

Powered wheelchair user survey report

November 2014

Research Institute for Consumer Affairs (Rica)



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Rica is a national consumer research organisation focusing on the needs of disabled consumers. With grant funding we research and publish free consumer reports. They are all based on rigorous research and provide practical information needed by disabled and older consumers. We also carry out commissioned research work with manufacturers, service providers, regulators and policy makers to improve products and services. Our aim is to increase their awareness of the needs of disabled and older consumers through specialist research.

The research reported in this document was funded by Motability Tenth Anniversary Trust, The Clothworkers' Foundation and Scope.

1 Executive summary

1.1 Powered wheelchair user survey

Between April and July 2014 Rica (Research Institute for Consumer Affairs) carried out a survey of 341 powered wheelchair users to identify views and experiences of choosing, funding and maintaining a powered wheelchair. Additionally, 23 people who had been unable to secure funding for a powered wheelchair completed part of the survey.¹

The survey was funded by Motability, The Clothworkers' Foundation and Scope and is part of a wider research and information project to provide the information that powered wheelchair users need to make informed decisions. The project is being led by Rica with the support of Scope, Spinal Injuries Association, Disability Rights UK, Muscular Dystrophy Campaign and Whizz-Kidz. The survey was made available to respondents online (www.rica.org.uk) and in paper format. It was extensively promoted by Rica and our partner charities online, through social media and published print and online Newsletters.

The survey found that wheelchair users experience considerable difficulty at all stages of acquiring a powered wheelchair from getting information about available and suitable equipment to funding, supply and maintenance.

The findings of the survey allow Rica to identify the shortcomings of current provision of powered wheelchairs and make the following recommendations for improvements in the models of provision:

- Putting the wheelchair user at the heart of the wheelchair service and providing a transparent national standard service specification, which gives clear responsibilities and powers to funding bodies.
- Removing barriers between public budgets and ensuring that different funders work together to meet users' needs.
- Providing clear information about funding sources.
- A common standard for assessments covering users' capabilities, environments and lifestyles and a commitment to provide these speedily on referral.
- Devolving purchasing power to wheelchair users, allowing them to make supported buying decisions for themselves.
- Community enterprises supported by national information and procurement networks to provide mobility services to a common specification in a way appropriate to local and community needs.

¹ Survey questionnaires can be seen on the Rica research reports page (http://www.rica.org.uk/content/powered-wheelchair-user-research).



1.2 Freedom of information exercise

As part of the same project, Rica carried out a Freedom of Information (FOI) exercise with NHS wheelchair services. We contacted 127 wheelchair services asking about their criteria for supply and their caseloads. The findings of this exercise are presented in *Section 5 Freedom of information exercise*.

The survey findings and the results of the FOI exercise will be used, along with additional market research carried out by Rica, to inform consumer guidance about getting a powered wheelchair, which will be published on Rica's website as a printed guide in 2015.

2 Background

Rica and the five partner disability charities – Disability Rights UK, Scope, Spinal Injuries Association (SIA), Whizz-Kidz, and Muscular Dystrophy Campaign identified a need to provide new, detailed practical information to help consumers choose and fund powered wheelchairs.

Powered wheelchairs provide independence to many disabled adults and children – whether at home, at work, studying or out enjoying themselves. For many disabled people the right supportive seating can help promote good posture, reduce the need for pain control and prevent deterioration in condition and possible interventions (eg surgery). However, we know that disabled people and their families are experiencing great difficulty getting suitable equipment in a timely manner. The problems are of two kinds:

Funding:

Statutory funders may exclude disabled people because they don't meet funding criteria or they may not fund the equipment a disabled person feels they need or not supply the best available solution and the process of provision may take too long. Non-statutory funders may be hard to find and may also have funding criteria that exclude certain groups or individuals.

• Consumer choice:

powered wheelchairs can be extremely expensive products (some cost over £40,000) and with more than 300 available models the options are bewildering. Many disabled people access the market through statutory bodies or private providers, both of which limit the range of products that is available to the user. Disabled people who try to buy powered wheelchairs directly find it difficult to get information on available products and features and whether they will be suitable to their needs.

Newlife (2012) found that statutory funders were limiting disabled children's access to necessary equipment because of budgetary constraints:

"Over three quarters (77%) of UK professionals supporting applications to Newlife for equipment reported that they didn't apply to their local statutory services ... because they knew there was no point."²

Similarly, Muscular Dystrophy Campaign (2013) found that disabled people were having to find additional funds to buy and maintain wheelchairs (almost half of respondents to their survey did not receive full NHS funding for its cost and over one third had to fund the maintenance of their wheelchair), that disabled people were forced to wait for a wheelchair

² <u>From the Front Line: Reporting on the UK's disabled children's equipment provision</u>. Newlife Foundation for Disabled Children, 2012.



to be provided (one third of patients waited more than six months between requesting an appointment and receiving a wheelchair) and that disabled people were not getting the most appropriate equipment to meet their needs:

"My son's wheelchair is adequate but seating is not – he aches and you cannot get the best you want for his comfort, just the cheapest!' – Parent, Surrey."

Following consumer complaints, the Office of Fair Trading (OFT) investigated the market for mobility equipment in 2011. They concluded that it can be extremely difficult for consumers to select the right products and get value for money. OFT (2011) and the All Party Parliamentary Group for Paediatric Wheelchair Reform (2011) also found that the larger suppliers of mobility equipment are predominantly focused on supplying public purchasers and that this has an effect on product development, price and the provision of information to consumers and on how users' needs are assessed.

NHS England and NHS Improving Quality are engaged in a review process looking at wheelchair provision. This project, *My Voice, My Wheelchair, My Life*, will be launched on 27 November 2014. It follows a Wheelchair Summit held on 25 February 2014 which highlighted some of the shortcomings of the current provision model. It is hoped that the survey data reported here will help to inform that process.

The Motor Neurone Disease Association has identified that the current provision model doesn't meet the needs of people with MND. Having to order items from other prescription forms as specials increases costs and time delays. With funding from the DoH they have worked with three wheelchair manufacturers (Invacare, Ottobock and Sunrise) to develop a specification for a powered wheelchair to meet the needs of people with a deteriorating neurological condition, which was launched in April 2014. Each manufacturer offers a suitable powered wheelchair as an 'off the peg' item and the provision process is supported by three specialist wheelchair services that provide an appropriate pathway for people with Motor Neurone Disease.

3 Key Findings

The key findings of the powered wheelchair user survey are summarised in this section. More detailed analysis is presented in the following sections.

3.1 Barriers

- Almost all respondents experienced problems in acquiring a powered wheelchair.
- Many experienced problems in multiple areas.
- Specific areas of difficulty were: information and advice, funding, servicing and maintenance and supply.
- Respondents suggested solutions to the problems they faced; these were improvements to current provision (particularly NHS provision), alternative models of provision and market-oriented solutions.

³ Get moving 2013: The case for effective Wheelchair Services. Muscular Dystrophy Campaign, 2013.

⁴ *Mobility aids: an OFT market study.* Office of Fair Trading, 2011. Available at: http://www.wheelchairmanagers.nhs.uk/pubs.html

⁵ "My wheelchair is my shoes" Making the case for wheelchair reform. All Party Parliamentary Group for Paediatric Wheelchair Reform, Whizz-kidz 2011.



3.2 Information

- The main sources of information used by respondents were NHS wheelchair services, the internet and commercial suppliers.
- 22% used only statutory sources of information; significantly 13% used only commercial sources.
- Powered wheelchair users are generally unsatisfied with the information resources available to them.

3.3 Assessment

- Many users, including those getting a powered wheelchair for the first time, did not have an assessment.
- Assessments are mostly carried out by occupational therapists or physiotherapists, or by company sales agents.

3.4 Funding

- The majority of powered wheelchairs are paid for in full or in part using the user's own funds.
- A large proportion of powered wheelchairs are funded by some sort of co-funding arrangement.
- A greater proportion of the under-20s receive charitable funding towards their powered wheelchair; the over-20s are more likely to use their own funds to pay for a powered wheelchair.
- One quarter (26%) of respondents have been refused funding for a powered wheelchair, by NHS wheelchair services or by funding charities.
- Only half (50%) of the powered wheelchairs covered by the survey are considered to have been good value for money by their users. Among under-20s this proportion falls to one third (33%).

3.5 Maintenance

 Maintenance is carried out by NHS wheelchair services, and by commercial maintenance services. There are problems associated with delays in getting equipment repaired and difficulties in getting parts.

3.6 Supply

- Supply is by NHS wheelchair services, commercial services, charities and private sales (12% of the total).
- Satisfaction is highest with charities and lowest with NHS services.

4 Survey results

4.1 Respondent profile

Most respondents (155) are aged between 40 and 59. 102 are aged less than 40 and 107 over 59.



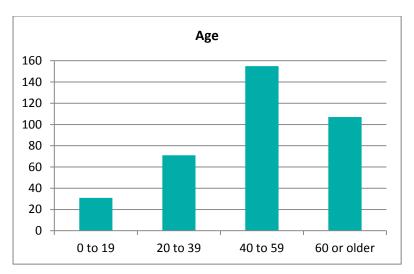


Figure 1 Age of respondents

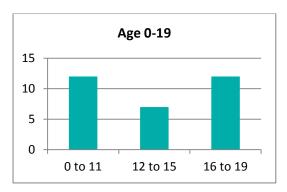


Figure 2 Age of respondents 0 to 19

Respondents represented a broad spread of new and long term wheelchair users.

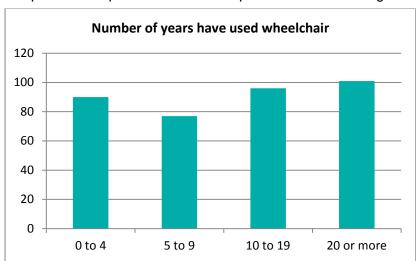


Figure 3 Number of years using a wheelchair



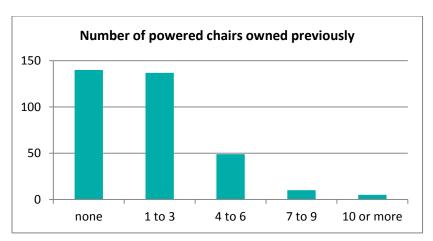


Figure 4 Number of powered wheelchairs owned previously

- More than half of respondents (201) have had more than one powered wheelchair in their lifetime (N=341; respondents to powered wheelchair users' survey only).
- Most respondents (241) also have a manual chair.
- The majority of respondents (233) have only one powered wheelchair, though 83 (24%) have two and 19 (5%) have three or more (N=341; respondents to powered wheelchair users' survey only).
- Two thirds of respondents (242), use an adapted vehicle. The majority of these (170) have a wheelchair accessible vehicle (WAV) while 55 use a boot hoist.

4.2 Barriers

4.2.1 Problems

Respondents were asked to identify the areas where they had experienced difficulty when getting a powered wheelchair. Responses are summarised in Table 1.

Have you (or the wheelchair user) experienced difficulty in the following areas?	Number of users	% of all users
Choosing a powered wheelchair to suit your needs	146	42%
Finding funding for a powered wheelchair	142	41%
Maintaining or servicing a powered wheelchair	131	38%
Getting assessed for a powered wheelchair	126	36%
Getting parts for a powered wheelchair	107	31%
Getting a powered wheelchair supplied at the time you need it (eg when discharged from hospital)	82	24%
Finding a suitable supplier for a powered wheelchair	69	20%

Table 1 Barriers

- Only 75 respondents reported no problems at all.
- Many respondents have experienced problems in multiple areas:

"As a parent it's very hard to know what your child needs and what is on the market. Trying to fundraise and get the right thing at the time they need it is very hard. On going service and maintenance is also our responsibility in addition to caring 24/7 and it becomes another problem especially as we rely so heavily on equipment."



 Over 2/5 of respondents have experienced difficulties getting information about powered wheelchairs:

"A lot of places just say no its not their responsibility and don't tell you where to go for advice/funding. Feels very big decision and no one to advise me."

"It is actually quite complicated sourcing a powered wheelchair. I originally went through Invacare but websites are vague and quite sales orientated. I ended up with a sit-to-stand powered wheelchair which subsequently proved unsuitable for me!"

 Over 1/3 of respondents have experienced difficulties getting assessed for a powered wheelchair:

"I could not get an NHS wheelchair assessment. The closest independent living centre is thirty odd miles away in the middle of nowhere and not accessible by public transport, and when I made an appointment for them to do an assessment and managed to get there, they told me they only do NHS referrals and that, without asking me, they'd given my referral to the Simplyhealth shop in the same building."

 Over 2/5 of respondents have experienced difficulties getting funding for powered wheelchairs:

"Funding - sent from pillar to post - not joined up and funding took a long time to be approved by ATW and they wanted me to part pay"

"Funding is a nightmare - it all takes far too long - if I'd have waited til all the assorted nightmare bureaucracies had finished, I'd have missed work for about 12 months and lost my job. They don't seem to know or care that disabled people can't just stop leaving the house/sofa/bed for a year or more while they tit about having meetings and setting stupid, irrational criteria for even accepting referrals. I've heard that even if you get funding it can take another six to twelve months for the NHS to actually supply a wheelchair and that it's often not as agreed when it arrives."

 Nearly 2/5 of respondents have experienced difficulties in repairing or maintaining a powered wheelchair and in getting parts:

"My NHS stopped the repair company from stocking many parts due to funding cuts. They now have to order most things in after it's been approved. This has made waiting for repairs a nightmare leaving me without a chair for weeks in one instance."

"The NHS contracted NRS Healthcare to service/repair my powered wheelchair but they are clueless, disorganized and amateurish. After 7-8 weeks of waiting, their engineer turns up without the part needed. I'm still waiting. They also damaged my chair in their workshop."

 1/4 of respondents have experienced difficulties in getting a powered wheelchair supplied:

"Powerchairs are costly, and so many places do not stock a wide range but order in on demand meaning that it is very difficult to get as soon as you need it, we struggled to find any hire places near that would hire one out without expensive fees"

"finding a reliable, flexible and responsive local partner to work with on my chair has been hard. Box shifters are everywhere, quality companies are rare."

4.2.2 Solutions

Respondents were asked to suggest solutions for the problems they identified.

• A number of responses focused on improvements to NHS provision:



"Better funding of NHS wheelchair service. Some choices of what powered wheelchairs were available at time of decision from assessment."

"NHS England has launched a project to improve the NHS Wheelchair System but it will take some time to achieve. Each of the 152 Wheelchair Services should have a Service User Group standing up for the rights of its local users and participation in the way the service is run and funded"

"Greater choice of powered wheelchairs provided by NHS. Assessment should cover all daily situations. Increased NHS funding for specialist technology such has mini joystick, tilt/recline/riser functions. More use of a combination of funding, e.g. NHS, Direct Payments, Mobility benefits, personal contributions. Wheelchair services need to provide better information on current technology."

"The wheelchair services need to get their act together and realise that's not good enough; that the goal has to be the greatest possible degree of independence, and that things like - will it go in the car? can I lift it? will it go on a bus? are legitimate factors to be considered when choosing a chair. I think there should be a time limit from referral to delivery of chair, and to be honest I'd like to see that under a month, although the standard NHS 18weeks would be a start. They need to take account of people's lives and responsibilities; that you can't just stop going to work until they get round to sorting you out, you can't stop getting shopping in and taking the kids to school, and that 'get someone else to do it for you' belongs in the dark ages - we're past that and it's time they caught up. Equally, I'd like to see social services acknowledge that especially for younger people, a decent wheelchair that actually meets their needs can replace a fair amount of care support, and that it may well be worth redirecting funding accordingly."

Others proposed alternative community-based services:

"An integrated service, one stop-ethical shop to protect, advise & serve users & their families from assessment, through to buying, service & maintenance."

"More assessment centres not necessarily NHS but could be OT funded by NHS. Access to training centres with a one stop shop service for assessment, advice, information, trying out the chairs, training to use it. advice on insurance, maintenance and follow up"

"A regional advocacy service would hugely assist a lot of people who maybe haven't been able to use the voucher scheme without some kind of help."

"Should be specialist OT available to anyone, even private funding. Access to Work should have been able to advise on what was needed especially if first chair."

Finally, others suggested market-oriented solutions:

"The manufacturers should make available demonstration models for short term loan, before buying, to ensure the person gets the most suitable chair for their needs."

"Equipment needed for the wheelchair should be in the UK and not sent from abroad making the wait longer. Funding should be available more because more people prefer these type of wheelchairs. Suppliers should keep their costs down to enable a user to buy from them more"

"Some degree of consistency in shape of some key parts e.g. arm supports, VERY important to do a whole life assessment not just look at the home. There needs to be funding support for all. Need chairs with standardised chargers and controllers. Need assurances that if sold that parts will be available quickly... waiting a week for parts is too long."



"Reduce the obscene mark-up on some parts for powerchairs. Batteries are expensive too, but these have much lower profit margins because of competition from many different suppliers."

"pressure on suppliers to stop using spare parts supply as a cash cow dependent on its captive audience."

4.3 Information sources

Respondents were asked which of the following information sources they used when acquiring their most recent powered wheelchair. Numbers of respondents who chose each are shown in the table. The right column shows what proportion of all respondents used each information source.

Sources	Number of users	% of all users
NHS wheelchair service	187	51%
Internet - commercial website	136	37%
Equipment supply company	128	35%
Internet - independent website	108	30%
Exhibition (eg Naidex)	87	24%
Shop	70	19%
Magazine or other publication	59	16%
Personal recommendation	58	16%
Publicly funded occupational therapist	53	15%
Internet - social forum	50	14%
Other	43	12%
National information/advice organisation	24	7%
Privately funded occupational therapist	17	5%
Local information/advice organisation (eg Independent Living Centre)	16	4%

Table 2 Information sources used

- NHS Wheelchair services were used by the most respondents.
- The internet also features prominently, as do commercial sources.

The information sources in Table 2 can be grouped into four classes:

- statutory (NHS, publicly funded OT)
- commercial (equipment supply company, shop, commercial website, magazine, exhibition)
- independent (privately funded OT, independent website, national or local information/advice organisation)
- social (internet forum, personal recommendation).

A large proportion of respondents got their information from commercial sources. Table 3 shows how many respondents received information **exclusively** from each kind of source.



Sources used exclusively	Number of users	% of all users
Statutory body	81	22%
Commercial source	46	13%
Independent advice	4	1%
Social/personal contact	3	1%

Table 3 Information sources used exclusively

• 46 respondents – 13% of the sample – received their information **only** from commercial sources.

Respondents rated their experience of using each of these information. Figure 5 shows ratings across all information sources. Table 4 shows the percentage of respondents who used each source of information who found it either unsatisfying or very unsatisfying.

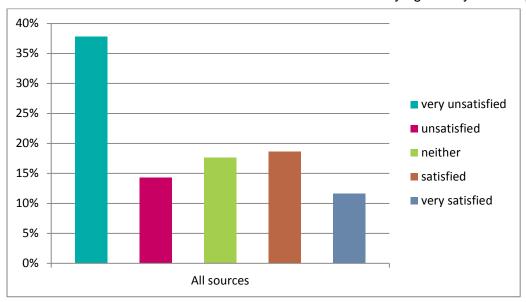


Figure 5 Satisfaction ratings – all information sources

'Unsatisfied' or 'very unsatisfied'	
NHS wheelchair service	37%
Internet - commercial website	56%
Equipment supply company	58%
Internet - independent website	67%
Exhibition (eg Naidex)	60%
Shop	64%
Magazine or other publication	63%
Personal recommendation	53%
Publicly funded occupational therapist	36%
Internet - social forum	71%
National information/advice organisation	59%
Privately funded occupational therapist	60%
Local information or advice organisation	64%

Table 4 Percent 'unsatisfied' or 'very unsatisfied' with each information source



 Satisfaction is generally low: more than 50% did not receive any satisfactory information; statutory bodies performed the least worst.

Satisfaction ratings for the different types of information source are shown in the following chart.

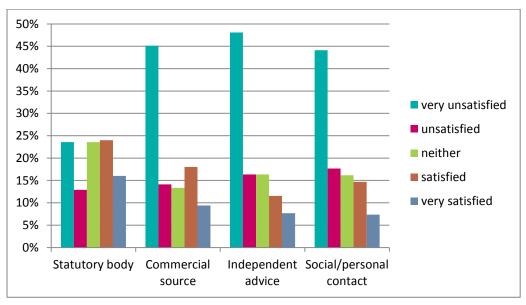


Figure 6 Satisfaction ratings for types of information sources

4.4 Assessment

134 respondents (37%) didn't have an assessment when they acquired their most recent powered wheelchair. Surprisingly, the proportion for first time users (people who have not previously owned a powered wheelchair) was the same. Under 20s are more likely to have had an assessment (23/31 = 74%).

Assessments were carried out by occupational therapists (OTs) or physiotherapists (PTs), mostly provided by statutory or voluntary bodies but also by rehabilitation engineers, company sales agents and 'others'.

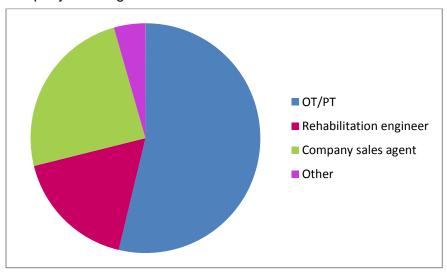


Figure 7 Who carried out the assessment?



Assessments covered needs relating to the user's condition (eg controls, suspension, support), surroundings (eg space in the home, terrain and gradient) and lifestyle (eg use with a car, sports and hobbies).

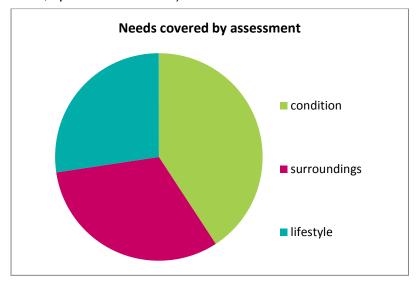


Figure 8 Needs covered by assessment

OTs/PTs and rehabilitation engineers were more likely to focus on issues relating to the user's condition:

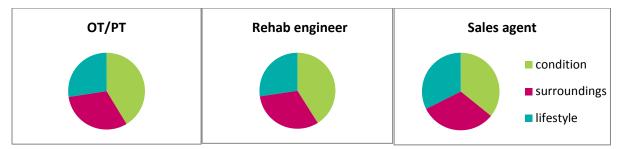


Figure 9 Needs covered by different assessors

Assessments for the under 20s focused on lifestyle and surroundings more than on the user's condition.

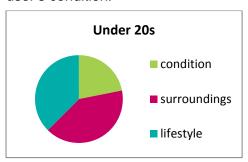


Figure 10 Needs covered in young people's assessments



4.5 Funding

4.5.1 Funding sources

Respondents were asked which of the following funding sources they used when acquiring their most recent powered wheelchair. Numbers of respondents who used each are shown in the table. The right column shows what proportion of all respondents used each funding source.

Funding sources	Number of	% of all users
	users	
Own funds	115	32%
Motability	3	1%
NHS wheelchair service	87	24%
Other NHS funding (eg Continuing Care)	3	1%
Access to work	13	4%
Other public funds (eg education)	1	0%
Charitable fund	19	5%
Combination of the above (co-funding)	123	34%

Table 5 Funding sources used

Funding sources – under 20s	Number of users	% of all users
Own funds	14	19%
Motability	1	1%
NHS wheelchair service	19	26%
Other NHS funding (eg Continuing Care)	0	0%
Access to work	1	1%
Other public funds (eg education)	1	1%
Charitable fund	18	25%
Combination of the above (co-funding)	19	26%

Table 6 Funding sources used – under 20s



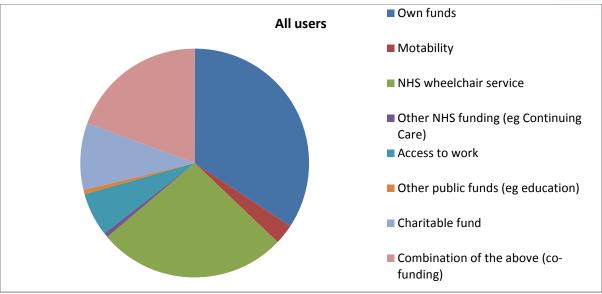


Figure 11 Funding sources used

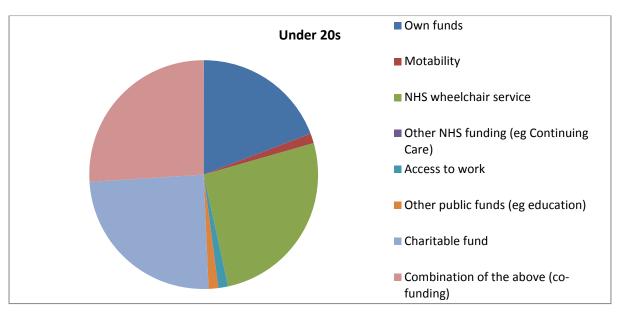


Figure 12 Funding sources used – under 20s

- The majority of powered wheelchairs are funded by some sort of co-funding arrangement or out of the user's own funds.
- A greater proportion of the under-20s receive charitable funding towards their powered wheelchair.
- The over-20s are more likely to use private funds to pay for a powered wheelchair.
- Public budgets other than NHS wheelchair services and Access to work (continuing care, education budgets) do not pay for powered wheelchairs except in very few cases.
- Not many respondents used Motability for their powered wheelchair.

4.5.2 Co-funding arrangements

Co-funding typically involves a statutory or other public funding body making a contribution towards the equipment, which the user tops up from their own funds or by recourse to



charity. The table shows how many co-funding arrangements each funding source participated in; the right hand column gives this as a percentage of all co-funding arrangements.

Funding sources in co-funding	Number of chairs	% of all co- funded chairs
Own funds	103	84%
Motability	15	12%
NHS wheelchair service	83	67%
Other NHS funding (eg Continuing Care)	1	1%
Access to work	26	21%
Other public funds (eg education)	3	2%
Charitable fund	41	33%

Table 7 Funding sources in co-funding arrangements

• The most common co-funding arrangements involve topping up NHS funding from private funds, followed by topping up one or more charitable grants with private funds and then topping up an Access to work grant with private funds.

Most common co-funding arrangements (funded chairs only – includes self-funded)	Number of chairs	% of co-funded chairs	% of all funded chairs
Own funds + NHS	55	50%	16%
Own funds + Access to work	21	19%	6%
Own funds + Charitable fund	27	24%	8%
NHS + Charitable fund	16	14%	5%
Access to work + Charitable fund	3	3%	1%

Table 8 Commonest co-funding arrangements

4.5.3 Satisfaction with funding sources

Respondents rated their experience of using each of these funding sources on a scale of 1 ('very unsatisfied') to 5 ('very satisfied'). The table shows the percentage of respondents who used each of the main funding sources who found it either satisfying or very satisfying. This table shows only respondents who successfully acquired a wheelchair using this source.

'Satisfied' or 'very satisfied'		
NHS wheelchair service	42%	
Own funds	44%	
Access to work	66%	
Charitable fund	86%	

Table 9 Percent 'satisfied' or 'very satisfied' with main funding sources



Satisfaction ratings for these four funding sources are given in this chart.

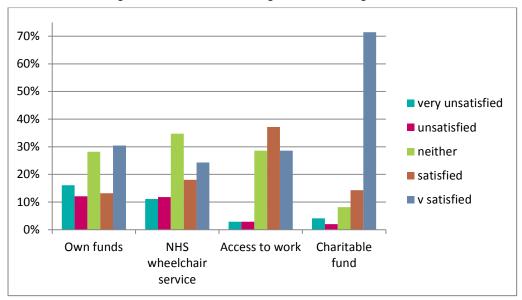


Figure 13 Satisfaction ratings for main funding sources

- The greatest level of satisfaction (86%) is with charitable funds.
- The least (42%) is with NHS wheelchair service.

4.5.4 Funding refusals

87 respondents (26%) have been refused funding for a powered wheelchair. This includes the 23 who filled in the additional survey for people who have not been able to get one.

Funding refused by	Number of users	% of all users
NHS wheelchair service	75	76%
Access to work	4	4%
Charitable fund	14	14%
Other	6	6%

Table 10 Refused funding for a powered wheelchair

- Even among those users who have been able to get one, 19% have been refused funding by some agency.
- Most commonly it is the NHS wheelchair service that will not provide an individual with a powered wheelchair.

In the vast majority of cases (73%) the reason for the refusal was that the user didn't meet the criteria of the wheelchair service or funding charity.

Generally, NHS wheelchair services do not supply powered wheelchairs if the user can use a manual chair, if they do not use a wheelchair in their homes (either because they don't need to or because their home isn't suitable) or if they are unable to operate a powered wheelchair independently. Many services also do not supply powered wheelchairs to people with visual impairments and many do not supply wheelchairs of any kind to people who can walk a little, even if only indoors or to people with short life-expectancy. Survey respondents fell foul of all of these criteria. Charitable funds sometimes operate similar criteria, and also sometimes means test applicants or refer them to other (eg public) funding sources.



4.6 Value for money

Two thirds of respondents (66%) feel their primary chair provides good value for money. When considering all powered wheelchairs they own, this proportion falls to half (50%). One of the reasons for people to own more than one powered wheelchair is that they have previously purchased an unsuitable one. This may help to explain this difference.

	Primary chair		All chairs	
	Number of chairs	% of all chairs	Number of chairs	% of all chairs
Yes	200	66%	273	50%
No	102	34%	272	50%
Total	302		545	

Table 11 Does your wheelchair provide good value for money?

	Number of chairs	% of all chairs
Yes	9	33%
No	18	67%
Total	27	

Table 12 Does your wheelchair provide good value for money? – under 20s

• Wheelchair users under 20 (or those that answered for them) were less likely to consider their wheelchair to have been good value for money.

Reasons that are given for considering a powered wheelchair not to have been value for money are of two sorts:

- that the price of the equipment is high, considering what you get:
 - "Yes it is a very high end chair but I think prices are too high for all types of chair" "Cannot see where the cost over £2000 is."
 - "I can't believe such a simple bit of kit costs so much. There again, anything to do with disabilities does, we find."
- that the quality of the equipment is low:
 - "Unfortunately NHS chairs are cheap and cheerful. They do not meet my needs, in the respect of durability or distance I would like to travel."

60% of negative responses focus on the high price of the equipment, 40% on its quality. For the under 20s, 75% of negative responses (14/19) focus on the high price.

Reasons that are given for considering a powered wheelchair to have been value for money are of five sorts:

- that the quality of the equipment is high:
 - "It has been extremely reliable and takes a lot of knocks and bumps and hardly anything has broken or snapped off. It's incredibly comfortable and also can be converted from rear wheel to front wheel drive to suit your need. It also has a tilt in space mechanism and elec elevating leg rests that make it very comfortable for long periods"



- that it was provided free of charge by some statutory or charitable body:
 - "I received this from social services"
- that the buyer was able to secure a good deal for their purchase:
 - "includes servicing and repairs through Simply Health. (£40 per week)"
- that the equipment contributes to a highly improved quality of life for the user:
 - "What price do you place on independence?"
- that the price of the equipment is low for what you get:
 - "cheaper than my manual chair"

46% of positive responses focus on the quality of the equipment, 20% on supply, 17% on an advantageous deal, 14% on the improvement in the user's quality of life and 3% on the price.

4.7 Maintenance

Wheelchair maintenance is carried out by NHS wheelchair services, by supply and maintenance contractors, by local shops and businesses and by users themselves. Numbers of respondents using each of these in the last 5 years are shown in Table 13. These figures relate to the main survey only (respondents who have acquired a powered wheelchair).

Maintenance services used	Number of users	% of responses
NHS wheelchair service	145	34%
Equipment supply company	138	32%
Shop	87	20%
DIY	59	14%
Other	2	0%

Table 13 Maintenance services used

Respondents were asked to rate each of the maintenance options they used. The table shows the number and percentage of respondents who found each option either satisfactory or very satisfactory.

'Satisfied' or 'very satisfied'		
NHS wheelchair service	49%	
Equipment supply company	57%	
Shop	62%	
DIY	73%	

Table 14 Percent 'satisfied' or 'very satisfied' with each maintenance service

4.8 Supply

Wheelchairs are supplied in a number of different ways including the following: directly by the NHS wheelchair service, directly by a funding charity, by an equipment supply company (as part of a private purchase or under contract from a funding agency), by a shop, by private purchase/exchange. Numbers of respondents using each type of supplier in the last



5 years are shown in the table. These figures relate to the main survey only (respondents who have acquired a powered wheelchair).

Suppliers used	Number	% of
	of users	responses
NHS wheelchair service	154	36%
Equipment supply company	115	27%
Shop	70	16%
From a charity	30	7%
Private sale (including second hand)	53	12%
Other	8	2%

Table 15 Supply routes used (main survey only)

Respondents were asked to rate each of the supplier types they used. The table shows the number and percentage of respondents who found each of the main supplier types either satisfactory or very satisfactory.

'Satisfied' or 'very satisfied'		
NHS wheelchair service	71	46%
Equipment supply company	64	65%
Shop	44	66%
From a charity	22	88%
Private sale (including second hand)	33	72%

Table 16 Percent 'satisfied' or 'very satisfied' with each supplier type

The chart shows all the satisfaction ratings for each supplier type.

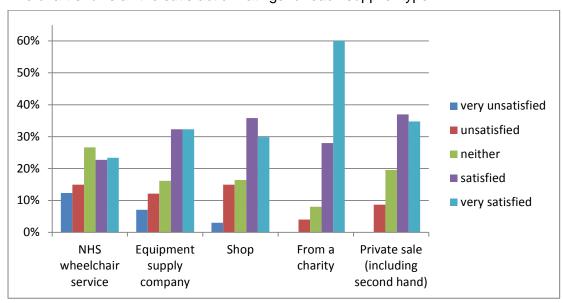


Figure 14 Satisfaction ratings for supplier types



5 Freedom of information exercise

This survey was supplemented by a freedom of information (FOI) request to NHS wheelchair services. The FOI request was sent to the commissioning bodies for all NHS wheelchair services in the UK and asked for details of:

- protocols and criteria applied
- caseloads
- numbers and costs of powered wheelchairs supplied
- supply and maintenance contracts.

The FOI request can be found in Appendix 1. The questionnaire was sent to wheelchair services on 30 July 2014 and responses should have been received by 17 August.

Responses were patchy: not all wheelchair services provided usable responses, and not all responses gave comparable figures for individual questions. However, we were able to draw some conclusions from the data. Findings are summarised here.

Requests were sent to 127 wheelchair services. Usable responses were received from 87 commissioning bodies, covering 94 wheelchair services.

5.1 Criteria for deciding suitability for a powered wheelchair

82 wheelchair services provided copies of service descriptions or criteria for supply, which included criteria for supplying a powered wheelchair. Almost all wheelchair services have their own policy document setting out the criteria for supply, though where one commissioning body is responsible for more than one wheelchair service it is usually the commissioning body that determines the service level. There is some variation in the criteria followed by each service.

5.2 Data on powered wheelchair supply.

5.2.1 Caseloads

- 11 of the services that responded gave no information about how many service users were registered with them, or gave information that was not usable. The remaining 83 gave usable information.
- These 83 wheelchair services have nearly 500,000 service users on their books. This
 tallies with the NHS purchasing and supply agency's (2000) finding that there are 1.2
 million wheelchair users in the UK.

5.2.2 Numbers of powered wheelchairs issued

- 75 wheelchair services gave useful information on the number of powered wheelchairs they issue each year. Between them these services issued a total of over 15,000 powered wheelchairs in 2014.
- We attempted to calculate the proportion of each service's clients who have received a powered wheelchair. The intention was to determine whether there is variation between services in their likelihood of funding powered wheelchairs. The figures we received are somewhat unreliable as few services gave us all the information we needed, and some interpreted our question in ways we did not anticipate, however, we have been able to draw the conclusions seen in Table 17.



	mean	highest	lowest	sample
New powerchairs provided in 2014 as a proportion of total caseload	1.73%	5.4%	0.36%	34
New powerchairs provided in 2014 as a proportion of new clients in 2014	11.65%	26.32%	3.75%	8
Powerchair users on caseload as a proportion of total caseload	6.27%	8.69%	2.41%	5

Table 17 Proportions of clients receiving or using powered wheelchairs

- The variation in these proportions is high, which suggests there is indeed variation between wheelchair services in the likelihood that they will supply a powered wheelchair.
- The ratio of new powered wheelchairs to new clients is greater than that of existing
 powered wheelchair users to existing clients, which suggests that wheelchair
 services may be issuing more powered wheelchairs with time. The samples for these
 ratios are very low, however.

5.2.3 Co-funding arrangements

 The majority of wheelchairs are fully funded by the wheelchair service or topped up from users' funds. 30 out of 94 wheelchair services have entered into part-funding arrangements with other agencies, but the numbers of wheelchairs supplied in this way are extremely small.

5.2.4 Costs

- 70 wheelchair services gave useful information on their total spend on powered wheelchairs. Many did not seem to have this information available.
- Between them they spent over £14 million in 2014 on the supply of powered wheelchairs.
- The average cost of a powered wheelchair to NHS wheelchair services is £1,400.
- Some services gave detailed information about average pricing: "EPICs average £1,000 per chair. EPIOCS average £2,000 per chair. Reconditioning costs average £300. Prices do not include clinical, admin or repairer time."
- 24% of the powered wheelchairs issued are refurbished.

5.2.5 Use of third parties

- 30 (out of 94) services contract out the provision of powered wheelchairs.
- 72 contract out maintenance services.



6 Conclusion and recommendations

6.1 Findings

Rica's powered wheelchair user survey found that:

- Almost all respondents experienced problems in acquiring a powered wheelchair, many experiencing problems in multiple areas.
- 22% of respondents used only statutory sources of information; significantly 13% used only commercial sources.
- Powered wheelchair users are generally unsatisfied with the information resources available to them.
- Many users, including those getting a powered wheelchair for the first time, did not have an assessment.
- The majority of powered wheelchairs are paid for in full or in part using the user's own funds.
- One quarter (26%) of respondents have been refused funding for a powered wheelchair, by NHS wheelchair services or by funding charities.
- Only half (50%) of the powered wheelchairs covered by the survey are considered to have been good value for money by their users. Among under-20s this proportion falls to one third (33%).
- Maintenance of powered wheelchairs is expensive and subject to delays in getting equipment repaired and difficulties in getting parts.

It is clear that there are shortcomings in the models for provision and maintenance of wheelchairs by statutory bodies, and that the market is not well positioned to meet the needs of private purchasers.

6.2 Recommendations

6.2.1 Public funding

Frequently, public funding bodies (mostly NHS wheelchair services) operate according to policies that exclude certain wheelchair users. In some cases they also exclude individual wheelchair users, or provide equipment that does not meet their needs in an apparently arbitrary way, in order to protect budgets.

To remove these problems it is necessary to put the wheelchair user at the heart of the wheelchair service. Public bodies should operate according to a transparent national standard service specification, which gives clear responsibilities and powers to the funding bodies.⁶

This should also be supported by the removal of barriers between budgets. Currently delays in the provision of wheelchairs or the provision of unsuitable wheelchairs cause greater demands on public funds in other areas because they prevent disabled people from being economically and socially active, cause them to be more dependent on other services and in some cases lead to expensive medical interventions to rectify preventable damage.

⁶ <u>CECOPS</u> operates a national code of practice for equipment providers. This is to be extended to cover wheelchair services in December 2014: *Code of Practice for Disability Equipment, Wheelchair and Seating Services (UK)*. CECOPS, forthcoming. The code provides specifications in the following areas: Commissioning and Governance, Service Provision and Clinical and Professional Responsibilities.



Wheelchair users need to have clear information about the funding that is available to them. This should be provided on referral and should include health and social care budgets, wheelchair services and Access to Work. All these notionally exist to meet the needs of disabled people and support them to live independent and productive lives. However, too often these services do not work together and wheelchair users find it impossible to navigate the funding system to get the equipment they need.

6.2.2 Assessment

Many wheelchair users require a detailed assessment to determine their needs. The assessment should consider their capabilities and condition, their environments (indoors and outdoors) and their lifestyles (including needs for work and the needs of their families and others around them). Wheelchair services should provide a suitable assessment speedily on referral.

Often, wheelchair users are seen by other professionals in eg schools and rehabilitation units who make recommendations about the equipment they need. Funding wheelchair services, however, cannot or will not accept these recommendations. This leads to delay and duplication. A standard for wheelchair assessments would make it possible for funding bodies to adopt specifications made by other professionals in this way.

This would also help ensure that private purchasers were able to get a suitable assessment if needed.

6.2.3 Consumer choice

Suppliers of wheelchairs do not generally consider the user to be their client. The contrast between the market for wheelchairs and that for mobility scooters makes this clear. The major wheelchair suppliers sell predominantly to public purchasers and their products, pricing structures and product information are directed towards this market.

Public purchasers themselves are also not very good consumers in that they find it difficult to use alternative suppliers because they hold stock from a particular supplier which is only compatible with other products from the same line, because they do not have time to investigate alternatives or because budget holders need to justify purchasing decisions and they find it easier to do so where they have an established product line.

In order to support consumer choice, purchasing power needs to be devolved to wheelchair users. Wheelchair users need access to information about funding sources, sources of assessment and advice and available and suitable equipment and they need to be able to make supported buying decisions for themselves.

6.2.4 Repairs and maintenance

Parts for powered wheelchairs are expensive. There is a great deal of fragmentation in the products, which means that users or maintenance engineers are required to buy parts from a single manufacturer. Repair and maintenance are also expensive, and often take too long. Wheelchair users cannot be left without a wheelchair, and Rica's powered wheelchair user survey showed that in many cases they are.

Additionally our FOI exercise showed that many NHS wheelchair services use private contractors for repairs and maintenance. As with the suppliers, these contractors are not focused on the wheelchair user, but rather consider the wheelchair services as their clients.

⁷ See Rica's report on the mobility scooter market: *Mobility scooters: a market study.* Rica, 2014.



The requirements of a wheelchair service are very different from those of a wheelchair user, so it is no surprise that the latter find the service does not meet their needs.

Rica considers that repair and maintenance services are best provided through community enterprises. Again, however, giving consumer power to wheelchair users themselves would help to ensure that existing suppliers provided a more appropriate service.

6.2.5 Purchasing and supply

As noted above, most wheelchairs are currently purchased by public bodies, chiefly NHS wheelchair services. It is striking, however, that this does not allow any economies of scale as each wheelchair service has to negotiate its own prices. Wheelchair users should be supported by a body that has the buying power to get favourable prices from suppliers. This service should be accessible to all wheelchair users regardless of where the funds are coming from.

Frontier Economics (2011) have shown how an intervention in the supply model can vastly improve services while also reducing costs.⁸ Rica would also welcome the involvement of disability and community groups in the supply of mobility equipment. Supported by national information and procurement networks, these could provide mobility services to a national specification in a way appropriate to local and community needs.

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⁸ Impact of Whizz-Kidz support to Primary Care Trusts. Frontier Economics, 2011.



Appendix 1 FOI request

Rica is a research charity specialising in consumer research for older and disabled people. We are currently carrying out research into the supply of powered wheelchairs in partnership with Disability Rights UK, the Muscular Dystrophy Campaign, Scope, Spinal Injuries Association and Whizz-Kidz.

As part of our research, we are seeking information on how [TRUST] set eligibility for powered wheelchair supply and how many wheelchairs are supplied. We are requesting this information under the Freedom of Information Act 2000.

The details of the request are outlined below. For more information, please feel free to contact me by email or telephone 020 7427 2460.

Freedom of Information Request

In this request, the term 'powered wheelchair' is used to refer to EPICs (electrically powered indoor powered wheelchairs) and EPIOCs (electrically powered indoor/outdoor powered wheelchairs).

1. Criteria for deciding suitability for a powered wheelchair.

Please supply copies of any documentation that sets out the criteria used to determine whether a person is suitable/eligible to receive a powered wheelchair, or funding towards a powered wheelchair, from [TRUST] – including clinical guidance.

2. Data on powered wheelchair supply.

Please supply the data listed below for the financial years 2011-12, 2012-13 and 2013-14.

- 2.1 Number of people who were registered with [SERVICE] in each year.
- 2.2. Number of people in each year who had a powered wheelchair which was entirely or partly funded by [SERVICE].
- 2.3 Of the people above (2.2), the number who:
 - a. had their powered wheelchair entirely funded by [SERVICE]
 - b. had their powered wheelchair partly funded by [SERVICE]
- 2.4 Specify whether [SERVICE] has, in the time period specified above, jointly funded a powered wheelchair with any of the following:
 - a. Education authorities (y / n)
 - b. Access to Work (y / n)
 - c. Charities (y / n)
- 2.5 Amount spent by [SERVICE] per year on funding for the supply of powered wheelchairs
- 2.6 Number of refurbished powered wheelchairs issued to people per year by [SERVICE]
- 3. Use of third parties for powered wheelchair supply and servicing.
- 3.1 Does [SERVICE] use a third party contractor (eg equipment supply company or CIC) to supply wheelchairs? If so which?
- 3.2 Does [SERVICE] use a third party contractor (eg equipment supply company or CIC) to service wheelchairs? If so which?