

Work ability in adults with PKU in Sweden in 2020

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Introduction

- PKU is an autosomal recessive disorder of phenylalanine (Phe) metabolism that requires lifelong dietary restriction of Phe to prevent severe intellectual disability, epilepsy, and behavioral problems^{1,2}
- Despite dietary intervention, many adults with PKU experience sub-optimal outcomes, including neurocognitive and psychosocial impairment and reduced quality of life³
- The socioeconomic impact of PKU – including on educational attainment and the ability to work – is unclear, with prior studies reporting conflicting results⁴⁻⁷
- The impact of PKU on education and employment in Sweden is unknown

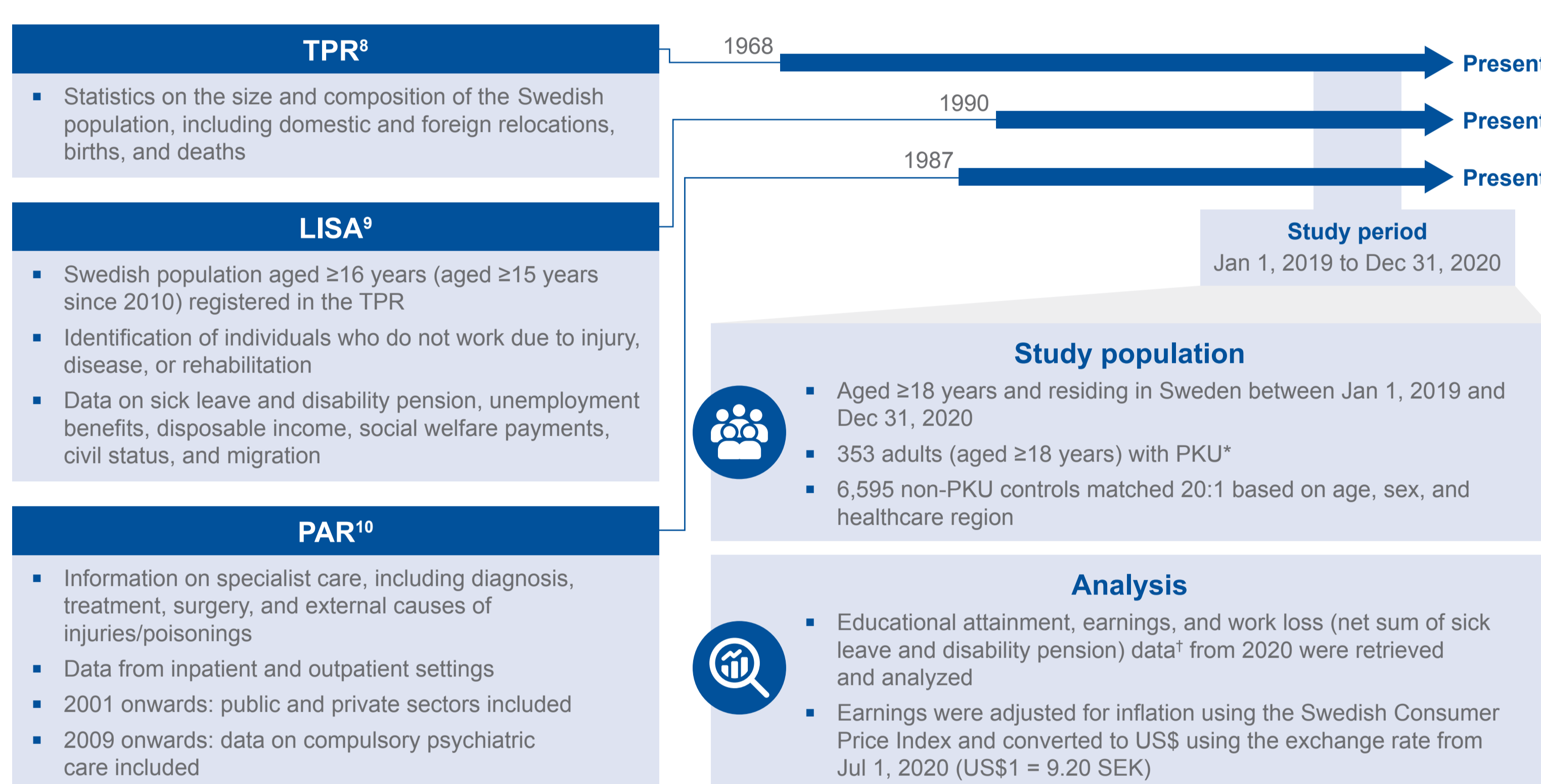
Objective

- To compare work ability and educational attainment between adults with PKU (the PKU cohort) and non-PKU controls in Sweden

Methods

- This was a national record-linkage study in Sweden linking population registry data (TPR and LISA) and specialist care data (PAR) to compare educational attainment, earnings, and work loss between the PKU cohort and matched non-PKU controls (Figure 1)

Figure 1. Study design



*Based on at least one ICD code for PKU (E70.0 [ICD-10], 270B [ICD-9], or 270.0 [ICD-8]) between Jan 1, 1965 and Dec 31, 2020 in PAR

¹The Swedish welfare system provides compensation for sick leave and disability pension (complete or partial). Sick leave is paid by the employer from day 2 to day 14, and episodes of >14 days are recorded by the Swedish Social Insurance Agency, which reimburses the employee for lost income from day 15 onwards. An individual with ≥25% reduced work ability (as evaluated by a physician) expected to last ≥1 year may receive a disability pension. Measure of work loss is the net sum of sick leave and disability pension. A person with 2 days of 50% work loss, for example, is coded as having 1 net day of work loss. Combining sick leave and disability pension gives a unified measure of work loss comparable over time and insensitive to institutional changes that may move individuals between benefit systems¹¹

Results

Demographics and characteristics of individuals

- 353 adults (aged ≥18 years) with PKU and 6,595 non-PKU controls matched 1:20 based on age, sex, and healthcare region, were analyzed (Table 1)
- Median age was 40 years; 51.8% were male
- Most individuals were born in Sweden, and 82% lived in Central or Southern Sweden
- In PAR, the median follow-up from time of PKU diagnosis to 2020 was 25.2 years, and was higher in individuals born in Sweden compared with those born elsewhere

Table 1. Demographics and characteristics of individuals

Demographic/characteristic	PKU cohort (N=353)	Non-PKU controls (N=6,595)
Age in 2020, years		
Mean (SD)	43.5 (17.6)	42.7 (17.0)
Median (IQR)	40 (28–55)	40 (28–55)
Range (min–max)	20–91	20–91
<65, n (%)	305 (86.4)	5,801 (88.0)
≥65, n (%)	48 (13.6)	794 (12.0)
Sex, n (%)		
Female	170 (48.2)	3,200 (48.5)
Male	183 (51.8)	3,395 (51.5)
Birth country, n (%)		
Sweden	310 (87.8)	6,095 (92.4)
Other	43 (12.2)	498 (7.6)
Missing	0	2 (<0.1)
Swedish region of residence,* n (%)		
Central	148 (41.9)	2,762 (41.9)
Northern	41 (11.6)	764 (11.6)
Southern	141 (39.9)	2,630 (39.9)
Missing	23 (6.5)	439 (6.7)
Follow-up from time of PKU diagnosis to 2020, years		
Mean (SD)	26.5 (14.1)	N/A
Median (IQR)	25.2 (16.7–38.4)	N/A
Range (min–max)	0.1–65.5	N/A

Percentages may not total 100% due to rounding

*Swedish regions of residence represent groups of healthcare regions

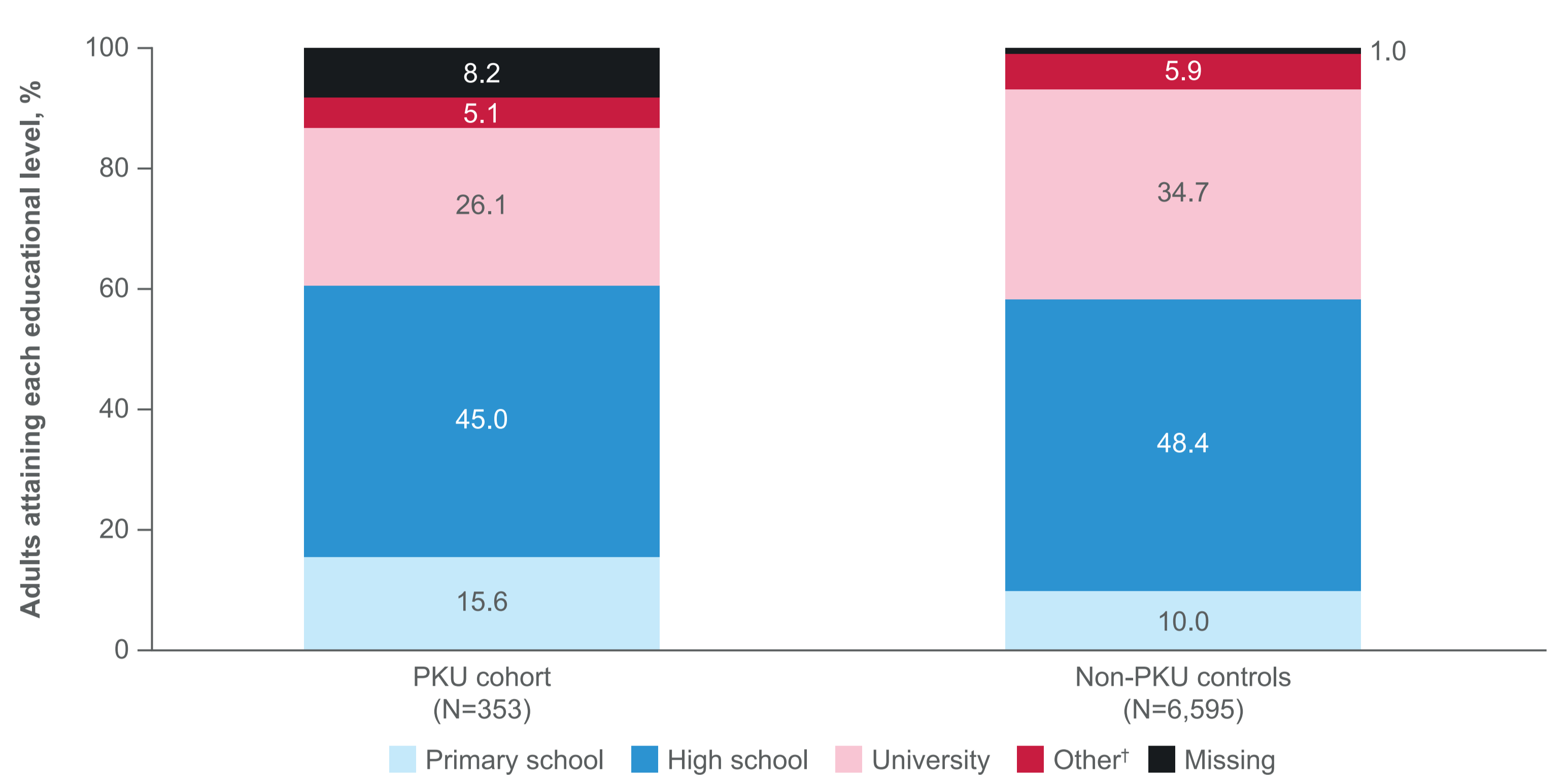
Conclusions

- Findings suggest that adults with PKU have reduced work ability compared with non-PKU controls, as shown by lower rates of post-secondary education and employment, lower earnings, and a higher number of work loss days
- These results highlight the substantial socioeconomic impact PKU has on individuals with PKU in adulthood, particularly in the most economically productive ages of 25–64 years (prime working age)

Educational attainment levels

- The PKU cohort had lower levels of educational attainment compared with non-PKU controls (Figure 2)
- The PKU cohort were less likely to attain high school, university, or other level education (PKU cohort: 83.0%; non-PKU controls: 89.9%; difference in proportions [95% CI]: 6.9% [3.2%, 11.4%]; individuals with missing data excluded)

Figure 2. Proportion of adults attaining each educational level*



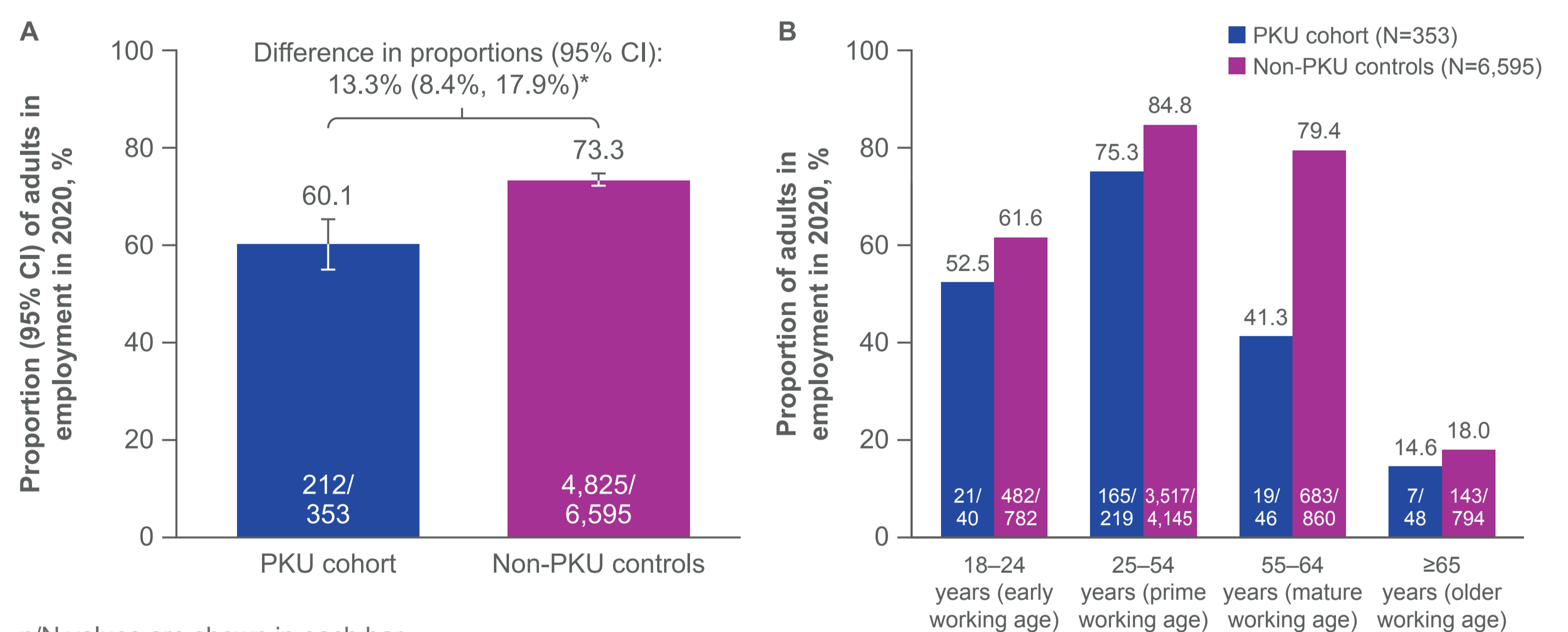
*Educational attainment was measured based on age in 2020

[†]“Other” included profession-specific programs and other courses for adults where the highest obtained education level was unknown

Employment

- The PKU cohort were less likely to be employed, both among all adults and within each age group (Figure 3)
- There were approximately 10% fewer adults aged 25–54 years with PKU in employment versus non-PKU controls in that age group (75.3% [95% CI: 69.0%, 80.8%] vs 84.8% [95% CI: 83.7%, 85.9%])

Figure 3. Proportion of adults in employment in 2020 (A) among all adults and (B) by age group

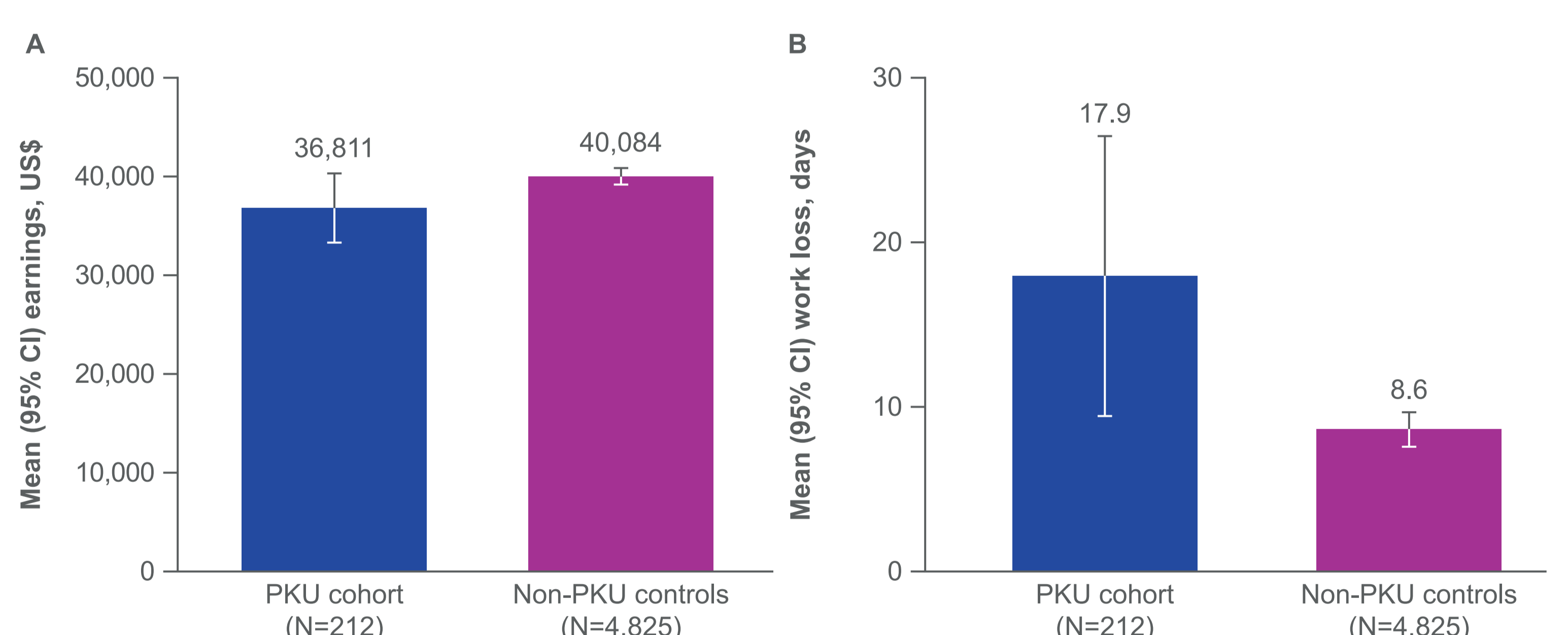


n/N values are shown in each bar

*Missing data are not included

- Mean earnings in 2020 were lower in the PKU cohort versus non-PKU controls (Figure 4A)
- Mean work loss days were two-fold higher in the PKU cohort versus non-PKU controls (Figure 4B)

Figure 4. (A) Earnings and (B) work loss days in 2020 among employed adults



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Abbreviations

CI, confidence interval; ICD, International Classification of Diseases; IQR, interquartile range; LISA, Longitudinal Integrated Database for Health Insurance and Labour Market Studies; N/A, not applicable; PAR, Swedish National Patient Register; Phe, phenylalanine; PKU, phenylketonuria; SD, standard deviation; SEK, Swedish Krona; TPR, Total Population Register.

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