

Independent Survey
of The
Users Of The NHS Wheelchair Service
Within Forth Valley

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COMMISSIONED BY

COUNCIL ON DISABILITY (STIRLING DISTRICT)
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Forth Valley NHS Wheelchair Users Survey

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Jane Griffiths
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Note on how this report is laid out

The main points of the Introduction and Findings are reported in the Summary, followed by the Conclusions, in full. This is available as a stand alone document.

The Findings are set out in six parts: the first five report on the Glasgow WESTMARC and Dundee TORT services separately (the former more comprehensively):

1. Overview of the survey
2. Overview of the performance of the Wheelchair Service, giving statistical analysis and illustrative comments
3. Different aspects of the Service, setting out key points, in some sections supported by detailed tabulated analysis
4. Statistical and qualitative analysis of what is valued and what is criticised
5. Particular issues for care homes
6. Analysis with illustrative comments of experience of living as a wheelchair user in Forth Valley

Summary

The survey and who took part

- 1 The survey was undertaken by Council on Disability (Stirling District) supported by NHS Forth Valley and assisted by Forth Valley Local Health Council. Their aim was to provide guidance on developing the NHS Wheelchair Service in Forth Valley, from wheelchair users' experience and views on what was working well and what needed to change.
- 2 Following protracted difficulties in obtaining reliable service user information from the main provider, 1282 wheelchair users served by WESTMARC (West of Scotland Mobility and Rehabilitation Centre) were surveyed in June/July 2004. 175 wheelchair users served by TORT Centre (Tayside Orthopaedic and Rehabilitation Technology) were surveyed in August/September 2004. The survey was carried out by postal questionnaire, with help offered as required. Sampling was weighted towards people with more complex mobility needs, on the basis of wheelchair types used.
- 3 There was an excellent response, of 41% from WESTMARC users and 49% from TORT users.
- 4 Age groups, wheelchair types and geographic distribution were all well represented, as were both newer and long-term wheelchair users. In the WESTMARC survey 45% were under 66, including 17 people under 16, and 54% people were over 65, including 45 people over 85. TORT respondents also included all age groups, with 69% being over 65.
- 5 The WESTMARC survey had 43% (217) attendant-propelled wheelchair users, 39% (199) self-propelled wheelchair users and 17% (90) powered wheelchair users. 60% (29) of TORT respondents had attendant-propelled wheelchairs, 25% (12) had powered wheelchairs and 15% (7) self-propelled wheelchairs.

How the Wheelchair Service is performing overall

- 6 74% of WESTMARC respondents said their wheelchairs met their needs overall, but 22% said they did not meet their needs or only partly met their needs overall. 81% of TORT respondents said their needs were met overall, but 19% said they were not.
- 7 47% of WESTMARC respondents were "satisfied" with the service and 22% were "very satisfied". 20% of TORT respondents were "satisfied" and 58% were "very satisfied".
- 8 27% of WESTMARC respondents were not satisfied, 9% of them being "dissatisfied". 19% of TORT respondents were not satisfied, with 6% of them saying they were "dissatisfied".
- 9 Among WESTMARC respondents
 - Over half under 45 were not satisfied
 - The age group 46-65 had most "very satisfied" people

- One in four users of self-propelled wheelchairs were “very satisfied”, as were 7 out of a total of 18 people who had indoor powered wheelchairs
 - More than one in three people with indoor/outdoor powered wheelchairs were not satisfied
 - Almost half of long-term, intensive users of the Service were not satisfied.
- 10 One third of TORT wheelchair users under 65 were not satisfied. All powered wheelchair users served by TORT were satisfied, almost all being “very satisfied”.
- 11 Many respondents who said they were “satisfied” and even “very satisfied” listed problems and advocated changes in reply to other questions.
- 12 67% of WESTMARC respondents reported one or more problems in using their wheelchairs. The most prevalent difficulties were getting wheelchairs (and/or their users) in and out of cars, and that wheelchairs were too heavy. One in three WESTMARC respondents experienced these problems.
- 13 58% of TORT respondents reported one or more problems in using their wheelchairs. Most prevalent problems were difficulties with wheelchairs and cars, and not getting all attachments needed (each 23%).

Changes people would like to see in the NHS Wheelchair Service

- 14 84% of WESTMARC users and 71% of TORT users said they would like a local service. Many respondents were very strongly in favour, because of the inconvenience of going to Glasgow or Dundee, as a means of getting faster repairs, and for many improvements coming from easier contact and communication. Distance from Centres was especially difficult for young wheelchair users and their families.
- 15 A voucher scheme would be welcomed by over half of WESTMARC respondents and under a third of TORT respondents, with many respondents being against it, on principle or because they could not afford to contribute to the cost of a better wheelchair.
- 16 Other changes wanted were
- A higher standard of wheelchair
 - A speedier, more efficient supply of wheelchairs
 - Improved information, about what was available and how the Wheelchair Service worked
 - A faster repair service, and better suited to the needs of users dependent on their wheelchairs
 - Regular servicing
 - Improved assessment
 - More follow-up contact by the Service
 - Changes in the allocation rules to meet people’s needs more effectively.

Service delivery in more detail

- 17 27% of WESTMARC users and 23% of TORT users had acquired wheelchairs in addition to their NHS wheelchairs.
- 18 Half of WESTMARC respondents (assessed since 2000) had had their wheelchair needs assessed or re-assessed only locally, over a third only in hospital, with many others being assessed by staff in both hospital and local settings. 16% had been assessed by Mobility Centre staff, mostly in combination with staff in other settings. Most TORT users had been assessed locally, with 12% assessed by TORT staff.
- 19 There was patchy involvement of WESTMARC users in assessments of their needs. 2 in 3 people were asked basic questions about what they wanted from their wheelchairs and approximately half were asked about car requirements. People who got powered wheelchairs and first-time users who got self-propelled wheelchairs were most involved in discussions about their needs (except in relation to cars).
- 20 Few respondents had been given information about different types of wheelchair (18%), even fewer (11%) offered a choice of wheelchair and only 7% given a trial of wheelchairs.
- 21 Most people had not been given any information about other ways of meeting their mobility needs.
- 22 There was no involvement of carers in 75% of assessments where it was relevant to do so.
- 23 Almost a third of recently assessed WESTMARC respondents were not satisfied with the waiting time for their wheelchairs and almost a third did not get enough help with being introduced to their wheelchair when it arrived.
- 24 There was a higher level of involvement of users (and carers) in TORT assessments. 19% and 11% respectively were dissatisfied with waiting times and help with being introduced to their wheelchair.
- 25 Most people who used the repair service were satisfied: 87% were satisfied with WESTMARC engineers, 10% were not, and 82% were satisfied with WESTMARC contractors and 16% were not. 10 made comments modifying satisfaction, mainly complaints about time. Users of self propelled wheelchairs and of powered wheelchairs recorded most dissatisfaction with repair services.
- 26 None of the 18 TORT respondents who had used a repairs service recorded dissatisfaction.

What makes people very satisfied with the Wheelchair Service?

People who said they were “very satisfied” referred to the freedom and improved quality of life their wheelchair had brought them and to the responsiveness of the Service in attending to their requirements.

- 27 Powered and self-propelled WESTMARC wheelchair users were more often “very satisfied” than users of attendant-propelled wheelchairs. Only 16% of attendant propelled wheelchair users were “very satisfied”, compared with 26% of powered and of self-propelled users
- 28 Generally “very satisfied” users had had better experience of all aspects of the Wheelchair Service, although 3 said their wheelchair did not meet their needs and another 3 that it only partly met their needs. 5 respondents referred to their need for a powered wheelchair.
- 29 “Very satisfied” TORT users reported few problems. 75% of people who had required adaptations were “very satisfied”.
- 31 21% of WESTMARC users who had purchased scooters or wheelchairs privately were “very satisfied”, with higher proportions in over 65 age groups. 74% of their purchases were scooters. Half of those who had purchased privately said they would welcome a voucher scheme. 56% of TORT users who had purchased privately were “very satisfied”; their additions were also mainly scooters.

Why are some people not satisfied with the Wheelchair Service?

- 32 The highest incidence of WESTMARC service users who were not satisfied was among younger people, people who had powered wheelchairs and people with long term and complex needs, as indicated by having successive wheelchairs and intensive use of the service. Of the 47 long-term, intensive users of the service, almost half, 23, were not satisfied; 18 were under 65.
- 33 Over half of the 139 people who were not satisfied felt their wheelchair(s) did not meet their needs well. Many of them described lengthy struggles to have very individual and also common needs met.
- 34 Respondents had poorer experience of all aspects of the service, especially of being involved in assessment processes.
- 35 Poor communication was highlighted by 55% of unsatisfied respondents in answering general questions.
- 36 Waiting was a key cause of dissatisfaction. 63% were dissatisfied with waiting time for wheelchair delivery. Of the 22 who were dissatisfied with repairs, many cited waiting time, as did others who were otherwise satisfied with the repair service.

37 In addition, 23% of unsatisfied respondents made critical comments about waiting for various aspects of the service in response to general questions.

38 25% of unsatisfied respondents had bought their own wheelchair or scooter. Many expressed resentment at having to do so. 8 out of 13 respondents who no longer had NHS wheelchairs had bought their own wheelchair because dissatisfied with the NHS wheelchair.

39 Amongst the 9 (19%) unsatisfied TORT service users 7 (78%) said their wheelchairs did not meet their needs well.

Care home issues

40 The main issues reported by care home residents, carers and managers were residents not getting an NHS wheelchair when needs developed whilst in the care home, and the discomfort of some wheelchairs for sitting in for long periods.

Living as a wheelchair user in Forth Valley

41 The most prevalent comment, often strongly expressed, was about the impediment of poorly designed and maintained pavements. Real difficulties were caused by the lack of sloped kerbs, thoughtless siting of such sloping kerbs as existed, rough surfaces, sloping camber, obstacles such as wheelie bins and parked cars. Access to shops and public buildings had improved but was very uneven and unpredictable. Selfish parking by other motorists compounded a lack of parking spaces.

Conclusions

The following conclusions were drawn from comparing the evidence from the survey (principally from the WESTMARC part) with the vision and aims for reorganised Mobility Services in the 1996 **Review of Artificial Limb and Appliance Centres**¹(see pages 16-17).

- 1 The majority of wheelchair users today are in the same position as at the time of the **Review**, that is they have wheelchairs which meet their needs and increase their mobility and independence.
- 2 For many of these people, wheelchairs have been an essential element in giving them a better quality of life.
- 3 However, a large number and high proportion of wheelchair users are not satisfied because their wheelchairs do not meet their needs and because they get a poor service in the manner of getting their wheelchairs and keeping them in a condition to meet changing needs and to survive occasional problems and break-downs with minimum interruption of use.
- 4 Most of the people who were not satisfied and whose needs were not met were under 65. Over half of respondents with complex needs and intensive use of the Wheelchair Service were not satisfied, most of them being under 65.
- 5 The Wheelchair Service is therefore not succeeding in closing the gap between the majority and others whom wheelchairs should be helping to lead full lives. It is not achieving the **Review's** vision of "maximising the potential" of sufficient people in "the permanently disabled population" who are most excluded from the activities of their peers, because of age and type of mobility support needed.
- 6 The Service is often unable to "prescribe optimal equipment" because, it appears, they have not built up an adequate stock of suitable good quality wheelchairs, apparently exacerbated by poor stock control (provider information on wheelchairs supplied appeared to be confused and highly inaccurate, and several respondents reported lengthy delays in collection of un-needed wheelchairs).
- 7 Inadequate stock and inadequate management of it also appear to be the cause of exceptionally long waiting times which further disable many WESTMARC users.
- 8 Effective assessment of needs may be inhibited by the lack of suitable remedies available. At any rate, assessment processes are at best patchy and often minimal in all assessment routes for WESTMARC. Holistic assessment of needs, which fully engages the wheelchair user (and where appropriate carer), clearly does not happen often. Much of the inutility of wheelchairs was down to a mismatch of wheelchair type with user needs, aims, environment and existing supports, particularly carers and cars.

¹ National Services Division, NHS Management Executive 1996 Review of Artificial Limb and Appliance Centres

Standardisation of assessment and supply appeared very often to be defeating the objective of economy, when it led to readjustments being necessary before wheelchairs could be used, to lack of use of wheelchairs and to costly deployment of user and service resources in negotiating later remedies.

- 9 Rationing of the limited improved resources available may also underlie other causes of dissatisfaction, such as poor information and lack of ongoing contact with service users, for review of needs or of condition of wheelchair. The Service aim of wheelchairs being an integral part of a rehabilitation service was not being achieved for the many users who felt neglected by the Service and who were uncertain how to use it.
- 10 All of these features, together with the high level of problems in use, decrease the value of the NHS investment in improved mobility and increase the cost to the NHS of repairs and adaptations, and probably of more expensive health services. Overall, survey evidence indicated that the Service was failing to “minimise handicap and improve quality of life as cost effectively as possible”.
- 11 The survey also indicated that some of the 1996 **Review’s** specific recommendations had not been implemented effectively. In particular:

a. Integration into main centres

Integration into main centres has been achieved, but the benefits to users vary, both between centres and between aspects of the service. The evidence from TORT users was that there was a better chance of getting a responsive and individualised service from a smaller unit, which had set up effective systems for establishing and maintaining contact with its service users.

Repairs appear to have been mostly good or improved across both Services.

b. Local access to integrated rehabilitation services

Failure to achieve this aim is a major issue throughout Forth Valley. Poor access to distant centres, particularly Glasgow, is preventing many people having evolving needs met effectively and from making the most of the Service.

Desire for a local Centre was wide-spread and strongly expressed, as a solution to these problems and to repair difficulties for people with constant need of their wheelchairs. However, it was also clear, that as well as physical location, improving access also means providing better information for users at all points of service delivery.

c. Users should be more involved in the choice from the available range of equipment and supplied with written information about equipment choice

The lack of involvement of service users (and of carers) was general in the WESTMARC service and was seen as a main barrier to providing an effective service by users at the complex need end of the spectrum and also by many whose needs were more straightforward. Improvement in cost effectiveness and overall effectiveness in terms of increasing mobility would need to be based

on new approaches to involving wheelchair users in what is a big decision for people everywhere on the needs spectrum.

d. A consistent definition of service should be developed

Eligibility criteria for powered wheelchairs and for second wheelchairs appear to be being applied fairly consistently. However there was strong evidence that these criteria are impeding the mobility of people who need conveniently accessed car transport in addition to a powered wheelchair for indoors and short outdoor journeys. There was also evidence that rigid application of the criteria in assessment and lack of review were resulting in many users not being able to achieve the mobility they desired, especially those with fluctuating and deteriorating conditions, and aging carers. Access to the much desired lighter wheelchairs appeared to depend on user determination or luck rather than clear criteria.

The evidence of this survey indicates that, to promote fair access to mobility support, eligibility criteria and quality standards should be reviewed in a more radical manner, and then implemented. The use of a voucher scheme as part of this process would need to take account of low income, especially of people disabled from birth or youth, and would need careful explanation and education.

e. Ideally all existing wheelchairs require to be replaced with their modern equivalent

The 2000 progress report² on **Review** aims recognised that “There is significant concern at each of the centres that this initiative will result in new, modern wheelchairs being designed which are highly desirable for users but unaffordable to the service”. Little progress appears to have been made in the strategies to tackle this critical development aim. The survey provided strong evidence that it is essential to do so, and that a voucher scheme with the right conditions could make an effective contribution.

12 Since the 1996 **Review**, individual aspirations of disabled people have been encouraged by society’s endorsement of equality and by technological advance. This survey provided plenty of evidence of the power of wheelchairs to promote equality but also too much evidence that presently justice was not being done, nor seen to be done.

13 However, as well as showing that many younger people with more complex mobility needs are not being well served and that there is much dissatisfaction with the gap between rhetoric and reality, the survey also confirms that a large number of people are very appreciative of a free service which gives them extra mobility. Many of them, especially older people, are happy to take what they get without much discussion and many buy their own wheelchairs or scooters without any expectation that the NHS might have given them a more useful deal.

² Rehabilitation Technology Services Advisory Group 2001 for the Scottish Executive Report on the Review of Rehabilitation Technology Services in Scotland

- 14 The evidence of this survey suggests that, were the NHS to review its strategy and focus on ensuring fair access to the most suitable equipment for individuals rather than “prescribing optimal equipment” it would find a receptive response.

It is likely that many would cooperate with a holistic approach by the NHS which gave them informed choices rather than the next available standard wheelchair which might or might not work for them.

- 15 This survey suggests that the NHS would be more likely to achieve its vision if it prioritised access to the best and most suitable wheelchairs for all who needed one. The many ways of doing this must include developing a larger stock of “the best” themselves for younger people who have been disabled from acquiring funding to give them a choice. It must also include assessing, informing and advising people who want to be so involved as to what is available across the board, and what is on offer from the NHS.

- 16 A shift to a clear and focused priority, and honesty about NHS capacity (plus a voucher scheme which extends to repair costs) would take the NHS well down the road to giving more people the most needed benefits of a wheelchair.

Introduction

1 Purpose of the survey

The survey was undertaken to provide guidance on developing the NHS Wheelchair Service in Forth Valley, from wheelchair users' experience and views on what was working well and what needed to change.

NHS wheelchairs have been provided in the Forth Valley NHS area in recent years by three external agencies:

- WESTMARC (West of Scotland Mobility and Rehabilitation Centre) at Southern General Hospital, NHS Glasgow
- the TORT (Tayside Orthopaedic and Rehabilitation Technology) Centre at Ninewells Hospital, NHS Tayside
- the Mobility Centre at Astley Ainslie Hospital, NHS Lothian.

NHS Forth Valley commissions the Wheelchair Service and estimates that 90% of wheelchairs are provided by WESTMARC, with two small areas in the north and the south east of the area being covered by the Tayside and Lothian Centres.

The need to find out how these arrangements were working for wheelchair users had long been recognised by service users' organisations and NHS Forth Valley. The Council on Disability (Stirling District) particularly wanted evidence on how long term users with complex needs were being served. They were aware from research elsewhere that progress in meeting people's increasing aspirations was patchy and that changes might be needed at national as well as local level.

The Council, a charity run by people with disabilities, aims to improve the lives of people with disabilities living in Forth Valley. They raised funding for the research and worked with NHS Forth Valley to set up the survey.

NHS Forth Valley (NHSFV) had a special interest in how repair services were working, and in whether people needed better access to the Wheelchair Service and different ways of getting the type of wheelchair that would best meet their needs.

2 Background to the survey

2.1 1990s review of mobility services

The present arrangements in Forth Valley were set up following a national reorganisation of mobility services in the late 1990s. A review in 1996 of "Artificial Limb and Appliance Centres"³ aimed to give services a new design for the 21st century, with service delivery standards consistent across Scotland. The long term aim for what were now renamed Mobility Services was defined as

³ National Services Division, NHS Management Executive 1996 Review of Artificial Limb and Appliance Centres

“To maximise the potential of the permanently disabled population by prescribing optimal equipment to minimise handicap and improve quality of life as cost effectively as possible. A philosophy of total patient care should ensure appropriate links with rehabilitation services to facilitate a care continuum for patients.”

The review’s recommendations for the future focused on:

- integrating all the rehabilitation services needed by disabled people in main centres of expertise
- maximising local access to integrated rehabilitation services, e.g. by satellite centres, outreach services, good patient transport within the constraints of financial resources

- developing quality standards and clear eligibility criteria
- involving service users more:
 - “in the choice from the available range of equipment”
 - supplying them “with written information about equipment choice and use”
 - through mobility centres being in regular contact with local service user groups.

A national review of progress in 1999-2000⁴ concluded that some of these objectives had been met but further work was required.

2.2 Research by service users

Higher expectations and technological advances led wheelchair users in other areas of Scotland to investigate how these arrangements were serving them. An Audit Commission report **Fully Equipped (2000)** on services in England and Wales was also influential. It reinforced concerns that standards of service in Scotland might be falling short of the aspirations of the 1990s reforms.

A survey of wheelchair users was carried out by Borders Disability Forum in 2002⁵, based on criteria which were important to service users. The survey led to an action plan, now implemented, involving the Forum, the service providers and the local health and social services authorities.

3 Approach to the survey

Council on Disability (Stirling District) found the Borders Report on the internet during their discussions with NHS Forth Valley on surveying wheelchair users in their area. Considering that the Borders approach reflected what they had in mind, they commissioned the same researcher to carry out a similar survey in Forth Valley.

The Council then worked with NHS Forth Valley and the main service provider, WESTMARC, to define the wheelchair user population to be surveyed. The Council's original intention was

⁴ Rehabilitation Technology Services Advisory Group 2001 for the Scottish Executive Report on the Review of Rehabilitation Technology Services in Scotland

⁵ Griffiths, J 2002 Survey of NHS Wheelchair Users in the Borders Borders Disability Forum & Borders Community Care Forum

to survey users of all three providers' services in the area. In the end difficulties in obtaining information restricted the survey to the main provider, WESTMARC, and, as a later exercise, users of the Tayside service in the northern part of the area.

Definition of the WESTMARC wheelchair user population required extensive analysis and refinement of the provider's database by an IT consultant, also commissioned by the Council. After many months work, including a check against the Community Health Index (CHI), misgivings persisted on the reliability of the database information, which indicated that the current number of wheelchair users in the area was substantially more than that estimated by WESTMARC using population frequencies.

With the total finally established at 4777 wheelchair users, it was decided to proceed with the survey, making further checks as a sample was drawn up.

The sample was constructed to ensure sufficient information collection from people with long term and more complex needs, known to be in the minority of the wheelchair user population. Sampling was therefore based primarily on wheelchair types as the most accurate reflection of level of need.

It aimed to include all users of powered wheelchairs, approximately one third of self-propelled wheelchair users, and 10% of attendant-propelled wheelchair users. Within the latter two categories, percentages were selected systematically by date of birth order. The resulting sample of 1651 was then double checked against other database information and against the Community Health Index (CHI). A further 522 records were added and CHI checked when the sample was reduced by the first CHI sample check.

Altogether 891 records were excluded by CHI checks of sampled records. This rejection rate of approximately 40% suggests that the total number of wheelchair users in the area was under 3000 at the time of the survey.

The final sample, of 1282, included all users of powered wheelchairs, a large proportion of self-propelled wheelchair users, and at least 10% of attendant-propelled wheelchair users. It had a good spread of all age groups and of geographic areas.

The sample included people in care homes, supported housing and hospital. The survey organisers recognised that there might be a low return rate in care homes and that there were likely to be different issues in wheelchair use in these settings. Five care homes and one supported housing provider were selected to receive additional questionnaires for wheelchair users and a brief questionnaire addressed to the care home/housing manager.

The Borders questionnaire was adapted to include additional Forth Valley issues. It was designed to give a general picture of the NHS wheelchair service as experienced by its users, and more detail about the different aspects of service delivery:

- assessment of needs
- delivery and introduction of the wheelchair
- wheelchairs in use
- repairs and adaptations.

The questionnaire also sought views on changes that might be needed, and on people's experience of being a wheelchair user in the Forth Valley area.

The survey organisers recognised that the views of wheelchair users who did not have NHS wheelchairs were also important. With limited resources, they therefore used the survey to gather information from people who were still on the service providers' database although they had decided not to have an NHS wheelchair.

The questionnaire was produced within an integrated survey software programme by Forth Valley Local Health Council (FVLHC). (The questionnaire is reproduced in the Appendix.)

Survey respondents were offered entry to a prize draw of £100, if they returned a covering letter which would be kept separate from anonymous questionnaires. All respondents were assured of confidentiality and offered help with completing the questionnaire.

FVLHC administered the mailing and receipt of questionnaires and answered respondent enquiries. They also offered visits to respondents in care homes to assist with completing questionnaires.

The survey of WESTMARC service users was carried out in July 2004. Information on 175 TORT Centre wheelchair users was received in August from NHS Tayside, sampled on the same basis, and a survey of 97 carried out in September/October. The results of both surveys are reported in the following pages. It is not intended to draw direct comparisons between the two services: as shown in the next section, the two surveys reflect different user profiles which are likely to have influenced the experience and views reported.

4 Questionnaire returns

A total of 521 useable questionnaires was received out of the original mailing to 1282 WESTMARC service users. This gives a response rate of 41%, which is considered excellent. (40 other notifications were received, that the addressee had died, or was not a wheelchair user, making the sample smaller and the return rate slightly larger, at 42 %.)

The total number of useable responses was increased to 522 by the single response to 29 extra questionnaires sent out later to care home residents (see above). Four out of the six managers of care homes/supported housing responded to the manager's questionnaire.

TORT service users returned 48 usable questionnaires, an even higher response rate of 49%. (2 questionnaires were returned marked "gone away", 3 addressees were dead and one did not give any information because unable to use the wheelchair whilst in a first floor flat.)

The results were analysed with the assistance of a survey software programme.

Findings

5 Profile of wheelchair users in the survey

NB the profile of respondents does not correspond with the profile of NHS wheelchair users in Forth Valley as a whole, because of the sampling bias towards people with long-term and complex needs. The wheelchair user population as a whole has a higher proportion of people over 65, estimated at 70-80%, compared with 53% of WESTMARC survey respondents and 69% of TORT respondents.

WESTMARC

Of the total 522 WESTMARC respondents, 13 said they did not have NHS wheelchairs and simply gave their reasons for having another supplier. Their replies are added to appropriate sections below. Most, but not all, chose another supplier because they were not satisfied with their NHS wheelchair.

The following analysis is of the remaining 509 NHS wheelchair user respondents, who all said they had NHS wheelchairs and completed all or a significant part of the questionnaire, although a few of them also appeared to have returned their NHS wheelchairs.

5.1 Age and gender

All age groups were represented, as shown on Table W1 below, with 45% under 66 and 54% over 65. 60% were female and 39% male. There was a higher proportion of women in all age groups except younger adults (16-45) where men were in the majority by 3; in the 66-75 group women outnumbered men by only 2. There were many more women than men in the two oldest groups.

5.2 Geographic distribution

Respondents came from most districts served by WESTMARC.

5.3 Types of wheelchair

In spite of the sample being weighted towards people with powered and self-propelled wheelchairs, the biggest group of respondents had attendant-propelled wheelchairs. (However, a random check of the provider database confirmed that many self-propelled wheelchairs were used and described on questionnaires as attendant-propelled. Several respondents listed their wheelchair as self-propelled but said it was only used as attendant-propelled.) There was good representation of all wheelchair types and therefore of levels of need within age groups.

TABLE W1

Types of wheelchair used by different age groups in WESTMARC area, showing % of total respondents and % of wheelchair type within age group

Wheelchair type: user age	Base & % in each age group	Attendant-propelled (AP)	Self-propelled (SP)	Powered indoor (EPIC)	Powered indoor & outdoor (EPIOC)	(no reply)
Base & % wheelchair types overall	509	217 43%	199 39%	18 4%	72 14%	3 .6%
- 16	17 3%	5 29%	8 47%	-	3 18%	1 6%
16-45	59 12%	12 20%	34 58%	3 5%	10 17%	
46-65	153 30%	47 31%	66 43%	6 4%	33 22%	1 0.7
66-75	134 26%	62 46%	48 36%	5 4%	18 13%	1 0.7%
76-85	96 19%	56 58%	31 32%	2 2%	7 7%	
85 +	45 9%	34 76%	8 18%	2 4 %	1 2%	
Age not given	5 0.8%	1 0.2%	4 0.7%			

Note: 88 respondents had 2 wheelchairs, 78 having combinations of a powered wheelchair and a self- or attendant-propelled wheelchair; all are listed above under their powered wheelchair. The 1 respondent who had 3 wheelchairs is listed under EPIOC. The 10 other respondents with 2 wheelchairs are listed under self-propelled where that was 1 or both of the wheelchairs used and under attendant-propelled where both were that type.

There was also good representation of long-term use as indicated by successive wheelchairs (36% of respondents). Long-term use was also indicated by comments from people who had had the same wheelchair for many years.

TORT All TORT respondents still used NHS wheelchairs.

5.4 Age and gender

All age groups were represented (see Table T1 below) but there was a much higher proportion of older people, 69% being over 65 (as mentioned above) and 19% being over 85. Only 7 (15%) were in the middle age group, 46-65, which was the largest age group of WESTMARC respondents.

There was a slightly higher proportion of women to men (63%:38%) than in the WESTMARC survey, reflecting the higher age balance among TORT respondents.

5.5 Geographic distribution

There was representation from all postal districts served by TORT.

5.6 Types of wheelchair

Over half (29) described their wheelchairs as attendant-propelled, with only 7 saying they had self-propelled wheelchairs as their main wheelchairs. There was good representation of people with indoor/outdoor powered wheelchairs (9) across age groups except the oldest. Three respondents had indoor only wheelchairs.

TABLE T1
Types of wheelchair used by different age groups in TORT areas

Wheelchair type: user age	Base & % in each age group	Attendant-propelled	Self-propelled	Powered indoor	Powered indoor & outdoor
Base & % wheelchair types overall	48	29	7	3	9
		60%	15%	6%	19%
- 16	4	3	-	-	1
	8%	75%			25%
16-45	4	1	1	-	2
	8%	25%	25%		50%
46-65	7	3	-	2	2
	15%	43%		29%	29%
66-75	13	8	2	-	3
	27%	62%	15%		23%
76-85	11	7	2	1	1
	23%	64%	18%	9%	9%
85 +	9	7	2	-	-
	19%	78%	22%		

Note: 11 respondents had 2 wheelchairs, 10 having combinations of a powered wheelchair and a self- or attendant-propelled wheelchair; all are listed above under their powered wheelchair, as is the 1 respondent who had 3 wheelchairs. One respondent had 2 attendant-propelled wheelchairs.

6 General views of the NHS Wheelchair Service

6.1 How well do NHS meet wheelchair users' needs overall?

People were asked to say whether overall their NHS wheelchair met their needs. They were also asked to comment on this.

WESTMARC

The majority said their wheelchairs met their needs but a substantial minority said their needs were not met or were only partly met.

- 416 (82%) said their wheelchair(s) did meet their needs
- 25 made a positive comment
- 40 said their wheelchair(s) met their needs overall but qualified this with a negative comment indicating their needs were only partly met or ticking “no” as well as “yes”, for example:
 - “Too bulky to fit in car and to go from room to room”
 - “I find the manual wheelchair difficult but not the electric one”
 - “But only because we “make do” not because the wheelchair is ideal”.
- A total of 64 people (13%) said their wheelchair(s) did not meet their needs
- 9 people out of 29 who did not answer the question commented that their wheelchair only partly met their needs
- Adding these 9 respondents to the 40 who gave a qualified “yes” gives a total of 49 (10%) whose needs were only partly met.

Taking these adjustments together, 74% (376) of respondents said their wheelchairs met their needs overall, 22% (113) said they did not meet their needs or only partly met them.

TORT

Overall, 81% said their needs were met, and 19% said their needs were not met or only partly met.

- 41 (85%) said their wheelchair(s) met their needs, but 2 gave a qualified yes
 - “Yes, but minimal only. Activity outside the nursing home is restricted to walk into town and back if a fine day coincides with my visit (carer)”
 - “At the moment no choice”
- 7 (15%) said their wheelchair(s) did not meet their needs overall. In 4 cases this was because there was no-one who could push them

6.2. How satisfied are wheelchair users with the service?

Towards the end of the questionnaire respondents were asked to rate their satisfaction with their overall experience of the wheelchair service. Replies are analysed by age groups and wheelchair types in the charts on the following pages. Key points were:

WESTMARC

- The large majority were satisfied (47%) or very satisfied (22%)
- Over 1 in four were not satisfied, with 9% expressing themselves as “dissatisfied”
- Over half in the 2 youngest groups were not satisfied
- In older age groups (45 upwards) half (slightly more in the oldest group) said they were “satisfied”
- The youngest and oldest age groups had least people who were “very satisfied”
- Age group 46-65 had most “very satisfied” users - one in four, with other groups having 1 in 5 people
- One in four users of self-propelled wheelchairs were “very satisfied”, as were 7 out of a total of 18 people who had indoor powered wheelchairs
- More than one in three people with indoor/outdoor powered wheelchairs were not satisfied.

Many respondents who said they were “satisfied” and even “very satisfied” listed problems and advocated changes in reply to other questions, confirming evidence from other studies of a tendency especially amongst older people to give positive satisfaction ratings regardless of actual experience (see page 59).

SATISFACTION RATINGS - WESTMARC

Chart 1: satisfaction ratings by age groups

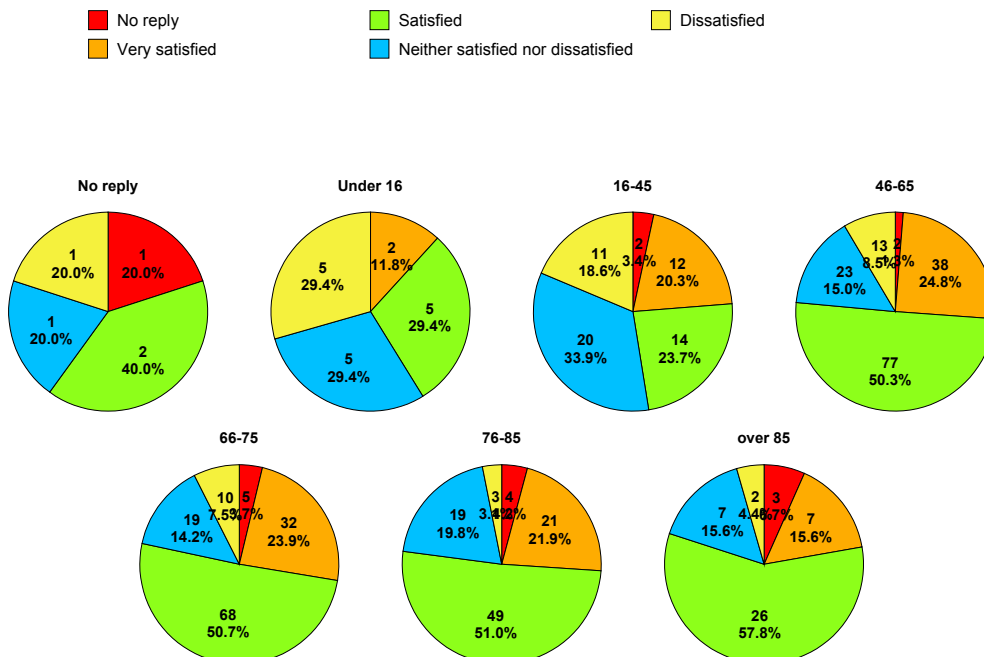


Chart 2: satisfaction ratings by wheelchair type: self-propelled

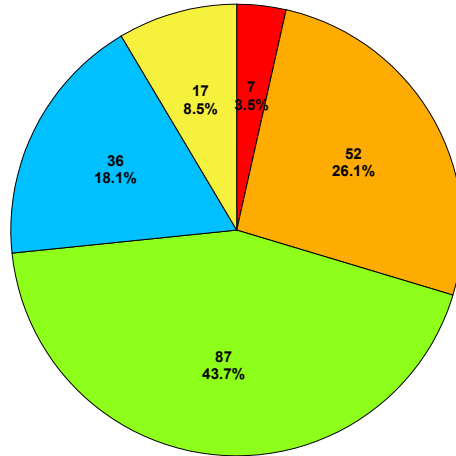
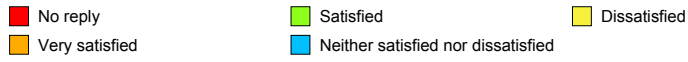


Chart 3: satisfaction ratings by wheelchair type: attendant-propelled

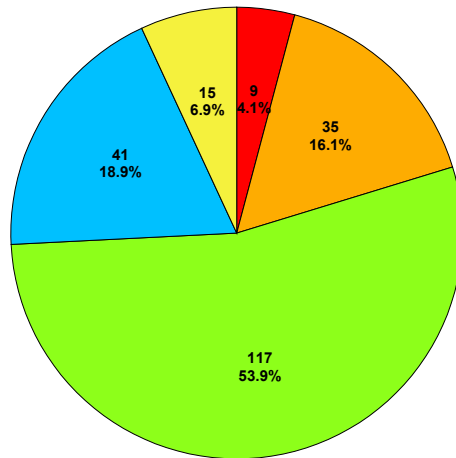
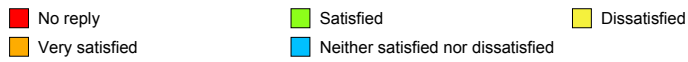


Chart 4: satisfaction ratings by wheelchair type: powered indoor (EPIC)

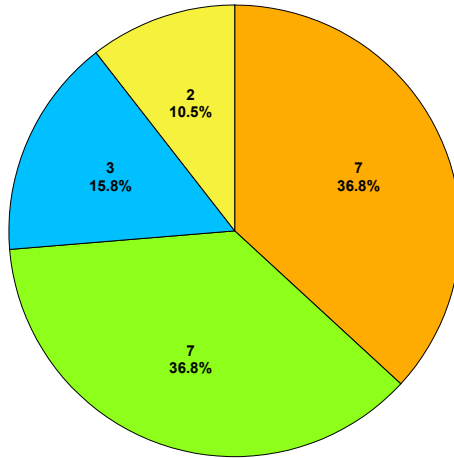
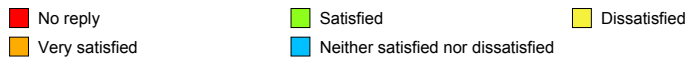


Chart 5: satisfaction ratings by wheelchair type: powered indoor/outdoor (EPIOC)

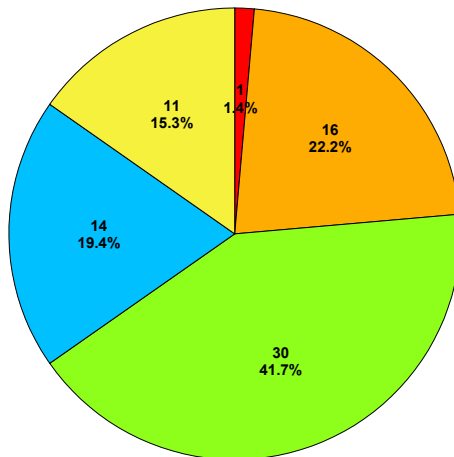
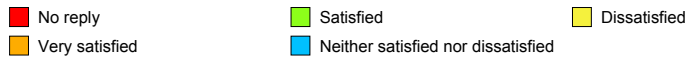
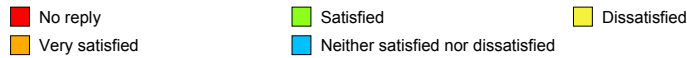


Chart 6: satisfaction ratings by wheelchair type: powered wheelchairs



TORT

- Over half of TORT users were “very satisfied” (28, 58%) and a further one in five (10, 21%) were satisfied
- All but one aged over 85 and 3 of the 4 respondents aged 16-45 were “very satisfied”; the other respondent in each of these age groups was “satisfied”
- 9 respondents (19%) were not satisfied, 3 stating they were “dissatisfied”
- 2 of the 3 dissatisfied respondents were in the 66-75 age group, the other in the 46-65 group
- The other 6 who were not satisfied were evenly distributed between age groups under 16, 46-65 and 66-75
- 10 out of the 11 people (91%) with powered wheelchairs were “very satisfied”, the other was “satisfied”
- 2 of the 7 people (29%) with self-propelled wheelchairs were not satisfied, although 4 (57%) were “very satisfied”
- 7 of the 29 people (24%) with attendant-propelled wheelchairs were not satisfied, although 14 (48%) were very satisfied.

Several TORT respondents also listed problems whilst expressing themselves “satisfied”, including 2 who said their wheelchair did not meet their needs.

6.3 Problems reported

Respondents were asked to report on specific problems and also given the opportunity to comment on any problems experienced at the different stages of getting and using a wheelchair. The most frequently cited problems are summarised in the following tables, W2 for WESTMARC and T2 for TORT.

TABLE W 2 Summary of problems reported

PROBLEMS	Number of respondents	% total respondents
Insufficient information when getting wheelchair	234	80%#
Wheelchair difficult to get in/out of car	171	34%
Long waiting times (w/chair and initial adaptations)	94	32%#
Wheelchair too heavy	163	32%
Insufficient help/shown how to manage w/chair	93	32%#
Attachments lacking	132	26%
Wheelchair difficult to manoeuvre	126	25%
Wheelchair does not meet needs adequately	113	22%

% refers to the 292 respondents assessed from 2000

TABLE T 2 Summary of problems reported

PROBLEMS	Number of respondents	% total respondents
Insufficient information when getting wheelchair	18	67%#
W/chair difficult to get in/out of car	11	23%
Attachments lacking	11	23%
W/chair difficult to manoeuvre	9	19%
Long waiting times (w/chair and initial adaptations)	5	19%#
Wheelchair does not meet needs	7	15%

% refers to the 27 respondents assessed from 2000

6.4 Changes needed

The questionnaire asked three questions about changes that might be needed to the NHS Wheelchair Service, two specific and one general.

WESTMARC

6.4.1 Local Centre

84% (430) said “yes” to the first specific question, whether they would welcome a local Centre; only 6% (29) said “no”. Additional comments by 92 respondents showed that

- Many were very strongly in favour of this change, for example
 - “Anything local is a great advantage”
 - “Very much desired”
 - “Desperately needed. Nonsense to have the nearest in Glasgow”
- The main reasons for wanting a local service were avoiding the inconvenience of journeys to Glasgow and having a better and faster repair service, for example
 - “It would save a long journey to Glasgow as we have to pick up other patients there and back”
 - “Badly needed as it is very difficult to get to Glasgow”
 - “It would be great as we might get repairs done more promptly”
 - “I wish there was a local wheelchair service shop where I could keep my chair serviced to a high standard and know it would be done quite quickly and properly as they know what they are doing and can also find any potential problems before they get too bad”
- Other reasons included better information for carers, easier contact, and a more user-friendly service, for example
 - “Family members need to know the pros and cons of the range available to assist in decision making”
 - “To have a contact number to phone who understood what you wanted and not be lost in the general hospital switchboard call system would be good”
 - “Local control over the system would hopefully lead to more focus for individuals in Forth Valley. The present system is monopolistic and unhealthy”
- The main reason for not wanting a local Centre was satisfaction with the present service. A few did not think a local service should be a financial priority
- Several people who said they were “very satisfied” with the existing service wanted a local Centre.

6.4.2 Voucher scheme

Opinion was more divided on the second specific change canvassed, of a voucher or direct payments scheme which would pay the cost of a more basic wheelchair and could be used towards a more expensive chair of a user's own choice. 50% (255) people were in favour, 29% (146) against. Amongst the 105 non replies, several comments indicated that people did not fully understand a voucher scheme; others felt advantages and disadvantages were finely balanced. (It is possible that some respondents thought a voucher scheme might be offered in addition to their present wheelchair).

The 92 comments made showed that

- The main reason why people would welcome a direct payment/voucher scheme was the possibility of improving on the wheelchair they had (several respondents expressing these views had said they were “satisfied” or “very satisfied” with the Wheelchair Service). For example:
 - “I need a better chair to get about in the house; am permanently in the house as I can't walk at all”
 - “Wheelchair is fairly basic, I now need one with better support, being reclining and with leg elevation would also be good”
 - “To enable me to get wheelchair to fit into car boot”
 - “NHS wheelchairs can't go in cars. This is a real and serious problem which limits wheelchair users. Going out and about is only possible if this changes”
 - “Could afford wheelchair more customised to individual needs”
- Others expressed a more general view of the desirability of increased choice and flexibility, for example:
 - “It is essential to increase choice. . .”
 - “Not all NHS wheelchairs will be best for some users; greater flexibility of acquisition would be useful”
 - “Would allow some choice and give flexibility from one fits all approach”
 - “Choice is not something always available to people in wheelchairs. It would be very empowering to feel we could upgrade our wheelchairs or change them to suit our personal needs”
- A few people said they would welcome a voucher scheme because they wanted to be reimbursed for buying privately, or because buying privately had made them aware of the financial burden, for example
 - “I would like money made available to purchase own choice of scooter. To be independent I had to buy my own as wheelchair lies in the garage. It's of no use to me as my husband can't push it. It's too heavy and cumbersome”
 - “Very much as had to buy electric scooter and also new shed and had to have electricity put in”
 - “I had to buy a manual wheelchair and dynamo unit because of inadequacy of NHS chairs. A voucher scheme would have been very welcome”

- The main reason for people not wanting a voucher scheme was the view that people who needed wheelchairs should get a good service as of right, for example
 - “The NHS should provide a good wheelchair service not a voucher scheme”
 - “Why should you have to buy a chair when it is your only means of getting about?”
 - “You should get the best wheelchair available for your requirements to give you a basic way of life – it should not be means tested”
- Misgivings about a voucher scheme were based on inability to use the scheme on a low income, for example
 - “It seems a good idea but my daughter is on benefits; if she wanted an electric wheelchair the cost starts from £2000 which she couldn’t afford”
 - “No answer as on benefits and so I couldn’t buy a better one. No matter how bad we have to put up with the ones given”
- Misgivings were also expressed about the cost of maintaining or replacing wheelchairs bought with vouchers, and about possible increased bureaucracy. For example:
 - “Quite hard to answer as this might create other problems, e.g. maintenance for one”
 - “X already has a lot of form filling which he is incapable of doing. Physical disabilities have increased with age and he needed a new chair. A bought wheelchair might be difficult to replace”
- The conditions of any voucher scheme were the main consideration for several respondents, for example:
 - “Yes, with specialist advice and consultation available”
 - “May be beneficial in certain circumstances – depends on the base level”.

Again, many people who said they were “satisfied” or “very satisfied” with the Service also said they would welcome a voucher scheme.

6.4.3 Other changes

The general question about what people would like to change in the NHS Wheelchair Service was answered by 38% (191) of respondents, 10% (52) saying they wanted no change and 27% (139) making a range of criticisms and suggestions. Many of the latter had said they were “satisfied” or “very satisfied” with the Service.

People who wanted no change mostly said “nothing” or “none”, although many had said they would welcome a local centre and some that they would like a voucher scheme. 9 respondents made positive comments, e.g.

- “Very satisfied”
- “Nothing, they are a first class service”.

Changes advocated included various aspects of service organisation and the wheelchairs supplied.

- 31 wanted a higher standard of wheelchairs, particularly more flexibility of design and other specification, so that individual needs could be better met, for example
 - “Basic red model is too heavy to handle on your own. . . would like to see 2004 being able to get lightweight chairs especially when you have to spend the rest of your life in one”
 - “Having a choice of wheelchairs and having components on them that do not rust”
 - “Various colours, various styles; more time taken for the right wheelchair to be supplied. A bigger choice of styles”
 - “Something that wasn’t like a supermarket trolley”
 - “When the doctor at SRI saw my wheelchair for the car he was annoyed and said I needed a new one . . . if I phone to explain this they just come out and repair it. It is unsafe to use. My grand-daughter hates pushing me in it because of this”
 - “More up to date wheelchair, lighter model”
 - “More sophisticated, with modern appearance, wheelchairs on the NHS in keeping with the 21st century”
 - “Electric (EPIOC) wheelchairs that go in a car. If motability means anything electric wheelchairs must be capable of going into a car”

- 20 wanted a faster repair service and some wanted it to be also more efficient and better adapted to the needs of users dependent on their wheelchairs. For example:
 - “Quicker repair service”
 - “More efficient repairs . . . sometimes chair is off the road 2-3 months (17 year old wheelchair)”
 - “More efficient repairs. It is not on that a person with one wheelchair has to wait for repairs that make them housebound or bed-bound”

 - “Just waiting time for repairs”

- 16 criticised slowness and bureaucracy, and wanted a speedier, more efficient supply of wheelchairs, for example:
 - “Less bureaucracy! More local, tailored service . . .”
 - “Service is far too slow; is too distant; does not meet specialist needs; lacks customer service and consideration . . .”
 - “Improve waiting time for assessment and provision”
 - “Had electric wheelchair test 5 years ago, still waiting; own normal wheelchair at repair centre 2-3 months; waiting new modified wheelchair following amputation!!!”

- 16 wanted improved information, about what was available and about how the service worked, for example:
 - “To be given more information about what is available to me”

- “Information leaflet to let person know exactly what is available to them specifically”
- “Clear guidelines as to who and where you have to go to get what you want”
- “More information about servicing and the types available”
- 14 wanted regular servicing, for example:
 - “Regular servicing 6-9 months”
 - “Make them phone or write to service once a year because they only fix the things that are wrong at the time”
 - “More assistance in keeping them repaired and up to date”
- 13 wanted improved assessment, for example:
 - “Assessment of carers needs as well as users”
 - “Assessed need to take account of lifestyle needs and carer needs”
 - “A more accurate assessment”
- 11 wanted more follow-up contact by the Service, for example:
 - “More communication between service and users”
 - “Wheelchair users’ case should be reviewed as their needs change as they get older”
 - “Would like re-assessment every 5-10 years to see if something else had become available more helpful to my condition”
 - “Hold the wheelchair clinic more than every 2 months, so that you don’t have to wait months for an appointment”
 - “Automatic, on-going referral system for re-assessment”
 - “More contact between NHS and user. No contact between NHS and myself since getting chair. Have carried out repairs at my own expense”
 - “Local centre so that patients don’t feel out of touch with the centre and the centre’s OTs”
- 8 wanted changes in the allocation rules to make better provision for individual need, particularly in relation to powered wheelchairs, for example:
 - “Assessment rules changed to make it easier for a 24/7 user to get an NHS powered wheelchair”
 - “24/7 wheelchair users to have a powered wheelchair and a lightweight one so that the carer doesn’t have to lift a heavy chair into the car every day”
 - “Supply chair for outside as well as indoors, not just push chair”
 - “Spare wheelchair when it’s your only way of getting around”.

TORT

6.4.4 Local centre

A local centre would be welcomed by 71% (34) TORT respondents, whilst 13% (6) said they would not welcome a local service. 8 did not answer.

- Of the 14 who said “no” or did not answer 6 commented that they were happy with the present arrangements
- 5 said “yes” conditionally: one “only if first class” and 4 from the same care home “depending on the length of time for assessment”
- 2 gave travel difficulties as their reason for saying “yes” and 2 others who said “yes” cited travel difficulties in another section (3 were under 16)
- 3 people thought a local service would give more contact.

6.4.5 Voucher scheme

A voucher scheme would be welcomed by fewer than 1 in 3 (15) TORT respondents, with 21 saying “no”. Only one person commented, commending the proposal for allowing more choice and flexibility.

6.4.6 Other changes

33% (16) responded to the general question about changes.

- 17% (8) said “no change”
- 6% (3) wanted more discussion of needs, one specifying the carer’s role
- 8% (4) wanted a better and more flexible range of wheelchairs.

7 Wheelchair users’ experience and views of different aspects of the Service

People were asked to provide further information to give a more detailed picture of their use of wheelchairs and of their experience and views of the different aspects of the Wheelchair Service.

WESTMARC

7.1 Wheelchairs used

7.1.1 Users with more than one NHS wheelchair

The majority of powered wheelchair users (EPIC and EPIOC) had a second wheelchair, 40 having an attendant- propelled and 39 a self-propelled model. An additional wheelchair has been standard issue for WESTMARC’s powered wheelchair users for some time. One user had 2 powered wheelchairs as well as a manual wheelchair. 9 other respondents had 2 wheelchairs (mostly self-propelled).

7.1.2 Ownership of other wheelchairs and scooters

A total of 139 people (27%) had bought or been given a wheelchair or scooter. 82 people had bought a scooter, 64 a wheelchair, 17 of them having bought both. It appears that 16 people had been given wheelchairs by family and friends (11) or charities (4) and one respondent did not specify. 6 of them had been given wheelchairs as well as having bought their own

wheelchairs or scooters. (A total of 47 people said they had been provided with a wheelchair by someone else, but it is likely that 25 respondents were referring to temporary use (e.g. of Red Cross wheelchairs whilst awaiting delivery of their NHS wheelchair) and that a further 6 were referring to the wheelchair and/or scooter which they said they had bought themselves in a previous answer).

Some respondents no longer used the wheelchairs or scooters which they had bought or been given. A few who had bought their own wheelchairs and/or scooters said they had returned their NHS wheelchairs.

The distribution of ownership of other wheelchairs and scooters among age groups was

Under 16	3	18% of age group	
16-45	21	36%	
46-65	46	30%	
66-75	39	29%	
75-85	21	22%	
Over 85	8	18%	No age given 1

The distribution of ownership of other wheelchairs and scooters among users of the different types of NHS wheelchair was

	Other wheelchairs		Scooters	
Electric powered in/outdoor	17/72	24%	8/72	11%
Electric powered indoor	4/18	22%	3/18	17%
Self-propelled	34/199	17%	43/199	22%
Attendant propelled	18/217	8%	28/217	13%

The highest distribution of other wheelchairs and scooters amongst NHS wheelchair type users, in age groups, was

Other wheelchairs			
Electric powered in/outdoor	age16-45	4/10	40%
	46-65	9/33	27%
Electric powered indoor	66-75	2/5	40%
	16-45	9/34	26%
Attendant propelled	16-45	3/12	25%
Scooters			
Electric powered indoor	66-75	2/5	40%
	66-75	12/48	25%

A few of these respondents had bought a wheelchair and a scooter

7.2 Assessment & delivery: how and when people got their wheelchairs

Only respondents who had been assessed since 2000 were asked to give information about being assessed for and taking delivery of their wheelchair. 57% (292) respondents said they had been assessed in this period. Of these almost two thirds (192) were assessed for their first wheelchair, the remainder were long term users who had had a re-assessment for a new wheelchair.

- Unsurprisingly there was a much higher proportion of first assessments in the under 16 and the two oldest age groups (over 76)
- Correspondingly, a higher proportion in these age groups overall had had a recent assessment: 88% (15 out of 17) respondents under 16 and 60% (84 out of 141) respondents over 75
- The second youngest age group (16-45) had the highest proportion of re-assessments of long term users: 72% (23 out of 32)
- In the middle age groups over a third were re-assessments: 37% (34 out of 91) of people assessed aged 46-65 and 34 % (23 out of 67) of people assessed aged 66-75.

7.2.1 Place of assessment

People were asked to say where they had discussed their needs for a wheelchair.

- 61% (178) had been assessed or re-assessed **locally**, by a GP, occupational therapist (OT) or other health professional.
 - 49% (144) had had only local assessment, 12 had also been assessed in hospital, 6 also in hospital and the Mobility Centre, 16 also at the Mobility Centre in Glasgow or a Mobility Centre home visit
 - 69% were new users, 30% were long term users
 - 64% (67) of new and 48% (15) of long-term users of **attendant-propelled** wheelchairs had local assessment, some in combination with other places of assessment
 - 65% (41) of new and 60% (28) of long-term users of **self-propelled** wheelchairs had local assessment, some in combination with other places of assessment
 - 61% (16) of new and 47% (9) of long-term users of **powered wheelchairs** had local assessment, mostly in combination with other places of assessment
- 39% (113) had been assessed in hospital
 - 31% (90) had been assessed only in hospital; 12 also locally as above, 6 also by local and Mobility Centre staff as above, and 5 also by Mobility Centre staff
 - 66% were new users, 48% were long-term users
- 16% (46) had been assessed by the Mobility Centre
 - 6% (17) had been assessed only by Mobility Centre staff, 6 in Glasgow, 10 in their homes and 1 in both; all but 3 were long-term users being assessed for a new wheelchair
 - 9% (27) were assessed by Mobility Centre staff in addition to others, as above; 14 were new users, 12 long term reassessments (one respondent did not give information about new or long term use).

7.2.2 How much are people involved in discussing their needs?

Questions about assessment aimed to find out the extent of people being involved in discussing their needs for a wheelchair:

- What they hoped for from their wheelchair, and the environment it had to operate in, including car type if relevant
- Whether they were given information about types of wheelchair
- Whether they were offered a choice
- Whether they were offered a trial.

7.2.3 Enquiry about needs

Questioning about needs was patchy: the majority were asked a basic question but with variations between new and re-assessed users and between wheelchair types.

- 2 in 3 respondents had been asked about what they wanted their new or replacement wheelchair to enable them to do
- Less than half had been asked questions about their home environment
- Just over 1 in 3 had been asked about cars which would carry their wheelchairs. A similar proportion of respondents said they were **not** asked about cars, with a third not answering the question, so it may be inferred that the question was relevant to at least two thirds of respondents, and that around half were asked, half not asked. However there may be other reasons for the non replies
- More respondents were asked all types of question at first assessment than were long-term users at re-assessment.

Analysis by wheelchair type showed that people who got **powered wheelchairs** and **first time users who got self-propelled wheelchairs** were most involved in discussion about their needs (except in relation to cars).

- Over 75% were asked about what they wanted their wheelchair to enable them to do at all places of assessment except hospital.
- Least often asked this question in these groups were the 9 powered wheelchair users re-assessed at hospital: 4 out of 9 recorded “no’s” and of the 5 recording “yes”, 3 were also assessed by Mobility Centre staff.
- Also in hospitals, amongst first time users of self-propelled wheelchairs, although 70% *had* been asked, 8 out of the 24 assessed at hospital recorded that they had not been asked this basic question.
- These groups also recorded the highest incidence of being asked about their home environment. However
 - powered wheelchair users re-assessed in hospital were least often asked; 4 out of 9 recording “no”
 - 5 out of the 13 powered wheelchair users re-assessed by Mobility Centre staff also recorded “no”
- Powered wheelchair users were infrequently asked about the cars they might use: 44% of new users and 47% of long-term users said they had not been asked about their cars.

- New users of self-propelled wheelchairs were most often asked about car requirements (46.8%) overall, although 7 new users of self-propelled wheelchairs assessed locally and 6 assessed at hospital said they were not asked.

The other 3 groups, **long-term users of self-propelled wheelchairs and new and long-term users of attendant-propelled wheelchairs**, recorded much lower incidences of being asked about what they wanted from their wheelchair and about their home environment. There was also a relatively high proportion of people giving a definite “no”, with a larger than average rate of “no replies” amongst new users of attendant- propelled wheelchairs.

Around a third of these groups were asked about their car requirements.

- Higher proportions of people being re-assessed for self- and attendant propelled wheelchairs said they were *not* asked.
- Over one third of respondents with new attendant-propelled wheelchairs did not reply to this question. However, since new users of attendant-propelled wheelchairs was the largest group (total 103), the number of people not being asked about car requirements was high, at 27, with proportions being roughly equal between local and hospital assessments.

The few manual wheelchair users assessed by Mobility Centre staff mostly recorded that they had been asked about what they wanted from their wheelchair. However 4 long-term self-propelled users and 3 new attendant-propelled users said they had not been asked this basic question.

Table W3

Summary of assessment discussions by wheelchair type showing % of the wheelchair type group assessed/reassessed who said they had or had not been asked about

- their aims for their wheelchair
- their home environment
- any car that the wheelchair would need to fit into.

Wheelchair	base no	Aims for wheelchair?		Home environment?		Car?	
		Yes	No	Yes	No	Yes	No
Powered (new)	27	81%	11%	56%	15%	22%	44%
Powered (re-assess)	19	79%	21%	47%	32%	16%	47%
						*	
Self-prop. (new)	62	76%	11%	55%	11%	47%	21%
Self-prop (re-assess)	50	58%	38%	30%	48%	36%	42%
Attendant (new)	102	62%	26%	33%	23%	32%	26%
				*		*	
Attendant (re-assess)	32	53%	31%	23%	44%	31%	38%
				*			

* over 1/3 in this category did not reply to this question

Tables W4-W6

Summary of assessment discussions by wheelchair type and place(s) of Assessment

showing % of users of different wheelchair types who said they were asked (Y) and were not asked (N) about their aims, environment and car requirements

Note: several respondents had been assessed in more than one place, mainly powered wheelchair users who had been assessed by Mobility Centre staff and in other places

Table W4 Aims questions

Wheelchair type	Local		Hospital		Mobility Centre		MC home visit	
	Yes	No	Yes	No	Yes	No	Yes	No
Powered (new)	88%	12%	78%	11%	90%	-	67%	33%
Powered (re-assess)	89%	11%	56%	44%	88%	13%	100%	-
Self-prop. (new)	80%	8%	71%	8%	100%	-	100%	-
Self-prop (re-assess)	61%	36%	67%	27%	60%	20%	50%	50%
Attendant (new)	66%	23%	57%	31%	-	100%	50%	50%
Attendant (re-assess)	75%	25%	50%	36%	50%	-	25%	25%

Table W5 Home environment questions

Wheelchair type	Local		Hospital		Mobility Centre		MC home visit	
	Yes	No	Yes	No	Yes	No	Yes	No
Powered (new)	59%	18%	56%	11%	80%	10%	-	67%
Powered (re-assess)	56%	33%	33%	44%	50%	38%	60%	40%
Self-prop. (new)	48%	13%	67%	8%	100%	-	100%	-
Self-prop (re-assess)	32%	48%	40%	33%	40%	20%	33%	50%
Attendant (new)	31%	26%	40%	19%	-	100%	-	50%
Attendant (re-assess)	25%	44%	36%	43%	-	50%	-	25%

Table W6 Car questions

Wheelchair type	Local		Hospital		Mobility Centre		MC home visit	
	Yes	No	Yes	No	Yes	No	Yes	No
Powered (new)	29%	41%	11%	56%	20%	50%	-	100%
Powered (re-assess)	22%	44%	11%	56%	25%	50%	20%	80%
Self-prop. (new)	48%	18%	46%	25%	100%	-	50%	50%
Self-prop (re-assess)	36%	42%	47%	27%	60%	20%	50%	50%
Attendant (new)	35%	29%	33%	24%	-	100%	-	50%
Attendant (re-assess)	44%	31%	29%	43%	-	50%	50%	25%

7.2.4 Consideration of different types of wheelchair: information, choice, trial

Very few respondents (18%) had been given information about different types of wheelchair, even fewer (11%) had been offered a choice of wheelchair and only 7% had been given a trial of wheelchair types (although in several cases it is likely from other comments that respondents tried out the wheelchair they had been allocated).

People with powered wheelchairs who were assessed or re-assessed by Mobility Centre staff more frequently got information than powered wheelchair users assessed elsewhere. About half of Mobility Centre assessments had provided information, the other half had not. The incidence of being offered choice was slightly less.

Five powered wheelchair users assessed by Mobility Centre staff had had a trial, as had another 6 who had been assessed in hospital. Four self-propelled users said they had had a trial (3 had Mobility Centre assessments), and 3 attendant-propelled users (2 with hospital, one with local assessments)

7.2.5 Additional information at assessment

Some further questions were added to the assessment section of the questionnaire, to find out whether people had been advised comprehensively about meeting their needs and about possible alternative means of meeting needs if the NHS could not. People were asked to say whether they had been advised on alterations and adaptations obtainable for their wheelchairs, and whether they had been told about alternative sources of wheelchairs and funding which might be available.

Most people had not been given any of this information.

- 16% had been given information about possible alterations and adaptations to their wheelchairs, the highest incidence being amongst people reassessed for attendant-propelled and for powered wheelchairs (just under a third of each of these groups)
- 8% had been given information about other sources of wheelchairs, 2/3 of them being first time assessments, attendant-propelled users.
- 3% had been given funding information, half of them new attendant -propelled users.

7.2.6 Involvement of carers in assessment

People were asked, if they had someone who helped them get about, whether that person had been involved in assessment. There was low involvement of carers across all places of assessment.

- Carers were not involved in 75 % of assessments where it was relevant to do so
- 25% of respondents said their carer had been consulted.

7.2.7 People's experience of getting their wheelchairs

People were asked about waiting times, whether they had got sufficient help with being shown how to manage their wheelchairs, and whether their wheelchair had needed adaptations when they got it. They were also asked to say whether they had been given other information which might have helped them, about

- other services
- other help from the Mobility Centre
- repair and maintenance arrangements.

7.2.8 Waiting times

Of those who could remember the waiting time for delivery of their chair, most had waited over a month. 28% said they could not remember the waiting time, most of them being attendant or self-propelled wheelchair users.

- The 4% who had 3-4 day delivery were almost evenly divided between attendant- and self-propelled wheelchairs, as were the 9% who got their wheelchair within 2 weeks and the 14% who waited 2-4 weeks (Respondents giving each of these waiting times included a single powered wheelchair user, who may have been referring to their manual wheelchair)
- Of the 42% who waited over a month, 33% (40) got self-propelled, 40% (49) attendant propelled wheelchairs, and 27% (33) got powered wheelchairs
- Over a third of self-propelled and attendant propelled users waited over a month, whilst 71% of powered wheelchair users waited for at least this period. Many of the latter added that they waited for nearly a year, a few for over a year.

57% of respondents considered waiting time satisfactory and 32% did not.

- There was less satisfaction amongst people being re-assessed than amongst new users, with 43% of the former dissatisfied compared with 26% of the latter, and 49% compared with 62% satisfied
- The highest level of satisfaction was amongst self-propelled wheelchair users, with 64% saying waiting time was satisfactory and 23% saying it was not.
- Least satisfaction with waiting times was expressed by powered wheelchair users, with 61% dissatisfied and 32% satisfied.

7.2.9 Help with managing the wheelchair

There was a slightly higher level of satisfaction with help given with managing the wheelchair, when it was delivered, with overall 63% saying they had got enough help and 32% who had not.

- There was less discrepancy between people being re-assessed and new users, with 39% of re-assessed users saying they did not get enough help compared with 28% of new users, and 58% of established users compared with 66% of new users saying they did get enough help.
- Powered wheelchair users were most satisfied, with 72% saying they got enough help and 28% who did not.
- Satisfaction amongst self- and attendant-propelled wheelchair users was similar, with 61% and 60% getting enough help, and 33% of both types who did not.

7.2.10 Adaptations needed when wheelchairs delivered

Almost 1 in 4 people (24%) required adaptations when their wheelchair was delivered, mostly following re-assessments.

- This happened more often for powered wheelchairs (45% compared with 22% and 17% of self-propelled and attendant-propelled wheelchairs)
- Two thirds (44) were satisfied with the wait for these adaptations, but a third (22) were not.

7.2.11 Further back-up information

People were asked to say whether they had had sufficient back-up information when they got their wheelchairs.

Almost half (47%) had not been given enough of any of this information. The proportions of respondents who did get sufficient information were:

- About other help 20%
- About other Mobility Centre help 16%
- About repair and maintenance arrangements 30%
- About insurance 10%

On the subject about which most received information, repairs and maintenance, over half of attendant- and self-propelled wheelchair users and 44% of powered wheelchair users did not get information. People who were assessed at the Mobility Centre were more often given repairs and maintenance information than at local or hospital assessments.

7.3 Experience of wheelchairs in use

Respondents were asked to report specific problems [as listed in Table W7] and any other problems experienced.

Over two thirds (67%) reported one or more problems.

- Overall the most frequently reported problems were that wheelchairs were difficult to get in and out of a car (33% of respondents), and that they were too heavy (32%)

- The car problem was reported by almost half of in/outdoor powered wheelchair users, and was also the most frequently reported problem by indoor powered wheelchair users, equally with the wheelchair being too heavy
- The wheelchair being too heavy was the most frequently reported problem by users of all types of wheelchair, except in/outdoor powered wheelchairs
- One in 3 users of powered wheelchairs found the seating uncomfortable
- The most common other problems reported were “unsuitable to needs” (16) and wheels and tyres (13)
- Other problems listed were “badly fitting” (7), quality (7), lack of servicing and knowing where to go (7).

Respondents were asked to say whether they had had any problems put right. 27% said that they had, and some described action that had been taken to address one or more of the problems they had reported, for example a respondent who had reported a wheelchair was “too heavy” said a lighter chair was supplied. Another respondent, who had ticked all specified problems, including poor manoeuvrability, reported “the wheel was changed but the chair still goes its own way”.

However, other comments suggested that many respondents were referring to one off problems such as break-down in answering this question. For example a respondent who had ticked 3 listed problems and also “problems put right”, commented “but had to wait a minimum of 7 days for repairs to be carried out, any time waiting for repairs confines me to bed and immobile (e.g. a wheel fell off and a part had to be renewed)”. Or several respondents who had ticked listed problems and explained a non reply to the question about problems put right with the comment “no problems”.

Table W7

Problems in use, showing % occurrence overall and within each wheelchair type

Problems in use	All wheelchair types		Powered (indoor)	Powered (in/outdoor)	Self-propelled	Attendant - propelled
	(Total 509)		(Total 18)	(Total 72)	(Total 199)	(Total 217)
Difficult to get in/out of car	170	33%	39%	49%	33%	27%
Too heavy	163	32%	39%	32%	36%	27%
Did not get all attachments needed	132	26%	28%	28%	27%	23%
Seating is uncomfortable	129	25%	33%	34%	24%	23%
Difficult to manoeuvre	126	25%	28%	30%	23%	24%

7.4 Repairs and adaptations for changing needs

7.4.1 Repairs

44% of respondents (226) had had repairs to their wheelchairs, with most having had repairs carried out by Mobility Centre engineers (50%) and/or Mobility Centre contractors (40%) (some having had both services). 18 respondents said repairs had been carried out by the manufacturer, 11 by a local repairer or garage, and 16 had had DIY repairs. Most people had had repairs carried out at their homes (90%), with just 12% saying repairs had not been done at home. A few said repairs had sometimes been carried out at home, and sometimes their wheelchair had been taken away.

The highest incidence of repairs was amongst powered wheelchairs, (71% of all powered wheelchair respondents), followed by self-propelled wheelchairs (48%) and attendant-propelled having the lowest (26%).

The large majority, 85%, said they were satisfied with repairs, with 12% saying they were not satisfied.

- 87% said they were satisfied with Mobility Centre engineers, with 11% saying they were not satisfied.
- 82% of people who had used Mobility Centre contractors said they were satisfied and 17% said they were not satisfied.
- Almost all people who had other repairs services were satisfied.

However 10 made comments modifying their expression of satisfaction, for example:

- “But later the repaired mechanism failed again”
- “Receptionist is very rude, impatient and authoritarian”
- “Repair satisfactory but time waited seemed quite unnecessary”
- “I think they take too long to come and repair my wheelchair which is usually brakes”.

Others commented favourably, for example:

- “Service was very quick and people were very nice”
- “Quick service by helpful engineers”
- “Very prompt and most helpful when I phoned”.

The groups who were least satisfied with the repairs service were

- Self-propelled wheelchair users who had had repairs carried out by Mobility Centre contractors (27% were not satisfied)
- Powered wheelchair users with repairs by Mobility Centre engineers (17% were not satisfied).

7.4.2 Adaptations

Respondents were asked to say whether they had needed adaptations to their wheelchairs as their needs had changed. 18% (92) said they had required adaptations. As would be expected, a higher proportion of long-term users (31%) had required adaptations than people with their first wheelchair (12%). The highest incidence of adaptations being required was

among younger age groups, with 38% of long-term users aged 16-45 and 3 out of the 6 users under 16 who had had previous wheelchair(s).

One in 3 powered wheelchair users had required adaptations, 1 in 5 self-propelled wheelchair users and just under one in ten attendant-propelled wheelchair users.

Comments which followed the question indicated that the majority of respondents who answered “yes” had had adaptations carried out or were expected shortly. In addition, at least 6 had identified adaptations which they needed but had not been carried out. For example:

- “Legs and ankles get very painful because of height of foot platform. I have to have my feet off”.
- “Not forthcoming. Refused a powered wheelchair for outdoors and indoors because I can self-propel inside. Can’t understand the logic”
- “Armrest too heavy to lift. I need a wheelchair which elevates”.

Some who answered “yes” used the comments section to describe action taken out with the NHS service, for example

- “Had to buy electric wheelchair”
- “Had to buy a stretcher between pushing arms, didn’t know NHS supplied these”.

Several who answered “no” also commented on needs that might be met by adaptations or on re-assessment of needs that might indicate adaptations, for example

- “I now feel I need more support but don’t know what wheelchairs are available on the NHS”
- “Never been reviewed”.

A few respondents who did not answer the question used the comments section to say that adaptations would be helpful, for example

- “Could do with electric adaptations as husband is nearing 60 and struggles to push it uphill”
- “Do not know what adaptations are now available, or if it’s possible to raise the seat or remove the arms to ease transfer from wheelchair to bed”.

The majority of the 69 respondents who used the comments section simply described adaptations which had been carried out or were likely to be done soon.

Thirteen respondents commented on adaptations which had been unsatisfactory, for example:

- “Poor, they were not tailored to needs”
- “Still waiting for adaptations to be corrected 7 months later”
- “Didn’t listen to what I did need and gave me plenty of what I didn’t”.

Two respondents made approving comments:

- “Previously slow to come out but recently the service has improved”
- Exchange of attendant-propelled for self-propelled wheelchair, when suited better, “no problem” through GP.

TORT

7.5 Wheelchairs used

7.5.1 Users with more than one NHS wheelchair

All but 2 of TORT users of powered wheelchairs had second attendant- or self-propelled wheelchairs and one had a third chair for the shower. One respondent had 2 attendant propelled wheelchairs.

7.5.2 Ownership of other wheelchairs and scooters

23% (11) respondents had acquired other wheelchairs, 4 having bought wheelchairs, 4 scooters, 1 both, and 2 (both under 16) having been given wheelchairs by charities. Family, friends and colleagues had contributed to the privately purchased wheelchairs, and others had had temporary loans.

Other wheelchair/scooter ownership was distributed across age groups, except the oldest.

4 users of NHS powered chairs owned wheelchairs and 3 owned scooters (1 owning both)
 3 attendant-propelled users owned a wheelchair and 1 a scooter
 1 self-propelled user owned a scooter.

7.6 Assessment and delivery: how and when people got their wheelchairs

56% of respondents (27) said they had been assessed during and after 2000. Of those assessed in this period, 15% were re-assessed, 3 under 16, 1 16-45. 85% were assessed for the first time, 14 over 75, 5 66-75, 3 46-65 and 1 16-45.

- Most of the people assessed for the first time had been assessed locally (11) or combinations of locally and other places (9)
- 3 had been assessed only in hospital, 3 also locally.
- 2 had been assessed at the TORT Centre, in combination with local assessments
- 4 had had assessments by TORT staff at home (all in care homes) as well as locally.
- People who were reassessed went to the TORT Centre (3) and local assessment (1).

7.6.1 How much were people involved in discussing their needs?

78% of people assessed for the first time had been asked what they wanted their wheelchair to enable them to do and 22% had not. 43% had been asked about their home environment and 30% had not. 35% had been asked about car requirements and 35% had not, which may indicate that half of those for whom the question was relevant were asked and half were not.

People who were re-assessed by TORT Centre staff had been asked all relevant questions but the young respondent re-assessed locally had not been asked any, nor had the parent/carer.

7.6.2 Consideration of different types of wheelchair: information, choice, trial

Of people assessed for the first time 43% said they had been given information about types of wheelchair and 57% said they had not.

17% said they had been offered a choice of wheelchairs and 9 % said they had tried them out (the 3 main wheelchair types were all represented as was each place of assessment in these answers).

Of the 4 respondents who were re-assessed, 2 had not been given information, nor offered a choice nor trial (one TORT, one locally assessed, both attendant propelled wheelchairs); one had been given information only and one information, choice and trial (both assessed by TORT, one self-propelled, one attendant propelled wheelchair).

7.6.3 Additional information at assessment

Over a third of new users were given information about other sources of wheelchairs, but none of the long-term users were given this information. 13% of new users also said they were given information about funding. 22% of new users and 50% of long-term users were given information about alterations and adaptations.

7.6.4 Involvement of carers

45% of first time users said their carer had been involved, 55% said they had not. All respondents being re-assessed, except one under 16 assessed locally, said the carer had been involved. Most new users who said the carer was not consulted were assessed locally, except 2 who were also assessed by TORT Centre staff.

7.6.5 Waiting times for wheelchairs

56% had waited over a month for delivery of their wheelchair but only 19% thought the wait was unsatisfactory. Others had shorter waits.

7.6.6 Help with managing the wheelchair

Most had had sufficient help but 11% (3 respondents) had not. All were first time users of attendant propelled wheelchairs.

7.6.7 Adaptations needed on delivery

26% (7 people) required adaptations. 1, a long term user, considered the waiting time unsatisfactory.

7.6.8 Further back-up information

Over two thirds of respondents received sufficient information on at least one topic. The proportion of respondents getting (and not getting) information was

- About other help 44% (48%)
- About other TORT Centre help 37% (56%)

- About repair and maintenance arrangements 56% (33%)
- About insurance 26% (63%)

(2 respondents did not answer any of these questions. 1 respondent did not answer the last 2 questions)

26% did not get enough of any of the information: 5 had attendant-propelled wheelchairs, 1 a powered and 1 a self-propelled wheelchair.

7.7 Experience of wheelchairs in use

54% of respondents listed one or more problems (6 people reported only that they did not get all attachments needed). The most frequently reported problems were difficulties with getting the wheelchair in and out of cars and lack of attachments, each reported by 23% (11) respondents.

The 7 respondents with self-propelled wheelchairs had the highest proportion of problems: 4 found them too heavy, 3 difficult with cars, 2 difficult to manoeuvre.

One in four powered wheelchair users listed difficulty with cars and the same number lack of attachments. Lack of attachments was the most frequent problem listed by attendant-propelled users (28%).

19% said they had had “problems put right”, but it is likely that most of them were referring to general problems, for example:

- “Good service from Dundee when required”
- “Repair to brake”.

7.8 Repairs and adaptations for changing needs

38% had had their wheelchair repaired, 83% of them by TORT Centre engineers. All repairs by the Wheelchair Service had been satisfactory. 2 respondents did not express a view: one did DIY repairs because of difficulties in a young user being without the wheelchair, another no longer used the wheelchair and did not specify the repairer.

4 respondents commented, two praising the service as “first class” and “very helpful”, one saying that the powered wheelchair had been serviced rather than repaired. A young user said that the wheelchair could not be repaired at school because out with the TORT area.

17% said they had needed adaptations for changing needs. Ten respondents commented on adaptations.

- 4 described satisfactory adaptations or changes of wheelchair, e.g. “smaller electric wheelchair”
- 1, a carer, described unmet needs of the user which now limited use of the wheelchair
- 1 lacked information “what adaptations are available? I don’t know.”
- 2 complained, one about the “long time to go through official channels”, one about lack of responsiveness to their needs over a period.

8 Further consideration of respondents' "satisfaction" with the Wheelchair Service

Recent literature on the increasing volume of social and health care surveys has outlined the limitations of "user satisfaction" as a measure of service quality⁶. These include:

- Answers to general questions about satisfaction mask varied opinions about specific aspects of services
- Older users are unlikely to express dissatisfaction and are more likely to express higher levels of satisfaction than younger people
- Older people often express satisfaction with a service at the same time as admitting needs unmet by the service
- Older people are often unwilling to criticise and to appear demanding

- Satisfaction can depend on people's expectations, which are closely related to life experiences and cultural values, and also to their knowledge of what is available

- Physical and mental health and wellbeing can have a strong influence on expressed satisfaction levels.

Several of these features were confirmed in this study and others are likely to have been present. Nonetheless, it is suggested that a closer look at the experience of respondents who place themselves at the two ends of the satisfaction spectrum helps to throw light on what people most value, what is working well and what is not working well.

This section analyses comments made by respondents as well as statistical evidence to examine factors leading to satisfaction and lack of satisfaction.

8.1 What makes people "very satisfied" with the Wheelchair Service?

8.1.1 WESTMARC

As reported above 22% of respondents said they were "very satisfied".

- The age group 46-65 had the highest proportion of people who were "very satisfied" (25%)
- The youngest and oldest age groups had least people who were "very satisfied" (12% and 16%)
- Powered and self-propelled wheelchairs had the highest proportion of "very satisfied" users (both 26%)
- Attendant-propelled wheelchairs had the lowest proportion (16%)
- People who had had long term and intensive use of their wheelchairs (as indicated by successive wheelchairs, having had repairs and adaptations) were less likely than others to be "very satisfied", except users of self-propelled wheelchairs

⁶ Summarised in Bauld L, Chesterman J, Judge, K (2000) Measuring satisfaction with social care amongst older service users: issues from the literature Health and Social Care in the Community 8 (5) 316-324 Blackwell Science Ltd

- 17% of this category were “very satisfied”: 2/16 powered wheelchair users and 1/10 attendant-propelled wheelchair users were “very satisfied”, compared with 5/21 self-propelled users
- Purchase of a wheelchair or scooter did not prevent people from being “very satisfied” with the NHS service, and may have enhanced satisfaction through providing a complementary mobility aid.
 - 21% of people who had purchased privately were “very satisfied”, with higher proportions in over 65 age groups. 74% of their purchases were scooters. (In a few cases, purchased wheelchairs may have been superseded by acquisition of an NHS wheelchair). Half of those who had purchased privately said they would welcome a voucher scheme.

63% (70) of “very satisfied” respondents gave one or more comments in different parts of the questionnaire. These indicate that what is most valued in the Wheelchair Service is improved quality of life given by a wheelchair and responsiveness of the Service.

Improved quality of life was referred to by 15 respondents, in general terms, and specifically the ability to get out and about, have freedom, be independent. For example:

- “I would not get out if I did not have the NHS wheelchairs” (EPIOC 46-65)
- “I can now go in buses when the car not available” (AP 46-65)
- “It allows me to get to places and do things I couldn’t do without it.” (SP 66-75)
- “My wife’s electric chair has improved her social life and made her more independent thank you” (EPIOC 66-75)
- “I’ve been a wheelchair user all my life, 30 years in hospital . . . in 14 years in the community have got on very well with my wheelchairs” (EPIC 46-65)

Approval of responsiveness of the Service was commented on most often in answer to questions about aspects of the Service: assessment, dealing with problems, carrying out repairs and adaptations, as reported below under **Experience of specific aspects**. 12% of respondents also commented in response to general questions, mainly about changes wanted in the Service. For example:

- “Nothing [changed], because I have always had pleasant service”
- “Very satisfied with service from present contractor”.

Several respondents expressed gratitude, for example:

- “So much a better quality of life and through the NHS I don’t have to fork out as I know they are expensive and for that I am grateful too. Always appreciate what you get” (SP 46-65)
- “I can’t say how pleased I am such a loan scheme existed Handed it back with many thanks and hoped the next person would get as much freedom as I did. Eternally grateful” (EPIC 76-85)
- “Very grateful to have this wheelchair. For the first time in 2 years I’m going to the flower show. 3 cheers!” (SP 76-85)

- “I am grateful for the wheelchair but as my husband now also disabled got scooter for flexibility and independence” (SP 46-65).

However, a number of “very satisfied” respondents expressed reservations about the service and problems in using their wheelchairs, as reported below under **Experience of specific aspects**. 5% of “very satisfied” respondents said that their wheelchair did not meet their needs or did not meet them well. One of these respondents was reporting on the current wheelchair and was pleased to be getting a powered wheelchair when allocated suitable housing. Two respondents were unable to use their wheelchairs because their pushers were no longer able or available, two because of deterioration in their own condition.

4% of “very satisfied” respondents referred to the need for access to powered wheelchairs or scooters through the NHS, for example:

- “Arthritis has spread to shoulders and elbows, difficult to self-propel and have to rely on family and friends. Lightweight electric chair would be a godsend” (SP 76-85)
- “Would be useful to be given chance to have a scooter on NHS as very expensive and I now require one to maintain independence as in the past”(SP 16-45).

8.1.2 Experience of specific aspects of the Wheelchair Service

Generally, “very satisfied” users had better experience of all aspects of the service.

Assessment:

“Very satisfied” respondents more often discussed their needs for a wheelchair than respondents as a whole (80% compared with 66% were asked the basic question about what they wanted of their wheelchair). They were also more often given information about different types of wheelchair (26% compared with 18%) and slightly more often offered a choice (15% compared with 11%). They got very slightly more other information than respondents as a whole, but a similar high proportion of carers were not involved (76% compared with 75%).

5 out of 11 approving comments from all respondents about assessment were made by “very satisfied” users, for example

- “Good support/guidance was provided “ (EPIOC 46-65)
- “Very happy with my self-propelled chair which suits my needs fine” (SP 76-85)
- “I got what I required and I am happy with it” (SP 46-65).

Delivery of wheelchair

80% were satisfied with delivery time, 11% were not, compared with 57% and 32% amongst all respondents.

Wheelchairs needing adaptations on delivery

13% required adaptations to their wheelchairs when delivered, compared with 24% overall; only 1 person was dissatisfied with the additional wait.

Help with managing

77% were satisfied, 10% were not, compared with 63% and 32% amongst all respondents.

Problems in use

Approximately half as many “very satisfied” users found wheelchairs heavy, difficult to manoeuvre or uncomfortable as amongst all respondents (16%, 12%, and 11%, compared with 32%, 25% and 25%). However the same proportion did not get all attachments (26%). 21% had difficulties with wheelchair and car, compared with 33% of all respondents. 9% described other problems.

Problems put right

One fifth of respondents used this section to emphasise they had no problems or to emphasise the extent or the speed with which problems were remedied. For example:

- “No problems, the wheelchair was made to take my weight”
- “Replaced front wheels very quickly”
- “Wheelchair tipped back on gradient, I fell out and cracked my head . . . taken to hospital . . . but no serious damage to my head, plenty to the wheelchair. It was replaced”
- “The first wheelchair needed maintenance, and the engineer replaced it as there was too much wrong”.

However not all of the problems listed or described in the previous section were put right.

Repairs

47% of “very satisfied” respondents had had their wheelchair(s) repaired compared with 44% of respondents overall. All, except one who did not reply, reported satisfaction. 9 respondents commented approvingly, for example:

- “Very satisfactory” (SP 46-65)
- “Very prompt and most helpful when I phoned them” (AP 76-85)
- “Everything is done when it needs done” (EPIOC 46-65)
- “The Mobility engineers are very good” (SP 76-85).

Adaptations

A slightly smaller proportion of “very satisfied” respondents had had adaptations (14% compared with 18% overall) but most of them made comments, mainly describing the extent of the adaptation. For example:

- “Special seating and back”
- “Originally given attendant-propelled wheelchair, it was good to get out and about but a self-propelled wheelchair was better when my husband was not there. I asked for it through my GP and exchange was not a problem”.

8.1.3 TORT

As reported on page 31 there was a high level of “very satisfied” users amongst the differently constituted TORT respondents. Over half were “very satisfied”: this included all but 2 in 2 age groups, over 85 and 16-45, and all but one of the 11 respondents with powered wheelchairs.

There appeared to be no significant factors related to long-term (having successive wheelchairs) or recent use, with only a slightly higher ratio of new to long term users than amongst TORT respondents as a whole.

Purchase of another wheelchair or scooter did not prevent people from being “very satisfied” with the NHS service. Over half of respondents who had bought wheelchairs or scooters (5 out of 9) were very satisfied, 4 of them having scooters along with NHS powered wheelchairs.

Experience of the service appeared to be entirely free of problems for almost 2/3 “very satisfied” service users and a few expressed enthusiasm for the service as a whole and for different aspects of it. For example:

- “Excellent service” (EPIOC 66-75 in response to the question “did you get any problems put right)
- “Excellent service from Dundee” (comment from 4 care home residents)
- “Very happy with existing arrangements. Ninewells always helpful, repair service excellent” (EPIOC 46-65)

All wheelchairs met needs without qualification, with 2 commenting on their limited need for their wheelchair and 2 on its importance to them.

One respondent on the WESTMARC database declined to give a satisfaction rating because “service varies between Health Boards” and praised TORT for giving a good service, commenting:

- “During 30 years of dealing with the service I have found
 1. delays between Health Boards. For [new item] I notify Forth Valley Health Board, who notify Glasgow, who request Dundee. Delay – 8 months
 2. Reason for requesting Dundee: staff have a) tailor made facilities in the unit: assessment, fitting and manufacturing rooms; b)highly experienced and understanding; c) end product of high quality – satisfied customer”.

8.1.4 Experience of specific aspects of the Wheelchair Service

Assessment and delivery

There was a much higher incidence of discussion and provision of information to “very satisfied” respondents than amongst respondents as a whole. Indeed, almost all the respondents who said that they had been asked questions about needs and given different types of information were “very satisfied”. Only 1 “very satisfied” respondent had not been asked about their aims for the wheelchair, but 3 had not been asked about car requirements. Few had been offered choice or a trial. All but one were satisfied with waiting times and all with being shown how to manage their wheelchair. Only one comment was made:

- “Needs and wishes were explored and taken into account and every help was given” (AP 76-85, assessed locally).

Problems in use

32% reported problems (compared with 54% of all TORT respondents), mainly lack of attachments (18%) and difficulties with wheelchair and car (14%).

Repairs and adaptations

All 9 “very satisfied” respondents who had had repairs were satisfied with them. It was notable that 6 out of the 8 respondents overall who needed adaptations were “very satisfied”.

8.2 Why are some people not satisfied with the Wheelchair Service?

8.2.1 WESTMARC

As reported above, 27% of WESTMARC respondents were not satisfied, 18% describing themselves as “neither satisfied nor dissatisfied” and 9% saying they were “dissatisfied”.

People who were not satisfied used the comments sections slightly more than other respondents to report on their experience and give their views. 86% of the 139 people who were not satisfied made comments, compared with 80% of the 353 people who were satisfied. All but 2 of 45 respondents who were dissatisfied used the comments sections.

Comments showed that the most prevalent reasons for people not being satisfied were that their wheelchair(s) did not meet their needs in a variety of ways which were important to them, poor communications by the Service, and waiting for wheelchairs and for repairs and adaptations.

8.2.2 Who are not satisfied with the Wheelchair Service?

As reported above (pages 25-26), lack of satisfaction was greatest in the following groups:

- The two youngest age groups – over half of respondents under 45 were not satisfied
- People with powered wheelchairs – one third were not satisfied
- Long-term and intensive users of the service (as indicated by successive wheelchairs, having had repairs and adaptations) - almost half, 23 out of 47 - were not satisfied. (2 long-term users did not give satisfaction ratings).
- 18 of the 23 unsatisfied, long-term intensive users were under 65, 5 over.

8.2.3 Wheelchairs “not meeting needs”

Over half (72) of respondents who were not satisfied felt that their wheelchair(s) did not meet their needs well. 47 of them said that their wheelchair(s) did not meet their needs overall. 10 did not answer the direct question about giving the help they needed, but 7 of them indicated in comments that their wheelchairs only partly met their needs, for example, “sometimes”. A further 18 of the 82 who said “yes” qualified their answer by comments also indicating that their needs were only partly met.

The table below shows the incidence of needs not being met by wheelchair types.

TABLE W8
People not satisfied with the Wheelchair Service: wheelchair types not meeting needs

	Total non-satisfied respondents	Powered wheelchairs	Self-propelled wheelchairs	Attendant propelled wheelchairs
Non-satisfied respondents	139	30	53	56
% of wheelchairs not meeting needs of non-satisfied respondents	52% (72)	63% (19)	53% (28)	45% (25)

(Respondents with 2 different types of wheelchair are listed as powered where they also have attendant- or self-propelled, and as self-propelled where they also have an attendant-propelled wheelchair)

Comments made by these respondents in various parts of the questionnaire reflected both key shortcomings in the Wheelchair Service reported by other respondents and the individuality and range of need to be met.

The following analysis is of the experience of those unsatisfied respondents who said that overall their needs were not met or only partly met by the different types of wheelchair they had. Although the numbers are relatively small, it is submitted that the information is important because

- meeting these respondents' needs is a key aim of the Wheelchair Service
- elements of their experience reflect that of many service users
- it indicates that resources are not being well used.

Powered wheelchairs

Six of the 19 respondents (32%) described the failure of powered wheelchairs to meet their key personal mobility needs, such as enabling them to transfer from one sitting position to another or of having support for particular parts of the body. For example:

- "Unable to transfer from bed to chair, from chair to toilet, from chair to easy chair; wheelchair height affects ability to eat. To avoid wife (over 60) manually lifting I bought a wheelchair for £6000".

Five described the poor and even dangerous performance of wheelchairs outside, for example:

- "Won't fold; can't cope with pavement camber (fallen out more than half a dozen times); keeps moving after I release joystick; loses power going uphill".

Arrangements for synchronising with car transport curtailed independence for most respondents, for example

- “I can’t walk or stand at all. NHS give self-propelled wheelchairs in addition to EPIOCs as EPIOCs are too heavy for car. The self-propelled is too heavy, I require a lightweight model, but am told “no” unless I return the EPIOC!”

One of the 3 with indoor only wheelchairs expressed extreme annoyance at having to depend on others to go outside, adding:

- “A chair for outside use would give me independence as would not have to rely on someone to take me out for a loaf or anything I need from a shop”.

One respondent summed up the frustration expressed by others in this group in their search for solutions to increase their mobility:

- “Poor service curtailed independence, uncomfortable chair makes longer outings stressful”.

Two respondents had “ended up having to buy” a better powered wheelchair, and one was considering doing so. Another considered that would be “impossible, even with a voucher scheme, as living on welfare benefits”.

Self-propelled wheelchairs

A key cause of frustration was inability to operate the wheelchair independently. 16 respondents (57% of self-propelled wheelchair users whose needs were not met) said they were unable to self-propel, or only indoors. Some said their pusher was no longer able to push. 9 of these respondents felt that they needed a powered wheelchair. A few of them had been able to purchase or acquire one. One respondent described the assessment process for the self-propelled wheelchair:

- “I was sent to WESTMARC where they decided to give me a self-propelled wheelchair. It has only ever been used in extreme circumstances because when my condition is bad I can’t lock or unlock the brake, let alone self-propel. I had to get [a charity] help with an electric scooter to give me the freedom I need”

6 described multiple problems which they had tried to resolve over long periods.

23 respondents (82% of this group) said their wheelchair was too heavy and 19 (68%) that they had difficulties in using it with cars.

Attendant-propelled wheelchairs

5 of the 25 respondents (20%) with attendant-propelled wheelchairs which did not meet their needs described long-drawn out efforts to find satisfactory solutions, for example:

- “Ongoing at present [in reply to “did you get any problems put right?”] but taking a very, very long time. Some alterations were totally inappropriate and have caused a great deal of discomfort”.

3 of the 5 had bought their own; one commented:

- “The chair was so awful I had to purchase my own”.

At least 4 respondents did not use their wheelchairs (and did not list problems in use) because they were not adjusted to their needs (including home environment). One had bought a scooter.

The most common difficulty was in pushing: 65% (17) said their wheelchair was heavy and/or difficult to manoeuvre and 7 commented. For example, a respondent who described wayward wheels “like a supermarket trolley” also said

- “The wheelchair is very hard for my daughter . . . so I stay at home rather than put her through this disaster”.

Two had bought scooters and one had bought a wheelchair and wanted to buy a scooter:

- “Would like to buy my own choice of scooter to be independent. Had to buy own wheelchair as NHS chair lies in the garage, too heavy and cumbersome for my husband to push”

Two other respondents in this group wanted powered wheelchairs or scooters.

Difficulties with getting wheelchairs in and out of cars were listed by 13 respondents (52%) and 3 described the difficulty of getting from wheelchair into car, for example:

- “I can’t stand so can only get into car via ramp, which enables me to leave house, go to wheelchair accessible places”.

One respondent (16-45) who described a lengthy and contentious process to have complex needs met had finally succeeded and reported

- “I am unable to walk so the wheelchair is a significant aid to independence inside and outside the home”.

8.2.4 Private purchase of wheelchairs

25% of unsatisfied respondents had bought a wheelchair or scooter. People under 65 had more often bought a wheelchair than a scooter. As indicated by comments quoted above, these alternatives were usually purchased resentfully because the NHS wheelchair was found wanting.

8.2.5 Poor communications

55% of unsatisfied respondents commented about poor communications, in reply to general questions, mainly about changes needed in the Service. Complaints included lack of contact by the Centre and lack of information about how to use the Service. For example:

- “My husband has not been re-assessed for 20 years. I think this is important”
- “Glasgow is too remote; local repair service worked well in past; advantage that known locally”
- “It was just delivered. . . I would have preferred a personal assessment”

- “ I do not know what adaptations now available, or if possible to raise seat, remove arms to enable transfer from chair to bed”
- “ I have been totally confined to a wheelchair in Forth Valley for the last 12 yrs, my experience is that the wheelchair service is non existent in this area”
- “Wheelchairs are issued then forgotten, no contact with user after that. Service is poor.”

Comments on the same theme were also made in response to questions about specific aspects of the Service (see below).

8.2.6 Waiting

23% of unsatisfied respondents made critical comments about waiting for various aspects of the service in response to general questions, and even more indicated in answers to questions about aspects of the service that waiting was a major cause of dissatisfaction (see below). Many of the replies to general questions indicated the difficulties caused by waiting for different elements of the service, for example:

- “User [16-45] is totally dependent on wheelchair outside the home. Any delay in repairs means he cannot go out or to the day centre, which causes disruption to the whole family”
- “I am still angry about [user under 16]’s treatment when waiting for the wheelchair. The old one was falling apart and getting dangerous. I was told by WESTMARC not to put her in it if I thought it was unsafe. What were we supposed to do – keep [user], in the house, off school until the new wheelchair came!!! Parts arrived 3-4 weeks after the wheelchair. We have had problems with just about every delivery of previous wheelchairs”.

A respondent who had waited over a year for a powered wheelchair gave a strong summing up of the frustration expressed by many respondents who were not satisfied with the Service:

- “If the objective is ‘independent living’ then the whole process should match that aspiration!?”
Since [crisis] in spring 2003 flagged up the need for an electric chair as urgent! it made no difference to the initial order in autumn 2002.
The system seems compartmentalised/centralised/bureaucratic/means tested/ and very ‘time-delayed’, and not fully geared to assist independent living aspirations/requirements”.

8.2.7 Experience of specific aspects of the Wheelchair Service

Assessment

As would be expected there was a higher incidence of respondents reporting lack of discussion, information and choice amongst the 83 unsatisfied respondents who were recently assessed or re-assessed than amongst respondents as a whole. The exception to this general trend was consultation with a carer, where consultation and lack of consultation were at similar levels to other respondents (23%:77% compared with 25%:75%).

35% (29) commented critically on how their needs were assessed, with comments ranging from brief references to a perfunctory process to descriptions of protracted interactions with the Service to secure more effective wheelchairs. For example:

- “Just given a chair” (AP over 85)
- “This was replacement for previous chair and there was no real discussion of needs” (SP 46-65)
- “We asked for a light chair for my mother but she got a heavy one” (AP 76-85)
- “Happy with them till now . . . man came from hospital and measured . . . made it too wide for some shops and footrests too wide apart. I have not made any complaint as I don’t want to be a nuisance” (SP 16-45)
- “Basically they [needs and wishes] were ignored. You are given a wheelchair and you either like it or lump it” (EPIOC 16-45)
- “My wheelchair is attendant propelled but no-one assessed the way in which the wheelchair would be used or by whom. My needs were not assessed. The wheelchair was given by the hospital and sent home. I live on top of a hill so the wheelchair cannot really be used!” (AP 76-85)
- “No-one discussed additional needs to help me maximise use of my wheelchairs, more so when it came to the electric model. Resulting problems: very limited mobility options long protracted, tedious, frustrating process . . . eventually a stressful day visit to Glasgow ” (EPIOC 46-65)
- “No account taken of needs and wishes . . . visits by OTs . . . legal action threatened . . . correspondence by GPs, OTs to WESTMARC unanswered. Still waiting on suitable wheelchair” (EPIOC 46-65)

Delivery of wheelchair

Waiting times were longer, partly reflecting the greater number of powered wheelchairs in the group. 63% people were dissatisfied with waiting times compared with 32% of all recently assessed respondents.

Wheelchairs needing adaptations on delivery

41% of respondents required adaptations before they could use their wheelchairs, compared with 24% overall; almost half were dissatisfied with the additional wait.

Help with managing

55% people were not satisfied with help given in managing their wheelchair compared with 32% of all recently assessed respondents.

Problems in use

As reported above, car, weight and discomfort were the main problems listed, with almost half of the 139 non-satisfied respondents listing each of these difficulties (50%, 50% and 47%), compared with under a third of all respondents listing car and weight problems (33%, 32%), and under a quarter listing discomfort (25%).

Problems put right

44% said they did not get problems put right, compared with 25% of all respondents. 25% of the 44 who added comments referred to the length of time taken to remedy problems; 30% referred to ineffectual or partial remedies.

Repairs

50% had had repairs carried out compared with 44% of respondents overall. 67% said they were satisfied and 31% that they were not, compared with 85% and 12% of all respondents. Several who said they were satisfied with repairs commented critically on the time and inconvenience involved.

- 9 of the 22 powered wheelchair users who had repairs were not satisfied with them
- 17 out of 43 long-term users (successive wheelchairs) were not satisfied, and 4 who said they were satisfied commented critically about waiting.
- 55% of the 29 people who commented complained about waiting, for example
 - “Repair satisfactory but time waited seemed to be quite unnecessary”
 - “NHS take too long, alternatives expensive. After all the wheelchair is my feet and legs”
 - “Repaired many times, away for months . . . always communication problems, not the information I gave them”.

Adaptations

29% had had adaptations (or needed adaptations) to meet changing needs, compared with 18% overall.

- 50% of the 36 people who commented referred to adaptations which had not worked adequately or were needed and not carried out.
- 19% referred to the wait for adaptations needed.

8.2.8 NHS Wheelchairs returned

8 respondents who replied to the questionnaire only by saying why they had returned their NHS wheelchairs had not been satisfied with the NHS Wheelchair Service. Another of these respondents said the NHS service “was good” but “we bought a new one because cleaner, lighter and we could fit removable motor”.

6 had got other wheelchairs because they gave them better mobility, and one because “NHS wheelchairs are all the same red colour and not as sporty and modern as private firms”.

The 6 who wanted better mobility described their NHS wheelchairs as “heavy” (3), difficult to manoeuvre or push outside (4), “rubbish, wheels buckled” (1).

The long wait for a powered wheelchair was also a factor in one of the above, and was the significant factor for two other respondents. One already owned a wheelchair, and hoped to get a more suitable NHS one, but it took many months to arrive, the respondent’s needs changed and the NHS model, when it eventually arrived, was the same as the owned one. The other bought a powered wheelchair to avoid a “2 year wait”, but also now needed a better one (and better service than they had had from the private supplier) and had been informed by the care home that the NHS would not supply once a wheelchair had been purchased.

8.2.9 TORT

19% (9 respondents) said they were not satisfied with the Wheelchair Service.

- One third of respondents (5) under 65 were not satisfied: 2 were under 16, 3 46-65
- 12% of respondents over 65 were not satisfied: 2 were 66-75, 2 76-85.
- 24% (7) of attendant-propelled wheelchair users and 29% (2) of self-propelled wheelchair users were not satisfied
- 19% (5) of respondents recently assessed or re-assessed were not satisfied
- 38% (3) of respondents who had had successive wheelchairs were not satisfied.

7 said they did not have their needs met, including 2 with self-propelled wheelchairs. One of the latter described a long process of trying to find solutions but the wheelchair was “completely unsuitable resulting in my purchasing my own wheelchair”. One of the under-16 users also required a privately purchased buggy which now worked well with an improved NHS wheelchair.

Inability to use the wheelchair on their own, and non-availability or inability of pusher restricted mobility for 4 respondents. 2 identified a need for a powered wheelchair, one reporting that a powered wheelchair would entail “a long wait (6-9 months) and then have to go to Dundee for 6 months training in use.”

5 respondents listed problems as “too heavy” and 5 as “difficult to manoeuvre”.

Poor performance of a “basic” attendant propelled wheelchair severely restricted a care home resident from being taken out by a relative, both because of increasing difficulties in transfer from wheelchair to car and because “very uncomfortable on anything other than totally smooth surface –i.e. indoor -, solid tyres, no suspension”. No information route had been apparent to find solutions.

Distance from Dundee and time taken was a particular problem for 2 young wheelchair users and their families.

9 Care home issues

The main issues arising from wheelchair users’ responses were the discomfort of some wheelchairs for sitting in for long periods, and difficulties in getting an NHS wheelchair as a care home resident. 2 respondents said they had been refused NHS wheelchairs when they went to a care home. They had been told “to use care home pool, i.e. other residents’ chairs or the few owned by the home” and commented that “not appropriate as can’t get chair when needed”.

One respondent who had purchased a wheelchair privately needed a replacement when in a care home but was told by the care home manager that the NHS “would not supply a wheelchair now that one had been bought privately”. The respondent added “No-one in the NHS or Social Services seems to take any interest in residents of care homes and their

mobility needs". Another reported – uncritically – that they bought a new wheelchair when in a care home because the respondent's NHS wheelchair was 30 years old.

A few respondents reported not using their own wheelchairs when they went into a care home and used the home's wheelchairs.

Two of the three care homes which responded to the managers' questionnaire indicated that the NHS did not supply their residents. They reported that wheelchairs only arrived with residents and one said that "NHS only supply if need special adaptations, otherwise residents need to buy their own",

The other care home said that either wheelchairs arrived with residents or residents were assessed on arrival.

The housing manager said that wheelchairs arrived with residents or later assessment or review could identify the need for a wheelchair or change of wheelchair.

The housing manager said that adjustments to wheelchairs were carried out frequently, the 3 care home managers that they were carried out occasionally. All were carried out by WESTMARC, with minor adjustments being carried out by housing association staff.

One care home said that regular weekly maintenance checks were made by staff and repair needs reported to WESTMARC.

The housing association and 2 care homes had repairs carried out by WESTMARC, the third care home by Millbrook. The latter added "The service supplied, especially for repairs, is very good with limited waiting time"

Arrangements for collection of wheelchairs no longer required appeared to vary slightly, with the housing association telephoning WESTMARC, 2 care homes sending forms to WESTMARC and the third "ask for collection but can wait a considerable time".

9.1 Changes advocated

One of the care homes that said the NHS did not supply residents said it would be helpful if the NHS "supplied wheelchairs to residents who become more frail within the home when required".

Another care home wanted "adaptations to suit individuals discussed on referral".

The housing association said it would like "regular maintenance – yearly at least – more information given when wheelchair delivered or changes are made."

All said that they would welcome a local Centre.

9.2 TORT

TORT service users were not included in the care home sampling but out of the high number of care homes on the TORT database nine respondents were care home residents. All but one were “very satisfied” with the service. A relative/carer who replied on behalf of a resident reported significant problems because the wheelchair did not enable the user to enjoy trips out of the home. Problems were compounded by not knowing where to seek a remedy (see page 57).

10 Living in Forth Valley as a wheelchair user

84 respondents from both surveys commented on their experience of living in Forth Valley as a wheelchair user. A few commented generally, mostly on poor access, although a few said access was good or at least had improved, for example

- “Things are getting better with shops and pavements being improved”.

Most respondents were very specific. The most prevalent comment, often strongly expressed, was about the impediment of poorly designed and maintained pavements. Over half of the 84 respondents complained about pavements, in the area generally and in some particular places. Real difficulties were caused by the lack of sloped kerbs, thoughtless siting of such sloping kerbs as existed, rough surfaces, sloping camber, obstacles such as wheelie bins and parked cars. For example:

- “Local shops inaccessible, pavements not wheelchair friendly, full of potholes”
- “Lack of ramped pavements (sometimes at one end and not the other), so have to use busy main road”
- “Pavements are badly maintained. Bins are an obstacle – no-one thinks of wheelchair users. Also parking on pavement”
- “Wheelie bins a nightmare for wheelchair users. Turn pavements into slalom course”
- “Stenhousemuir has no easy access to shops. Pavements are not lowered except at the Health Centre, I have to go to bottom of the street to cross”
- “I have had 2 bad accidents (thrown out of wheelchair) because of uneven pavements . . .”
- “Uneven bumpy pavements and lack of lowered kerbs and steep cambers on paths make life very difficult”.

These problems with pavements often combined with the condition and layout of roads to restrict wheelchair users. 10 respondents commented on roads, for example:

- “Pavements and roads are very narrow in the Falkirk area – difficult to use the wheelchair in places”
- “Crossing my street impossible without support, even then dangerous”
- “Pedestrian crossings do not give you long enough”
- “Some pavements & road surfaces not what they should be for wheelchair users”

- “Studded paving at junctions should include clear smooth path for wheelchairs, perhaps with allowance for non straight to ensure blind people don't miss the studs. Cobbles! In middle of path, e.g. riverside car park in Callendar, which force wheelchairs to find totally devious route”.

Access to buildings and particularly to shops was criticised by over half of commentators, with 12 people specifying public buildings generally and 31 specifying shops, for example:

- “Still too many public buildings with stairs”
- “Not enough shops wheelchair users can get in & out of”
- “Can't go upstairs in shops with no lifts. Husband looks for my things”
- “Many buildings & shops in Dollar wheelchair inaccessible”
- “Still shops in Falkirk I can't enter although there's been improvements. I wish shop assistants would see me as a person in my own right. All they see is the wheelchair and always talk to my husband or daughter about what I require. It's hard to find wheelchair trolleys in supermarkets. Pallets and packages in aisles make difficulties”
- “Still shops in Forth Valley which are unsuitable, especially the shop at Callendar House. House is wheelchair friendly but not shop or tearoom. Some health centres not wheelchair friendly enough, could do with electric doors”
- “Access to business premises [would be helpful]. I don't like to discuss my business outside shops and banks. Hopefully things are about to change, new buildings will have to have access”
- “Shops - may not prevent entry but can't move inside due to ridiculously narrow aisles within shop”.

5 people commented on restrictions on outings to shops and other places because of lack of properly accessible toilets. Three said there had been improvement but better provision was still needed, for example:

- “In last 20 yrs access and especially toilets have improved greatly. But many toilets still too small for carer and wheelchair user together. Tesco size poor, BHS, Safeway great. Specification for accessible toilets needs to be revised to allow manoeuvre for people who can't walk at all. How many have been designed with advice from wheelchair users?”

Inadequate parking spaces were commented on by 12 respondents, who complained of the lack of suitable provision but even more of thoughtless use by non-wheelchair users. For example:

- “No parking space for rear door extending car”
- “Disabled parking: not enough, not monitored - why?? In France I saw signs **si vous prenez mon place prenez aussi mon handicap!** In US they have towing & clamping. Issue wheelchair users with stickers/cards to place on offending cars? If someone takes up space I can't go to bank, shopping etc.”

- “Hardest things are getting access to some buildings and people who're not disabled parking in our parking spaces”
- “Disabled parking at hospital inadequate; being dumped on own whilst husband finds somewhere to park is worrying”.

For people with limited or no access to cars public transport was a barrier, explained by 6 respondents, for example:

- “Penalised as wheelchair user by price of any transport (taxi or dial a journey) which forced to use”
- “Difficult getting transport. When you do get Dial A Journey, quite expensive daily rate, return journey from DAJ not much time to spend from being dropped off to pick up time as it's a very busy service”
- “Buses for wheelchair users are few and far between”
- “Accessible transport [needed] for rural areas where multiple bus journeys make the desired bus journey impractical”.

A few respondents mentioned here (and others elsewhere in the questionnaire) that their mobility was restricted by lack of a pusher. One said

- “Would like to hear from any organisation that could take me out and about sometimes”.

Four respondents praised Shopmobility highly, for example:

- “Shopmobility is brilliant. They have superior wheelchairs to the NHS”.

A few respondents compared the environment for wheelchair users in the UK unfavourably with other countries, for example:

- “It's not just Forth Valley, Britain in all is a disgrace for disabled people. You go to America or South America it's a joy to use my wheelchair there. I can go in all trains, buses and planes. I couldn't take my wheelchair to London via Easyjet as they said it's too heavy, yet Britannia would fly it from London to Mexico, an 11 hr flight no problem. Britain is ignorant of disabled travellers”.

The carer of a wheelchair user who had been confined to the UK and a manual wheelchair for over 20 years said:

- “I sometimes feel wheelchair users are the forgotten people. For example, shops with no automatic doors, road layouts always including steep climbs. Also where do you buy waterproof covers? I know to some people these problems may seem trivial but to a wheelchair user and attendant they are important”.

Council on Disability

WHEELCHAIR SURVEY

Tick or mark the boxes that apply
If you need more space for your replies,
please use the back page.

SECTION A About you and your wheelchair

Please give the following information

- Q1 Age Group**
Under
16..... 16-45..... 46-65..... 66-75..... 76-85..... *over*
85.....
- Q2 Gender**
Male..... *Female*.....
- Q3 Postcode:**
- Q4 Do you have an NHS wheelchair?**
Yes..... *No*.....
- Q5 If you answered NO, please tell us why you chose to have another wheelchair supplier, THEN go to Section H.**
- Q6 Do you have more than one NHS wheelchair?**
No..... *Yes - 2*..... *Yes - 3 or more*.....

SECTION B About the type(s) of wheelchair you have.

Q7 What kind(s) of NHS wheelchair do you have?

Self propelled..... *Attendant propelled*..... *Electric for indoors*..... *Electric for both indoors & outdoors*.....
Other (please describe)

Q8 Please state models if known

Q9 Is this your first NHS wheelchair?

Yes..... No.....

Q10 Have you ever bought your own wheelchair?

Yes..... No.....

Q11 Have you ever bought your own scooter?

Yes..... No.....

Q12 Has any one else provided you with a wheelchair? e.g. your family or a charity.

Yes..... No.....

Please state provider:

Q13 When did you get the NHS wheelchair(s) which you have just now?

Before 2000 (Then go to Section E)..... *During or after 2000 (Then go to Section C)*.....

SECTION C How you got your NHS wheelchair.

(if you have received more than one NHS wheelchair since 2000 , please tell us about the one you use most frequently)

Q14 Where did you discuss your needs for a wheelchair? Tick all that apply

<i>With your GP, Occupational Therapist or other health professional in a surgery, health centre or at your home.....</i>	<input type="checkbox"/>	<i>At a hospital.</i>	<input type="checkbox"/>	<i>At the Mobility Centre in Glasgow.....</i>	<input type="checkbox"/>	<i>With a person from the Mobility Centre at your home.....</i>	<input type="checkbox"/>
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Q15 In the discussions about your needs for a wheelchair, were you asked questions about any of the following?

<i>What you wanted your wheelchair to enable you to do. e.g. in your social and home life, at school, at work, getting about.</i>	Yes	No
	<input type="checkbox"/>	<input type="checkbox"/>
<i>About where you lived</i>	<input type="checkbox"/>	<input type="checkbox"/>
<i>If you had a car or regular use of someone else's car, what type it is.</i>	<input type="checkbox"/>	<input type="checkbox"/>

Q16 Were you given information about different types of wheelchair?

Yes..... No.....

Q17 Were you offered a choice of wheelchairs?

Yes..... No.....

Q18 Did you try out different types of wheelchairs?

Yes No.....

Q19 If YES, did you try out the wheelchairs on different surfaces and gradients?
Yes..... No.....

Q20 Were you given any information about the following?

	Yes	No
<i>Other places where wheelchairs might be obtained</i>	<input type="checkbox"/>	<input type="checkbox"/>
<i>Funding and grants which might be available to you</i>	<input type="checkbox"/>	<input type="checkbox"/>
<i>Alterations and adaptations which might be possible for your wheelchair</i>	<input type="checkbox"/>	<input type="checkbox"/>

Q21 If you have someone who helps you to get about, were they asked about your wheelchair?
Yes..... No.....

Q22 Please make any comments about how your needs and wishes were taken into account before you got your NHS wheelchair(s).

SECTION D When you got your NHS wheelchair

Q23 How long did you have to wait to get your wheelchair?
3-4 days 2 weeks 2-4 weeks Over a month Can't remember

Q24 Did you consider the waiting time satisfactory?
Yes No

Q25 Did you get enough help in being shown how to manage your wheelchair?
Yes..... No

Q26 Did your wheelchair require adjustments/adaptations when you got it?
Yes..... No
Briefly , please describe

Q27 Did you consider the waiting time for adjustments/adaptations satisfactory?
Yes..... No

Q28 Did you get enough information about the following?

<i>Other services that might help you</i>	Yes <input type="checkbox"/>	No <input type="checkbox"/>
<i>Other help that the Mobility Centre could offer</i>	<input type="checkbox"/>	<input type="checkbox"/>
<i>Repair and maintenance arrangements</i>	<input type="checkbox"/>	<input type="checkbox"/>
<i>Insurance for your wheelchair</i>	<input type="checkbox"/>	<input type="checkbox"/>

Please describe any other information or help which would have been useful when you got your wheelchair.

Q29 Please make any further comments about getting your wheelchair.

SECTION D When you got your NHS wheelchair

Q23 How long did you have to wait to get your wheelchair?
 3-4 days 2 weeks 2-4 weeks Over a month Can't remember

Q24 Did you consider the waiting time satisfactory?
 Yes No

Q25 Did you get enough help in being shown how to manage your wheelchair?
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Q26 Did your wheelchair require adjustments/adaptations when you got it?
 Yes..... No
Briefly , please describe

Q27 Did you consider the waiting time for adjustments/adaptations satisfactory?
 Yes..... No

Q28 Did you get enough information about the following?

<i>Other services that might help you</i>	Yes <input type="checkbox"/>	No <input type="checkbox"/>
<i>Other help that the Mobility Centre could offer</i>	<input type="checkbox"/>	<input type="checkbox"/>
<i>Repair and maintenance arrangements</i>	<input type="checkbox"/>	<input type="checkbox"/>
<i>Insurance for your wheelchair</i>	<input type="checkbox"/>	<input type="checkbox"/>

Please describe any other information or help which would have been useful when you got your wheelchair.

Q29 Please make any further comments about getting your wheelchair.

SECTION E Your NHS wheelchair in use

Q30 Have you experienced any of the following problems in using your wheelchair?

	Yes	No
<i>Too heavy</i>	<input type="checkbox"/>	<input type="checkbox"/>
<i>Difficult to manoeuvre</i>	<input type="checkbox"/>	<input type="checkbox"/>
<i>Seating is uncomfortable</i>	<input type="checkbox"/>	<input type="checkbox"/>
<i>Did not get all the attachments needed</i>	<input type="checkbox"/>	<input type="checkbox"/>
<i>Difficult to get in and out of a car</i>	<input type="checkbox"/>	<input type="checkbox"/>
<i>Any other problems? Please state:</i>		

Q31 Did you get any problems put right?

Yes..... No.....
Please comment:

Q32 Overall, does your NHS wheelchair give you the help you need?

Yes..... No.....
Please comment:

SECTION F Maintenance and repair of your NHS wheelchair

Q33 Have you ever had your wheelchair repaired?
Yes..... No.....

Q34 If YES, who repaired it? Please tick all applicable

	Yes	No
Mobility Centre engineers	<input type="checkbox"/>	<input type="checkbox"/>
Mobility Centre contractors	<input type="checkbox"/>	<input type="checkbox"/>
The manufacturer	<input type="checkbox"/>	<input type="checkbox"/>
Local repairer/garage	<input type="checkbox"/>	<input type="checkbox"/>
DIY	<input type="checkbox"/>	<input type="checkbox"/>
Other (Please state)		

Q35 Were the repairs carried out at your home?
Yes..... No.....

Q36 Was the repair service you used satisfactory?
Yes No.....
Please Comment:

Q37 Have you needed adaptations to your wheelchair as your needs have changed?
Yes..... No.....
Please comment:

SECTION G Overall satisfaction with the NHS wheelchair service

Q38 How would you rate your satisfaction with the NHS wheelchair service overall?

Very satisfied..... Satisfied..... Neither satisfied nor dissatisfied Dissatisfied...

Q39 Would you welcome a local Centre within Forth Valley which could assess your requirements, supply wheelchairs and accessories, and carry out repairs and adaptations?

Yes..... No.....
Please comment:

Q40 Would you welcome a voucher or direct payments scheme, which would pay the equivalent of the cost of a more basic wheelchair or could be used by people to buy a more expensive wheelchair of their own choice?

Yes..... No.....
Please comment:

Q41 What, if anything, would you like to change about the NHS wheelchair service?

SECTION H Comments on being a wheelchair user in Forth Valley

Q42 Please use this space to make any other comments on the NHS wheelchair service and on being a wheelchair user in Forth Valley.

END