

# Spinal Injuries Association (SIA) Campaigning for Change (CfC) 2008 Survey

## Final Report

### Background

In August and September 2008, SIA surveyed our membership and the wider Spinal Cord Injured (SCI) community via the internet and hard copy questionnaires to establish our campaigning priorities for 2009 – 2011.

The survey's aims were:

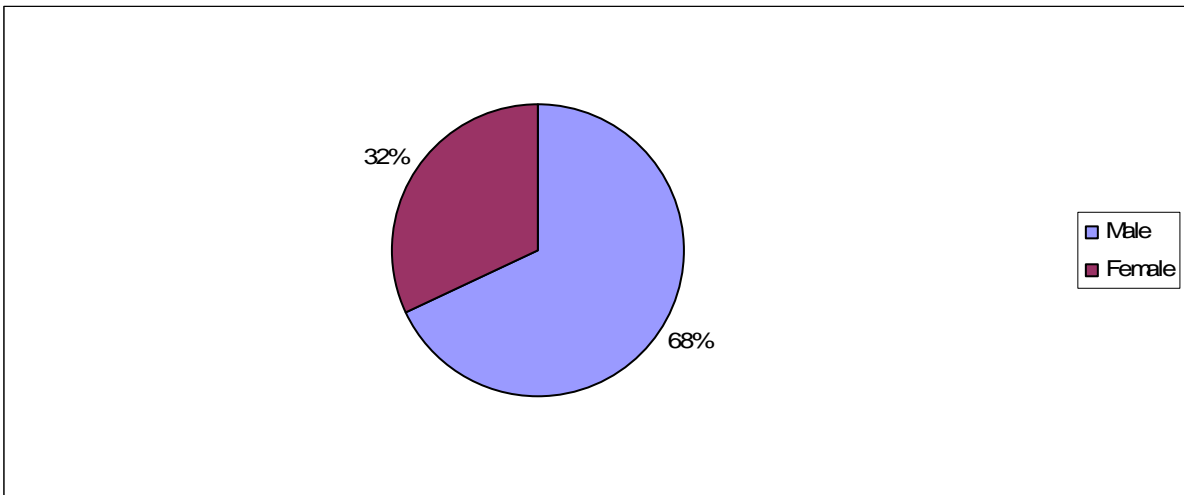
1. To seek SCI people's experiences and views and feed them into an updated version of SIA's CfC Manifesto, which was originally launched in 2006.
2. To gather statistics and data and seek SCI peoples experiences to map the current state of the national SCI Centre service.

The survey concentrated on the following key areas:

- The national SCI Centre service Page 5
- SIA current and future campaigning Page 9
- SCI Awareness in Hospitals other than SCI Centres Page 13
- Access to Care Services Page 16
- Wheelchair and Equipment services Page 21
- Welfare Benefits Page 26
- Shaping SIA future campaigning activity Page 29

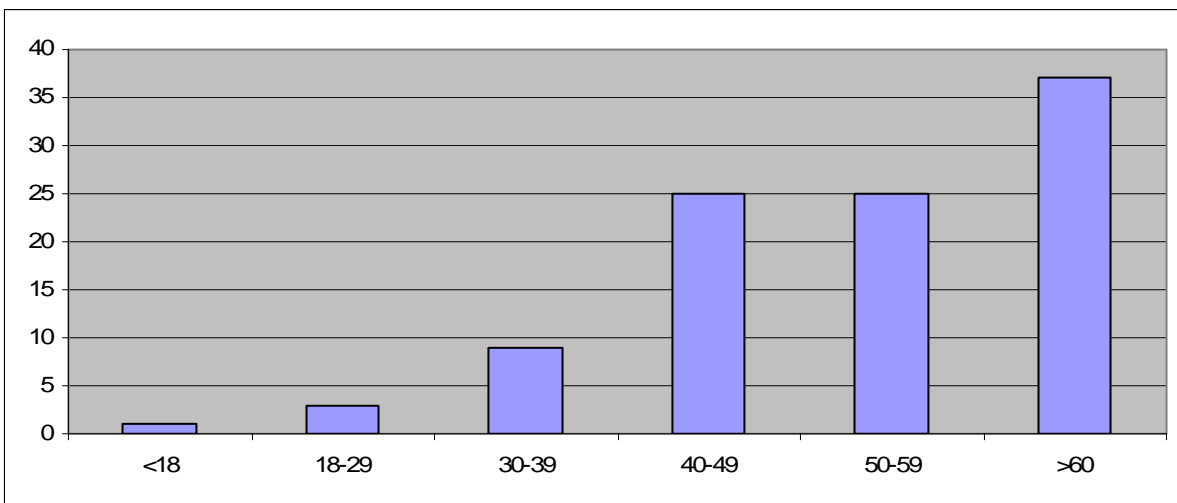
## Demographics of survey responders

### Sex



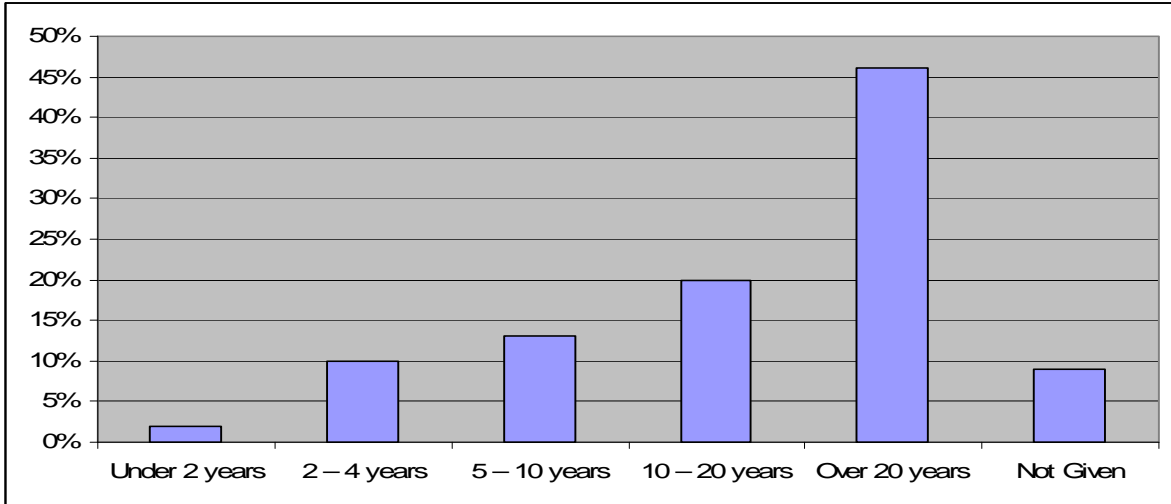
Of 812 responses

### Age



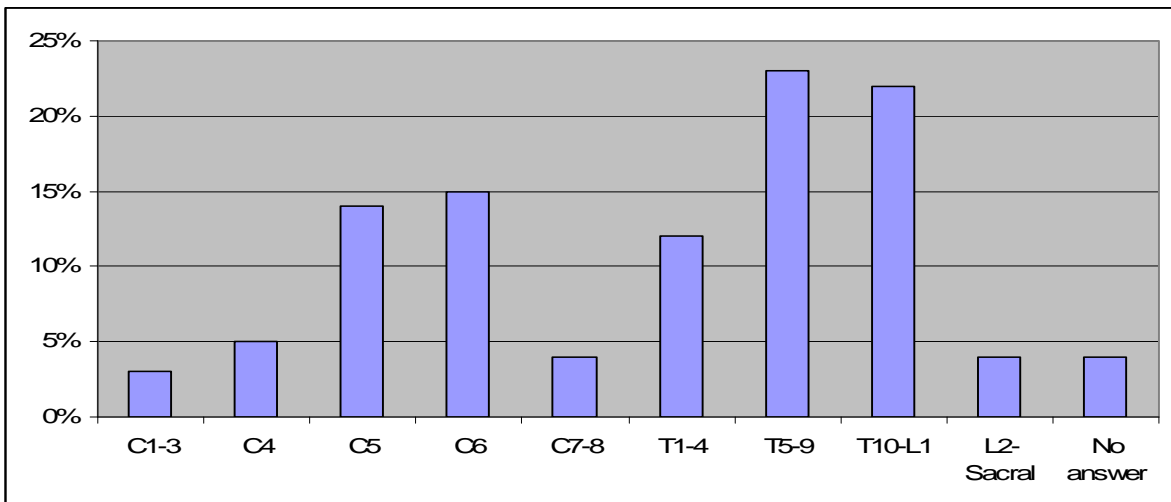
Of 731 responses

### Years since responders had their SCI



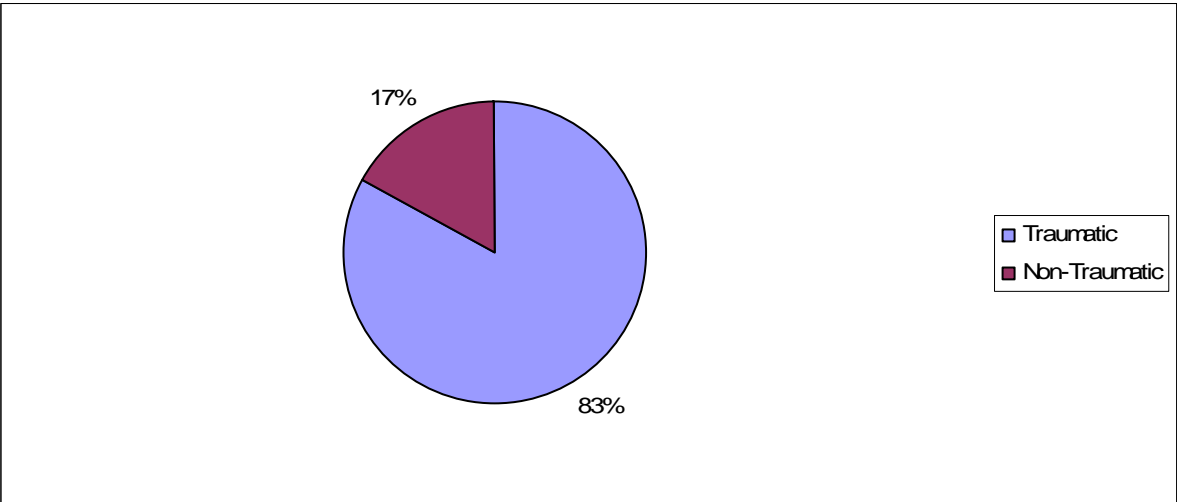
Of 749 responses

### Level of Injury



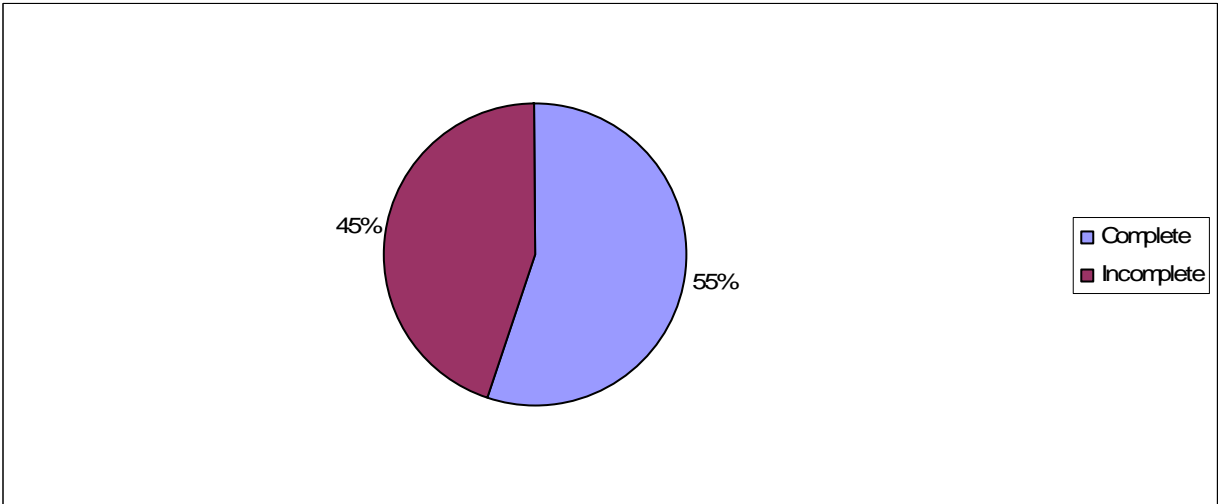
Of 797 responses

**Cause of SCI**



Of 749 responses

**Severity of injury**

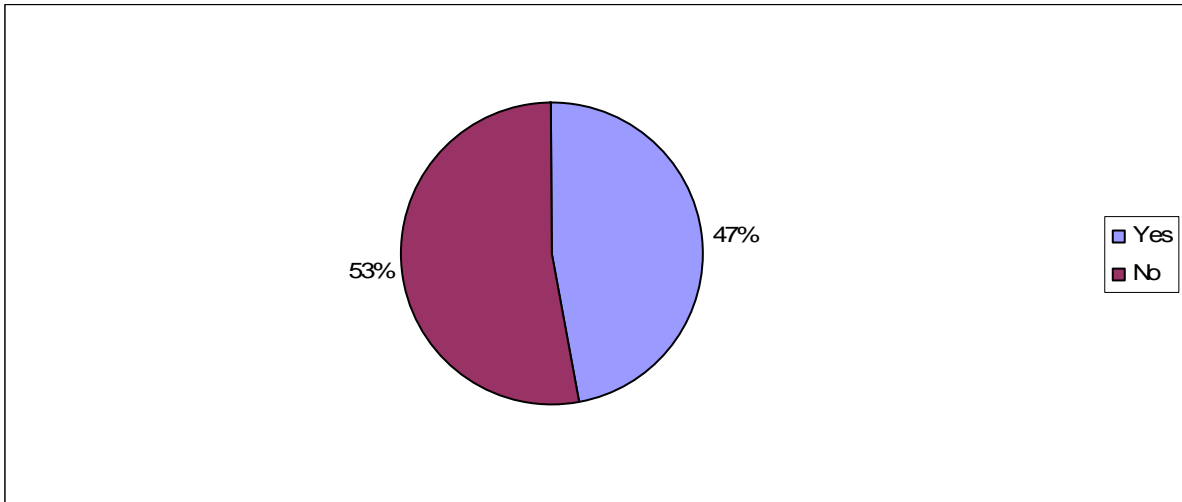


Of 801 responses

## Preserving and developing the SCI Centre service

### Question 1

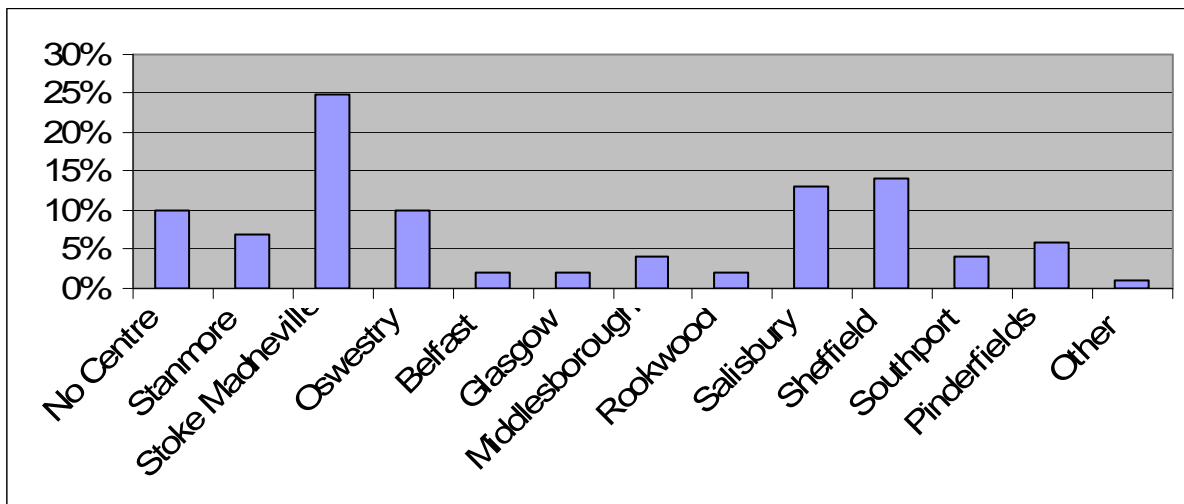
Do you have any additional medical conditions?



Of 764 responses

### Question 2

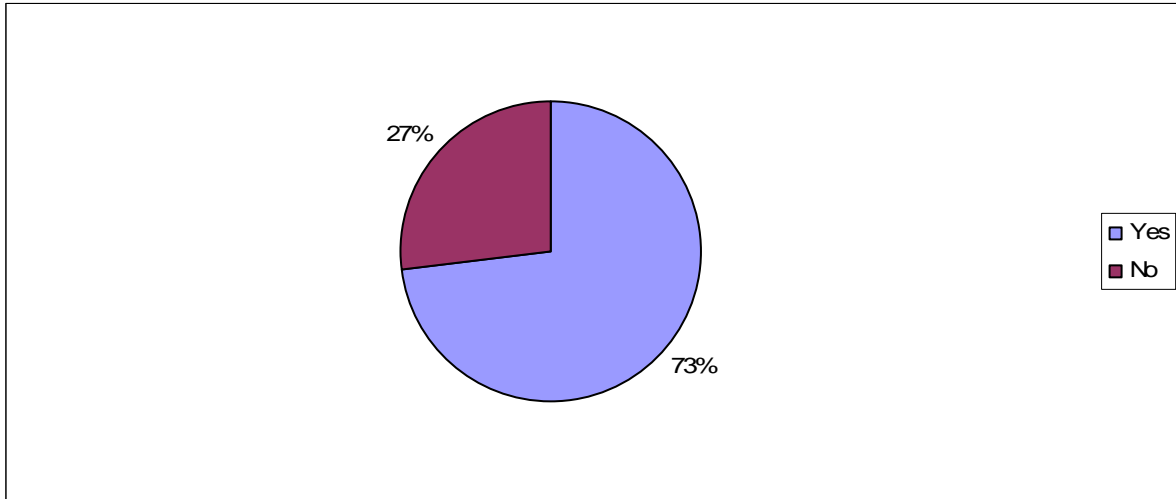
What SCI Centre are you under the care of?



Of 796 responses

### Question 3

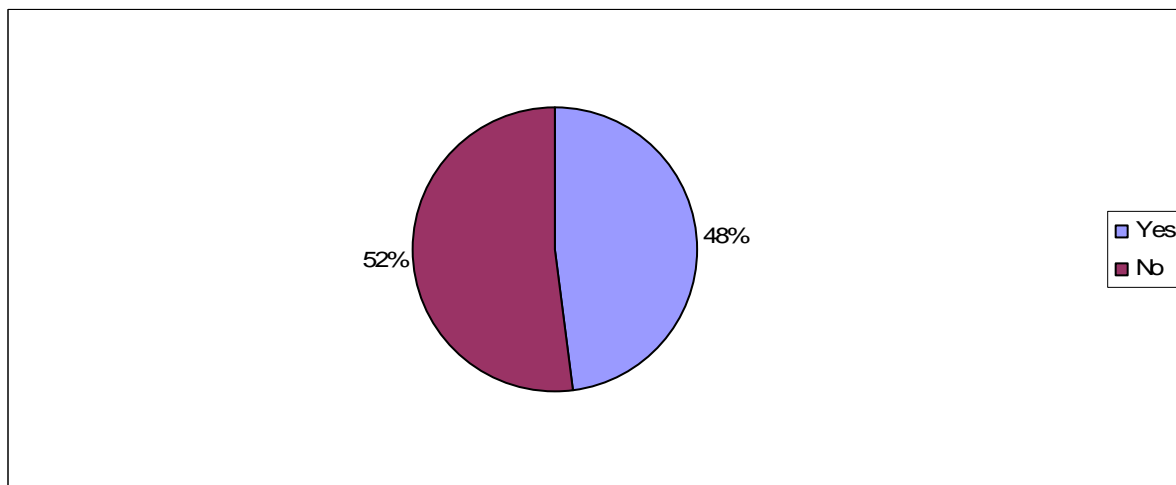
Have you always been under the care of this SCI Centre?



Of 756 responses

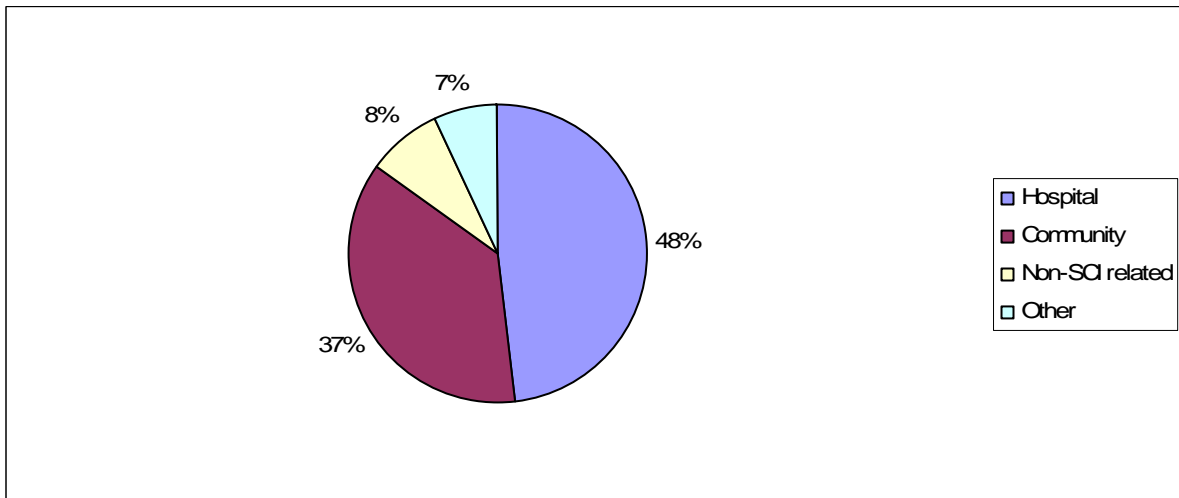
### Question 4

Are you under the care of any other health services?



Of 753 responses

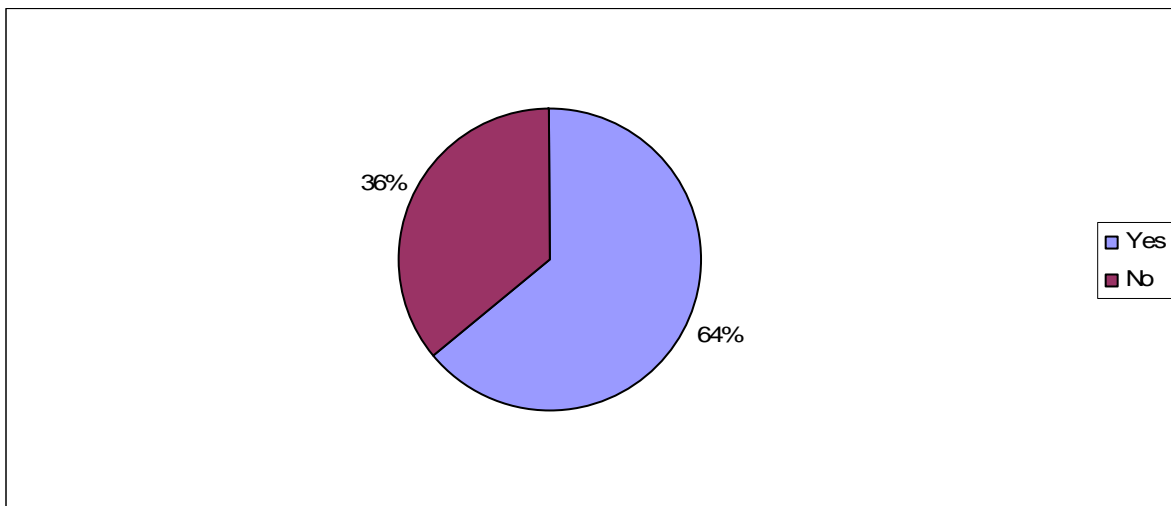
If YES, which services do they provide for you?



Of 336 responses

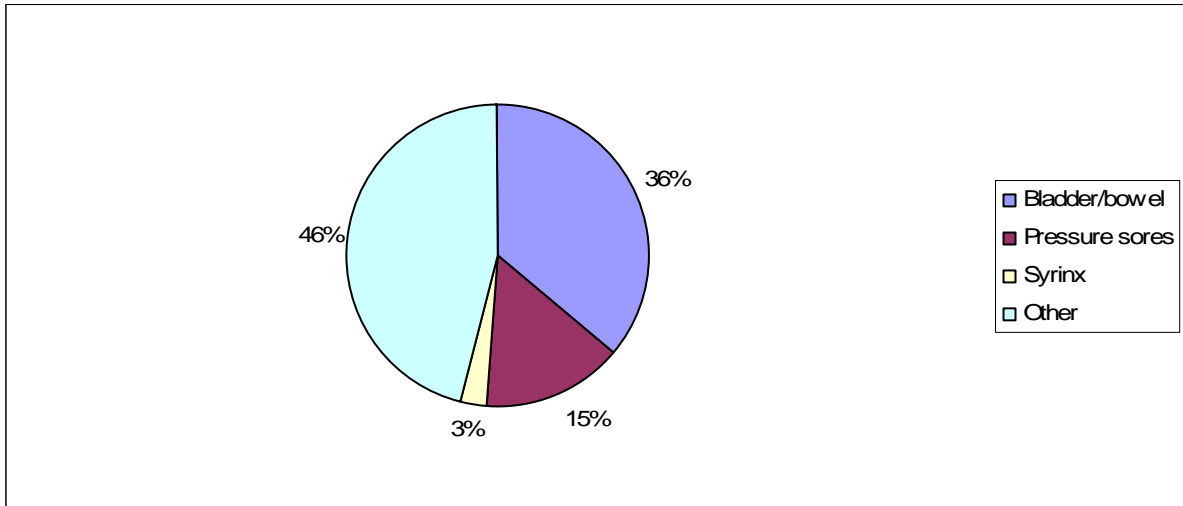
### Question 5

Have you experienced any significant health problems or complications since your discharge from the SCI Centre?



Of 749 responses

If YES please give details.

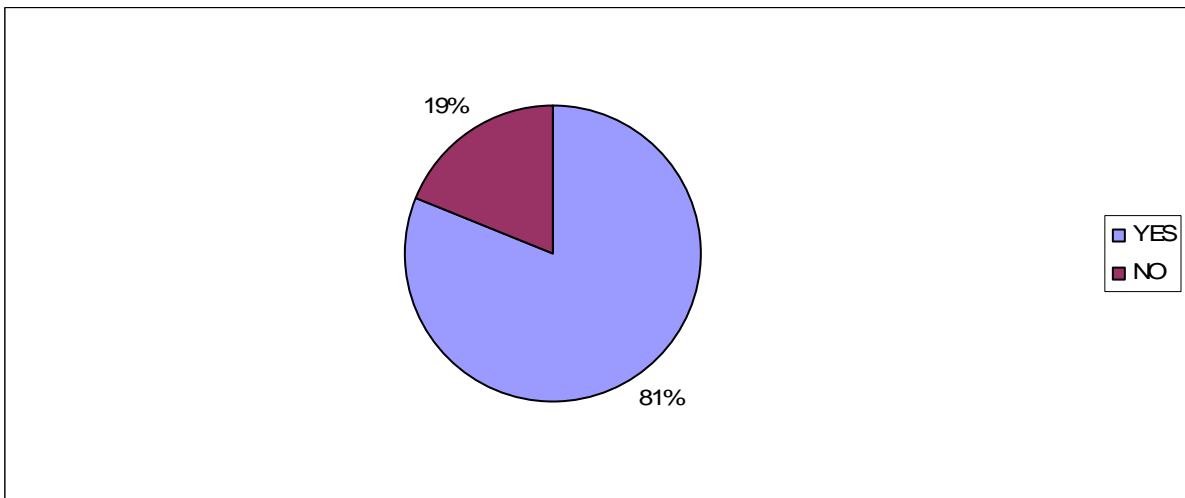


Of 486 responses

## SIA current and future campaigning

### Question 1

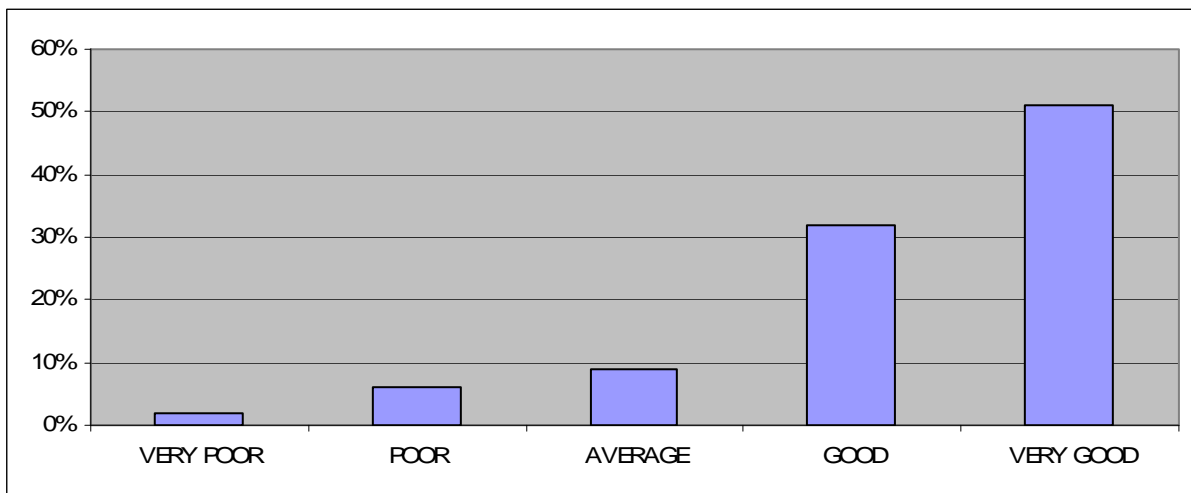
Were you treated in an SCI Centre immediately after your SCI?



Of 786 responses

### Question 2

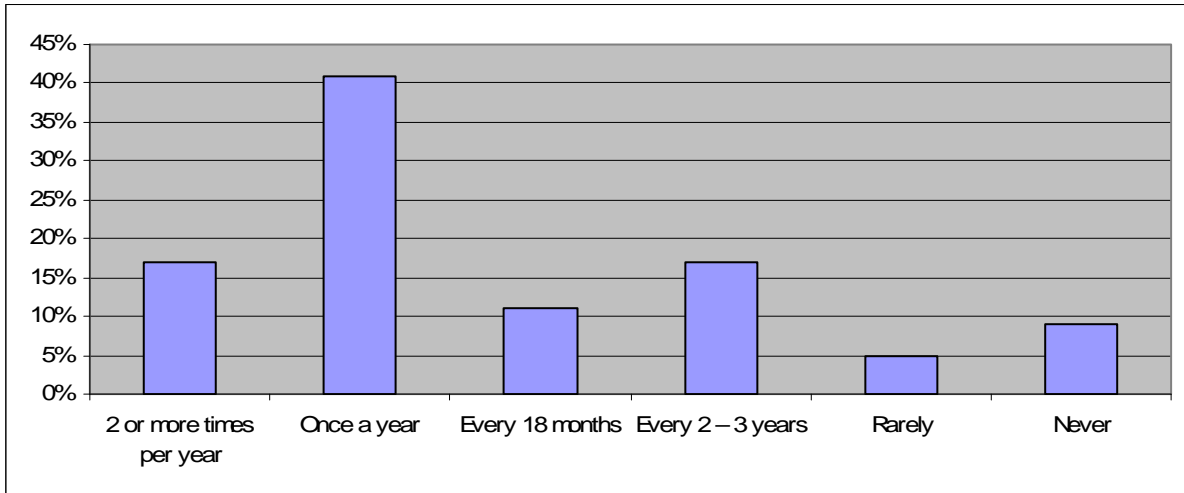
How would you rate the treatment and rehabilitation you received?



Of 677 responses

### Question 3

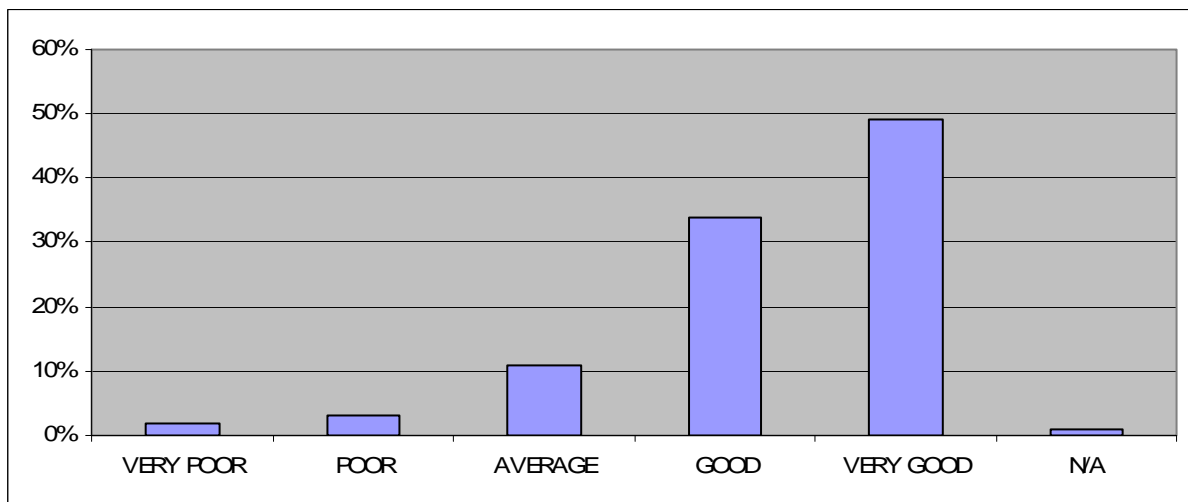
On average, how often do you go back to an SCI Centre for a check-up or treatment?



Of 772 responses

### Question 5

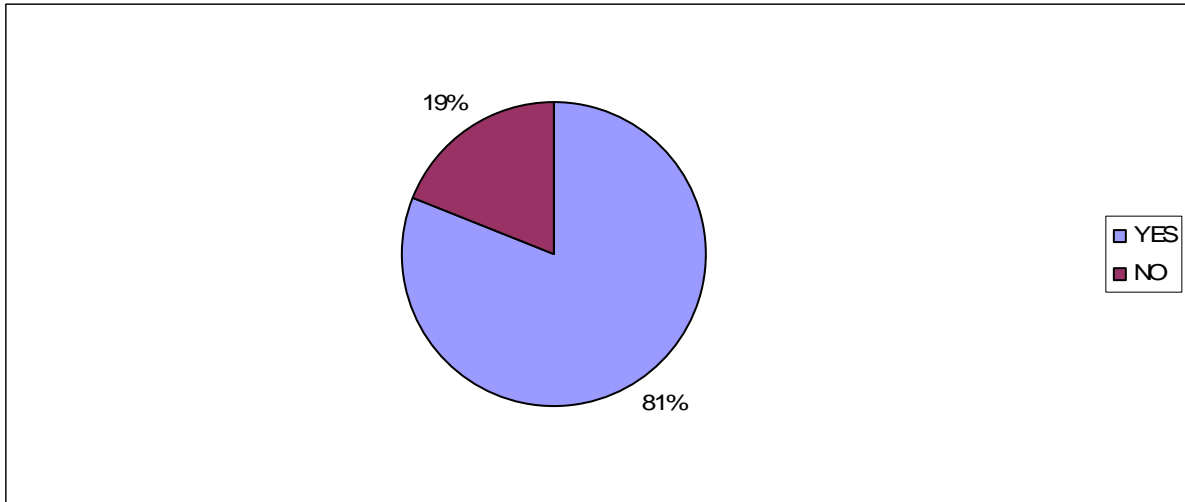
How would you rate the service you received when last in an SCI Centre?



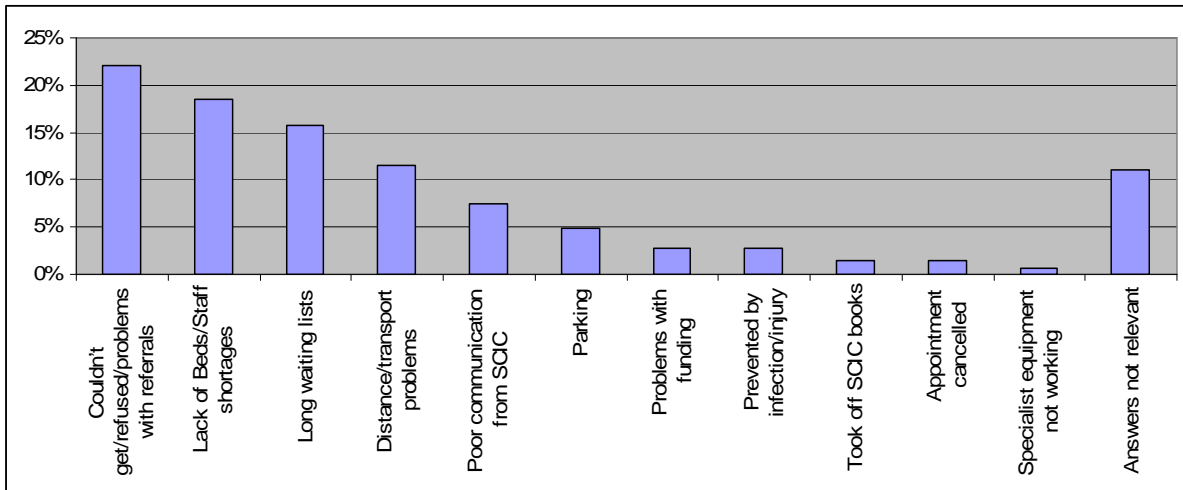
Of 724 responses

### Question 6

Have you experienced any difficulty in accessing an SCI Centre?'



24% of responders who had experienced a difficulty in accessing an SCI Centre gave the following reason(s) why this was:



### Question 7

Using your experience of an SCI Centre, please grade the benefit in the following areas:

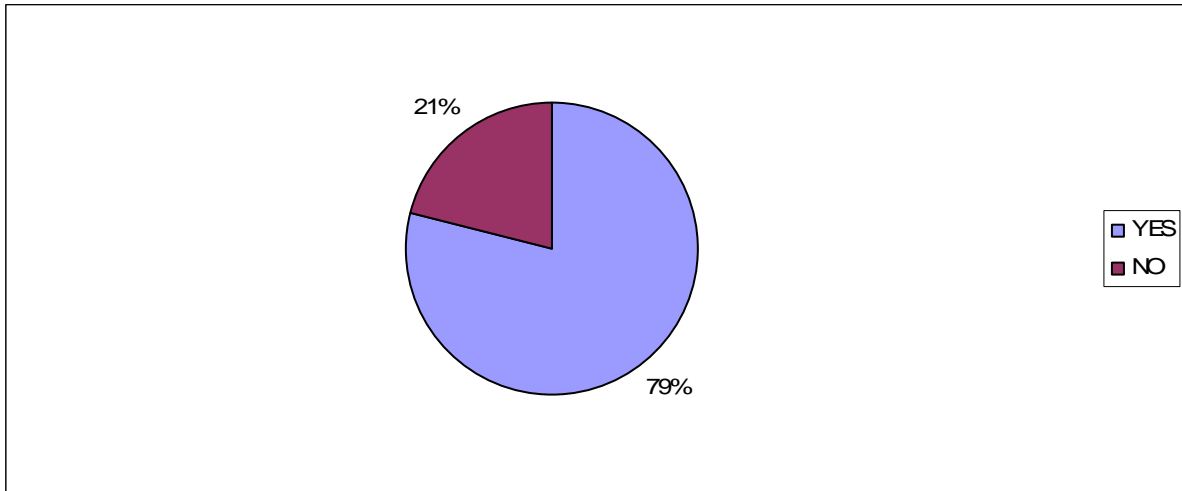
	<b>Little or No Benefit</b>	<b>Some Benefit</b>	<b>Great Benefit</b>	<b>Substantial Benefit</b>
Experienced Staff re: Bowel, Bladder & Pressure Care	2%	12%	37%	49%
Multi-disciplinary Experienced Staff	4%	21%	36%	39%
Specialist Rehabilitation	8%	20%	32%	40%
Education in Managing SCI	7%	21%	35%	37%
Equipment	5%	28%	38%	29%
Support For Your Family	24%	26%	25%	25%
SIA Peer Support	23%	34%	24%	19%
Psychological Support	34%	27%	21%	18%

Of 679 responses

## SCI Awareness in Hospitals other than SCI Centres

### Question 1

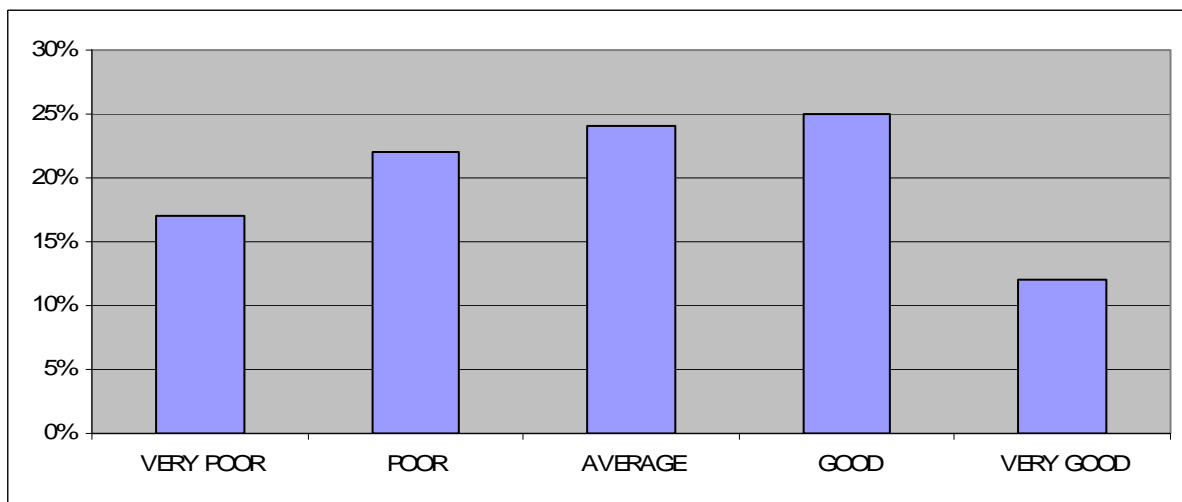
Have you been treated in a hospital other than an SCI Centre since your SCI?



Of 792 responses

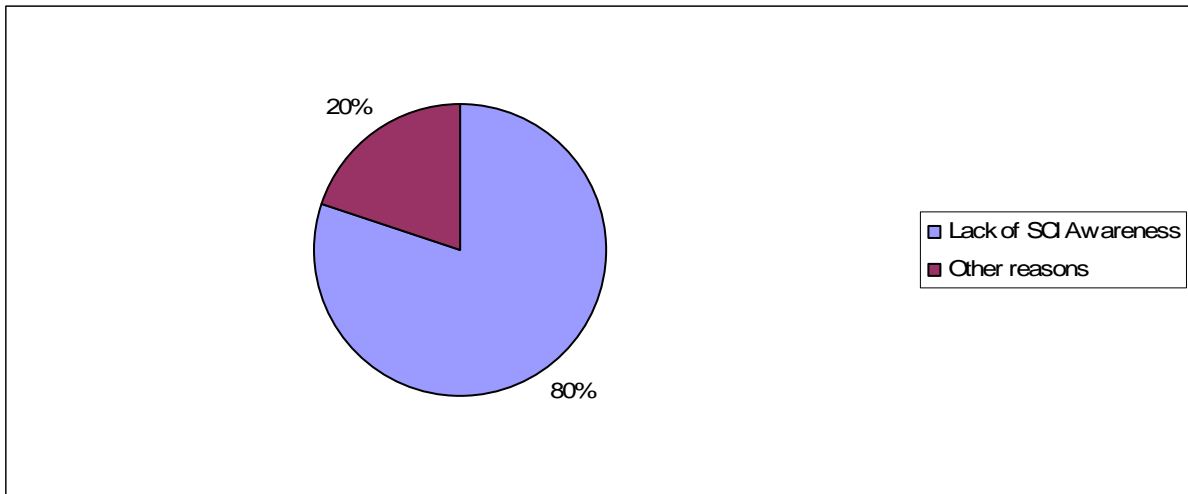
### Question 2

If you answered YES to question 1, how was the treatment you received?



Of 621 responses

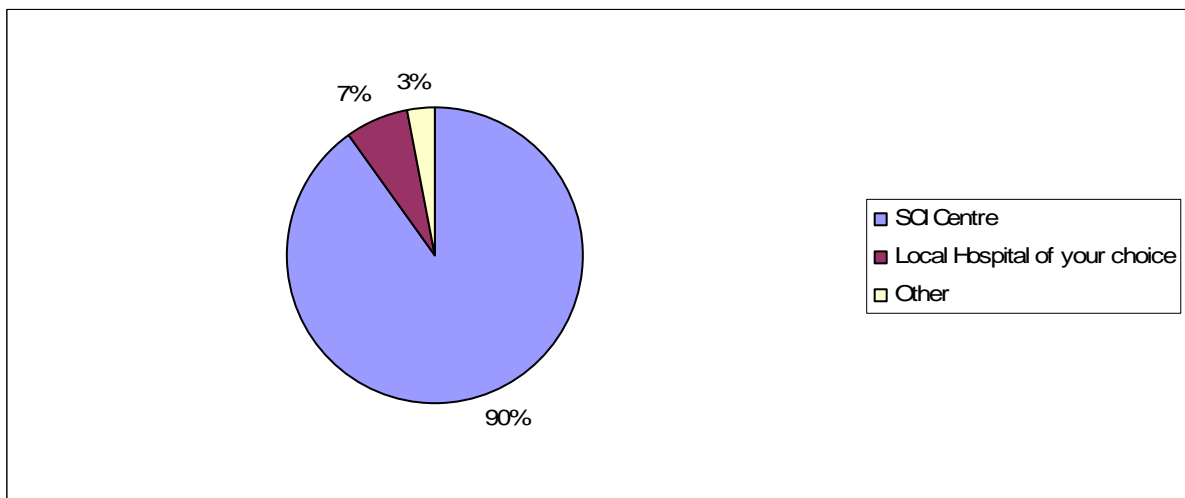
If POOR or VERY POOR, what major problem(s) did you experience?



Of 257 responses

### Question 3

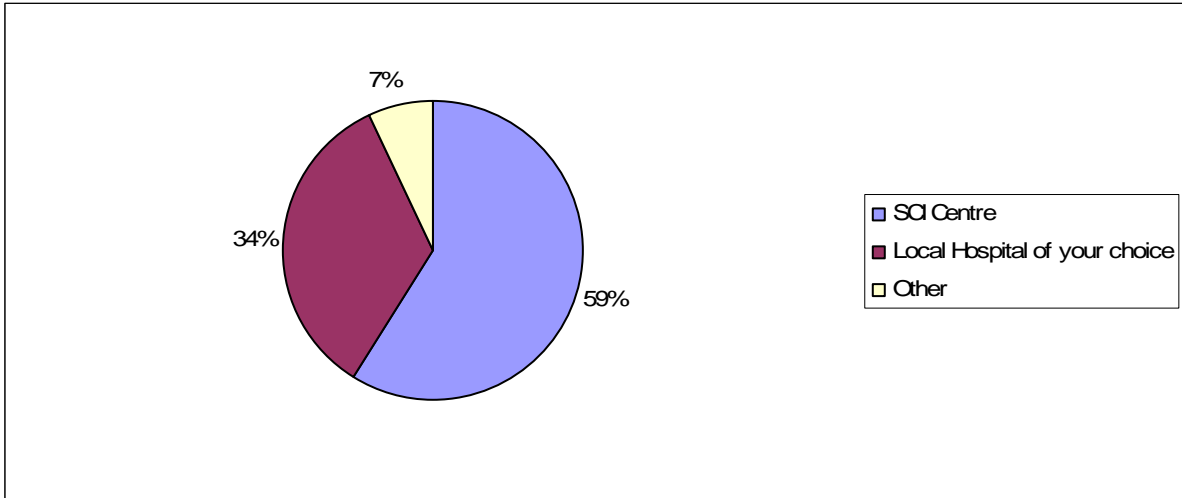
If you were to develop a medical condition related to your SCI which of these treatment options would you choose?



Of 754 responses

#### Question 4

If you were to develop a medical condition NOT related to your SCI which of these treatment options would you choose?

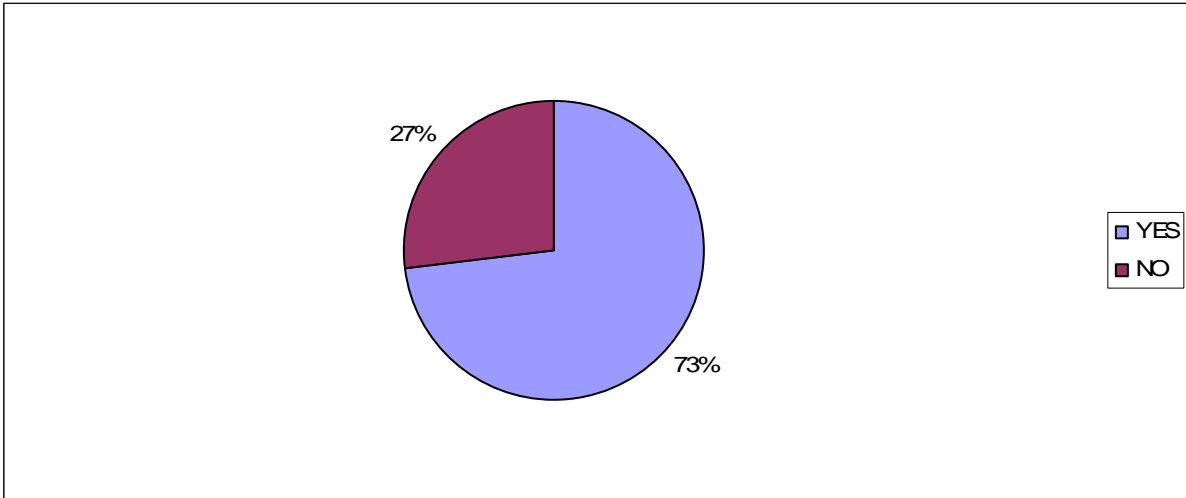


Of 777 responses

## Access to Care Services

### Question 1

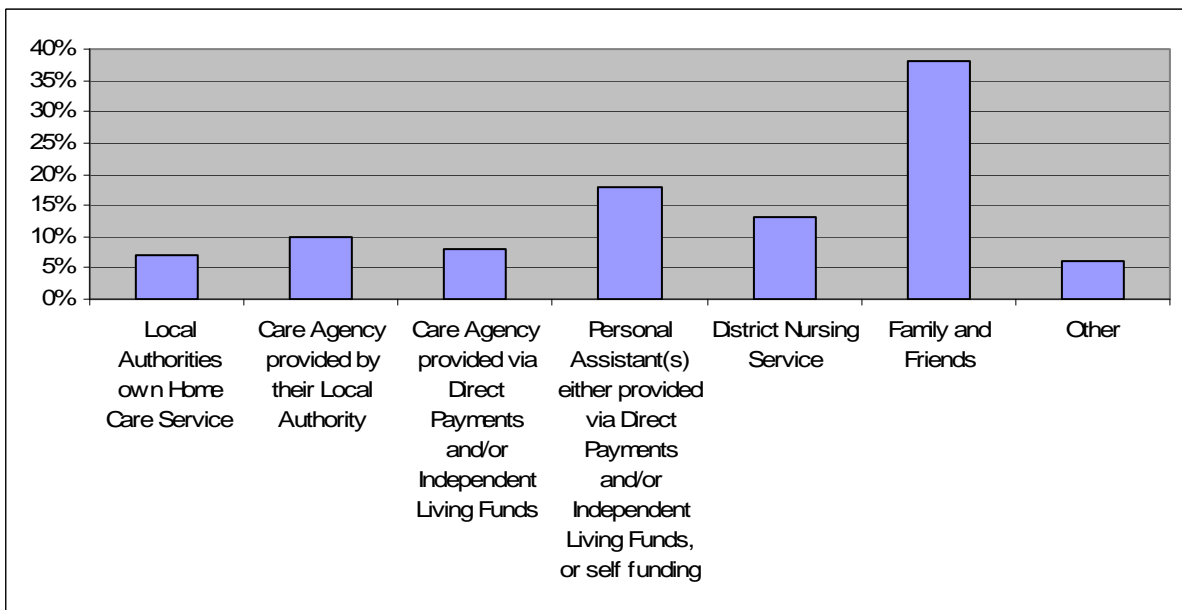
Do you require assistance to help you manage your SCI and help you get about?



Of 777 responses

### Question 2

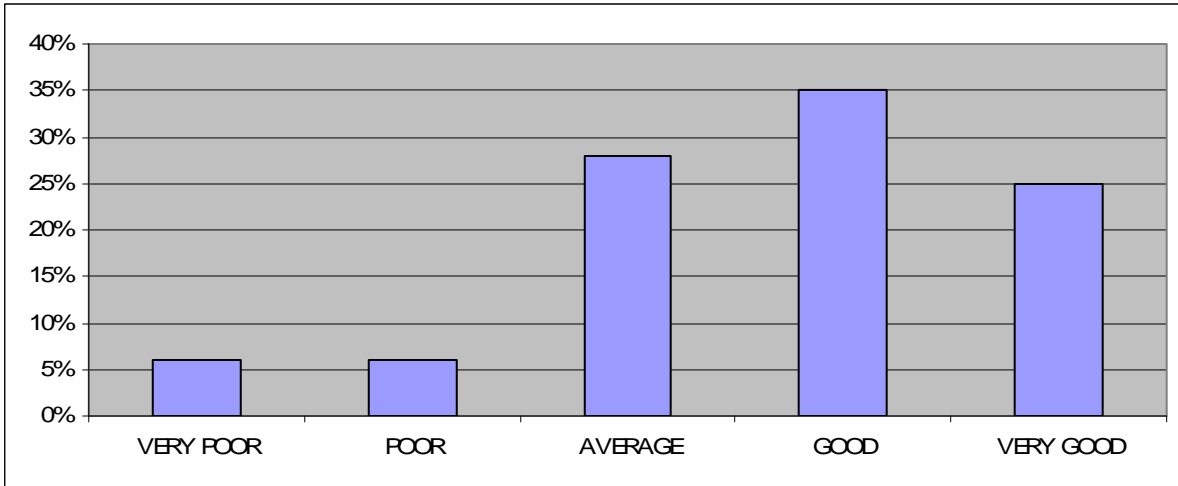
If you answered YES to question 1, who gives you this assistance?



Of 570 responses

### Question 3

Not including friends and family, how would you rate the assistance you receive?



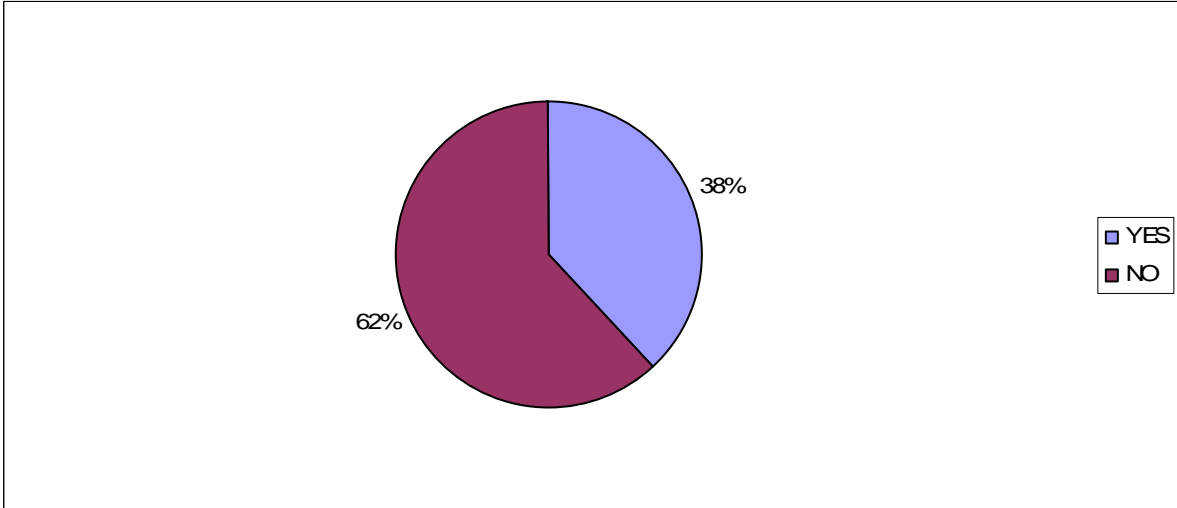
Of 493 responses

If VERY POOR or POOR, what major problems did you experience?

- Intrusion of privacy
- Support hours given limited or more support needed
- No service provided
- Lack of training/reliability in care staff
- Funding/service withdrawn
- Delay in service provision
- Management/administration staff poor
- No specialist help/assistance available
- Issues with bowel care
- Means testing
- Service not client centred
- Difficulties with District Nurses

**Question 4**

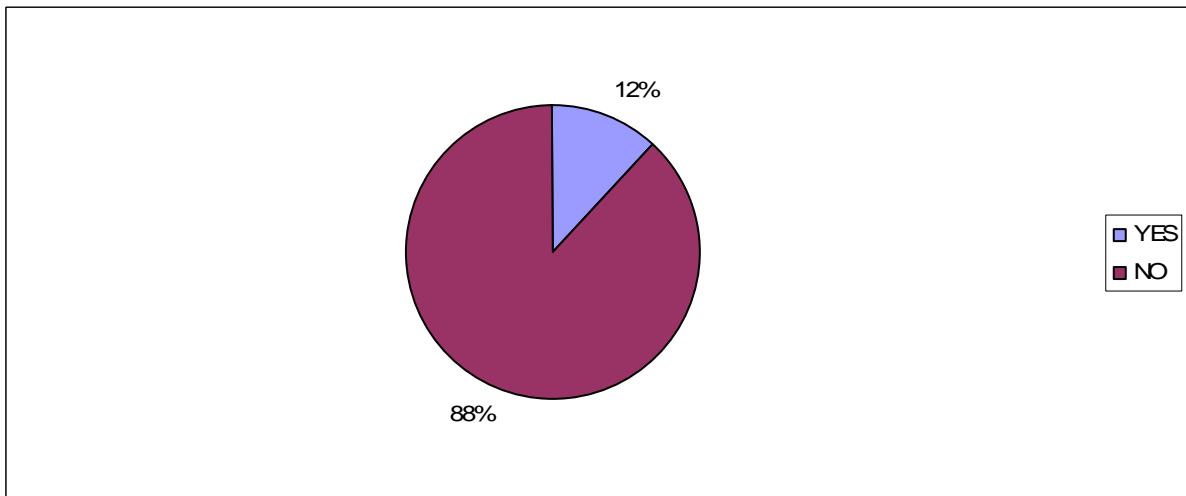
Do you need financial support for a personal assistant?



Of 561 responses

**Question 5**

Have you ever been refused financial support for a personal assistant?



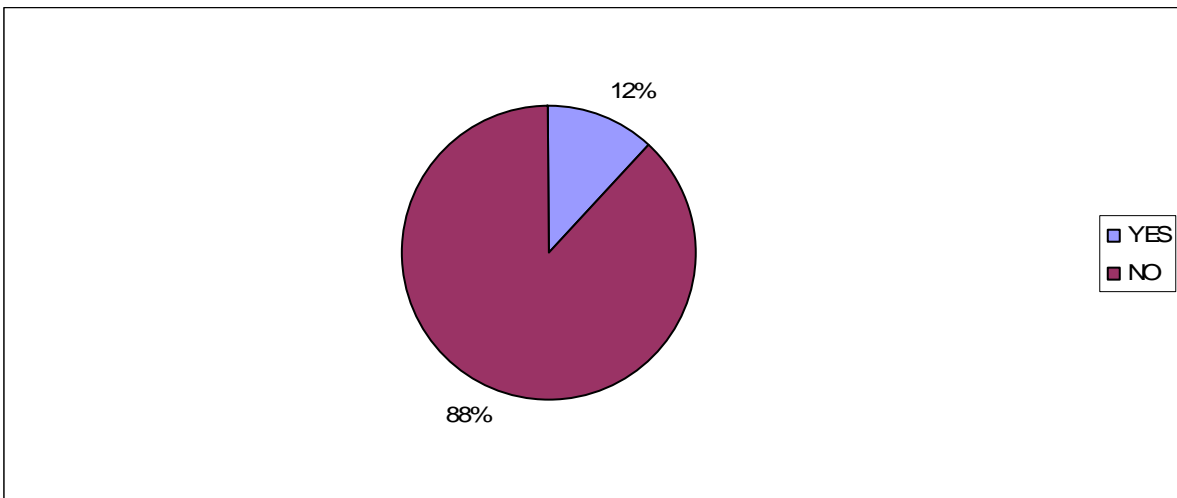
Of 444 responses

Reasons given for refusal of financial support were as follows:

- Partners pension
- Meant to be funded by Primary Care Trust
- Funding reduced
- Spouse provides care
- Savings/capital to high
- ILF and Social Services arguing between each other

**Question 6**

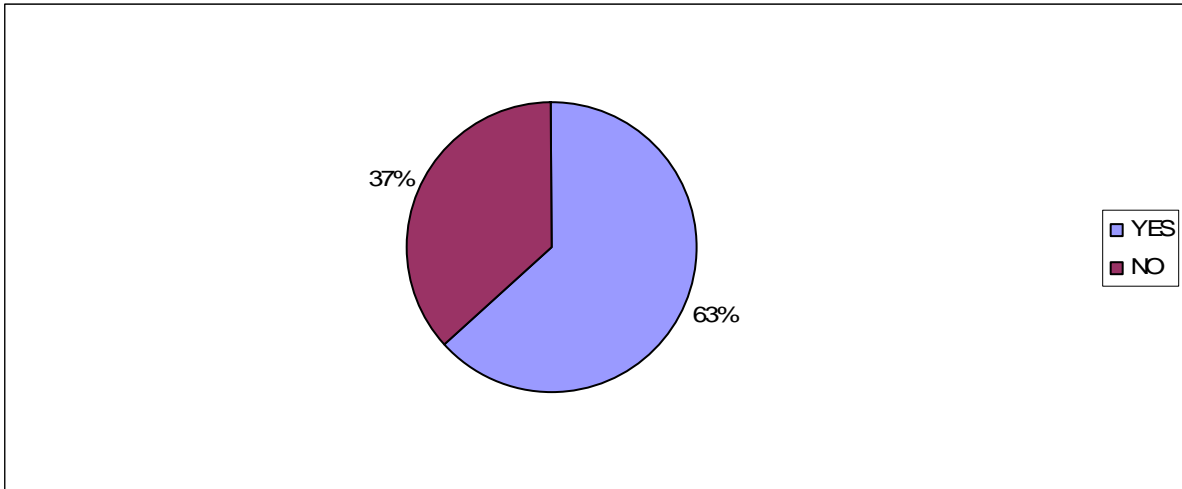
Have you ever applied for Continuing Healthcare Funding?



Of 648 responses

## Question 7

If you answered YES to question 6, were you successful?



Of 72 responses

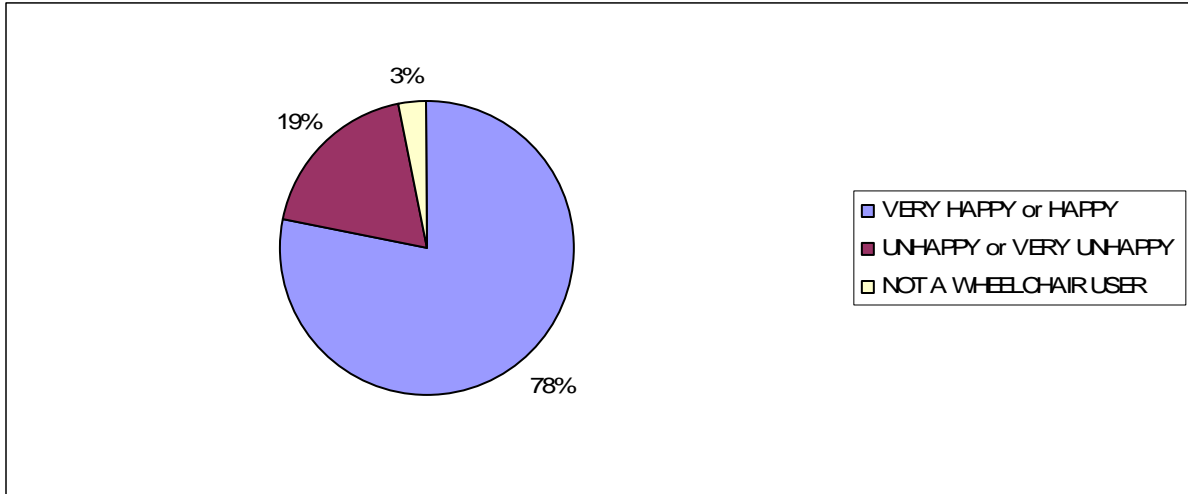
The following reasons were given for being unsuccessful:

- Too young to qualify
- Terminally ill – palliative care alternative available
- Failed eligibility criteria
- Did not have enough information to successfully apply
- Not enough healthcare needs
- Only received 50% of care costs
- SCI self inflicted
- Only terminally ill people qualify (advice given by Social Services)
- SCI Centre failed to fill out form correctly
- Failed on purpose – because would not have a choice of hiring Personal Assistants and/or Care Agency

## Wheelchair and Equipment services

### Question 1

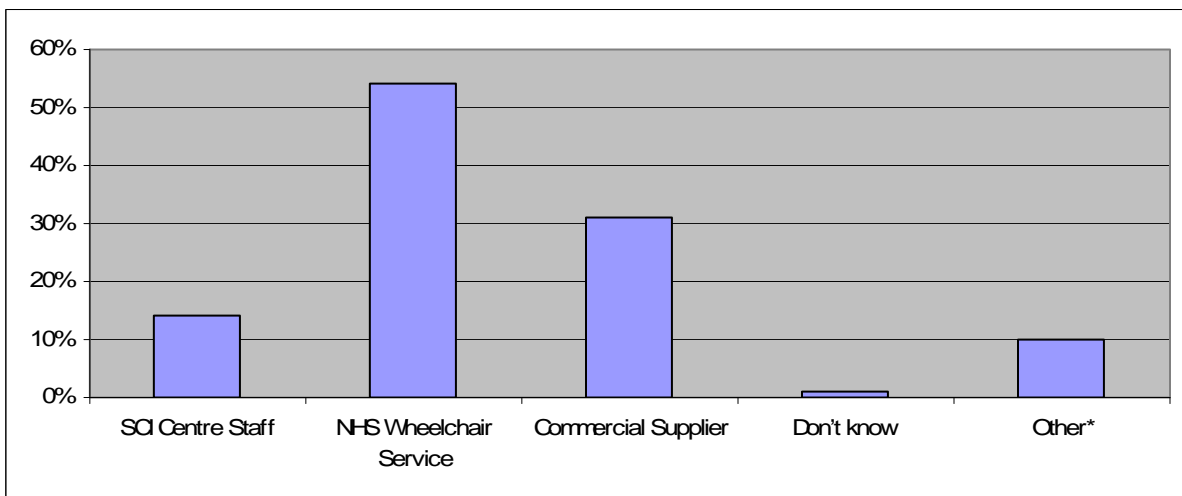
How happy are you with your current wheelchair(s)?



Of 781 responses

### Question 2

Who assessed you for your current wheelchair(s)?



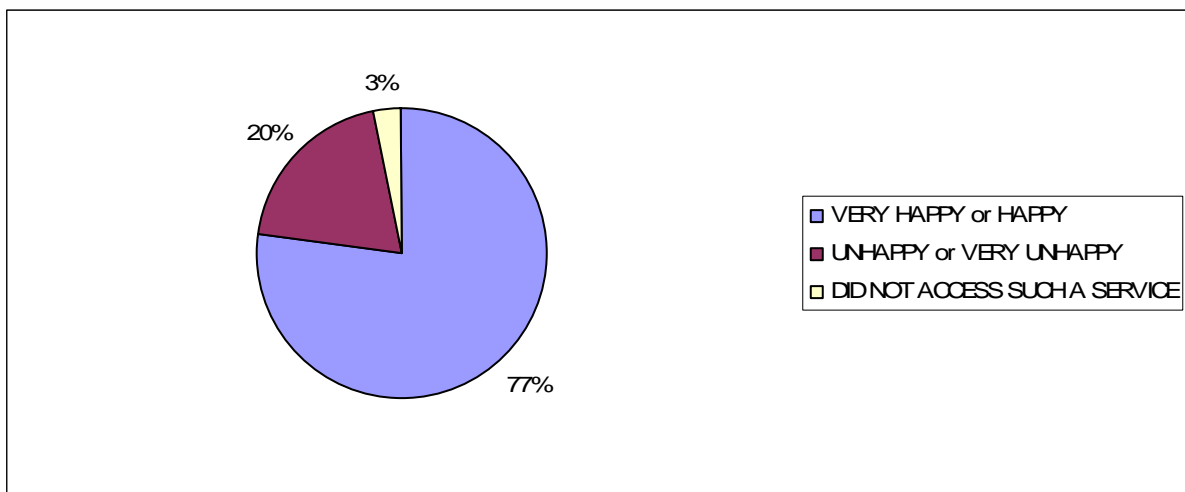
Of 756 responses. Some responders gave more than one answer.

*\*NB - of those answering 'other' 46% said they had self assessed while the rest said they had been assessed by the following:*

- *Access to Work*
- *Artificial Limb and Appliance Centre (ALAC)*
- *Foreign Health Service*
- *Local Disability Advice Centre*
- *Ministry of War Pensions*
- *Private Physiotherapist/Specialist*
- *Royal British Legion*
- *Whizz Kids*

### **Question 3**

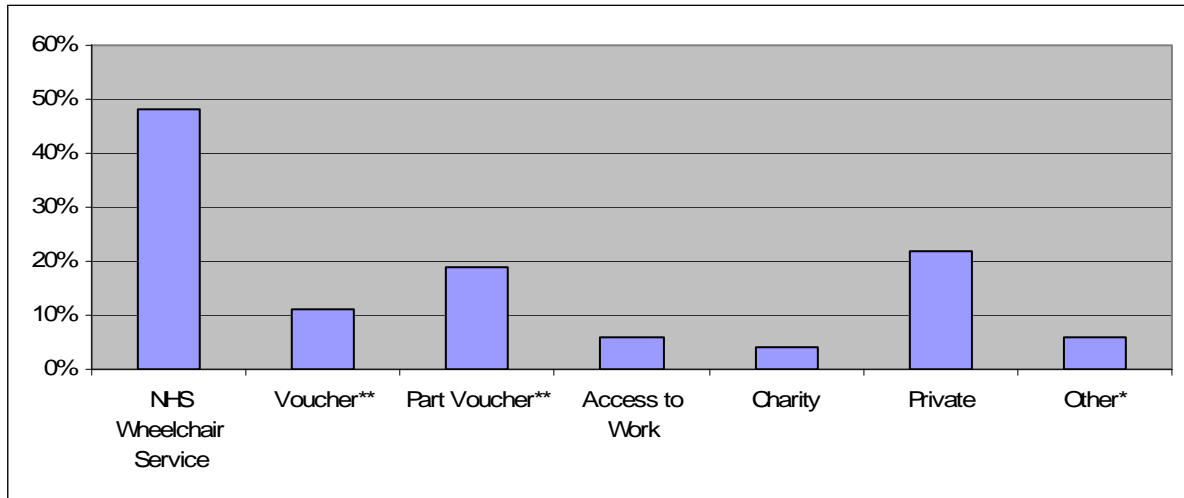
Overall, were you happy with the assessment, choice on offer and provision of the wheelchair?



Of 737 responses

#### Question 4

Who funded your wheelchair?



Of 749 responses. Some responders gave more than one answer.

*\*NB - of those answering 'other' 66% indicated that they had self-funded either the full cost or via part voucher and should have answered affirmative to Part Voucher or Private in the first instant. While 7% gave the name of a charity instead of answering affirmative to Charity in the first instant.*

*7% answering 'other' said the wheelchair was funded by their employer. Other funders were:*

- *The State of Jersey*
- *Ministry of War Pensions*
- *'The Geriatric Centre they hid me in'*

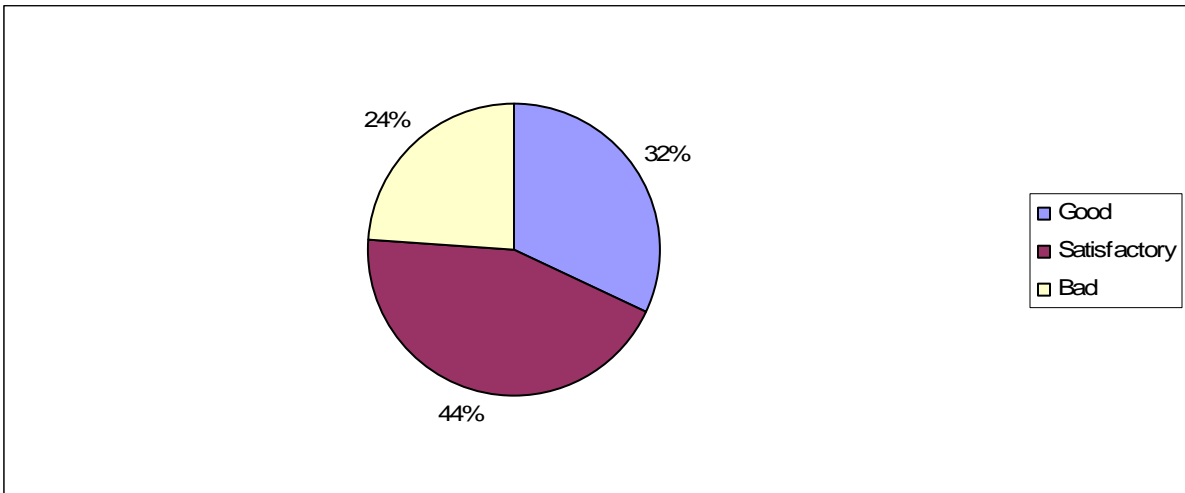
#### Question 5

If funded via a voucher or part of a voucher, how much was the voucher worth?

£1,005.38 average of 227 responses

### Question 6

If you have accessed an Equipment Service recently how do you rate that service?

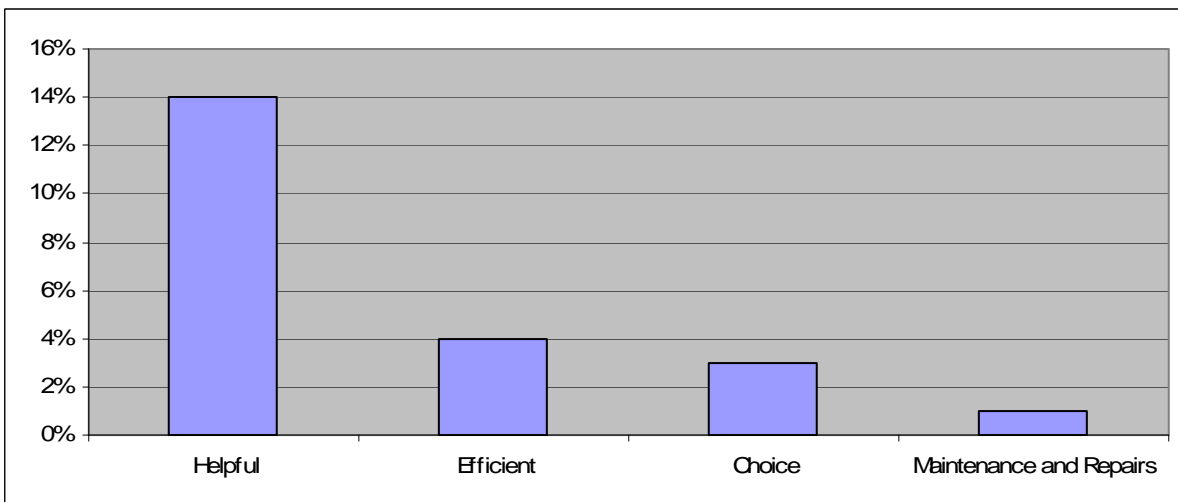


Of 413 responses

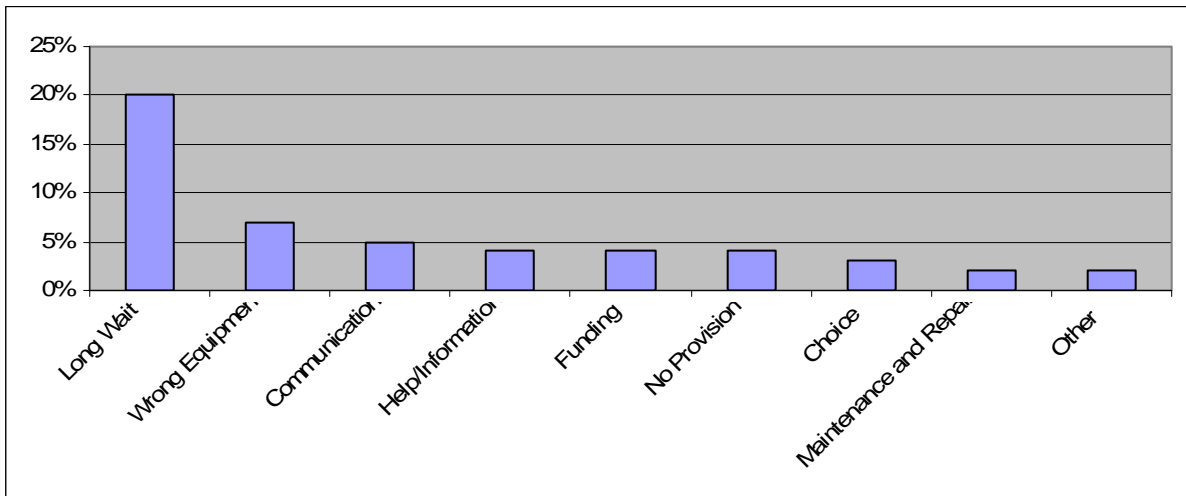
### Question 7

Please give a brief description of the good and bad aspects of the service you received:

Good



## Bad

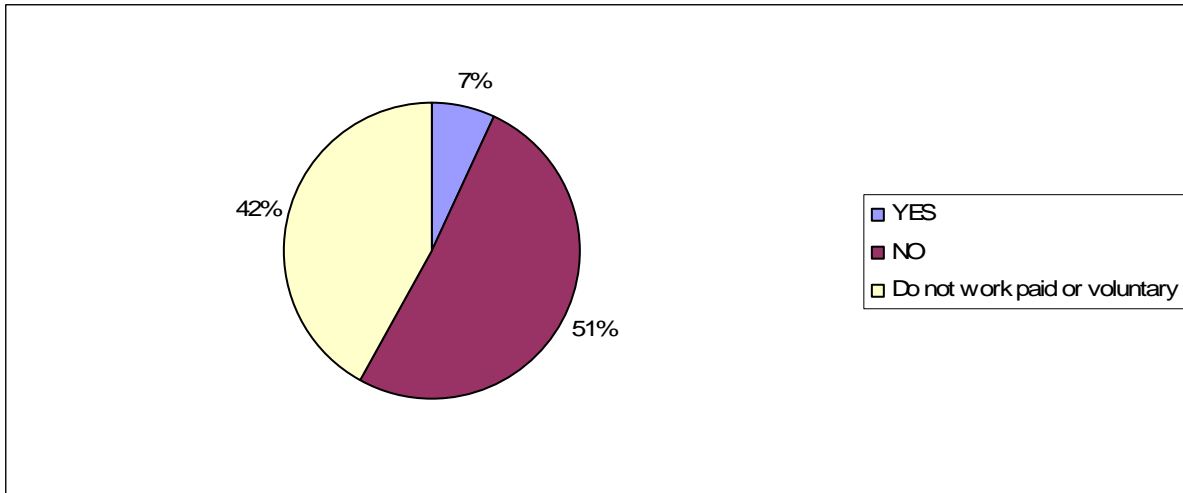


Of 271 responses

## Welfare Benefits

### Question 1

Have you experienced any problems accessing Welfare Benefits because you work or undertake voluntary work?



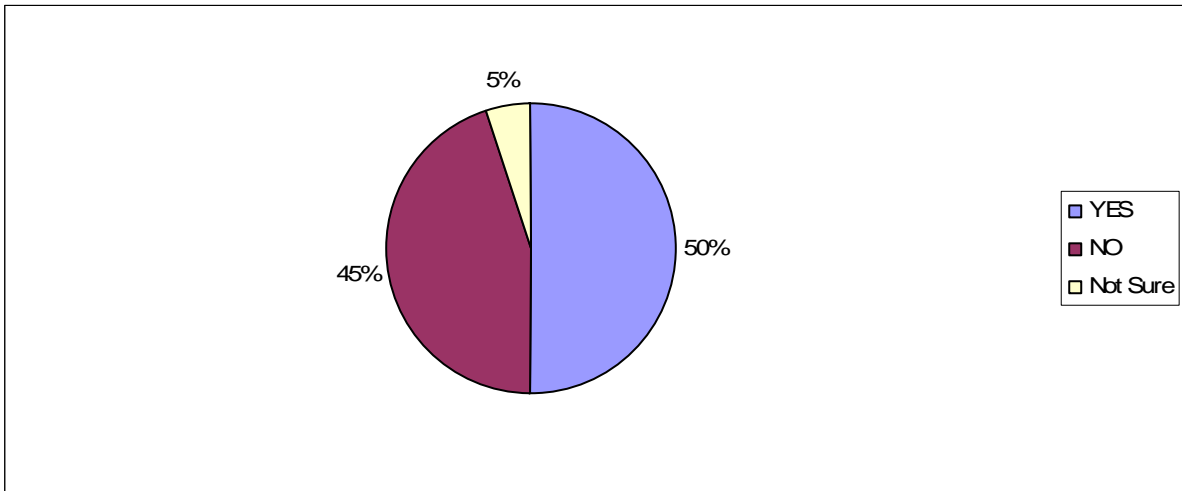
Of 760 responses

If YES, what is the major problem you experienced?

- Constant fear of losing benefits
- Lack of information
- Inflexible and confusing system
- Couldn't afford to stop work despite health problems
- Work more than 16 hours per week so benefits are cut
- Wages taken too much into consideration
- Out goings not taken into account
- Only able to take expenses because of impact on benefits
- Low pay, lack of respect and facilities
- Difficulty filling in application form
- DWP refused to have work considered as 'Permitted Work'
- Attendance Allowance stopped when started work
- Lost mobility component of Attendance Allowance and had personal care taken away
- Benefits stop and it takes time for them to be reinstated
- There was an attitude; 'because I work I don't need benefits'
- No help for spouse who is carer and works full time
- DWP didn't understand a structured settlement
- Not getting all care needs funded

## Question 2

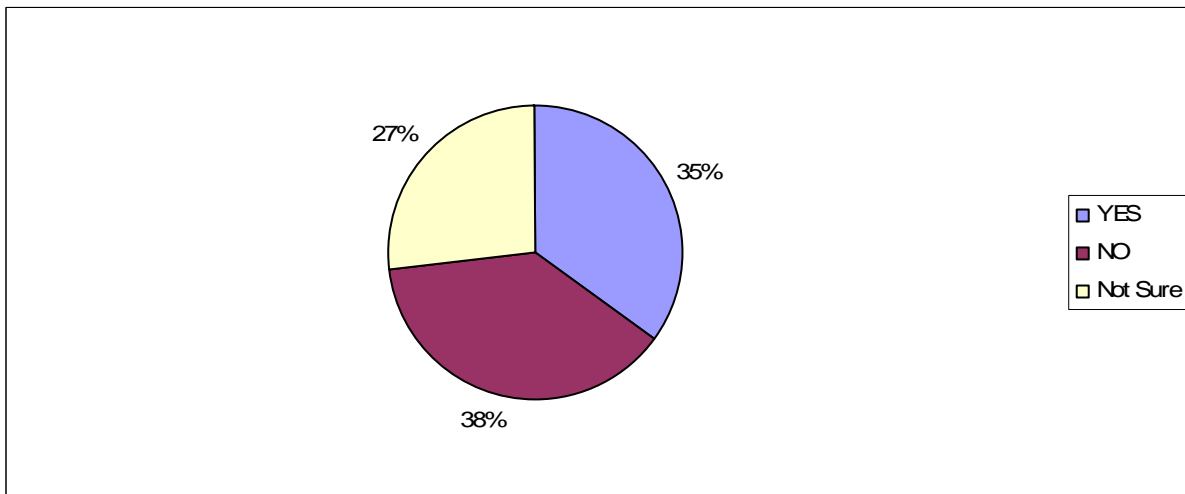
Would you say that you were reliant on Welfare Benefits?



Of 785 responses

## Question 3

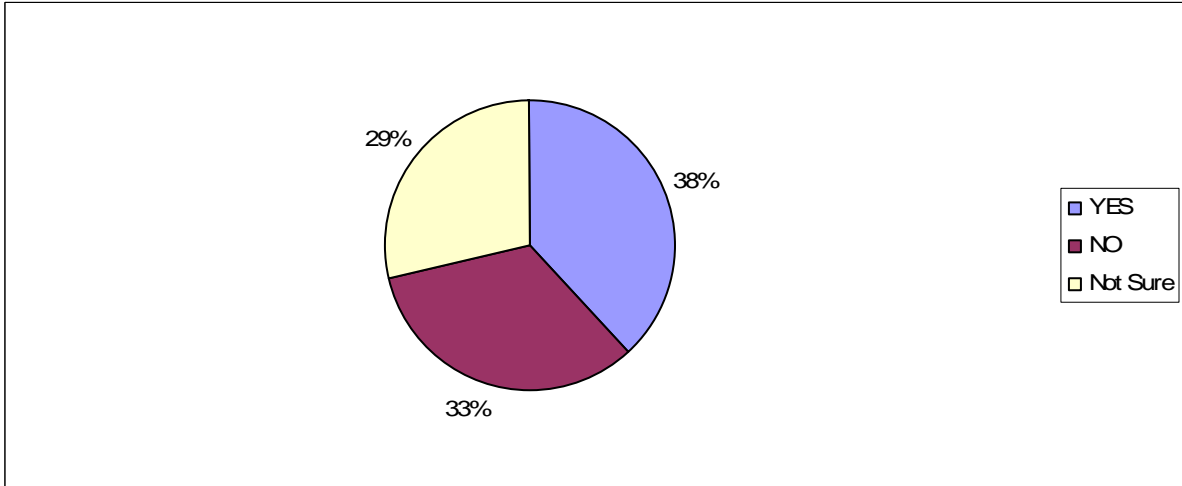
Are you aware of the current proposed welfare reforms?



Of 780 responses

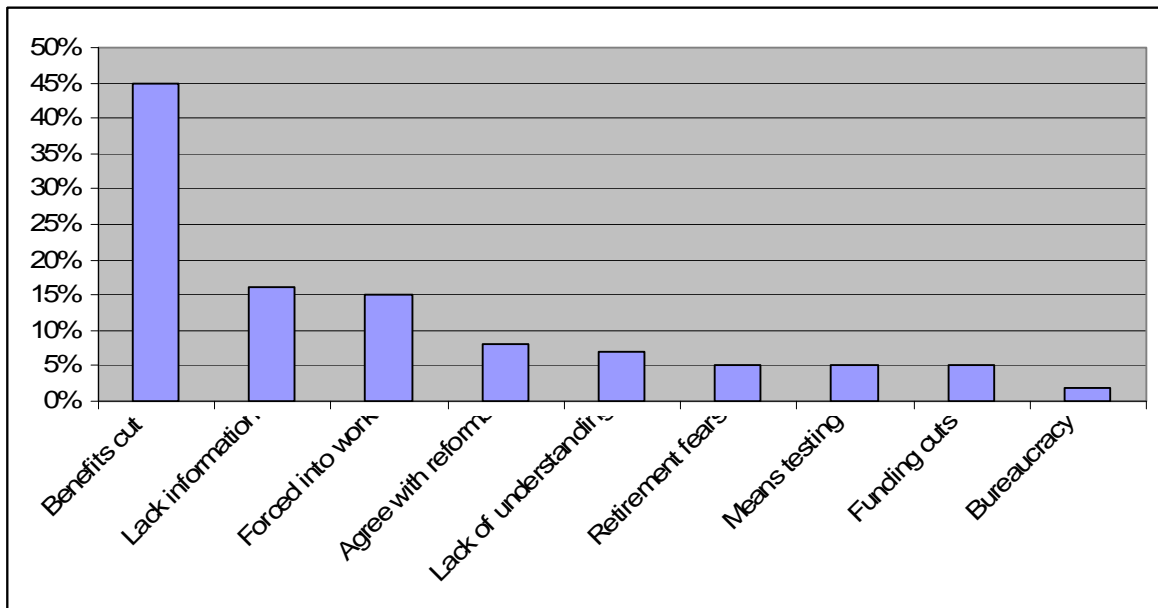
#### Question 4

If you answered 'YES' to question 3, are you worried how these reforms might affect you?



Of 372 responses

In what ways do you think you might be affected?



NB – some responders answers covered more than one area

## Shaping SIA's future campaigning activity

To help SIA identify the priorities we should be campaigning on in the next three years, please tell us how important you believe the following areas are.

	<b>Low Importance</b>	<b>Important</b>	<b>High Importance</b>	<b>Very Important</b>
Access to Buildings & Services	0%	8%	20%	72%
Accessible Toilets	2%	12%	22%	64%
Blue Badges (Abuse/Enforcement)	2%	13%	22%	63%
Community Care for SCI People	1%	15%	26%	58%
Equipment	2%	18%	31%	49%
Public Transport & Taxis	4%	16%	31%	49%
Winter Fuel Payments (under 60's)	7%	17%	22%	54%
Disability Awareness & Equality	4%	23%	28%	45%
Hotel & Holiday Accomodation	7%	26%	28%	39%
Education & Training	5%	30%	34%	31%
Employment	9%	29%	27%	35%
Private Cars etc	11%	26%	29%	34%
Air Travel	23%	37%	19%	21%
<i>Other (area given)</i>	5%	8%	15%	72%

Of 806 responses

The following areas came under the 'other' section:

Access to Buildings & Services	Housing
Access to Work	Information
Air Travel	IT
Alternative Treatments	National SCI Service
Blue Badges	NHS Funding
Bowel Care	Passports
Breakdown cover (cars/wheelchairs)	Personal Assistants
Car design	Post Code Lottery
Community Care	Public Transport
Concert Tickets	Rehabilitation
Continence Supplies	Research
Counseling	Residential Care
DDA Enforcement	Respite Care
Disability Awareness	SCI Awareness (NHS)
Empowerment	Toilets
Equipment	Voluntary Work
Family Support	Welfare Benefits
Fitness & Sports	Wheelchair provision
Footpaths	Winter Fuel Payments
Grants	
Hire cars abroad	

### **Campaigning for Change Action Group**

357 responders left their name/contact details to enable them to be more informed and take an active role in SIA's campaigning activity.