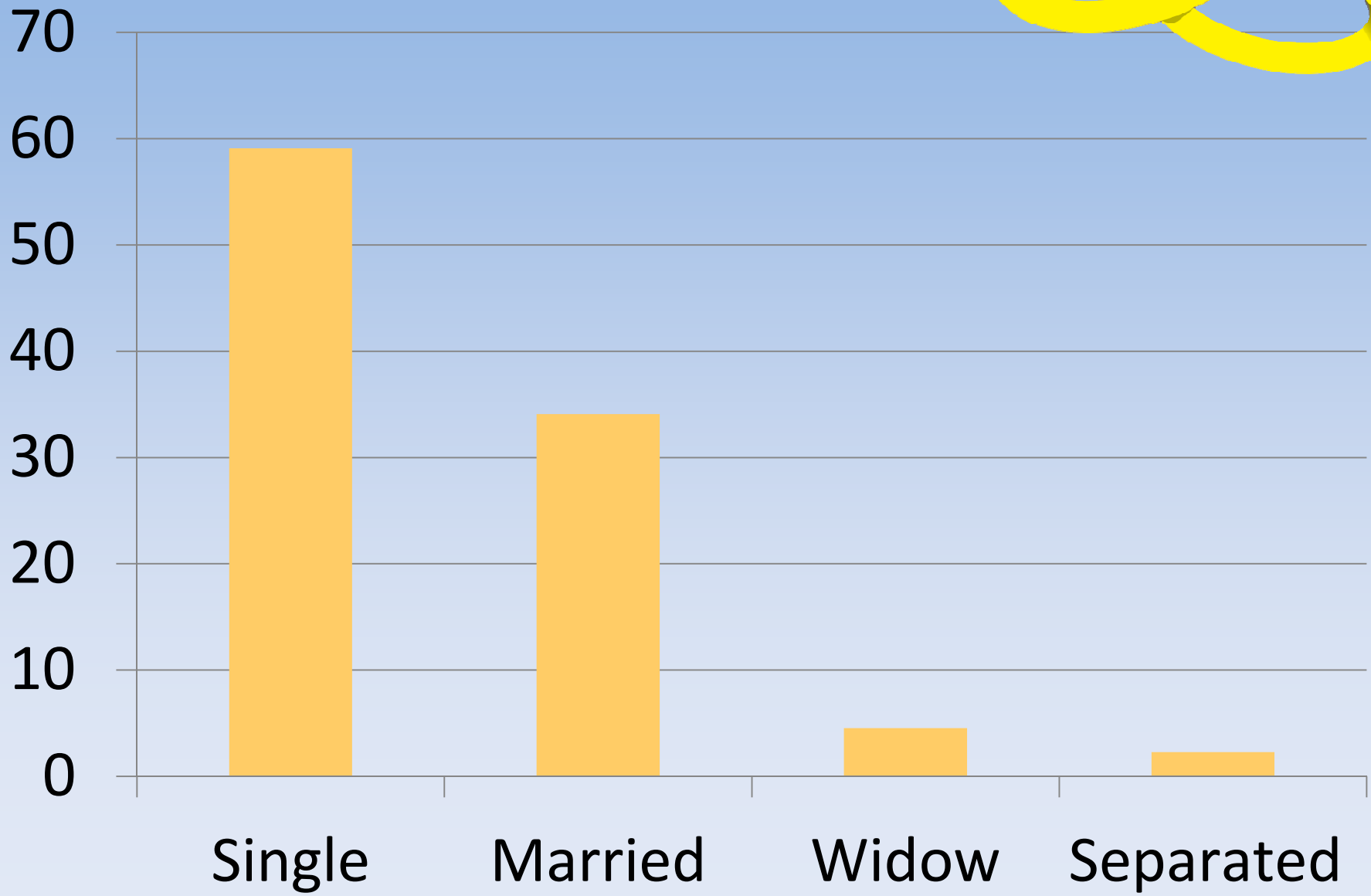
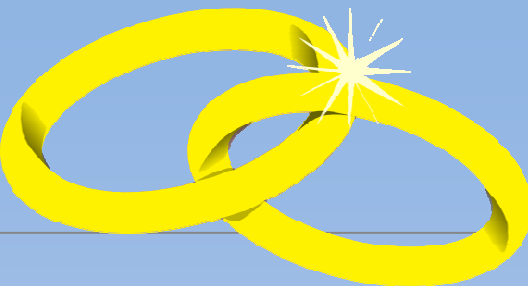


Country of origin

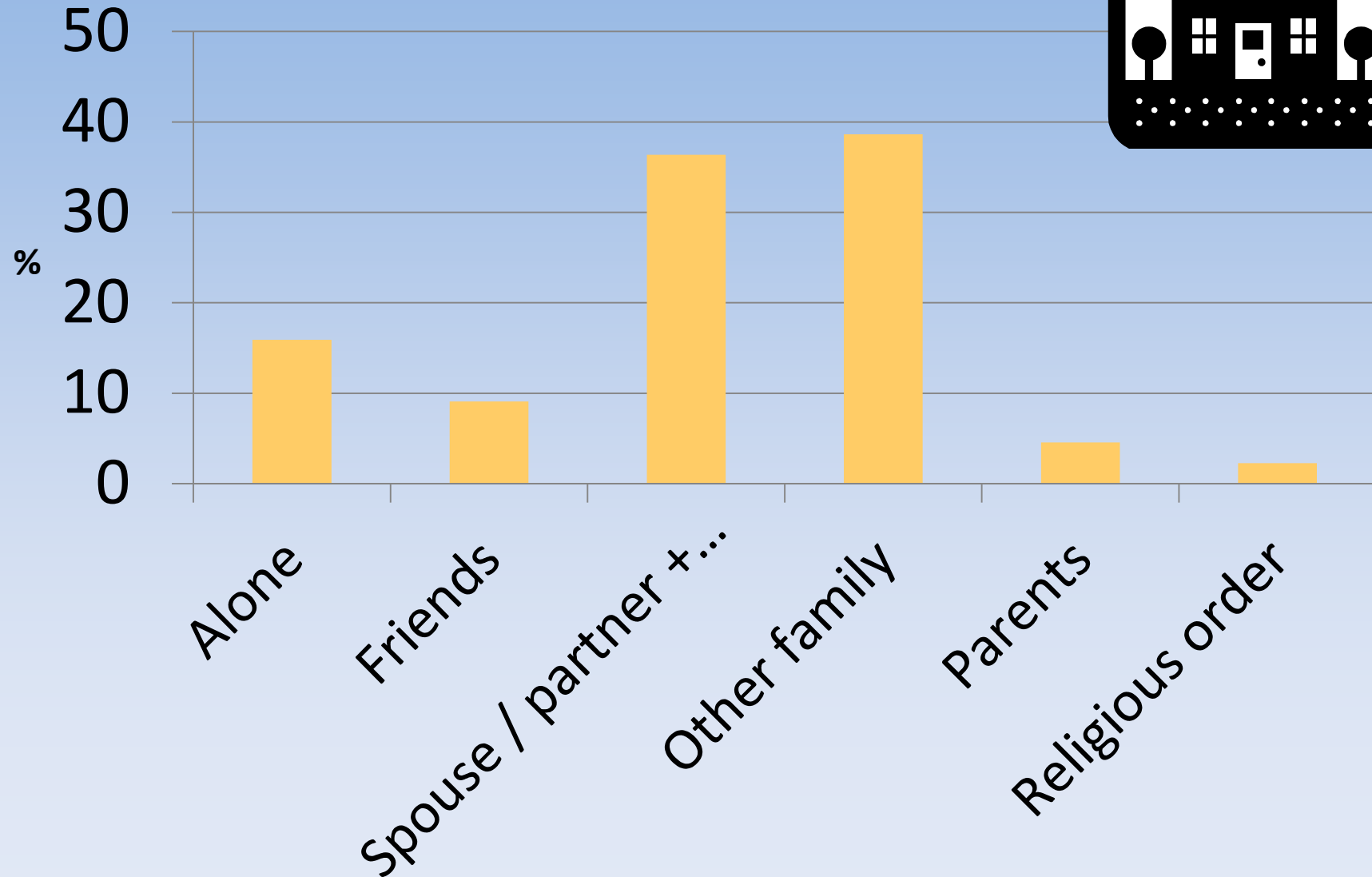




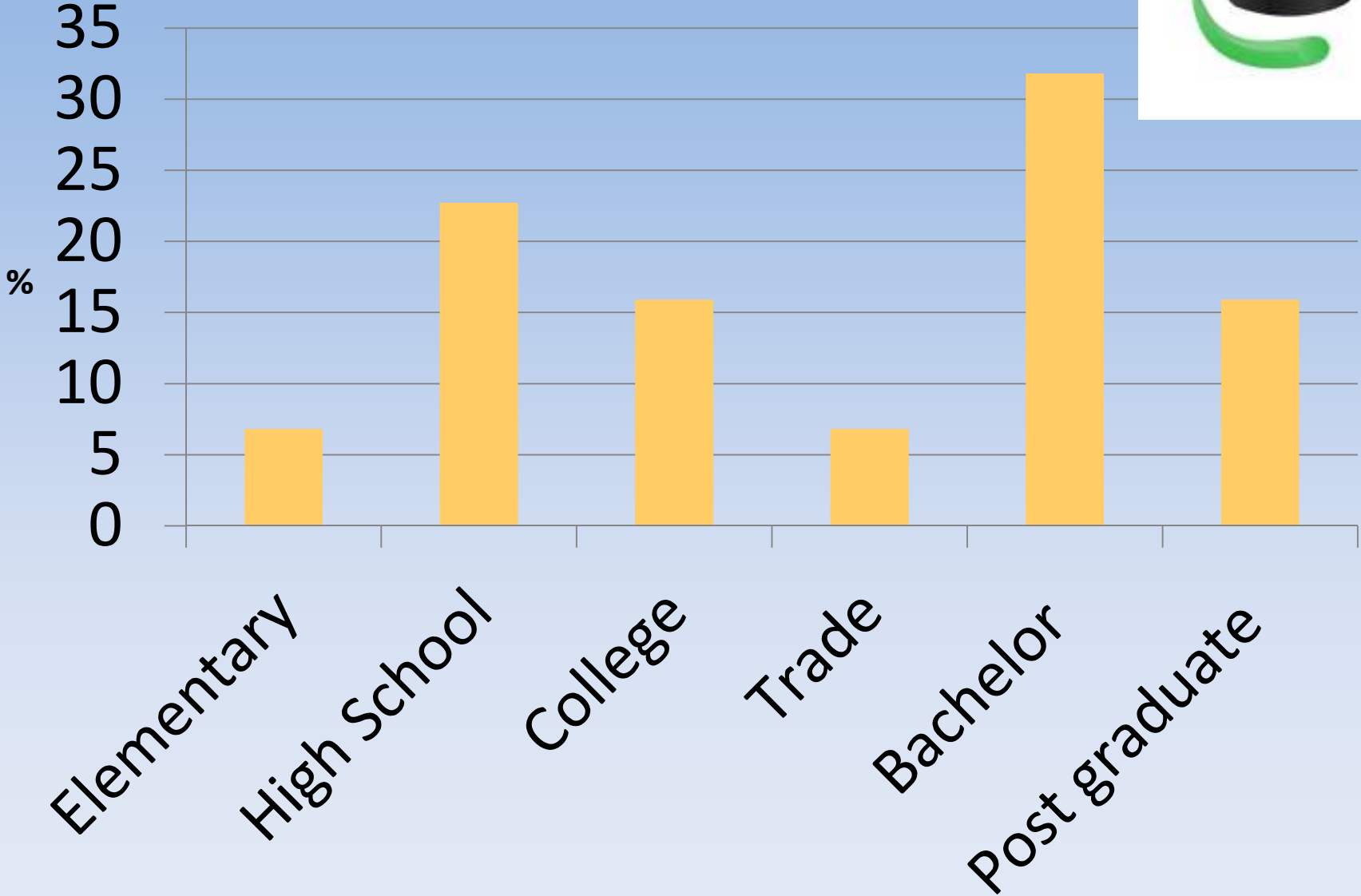
Marital status



Living Arrangements

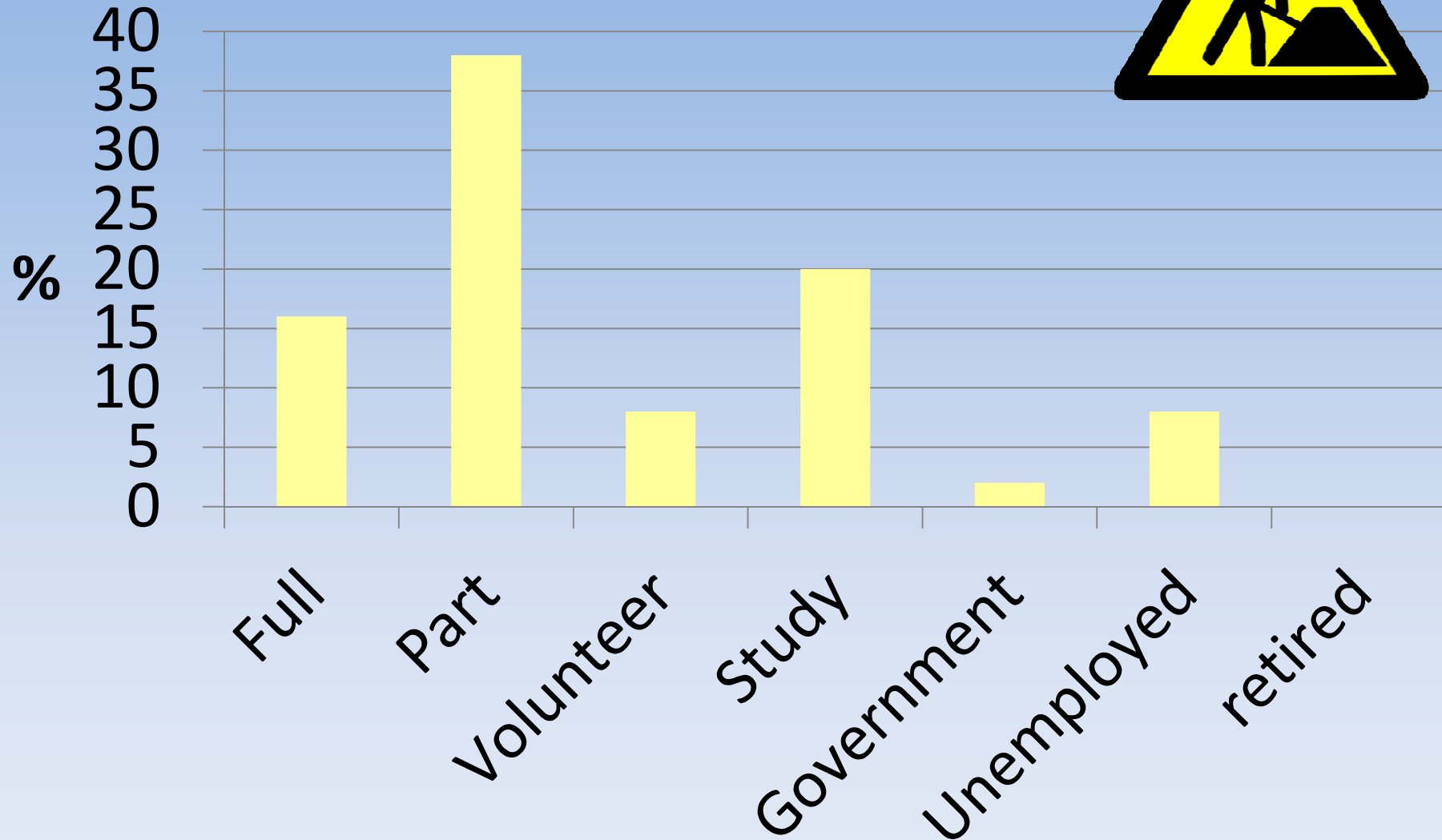


Education Level

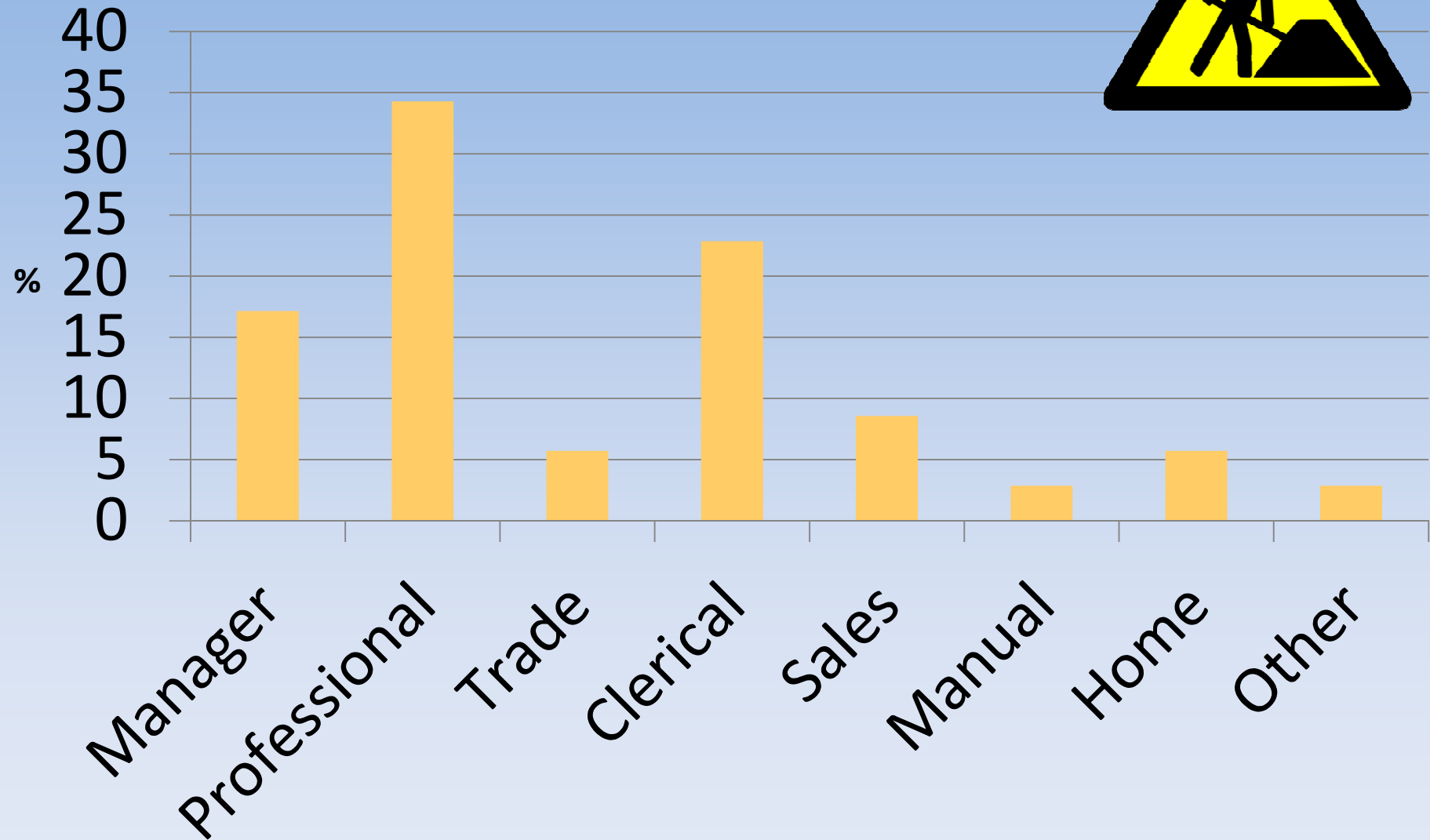




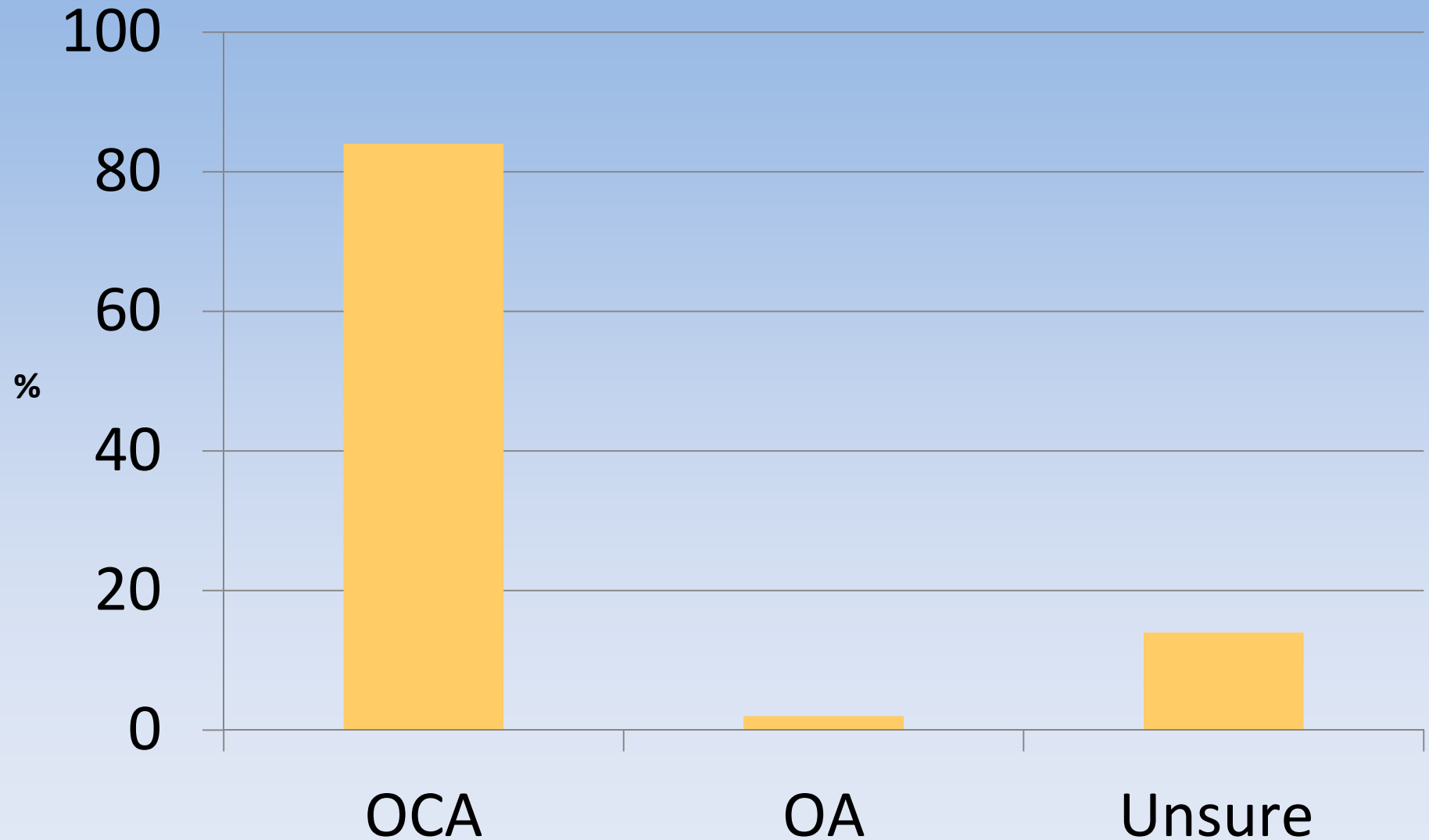
Employment Status



Type of work



Type of Albinism



Pain

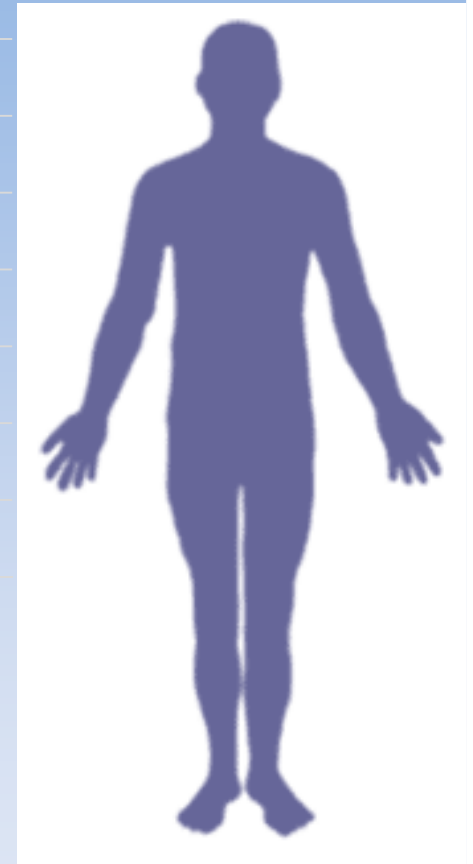
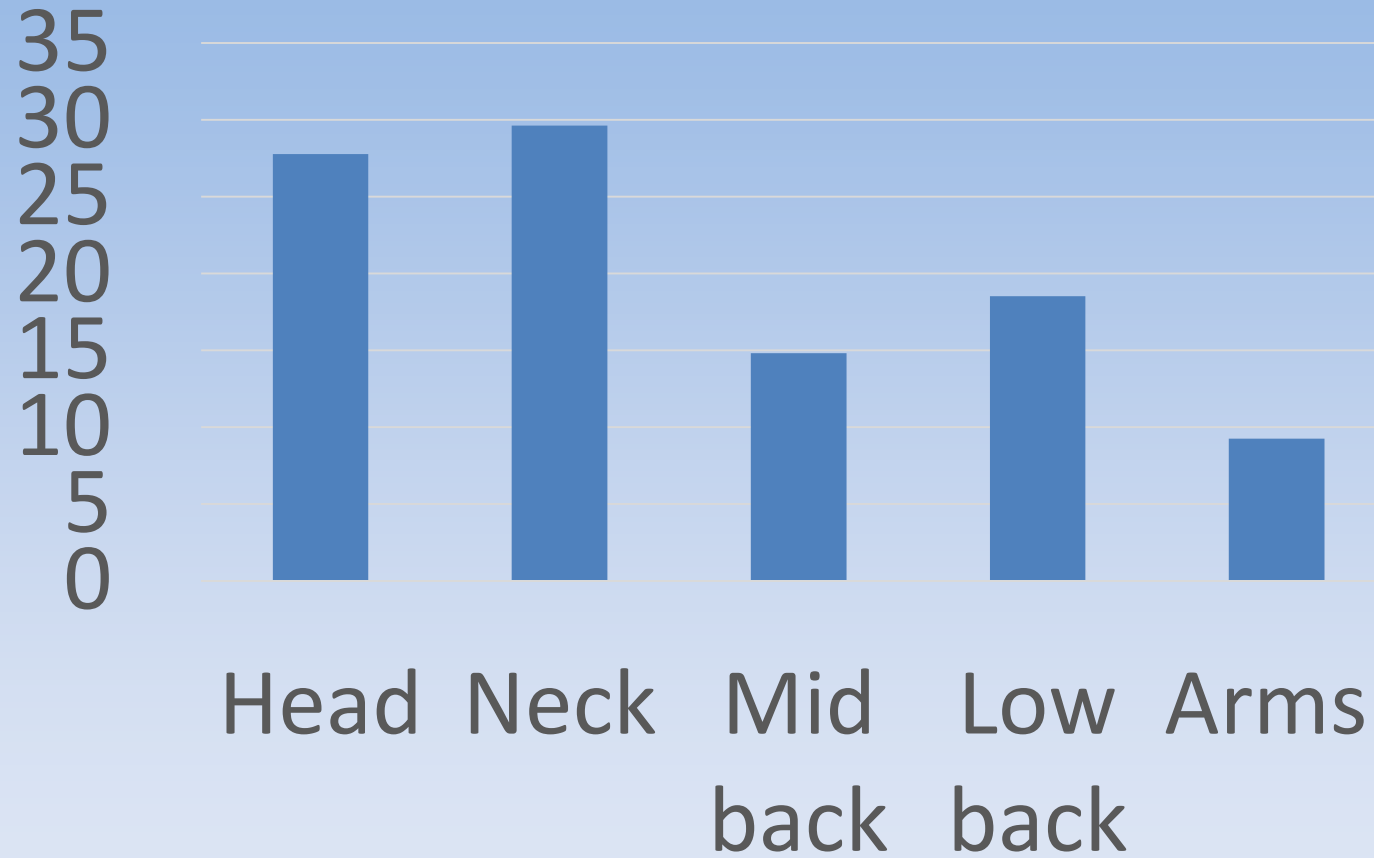


84% reported pain

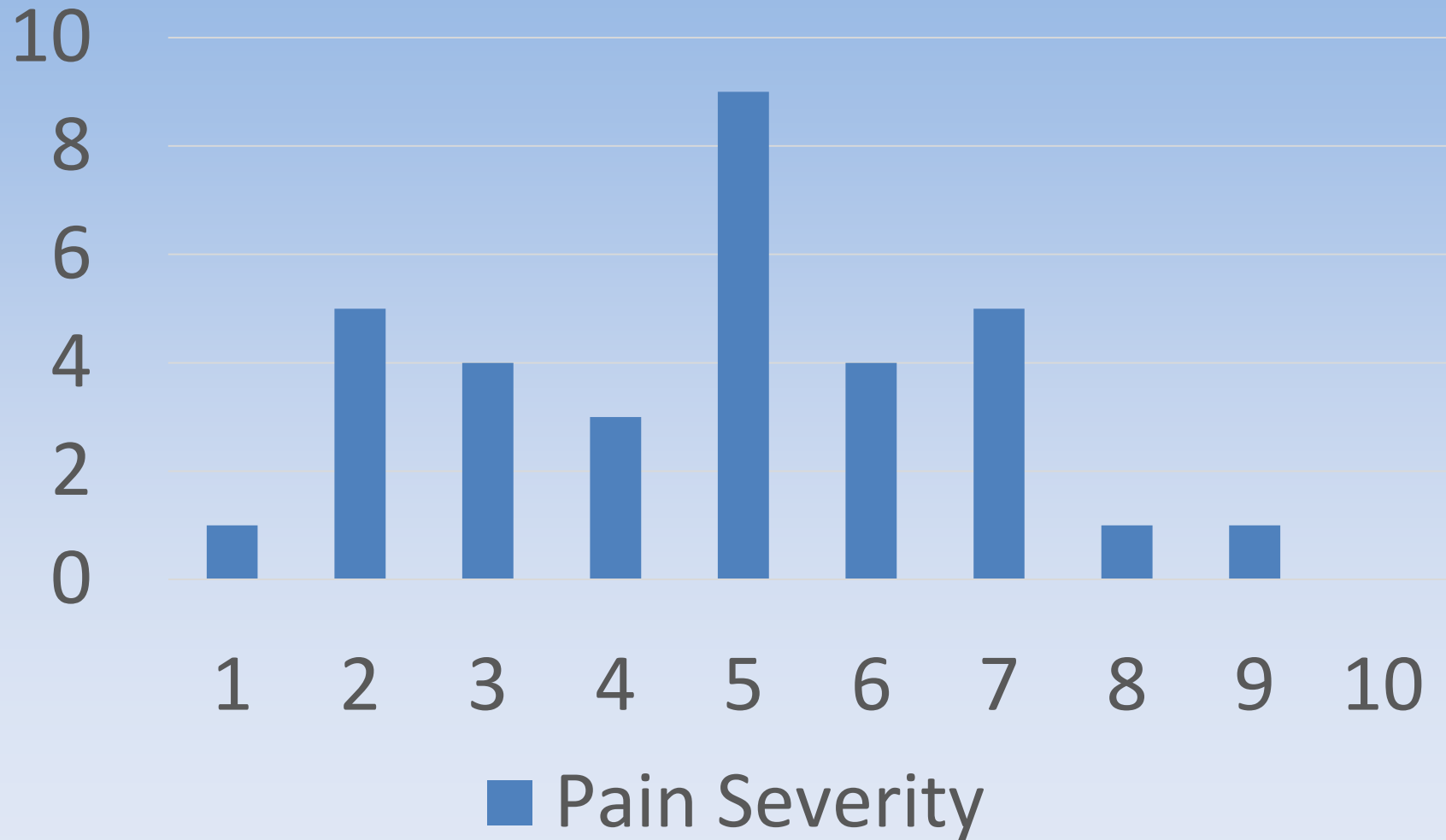
Stated Cause



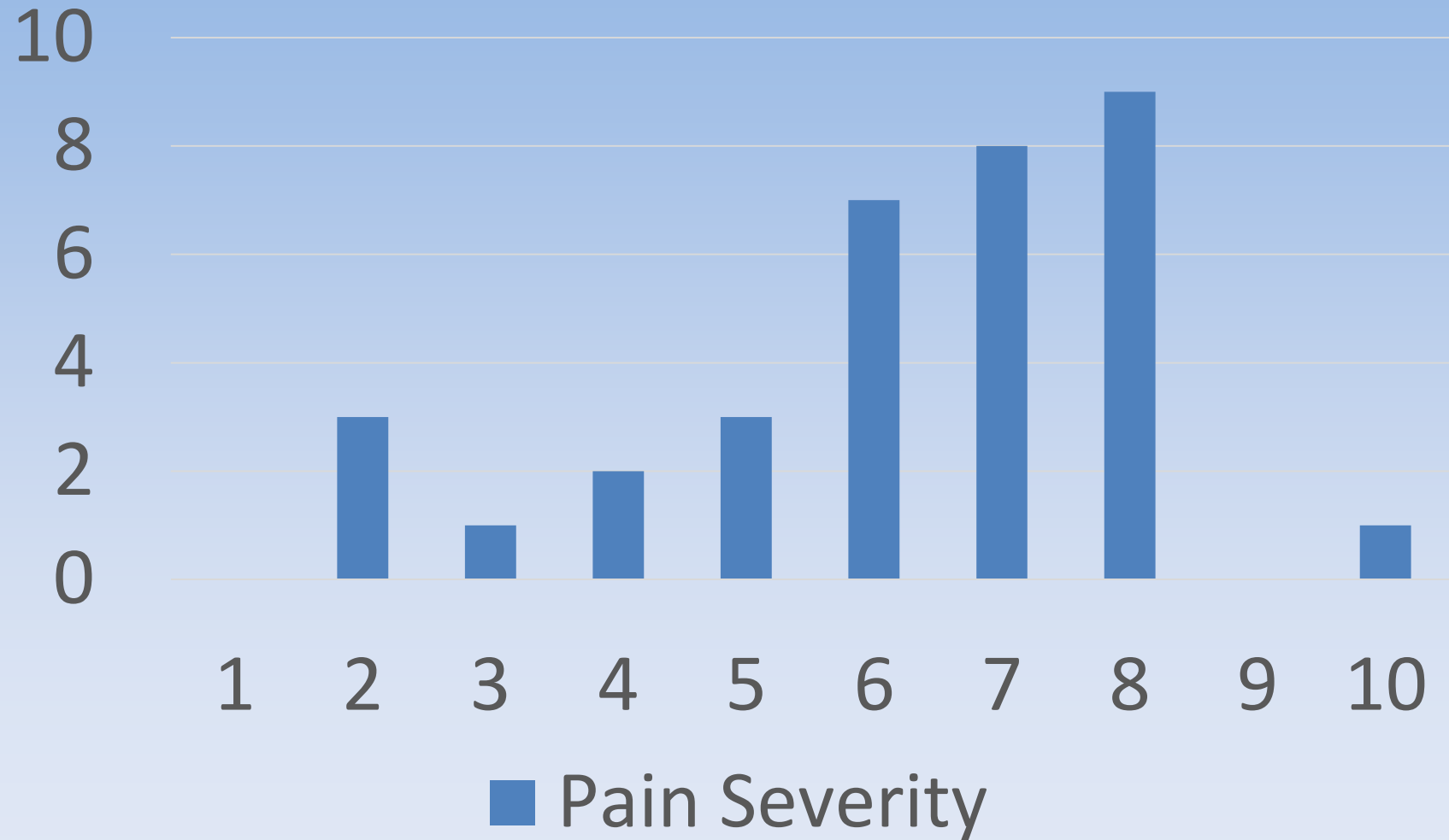
Location



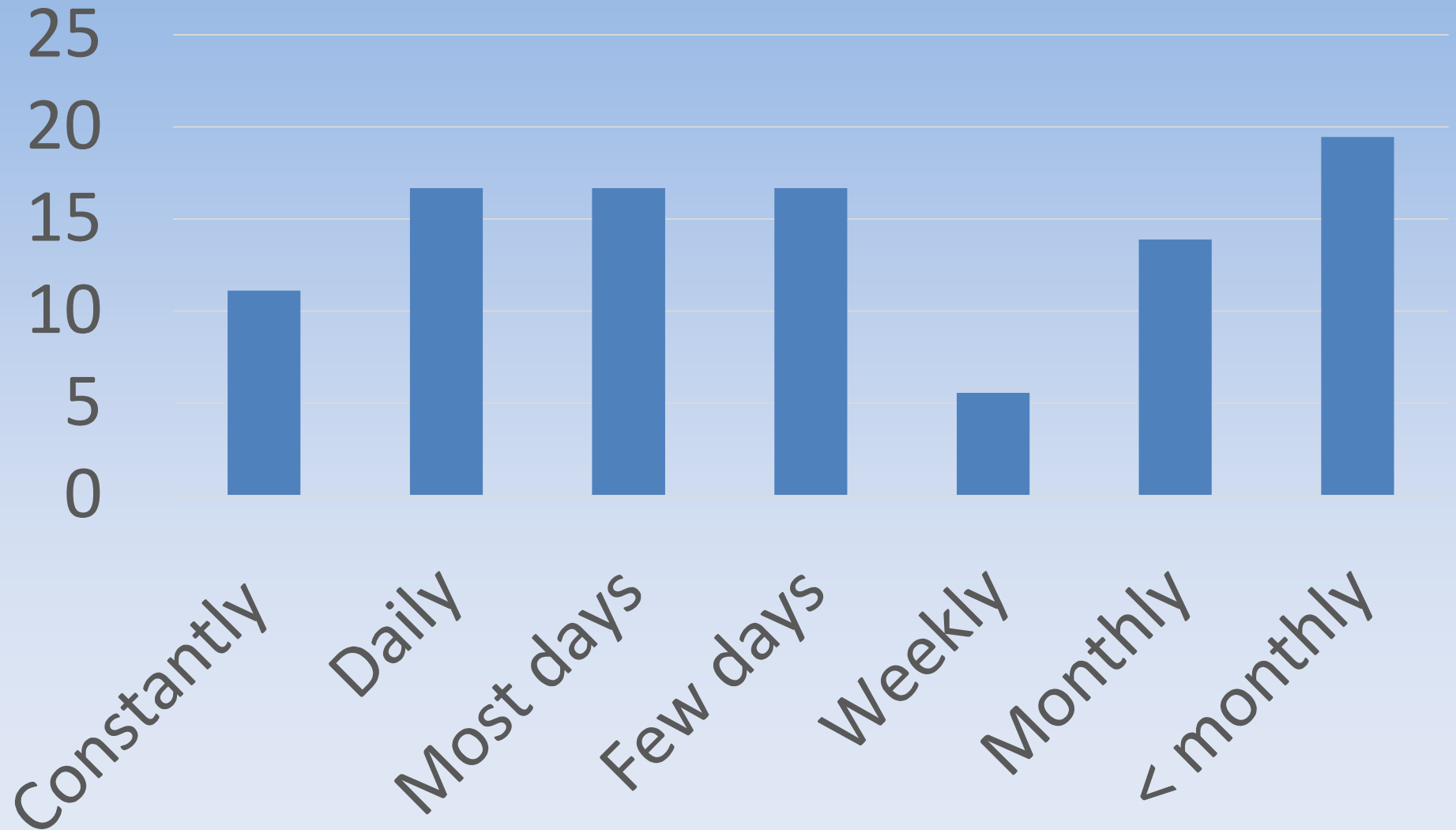
Average pain severity 4.8/10



Worst pain Average 6.2/10



Frequency of episodes

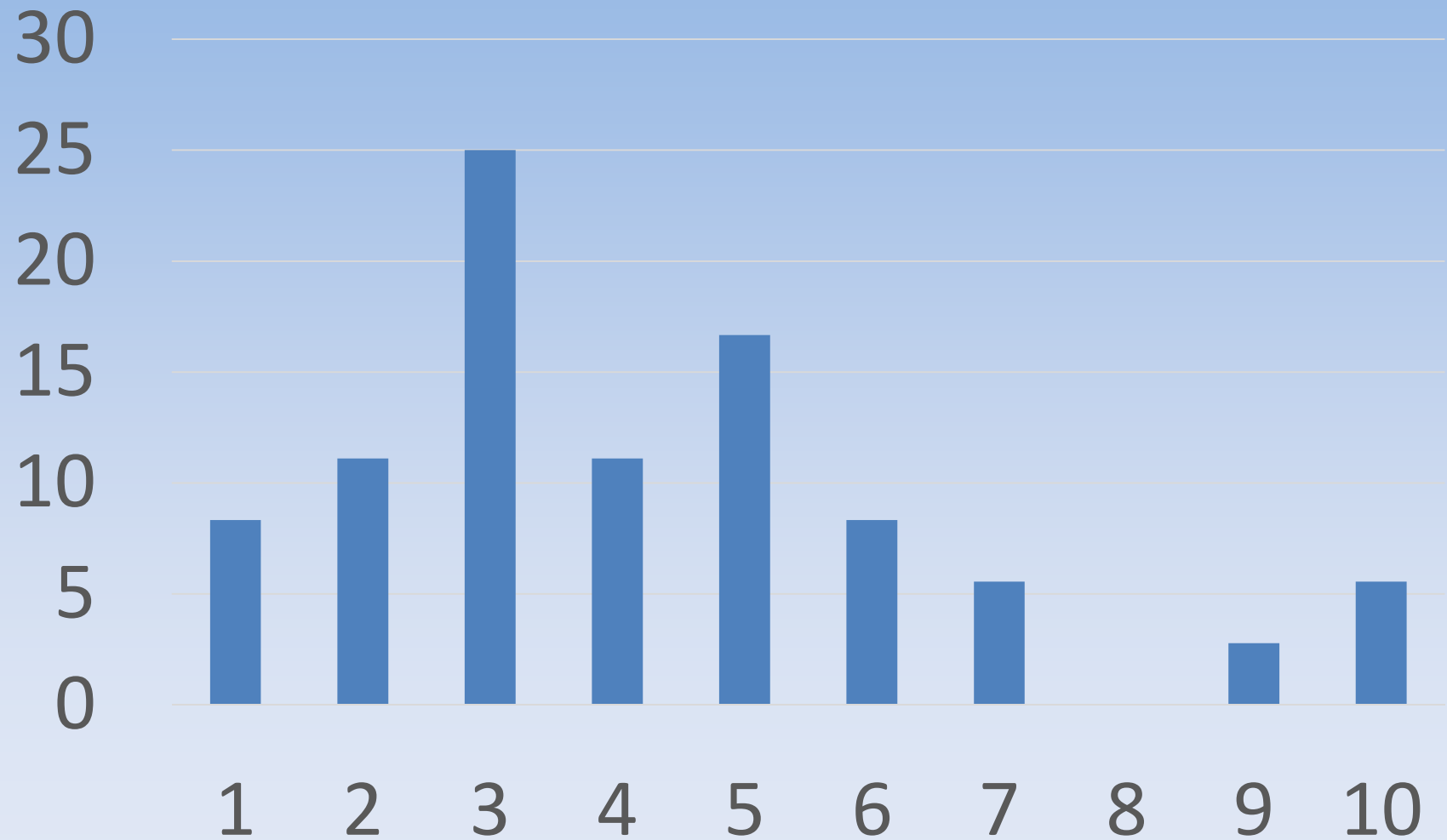


Impact of pain

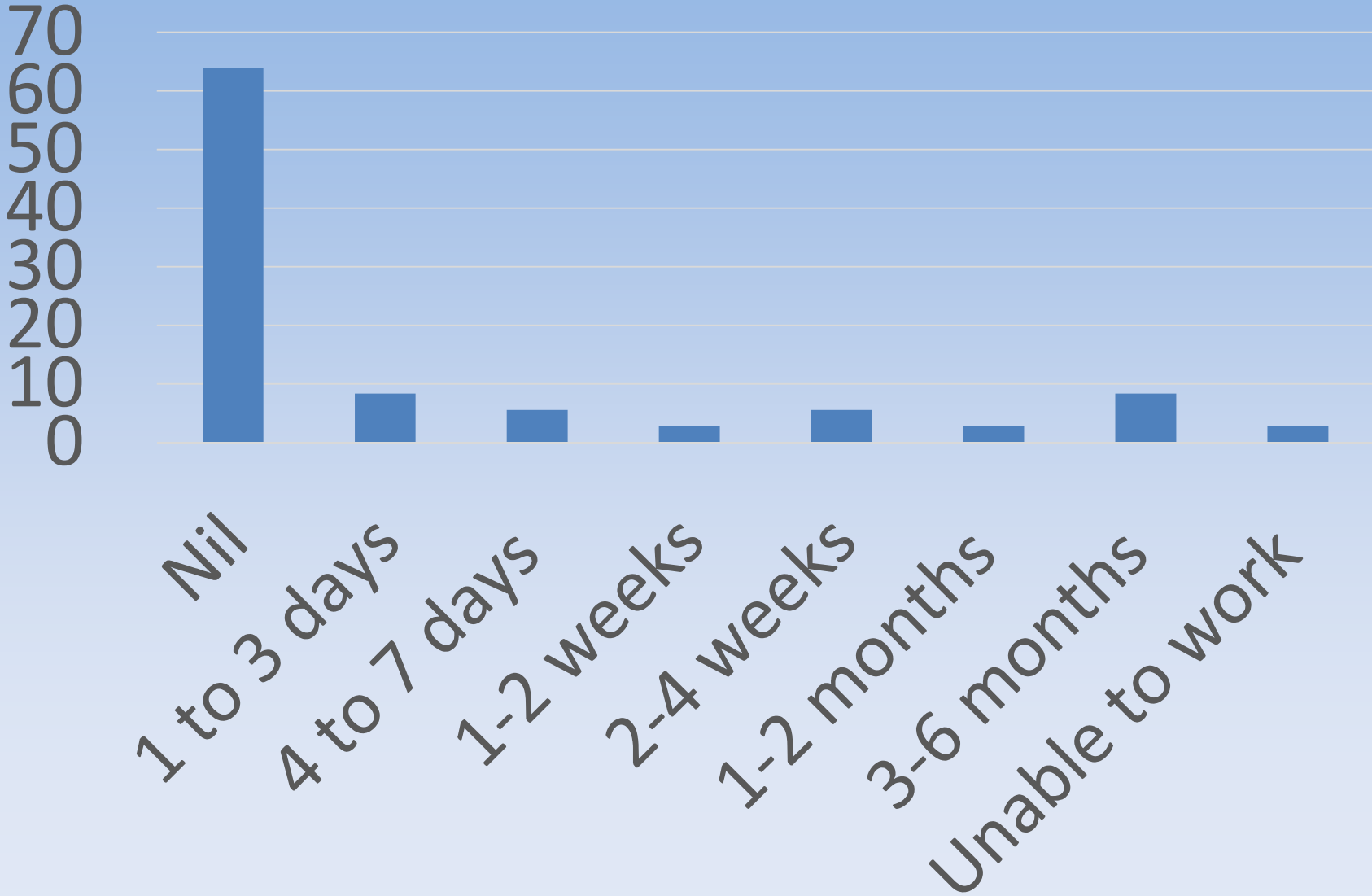


Impact on usual activity

Average 3.6/10



Absenteeism



Health Care Utilisation

	Episodes per year
General Practitioner	0.51
Specialist	0.30
Admission	0.14
Allied Health	1.3
Alternative Practitioner	1.1
Imaging	0.19



Health Related Quality of Life

- **Quality of life related to your health**
- **Individual's perspective**
- **Physical, psychological, social**
- **Generic**
- **Condition specific**

4. Health Related Quality of Life Short Form 8 (SF8)

- **8 questions**
- **8 domains**
- **Grouped into 2**
- **Physical**
- **Emotional**



Health Related Quality of Life SF8

- Two summary scores:
- Physical Summary
- Mental Summary
- 0 to 100
- 50 is population average
- High is good low is bad
- Physical + Mental = HR QOL

General Health Item

- **Overall, how would you rate your health during the past four weeks?**

Excellent

Very Good

Good

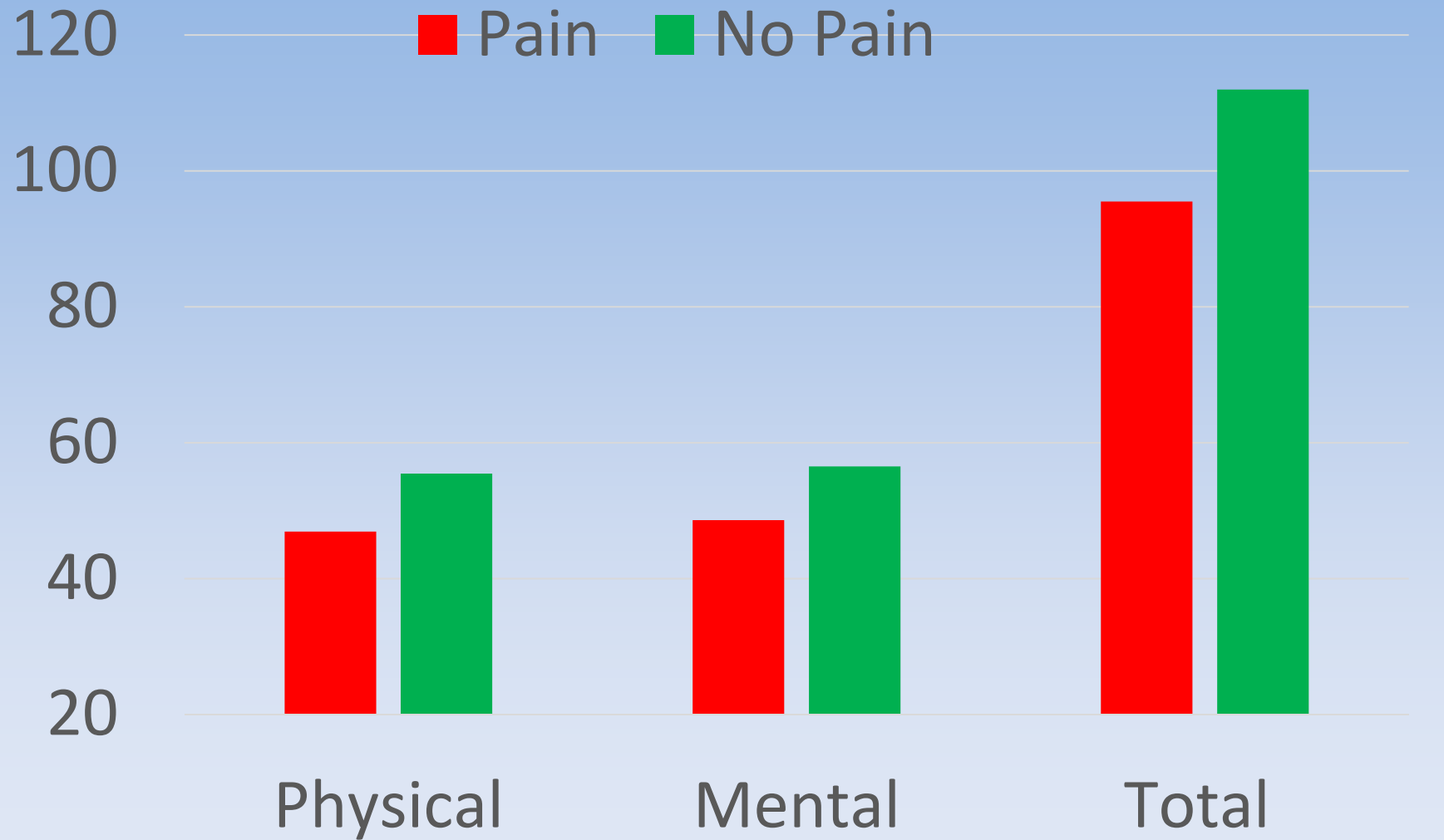
Fair

Poor

Very Poor

- **This item is a strong and significant predictor of:**
 - Mortality
 - Use of health resources
 - Change in functional status
 - Recovery from episodes of ill health

Quality of life

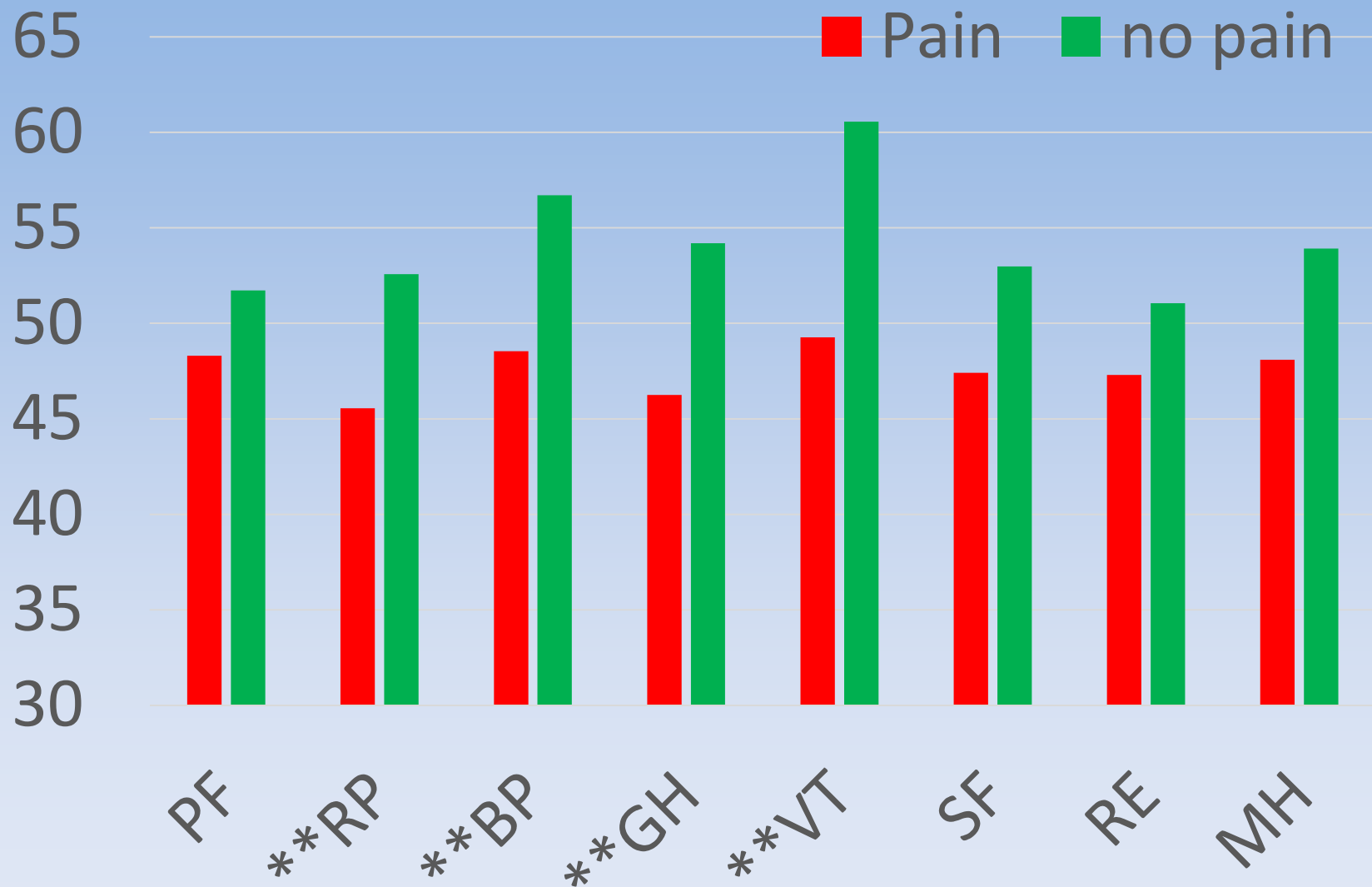


****p = 0.01**

***p = 0.08**

****p = 0.003**

Quality of life





Pain predicting factors

Associated Factors

Predictive

- **Photophobia**
- **Prolonged computer use**
- **Prolonged reading**
- **Flat desk**
- **Driving**
- **Fluoro and down lights**
- **Scoliosis**

Protective

- **Using sloped desk**
- **Using visual aids**
- **Walking**
- **Exercise**
- **Neck and back exercises**
- **Adequate sleep**
- **Indirect lighting**
- **Standard light globes**

	Pain	No Pain
*Age	38	43
**Gender	33% male	86% male
Acuity Smallest print	No significant difference	
*Photophobia	6.6 / 10	5.1 / 10
No significant difference for <ul style="list-style-type: none"> • Living arrangements • Marital status • Education • Employment 		



Pain predicting factors

Lighting – no significant difference between PWA with and without pain for different types of lights used

Use of vision aids – no significant difference between PWA with and without pain

Scoliosis – 16% of PWA with pain had scoliosis versus 0 in those without pain

Activities



Activities

Hours spent:	Pain	No pain
*Computer	3.5	1.4
Reading	0.9	0.9
*Flat desk	2.4	0.8
**Sloped desk	0.1	1.6
Walking	1.8	1.1
**Exercising	0.3	1.1
Sleeping	6.6	6.7

Summary



Summary

- **Pain is common in PWA 84%**
- **Neck pain and headache common**
- **Average pain 5/10**
- **40% pain on most days of week**
- **Moderate impact on functioning**
- **Pain → poor health related quality of life, especially physical**

Associated Factors

Risk factors

- Female
- Using computer
- Use flat desk
- Photophobia

Protective

- Male
- ? Getting older
- Sloped Desk
- Exercising

Discussion – why might PWA get pain? And What can we do about it?



Why might people with albinism get pain?

1. “Asthenopia” eye strain

Eye pain, headaches, neck pain, fatigue, blurred or double vision, burning or dry eyes, photophobia

2. Posture related

→ Eye related

→ Environment

→ Personal factors

Why do PWA get pain?

Eye related

1. Photophobia
2. Scoliosis
3. Head tilt
4. Strabismus
5. Refractive errors
6. Foveal hypoplasia

Environment

7. Computer
8. Print size
9. Light

Personal factors

10. Diet
11. Stress
12. Fatigue
13. Psychological

Why might PWA get pain?

What can be done about it?

1. Photophobia / light environment

→ Muscle overactivity / spasm

- Constrictor pupillae (CNIII)
- Corrugator
- Obicularis oculi

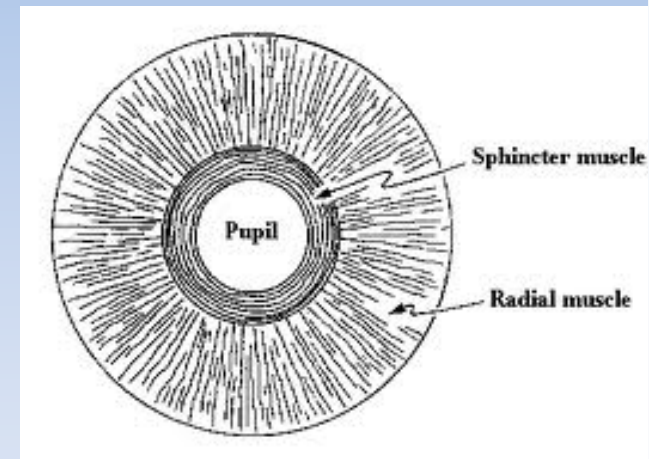
✓ **Sunglasses**

✓ **Hat – even when indoors**

✓ **Tinted contact lenses**

✓ **Avoid down and fluoro lights**

✓ **Indirect Light**





Why might PWA get pain? What can be done about it?

2. Scoliosis

- 5* increase
- Scoliosis may be related to ↓balance
- Vision important in postural control and balance

✓ **Scoliosis Screening**

3. **Head tilt** – nystagmus null point

✓ **Nystagmus null point surgery**

Why might PWA get pain? What can be done about it?

4. Strabismus

- Imbalance of extra-ocular muscles

✓ **Corrective surgery**

5. Refractive errors

- Greater use of muscles for accommodation and convergence

✓ **Correct refractive errors – glasses, ?
Laser, insertion of intra ocular lenses**

Why might PWA get pain? What can we do about it?

6. Computer and print size

- Ciliary muscles (change lens shape) for viewing items at near distance (accommodation)**
- Worse if uncorrected refractive errors / Eye muscle imbalance / strabismus**
- Worse when reading on computers vs hard copy**

Why might PWA get pain? What can we do about it?

Reduce asthenopia / Eye Strain

- ✓ Enlarge, audio, bring things closer**
- ✓ Hard copy preferable to computer**
- ✓ Regular breaks, 5 mins – focus in the distance**
- ✓ Moisture – blink, artificial tears**

Can we reduce Asthenopia with diet?



7. Diet?

- **RCT placebo / active supplement 4 weeks**
- **3 ingredients in supplement capsule**
 1. **Fish oil (DHA, EPA) - Antioxidant, accumulates in retina, role in preventing MD**
 2. **Bilberry Extract (anthocyanins) – Antioxidant, helps restore rhodopsin**
 3. **Lutein - Antioxidant accumulates in retina, especially macula**

Treatment group – significantly lower scores on asthenopia questionnaire (stiff shoulder, dry eye, frustration, stuffy head), & ↓ mental fatigue

Why might PWA get pain? What can we do about it?

8. Poor macular development

- Close focal point
- Postural alterations to bring the eyes closer to the item of interest
- Hunching & **poor posture**

9. Stress / Fatigue / poor self esteem

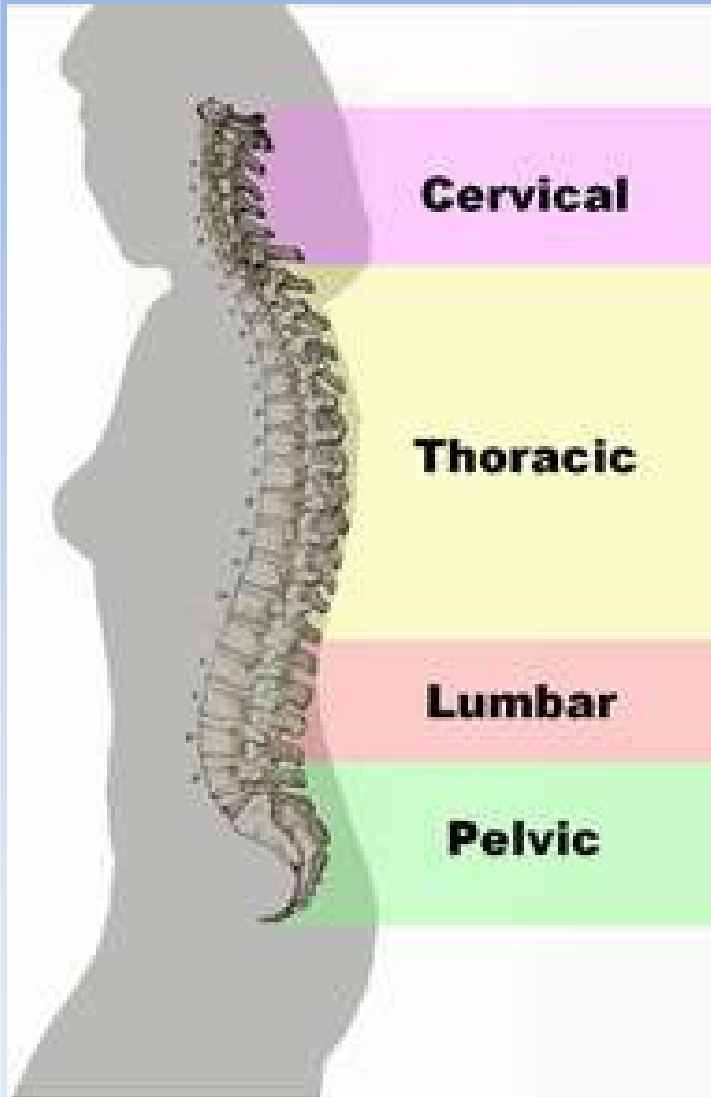
→ **poor posture**

- Study – people in erect vs hunched posture
- Hunched posture → helplessness, reduced persistence in tasks, greater sense of stress
- Hunched posture associated with ↓MH



**Poor
Posture
– loss of
the
neutral
spine**

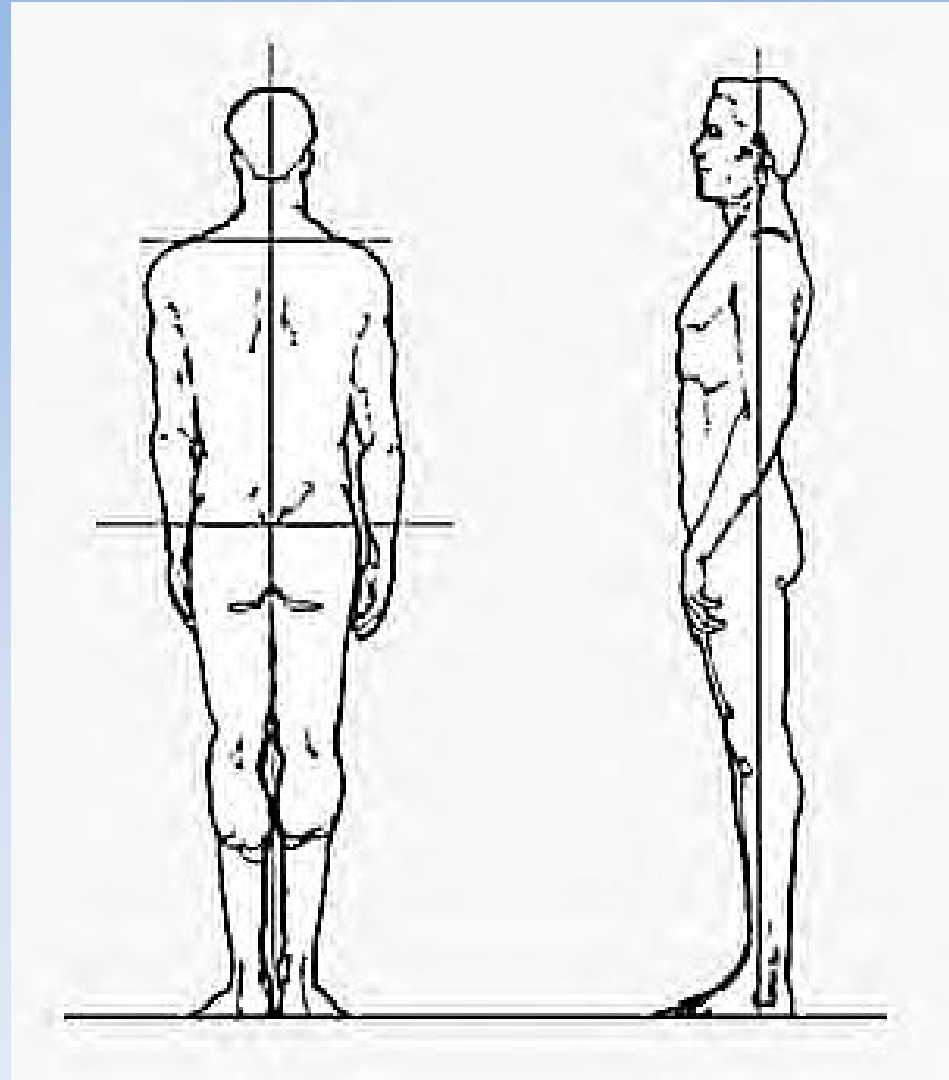
ALIGNMENT – The Neutral Spine



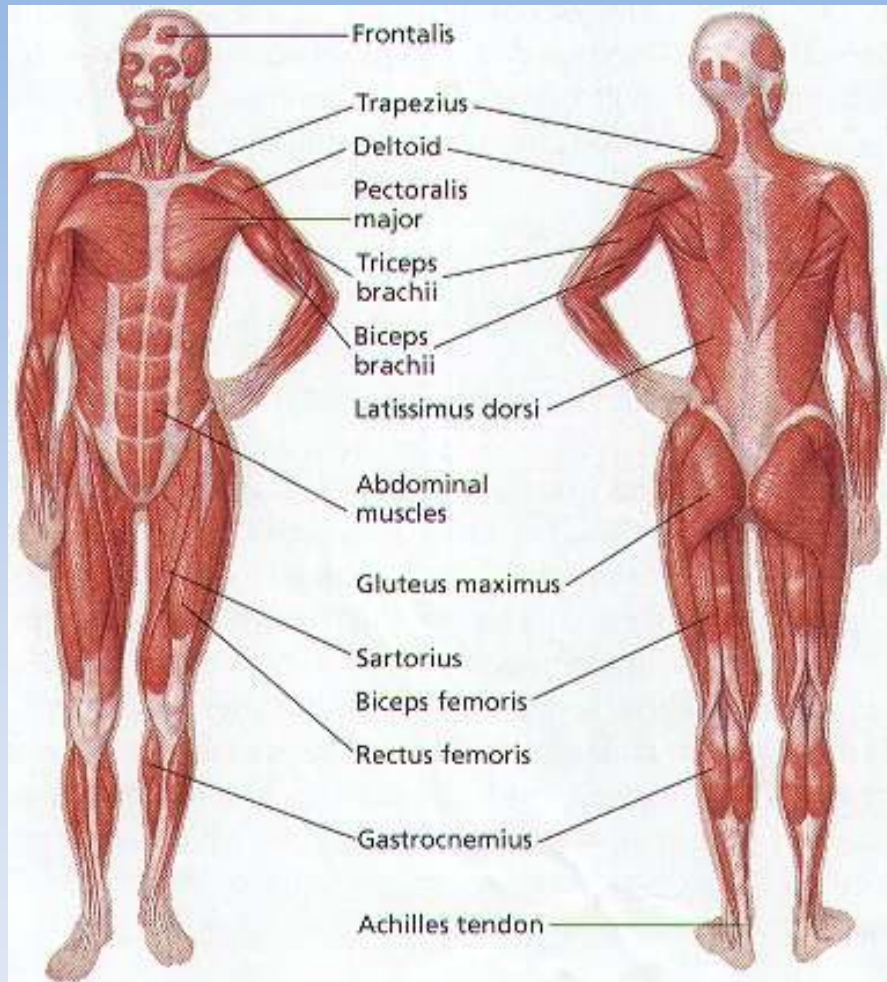
- 3 Primary curves
- Cervical lordosis (in)
- Thoracic kyphosis (out)
- Lumbar Lordosis
- Should be subtle

ALIGNMENT – The neutral Spine

- Line up
 - Ear hole
 - Tip of shoulder
 - Outer hip
 - Mid knee
 - Just in front of bone



MUSCLES

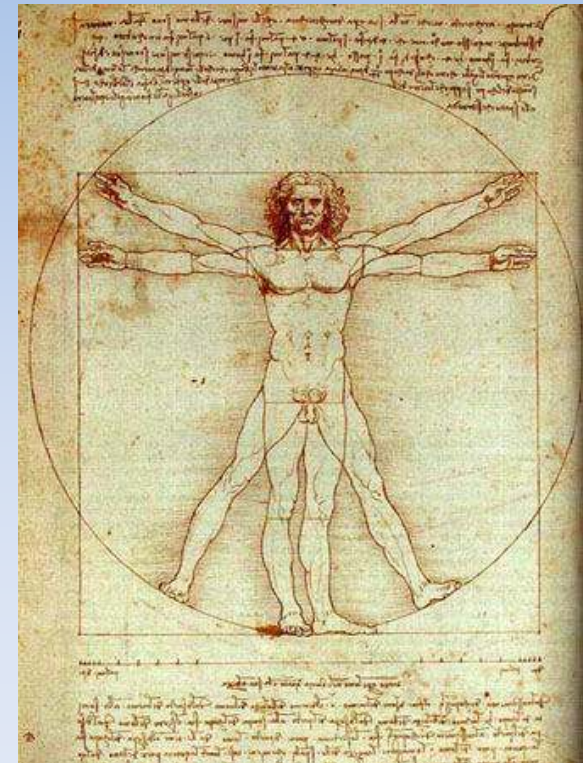


**1. Movement -
Sprint
muscles**

**2. Scaffolding
Marathon
muscles**

In the Neutral spine

- **Marathon Muscles switched on**
- **Bones aligned**
- **Use 5 X less energy**
- **Slow down wear and tear**

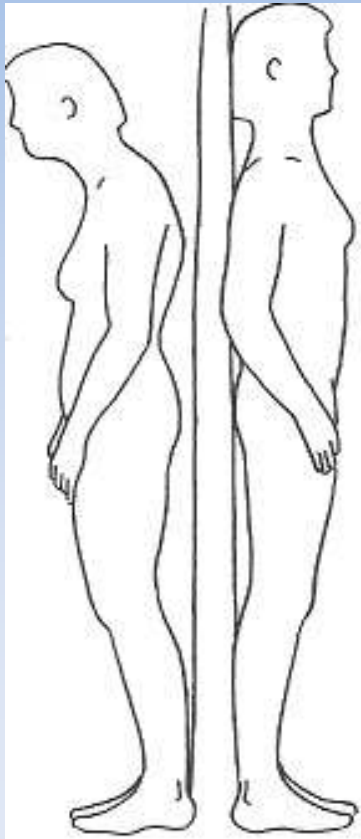


**OUT OF BALANCE
OUT OF CONTROL**

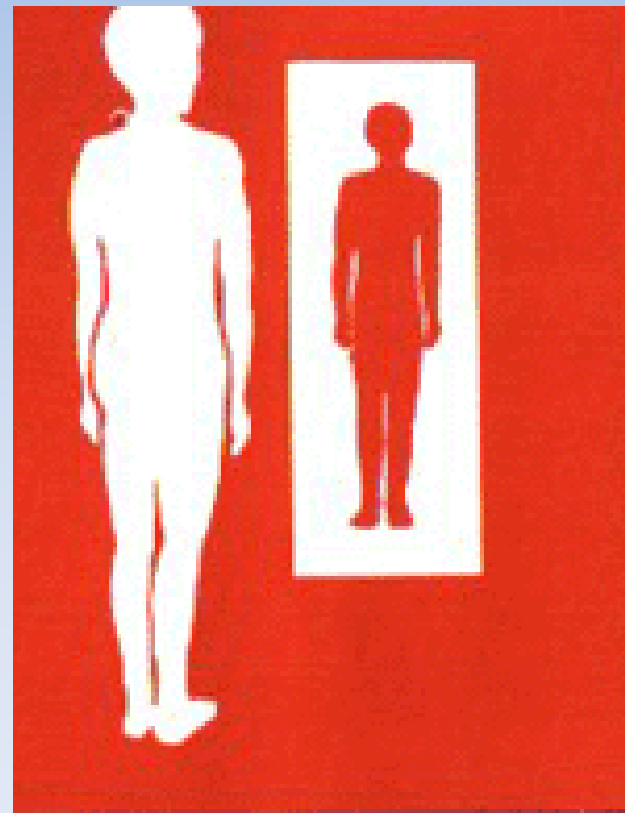


Do I have a Neutral Spine?

Wall test



Mirror test

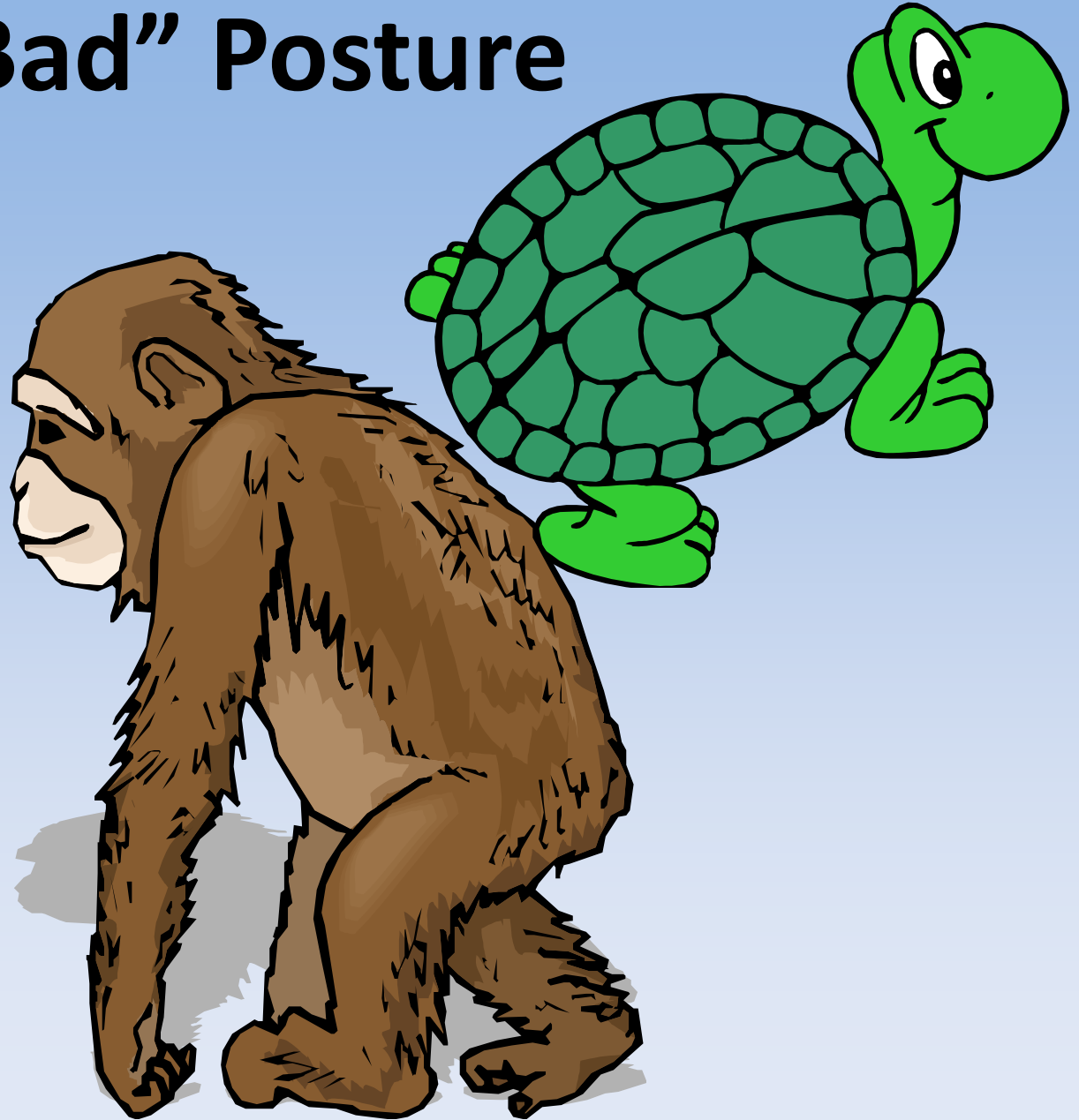


Posture and Pain

- **The Turtle Gorilla – neck pain and tension headaches. 1 inch = 10 pounds extra weight**
- **Factors associated with neck and upper back pain in school children**
 - Prolonged sitting
 - Bending forward > 20 degrees
 - Depression and stress

“Bad” Posture

**The
Turtle
Gorilla**



**Overactive
muscles**

**Short and
Tight**

Fatigued

**Build up
lactic acid**

Acute pain

**Chronic
pain**

**Wear and
tear**

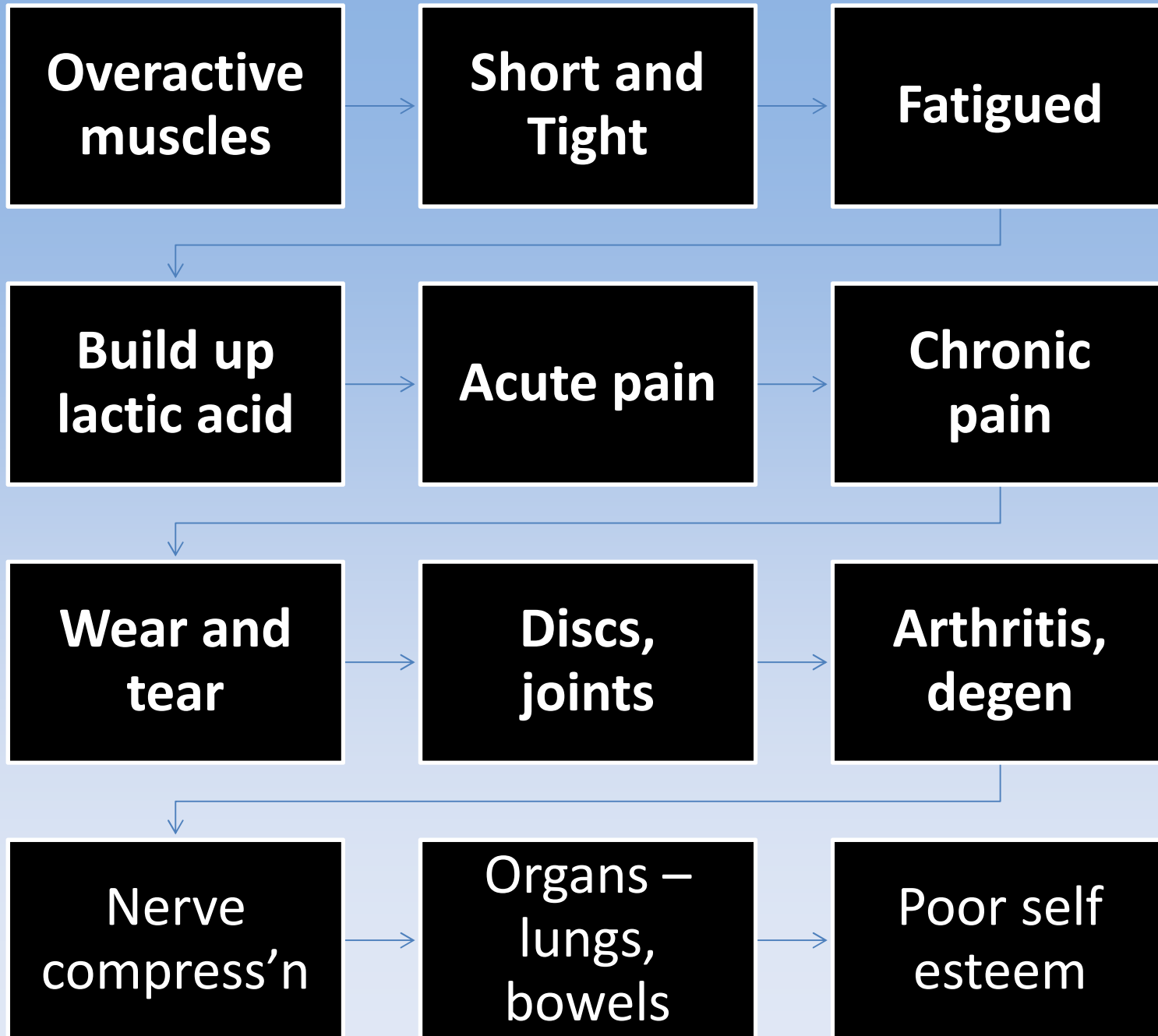
**Discs,
joints**

**Arthritis,
degen**

**Nerve
compress'n**

**Organs –
lungs,
bowels**

**Poor self
esteem**





Benefits of Improving your Posture

- ☺ **Less risk of chronic pain**
- ☺ **Better control of pain if present**
- ☺ **Improvement in self confidence –
↑ sense of own power and more
likely to take action**
- ☺ **Perceived by others**
 - **Thinner and more attractive**
 - **More confident and successful**





Improving Posture

- ✓ Object to the eyes
- ✓ Sloped desks
- ✓ Gadgets – CCTVs, Monoculars
- ✓ Make use of audio technology
- ✓ Ergonomics - Avoid forward postures
- ✓ Enlarge ENLARGE!
- ✓ Strengthening deep flexors (evidence)
- ✓ Range of motion, stretching
- ✓ Walk tall and proud – consider use of cane

Improving Posture

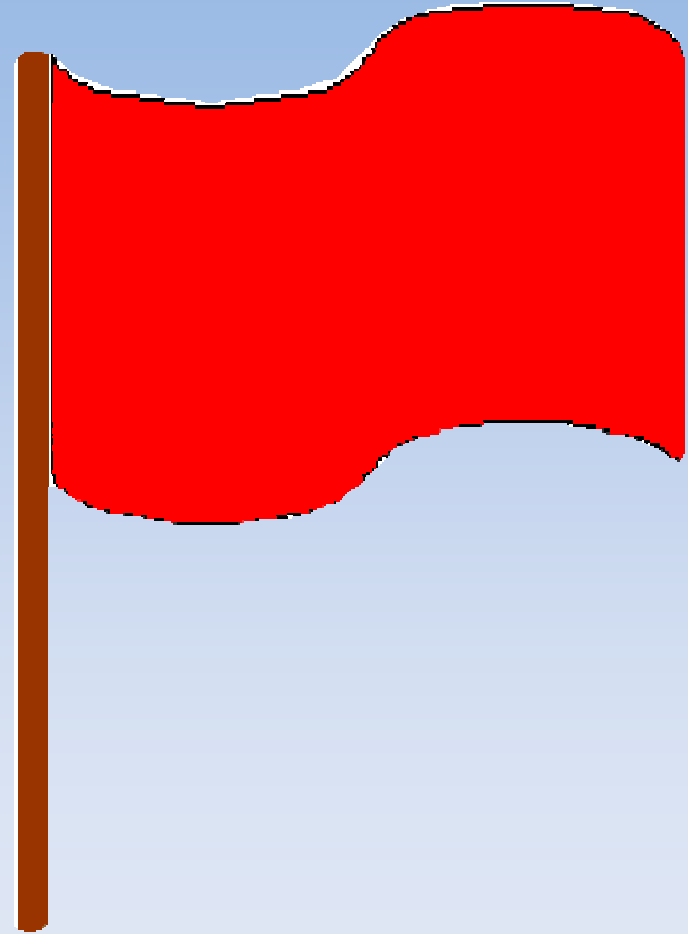
- ✓ Lose weight if necessary
- ✓ Exercise, especially in nature
- ✓ Firm mattress, single pillow, no tummy sleeping!
- ✓ Seek help for stress / anxiety / depression
- ✓ Improve self esteem
- ✓ Be Proud of who you are
- ✓ Relaxation, meditation
- ✓ Look on the “lighter” side of life 😊
- ✓ Correcting the “wall test”



What to do if you do have pain

Red flags

- Severe pain
- Doesn't settle
- Sensory changes
- Weakness
- Bowel / bladder





If Problems do Occur

- Stretches, Hot pack, warm shower
- Simple analgesia
- Resume normal activity, don't go to bed!
- TENS, traction, ultrasound, massage, mobilisation, manipulation.....
- Prevention better than cure
- Seek medical attention if “red flags”



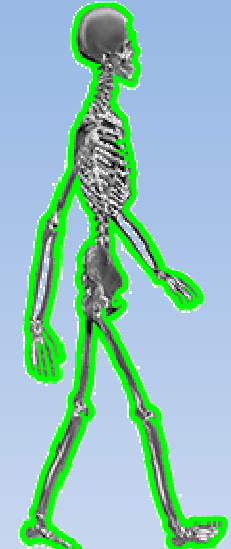


To Sum Up

- Pain is frequent
- Significant impact
- Contributions from vision, environment and personal factors
- Many can be mitigated
- Importance of self-efficacy



Before



After

Where to from here?

- **Extend this pilot study via online survey to get greater numbers**
- **Research into Vitamin D in PWA**
 - **Survey of knowledge and attitudes**
 - **Study looking at Vitamin D levels**

**[www.surveymonkey.
com/s/paininalbinism](http://www.surveymonkey.com/s/paininalbinism)**

References

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Thankyou – Questions?