

# Self-reported Education, Work and Health Status among 53 Norwegian Men with SCA

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## Background

Sex chromosome aneuploidies (SCA) in men are associated with multiple challenges, but little is known about self-reported functioning among men with SCA. This is the first survey of Norwegian men with SCA, and the study aims to contribute to the increasing knowledge about health and functioning within this group, particularly related to education and work status.

## Method

A cross-sectional survey of self-reported education, work, and health status conducted with 53 men with SCA aged 19 to 67 years (mean age = 36.8 years, SA = 12.3) recruited from a user organization and Frambu resource centre for rare disorders. Participants received a background questionnaire developed for this study, covering six themes (demographics, education, work, communication problems, learning style and diagnosis). In addition, three standardized questionnaires on health, personal wellbeing and sleep were included.

### Karyotype

47XXY	77.7 %
47XYY	3.8 %
48XXYY	3.8 %
Mosaic	3.8 %
Not reported	11.3 %

### Highest education

Primary school	3.8 %
Secondary school	22.6 %
High school	54.7 %
< 3 year post high school	13.2 %
> 3 year post high school	0.0 %
Not reported	5.7 %

### Marital status

Living alone	56.6 %
Cohabiting/married	30.2 %
Living with parents	13.2 %

### Work situation

Working	37.7 %
Disability pensions	35.8 %
Student	11.3 %
Early retirement	3.8 %
Unemployed	1.9 %
Other	9.4 %

### Characteristics

	Mean
Age when diagnosed	21 years
Height	186 cm
Weight	98 kg
Body mass index	27.9

### Among those working:

NLWA assisted job	17.0 %
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## Results

### Masculinity, Body Image and Sexual Confidence in 53 Men with Sex Chromosome Aneuploidies

Variable (on a scale from 1 to 7)	Mean
Feminine personality (1) - masculine personality (7)	5.3
Feminine body image (1) - masculine body image (7)	4.9
Body too thin (1) - body too fat (7)	4.6
Overall body image: poor (1) - excellent (7)	4.1
Sexual confidence: poor (1) - excellent (7)	5.1

### Personal Wellbeing Index (0-100) in 53 Men with Sex Chromosome Aneuploidies

Wellbeing domain	Mean
Overall life satisfaction	68.0
Standard of living	72.1
Personal health	52.2
Achievement in life	67.4
Personal relationships	75.8
Personal safety	76.3
Community connectedness	64.8
Future security	69.2



### SF-36 Scores in 53 men with Sex Chromosome Aneuploidies

	Mean	Norm*	d
General health	51.4	77.4	-1.20
Physical functioning	72.5	89.8	-1.06
Role - physical	46.2	80.5	-1.01
Role - emotional	62.2	84.5	-0.73
Vitality	45.6	63.2	-0.88
Mental health	67.4	80.0	-0.48
Social functioning	65.0	87.6	-1.06
Pain	53.7	77.2	-0.93

SF-36: Short Form Health Survey. \* Compared with normed based data from 1138 Norwegian males age 19 to 80 years, M age = 44.9 years (Loge & Kaasa, 1998). All effect sizes are medium to large. d = effect size difference (> 0.80 = large). Higher scores indicate better health.

## Conclusion

Our results document low education, poor socio-economic status and weaker labour connections among men with SCA (in line with international studies). Our survey also provides new insights into self-perceived physical and mental health. Men with SCA reported poorer health on all SF-36 scales compared to Norwegian male norms (average effect size d = -0.92).

An important objective was also to gain knowledge on self-reported learning difficulties and learning style in this group of men, and how these challenges, combined with socio-emotional difficulties, influence the choice of education and work participation. For professionals, the practical implications include ensuring thorough cognitive and psychological assessment, offering practical education in high school and offering flexible working hours.