



Maintaining mobility

Understanding the unmet need
for short-term mobility aids

Policy, Research and Advocacy

Research conducted by

KANTAR PUBLIC

“He was a prisoner. It was upsetting – he couldn’t get to work, or stay as active as we usually are. With a [wheel]chair, he could have got to his job, done paperwork, been focussed and productive. Not destructive.”

Wendy, wife of Jeremy, amputee

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Executive summary

The British Red Cross started providing short-term wheelchair loans during World War One for both injured combatants and the general population. In 2017 we loaned 57,800 wheelchairs and 72,500 people were supported through our mobility aids service.

While the provision of wheelchairs, for long-term use falls under the remit of the NHS, providers are not obliged to meet the need for short-term (generally classified as a period of six months or less) wheelchair loans (NHS 2014). This lack of statutory duty has particular impact on those needing a wheelchair for a short period of time.

“Everyone who needs a wheelchair should have a right to quickly and easily get one that is right for them, for as long as they need it. Everyone who uses or handles a wheelchair should know how to do so safely and comfortably.”

British Red Cross humanitarian vision

Despite short-term loans of tens of thousands of wheelchairs per year across the UK, the Red Cross is concerned that an unmet need persists and can have devastating impact on people and their ability to recover from crisis. Those unable to access a short-term loan of a mobility aid, including a wheelchair, may be unable to go back to work, may become socially isolated or be at risk of falling. The carers of these individuals can also become socially isolated and confined to the house. Evidence shows that the provision of short-term wheelchair loans could save money for our hard-pressed statutory services; prevent, reduce and delay the need for further care and support; aid recovery; enable independence; and hasten hospital discharge (McNulty et al. 2015).

Research aims and methods

To identify the need for short-term loans of mobility aids, particularly wheelchairs, and the effect of lack of provision, the Red Cross commissioned a research project from Kantar Public. The aims were to:

- **Establish the need for services providing short-term wheelchair loans in the UK.**
- **Establish the level of short-term need that is currently met and unmet.**
- **Explore the characteristics of people who experience a short-term need for a mobility aid, including a wheelchair, and examine how, if at all, this varies by geography and/or demographic variables such as age, gender and employment.**
- **Examine the barriers to meeting short-term need for a wheelchair.**

These aims were met through a mixed-method design, including a face-to-face survey of 4,236 individuals aged 16 or over. The research also included four area-based case studies based on in-depth interviews with individuals who have experienced an unmet short-term need for a wheelchair and their wider support networks. Interviews were also conducted with healthcare practitioners.

Key findings

- **Most statutory wheelchair providers (82 per cent) do not supply wheelchairs for short-term use**, and provision is a postcode lottery, with only providers in some areas offering wheelchairs for short-term use. Equally, certain health conditions are eligible for short-term wheelchair loans in some areas, but not in others.
- **The study found that those who had accessed a short-term wheelchair loan were very positive about their experience.** Most (90 per cent) said the wheelchair was very helpful and had enabled them to carry out day-to-day activities; 87 per cent said it had made it easier for family and friends to help them; and nearly half (49 per cent) said it had hastened their recovery time.
- **Those with an unmet mobility need had been affected in a range of ways, with the majority (65 per cent) experiencing significant negative impacts on their quality of life.** These effects ranged from having to stop working to becoming increasingly dependent on family and friends, or becoming socially isolated and housebound.
- **Respondents with a short-term mobility need were more likely than the general population to be retired, out of work, in the lowest socioeconomic group**, and to report that their health was poor or very poor, or that they have a long-term health condition.
- **One-fifth (21 per cent) of respondents who saw the potential benefits of a wheelchair believed that using one would have reduced the likelihood of further injury;** a similar proportion (18 per cent) thought it

would have helped to maintain their general health and wellbeing; and ten per cent said it would have hastened their recovery time.

- **Some 8.1 per cent of respondents across the UK had experienced a short-term mobility need in the past 12 months;** grossed to the UK population, this represents an estimated 4.3 million people.
- **The study found that 7.9 per cent of respondents had experienced a short-term mobility need but had not accessed a wheelchair, and 44 per cent of this group thought that they would have benefited from a wheelchair loan** since this would have allowed them to leave the house to go on errands, attend hospital and GP appointments, and generally get out and about.
- **However, of those respondents who did not access a wheelchair and thought they would have benefitted from one, many (42 per cent) said they did not want to use a wheelchair anyway.** There could be many reasons for this, but participants in the case studies mentioned the stigma around wheelchair use, and that it can be seen as a sign of ageing and/or weakness.

Conclusion

The Red Cross believes that everybody who needs a mobility aid, including a wheelchair, should be entitled to access one, for as long as they need it. Achieving this vision will require changes to regulatory frameworks met with the necessary resources. Improvements will also need to be made in service delivery, needs assessments, and information and advice services.

Research aims and methodology

The aims of the research were to:

- Establish the need for services providing short-term wheelchair loans in the UK.
- Establish the level of short-term need that is currently met and unmet.
- Explore the characteristics of people who experience a short-term need for a wheelchair and examine how, if at all, this varies by geography and/or demographic variables such as age, gender and employment.
- Examine the barriers to meeting short-term need.

Researchers from Kantar Public sought to meet the research aims through adopting a mixed-method design, which included:

- A nationally representative (UK-wide) face-to-face survey of 4,236 individuals aged 16 or over.
- Four area-based case studies centred on in-depth interviews conducted with individuals who have experienced a short-term unmet need for a wheelchair, and their wider support network.
- Interviews with healthcare practitioners in the four areas covered by the case studies.

In addition, the British Red Cross called all of the 139 publicly listed statutory wheelchair providers

in the UK, predominantly hospital trusts, to request information regarding the short-term provision of wheelchairs.

More information on the methodology is provided in the appendix.

Defining short-term need: For the purposes of the research, short-term is used to refer to a period of six months or less. The definition of need was constructed in collaboration with the Red Cross and key stakeholders, including consultation with healthcare professionals.¹ Overall, short-term need was classified in the survey as:

- **A met need:** where the respondent used a wheelchair to meet the short-term need.
- **An unmet need:** where the respondent did not use a wheelchair to meet the short-term need, but where one may have been beneficial.²

Defining met need: Met need was measured by asking respondents if they had used a wheelchair for a period of time that lasted or was due to last for no more than six months.

Defining unmet need: Defining unmet need was more challenging; there are many occasions or situations where it could be beneficial for an individual to use a wheelchair for a short period of time. To avoid simply asking respondents

to define whether they had an unmet need, which could have excluded those who were not aware of the potential benefits of using a wheelchair, they were asked if they had experienced a condition or situation, selected from pre-defined categories, where the short-term use of a wheelchair could have been beneficial. These categories were developed in collaboration with the Red Cross and key stakeholders:³

- **Weight-bearing need:** in relation to a lower limb injury/surgery where the respondent was advised to keep the weight off their injury, or while waiting for a long-term wheelchair.
- **Illness or health condition need:** where the respondent had difficulty standing or walking short distances due to a health condition or treatment for a health condition.
- **Functional need:** where the respondent was not able to complete certain activities due to difficulty standing or walking short distances.

Throughout the report we refer to people in these three categories as having an unmet need. It is important to note that survey information was not collected on the use of other potentially beneficial mobility aids, such as crutches or walking frames.

¹ This discussion centred on medical situations where a wheelchair could be beneficial, for example following an injury or operation. It was agreed that the need to keep the weight off an affected area was the deciding factor in whether a wheelchair would be beneficial to recovery. As such, this was built into the definition of need, in particular a health injury need.

² This includes situations where other mobility aids may also have been beneficial.

³ Please contact the Red Cross to request a copy of the questionnaire. Please note that these phrases themselves were not used within the questionnaire.



Findings

Wheelchairs are recognised by the NHS to be

“Not simply a piece of medical equipment, but often essential to all aspects of a person’s life.”

NHSIQ 2014: 37

This importance is reflected in the survey findings.

3.1 NHS provision of short-term wheelchair loans in the UK

Having seen the results of the Kantar research, British Red Cross made enquiries with all publicly listed NHS wheelchair providers to establish whether they provide short-term wheelchair loans. The findings showed that:

- Fewer than a quarter (25 providers, or 18 per cent)⁴ of all 139 listed NHS wheelchair providers supply wheelchairs for short-term use.
- Almost half (54 providers, or 47 per cent) of those who do not provide short-term wheelchair loans said it was because there was no statutory duty to do so and 16 providers (14 per cent) cited a lack of funding and resources.
- The providers that do make wheelchairs available on a short-term basis apply a range

of criteria, from anybody referred by a clinician, to aiding recovery after surgery or helping people with fluctuating long-term needs.

3.2 Estimating the prevalence of short-term need for a wheelchair

Overall, 345 (8.1 per cent) of survey respondents met our definition of having a short-term need for a wheelchair or similar mobility aid. This means they may have used, needed or benefited from the short-term use of a wheelchair within the past 12 months. Some 7.9 per cent of respondents had not accessed a wheelchair during this time and were defined as having an unmet need, while 1.1 per cent had their need for a wheelchair met. See Figure 1.

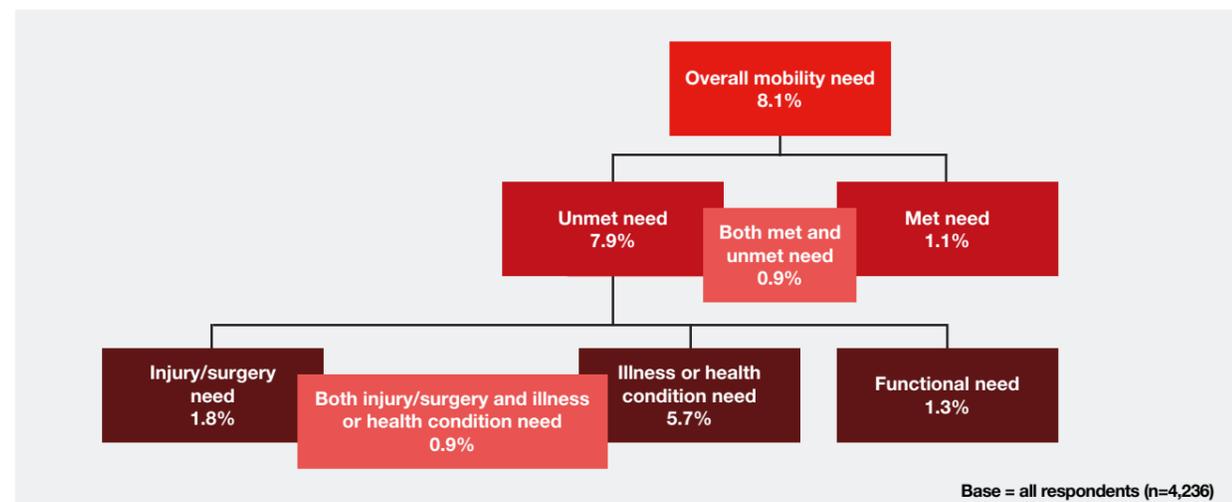


Figure 1. Respondents who experienced a short-term mobility need in the past 12 months

Note: Functional need was captured only if respondents had not experienced the other two types of unmet need, so its prevalence is likely to be higher than reported here.

⁴ This does not include the provision of wheelchairs at the end of life. There are supposed to be provisions already in place to help this cohort of people access wheelchairs. As stated in NHS (2017a), service users with a terminal illness will be fast tracked within 24 hours for a wheelchair. If a bespoke or specialist wheelchair is required, which cannot be sourced within 24 hours, the provider will allocate a temporary wheelchair that best meets the needs of the service user.

Prevalence of need was somewhat higher than anticipated by the researchers, and it is worth noting that a number of individuals fulfilled the survey criteria of having an unmet need, yet did not self-define as having a need for, or seeing the benefits of using, a wheelchair. It is important to note that only 17 per cent of those defined as having an unmet need had considered using a wheelchair at the time.

When the survey results are extrapolated to the UK population as a whole, it is estimated that, within the last 12 months, 4.3 million people would have experienced a short-term mobility need and either used, or could have benefited from using, a mobility aid like a wheelchair.⁵

- **Met need:** the researchers estimate that, in the past 12 months, more than **625,000 adults** in the UK used a wheelchair for a period of six months or less.⁶
- **Unmet need:** the researchers estimate that, in the past 12 months, **4.2 million adults** in the UK may have needed or benefited from the short-term use of a wheelchair, but did not use one.⁷

3.3 Characteristics of individuals with short-term need for a mobility aid, including a wheelchair

As stated in the previous section, 8.1 per cent of survey respondents (aged 16 or over) reported experiencing a short-term need, and used or could have benefited from using a wheelchair in the last 12 months.

As might be expected, need varied by age, rising with increasing age. Individuals with a short-

term need were also more likely than the general population to be the following.

- **Retired:** 49 per cent of individuals with a need were retired compared with 25 per cent of the general population.
- **Of low socioeconomic status:** 23 per cent of individuals with a need were from socioeconomic group E, compared with 12 per cent of the general population.⁸
- **Be out of work:** 22 per cent of individuals with a need were out of work, compared with 14 per cent of the general population.⁹
- **Report that their health was poor or very poor:** 27 per cent of individuals with a need rated their general health as bad or very bad, compared with only six per cent of the general population (ONS 2011).
- **Have a co-existing long-term health condition:** 62 per cent of individuals with a need reported that they had a long-term physical or mental health condition lasting or expected to last for 12 months or more, compared with 39 per cent of the general population of England (NHS 2016).

3.4 Experiences and perceptions of individuals with a met need for a wheelchair

This section explores the experiences of individuals who used a wheelchair to meet a short-term need within the past two years. Due to the low incidence of individuals experiencing this (56 people in total), it is not possible to break the results down into subgroups.

⁵ Confidence intervals consist of a range of values (interval) that act as good estimates of the unknown population parameter. A 95 per cent confidence estimate was used so it is expected that between 3.7 million and 5.0 million people would have experienced a short-term need in the last 12 months.

⁶ Based on a 95 per cent confidence interval, this figure is expected to be somewhere between 401,866 and 849,685 adults.

⁷ Based on a 95 per cent confidence interval, this figure is expected to be somewhere between 3.6 million and 4.8 million adults.

⁸ Based on approximated social grade, a socioeconomic classification produced by UK Office for National Statistics, E sits at the bottom of the scale (A, B, C1, C2, D and E).

⁹ An individual was considered to be out of work whether they were looking for employment or not, but not if they were retired.

3.4.1 Perceived benefits of short-term wheelchair use

The benefits of short-term use of a wheelchair were widely felt. The vast majority of individuals found the wheelchair helpful (with an average score of 9 out of 10, where 1 is 'not helpful at all' and 10 is 'very helpful') and felt that it improved their quality of life (with an average score of 8.4 out of 10, where 1 is 'not at all' and 10 is 'a lot'). Additionally, just over three-quarters (76 per cent) gave a top score of 10 out of 10, when asked on a scale of 1 to 10 how helpful the wheelchair was (where 10 was 'very helpful').

Respondents were also asked about the recovery-related benefits of short-term wheelchair

use, and the majority of individuals (72 per cent) saw the value of a wheelchair in preventing further injury, while almost half (49 per cent) said that using a wheelchair hastened their recovery time.

To explore the wider impact of using a wheelchair to meet a short-term need, respondents were asked to what extent they agreed or disagreed with several different statements about their experience of using a wheelchair (Figure 2).

Overall, the greatest perceived benefits of short-term wheelchair use were: making it easier for friends and family to help (87 per cent agreed); improved quality of life (81 per cent agreed); and making life a lot easier (81 per cent agreed).

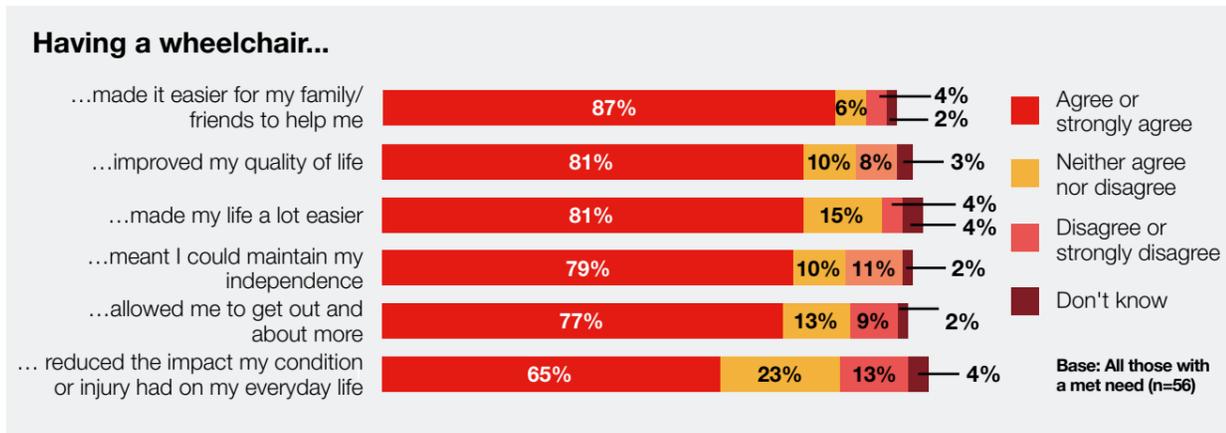


Figure 2. Respondents' experiences of short-term wheelchair use

3.4.2 Short-term wheelchair use and daily activities

Respondents also generally agreed that having the use of a wheelchair helped them to attend appointments or take part in social activities. Nine out of 10 (90 per cent) felt a wheelchair helped

them to do at least one activity (Figure 3), such as going on short trips or getting around the house. Respondents were able to select more than one option, and the most commonly selected activity helped by having a wheelchair was going shopping, with 40 per cent saying they could not have done this without a wheelchair.

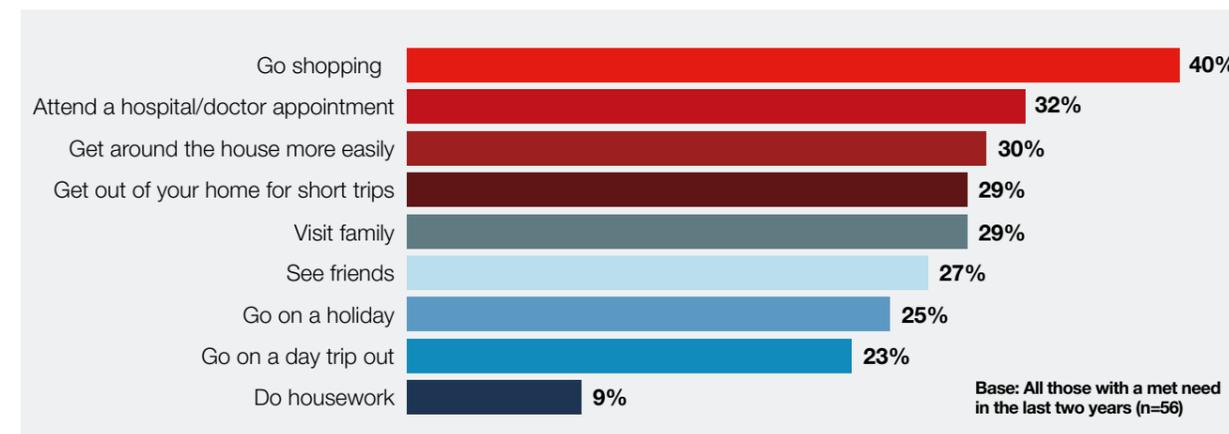


Figure 3. Activities made possible by the use of a wheelchair

3.4.3 Accessing a wheelchair for short-term use

The majority of NHS wheelchair services do not offer a wheelchair for short-term use and may signpost individuals to other organisations (McNulty et al. 2015). A total of 114 out of 139 publicly listed wheelchair providers in the UK confirmed to the Red Cross that they did not provide wheelchairs for short-term need.

"I didn't get anything from the NHS to tell me there was any other help out there. I didn't know if there were any charities who could help."

Individual with an unmet need, London

However, 33 per cent of survey respondents with a short-term need were able to loan a wheelchair from the NHS. A similar proportion (30 per cent) bought a wheelchair privately from a shop or online, and six per cent reported obtaining a wheelchair from the Red Cross.

3.5 Experiences and perceptions of individuals with a short-term unmet need for a mobility aid, including a wheelchair

This section explores the experiences and perceptions of individuals with a short-term unmet need for the use of a wheelchair within the past two years.

A total of 225 (44 per cent) of respondents with an unmet need¹⁰ reported that having a wheelchair would have benefited them in some way, such as reducing the risk of further injury, being able to undertake activities that would not be possible without a wheelchair and helping to maintain independence (Figure 4).

The potential benefits reported were connected primarily with the need to undertake activities and employment.

3.5.1 Impact on quality of life

Respondents with an unmet need were asked to what extent their quality of life was affected by the condition or situation they experienced (when a wheelchair may have been useful). Responses were given on a scale of 1 to 10, where 1 is 'not

Summary statistics may not add up to 100% because percentages have been rounded for ease of reading.

¹⁰ This measure has been created by collating positive responses to a number of statements about possible benefits to having used a wheelchair.

at all' and 10 is 'a lot'. Overall, the majority felt their condition or situation had a negative impact on their overall quality of life.

- The majority (65 per cent) gave a score of 6 or higher, and more than half (54 per cent) gave a score of 7 or higher.
- One in 5 (22 per cent) gave a score of 10 out of 10.

Respondents were also asked how they perceived what the impact of using a wheelchair could have been on their condition or situation were they to have accessed one. One-quarter (25 per cent) agreed that using a wheelchair would have allowed them to get out and about, and 22 per cent said it would have made it easier for their friends or family to help them. Figure 4 shows the full range of responses.

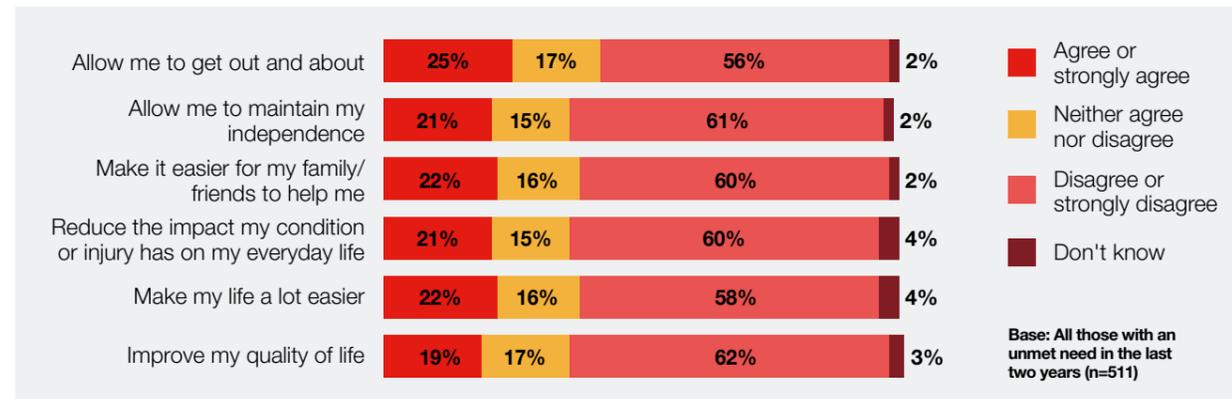


Figure 4. How a wheelchair could have improved quality of life

3.5.2 Recovery-related benefits of using a wheelchair

In certain situations, the short-term use of a wheelchair can aid recovery through reducing the likelihood of further injury or allowing the injury to heal by avoiding overuse of the affected limb, as with a broken leg (NHS Choices undated).

One-fifth (21 per cent) of respondents believed that a wheelchair would have reduced their likelihood of further injury, and a similar proportion (18 per cent) thought it would have helped to maintain their general health and wellbeing, while 10 per cent said it would have hastened their recovery time (Table 1). However, 25 per cent of the same individuals reported that their doctor said a wheelchair was not necessary.

The qualitative case studies highlighted the fact that individuals do not always feel confident using crutches and may feel shaky or unsteady on their feet as a result of their condition or situation.

3.5.3 Activity-related benefits of using a wheelchair

The wider positive benefits of using a wheelchair, such as being able to attend hospital or doctors' appointments, get to work, attend events for special occasions, get out and about, and see family and friends, were widely reported by those with a met need. However, those with an unmet need were less likely to feel the use of a wheelchair would have allowed them to do these things.

One-quarter (26 per cent) of respondents said a wheelchair would have helped them complete at least one daily activity (Figure 5). Respondents were able to select more than one option, and the activities selected most commonly by this group were shopping or other short trips, attending medical appointments and visiting family and friends. The qualitative case studies suggest that inability to get out and about has an emotional impact and can lead to isolation for the housebound individual and, sometimes, for those who care for them.

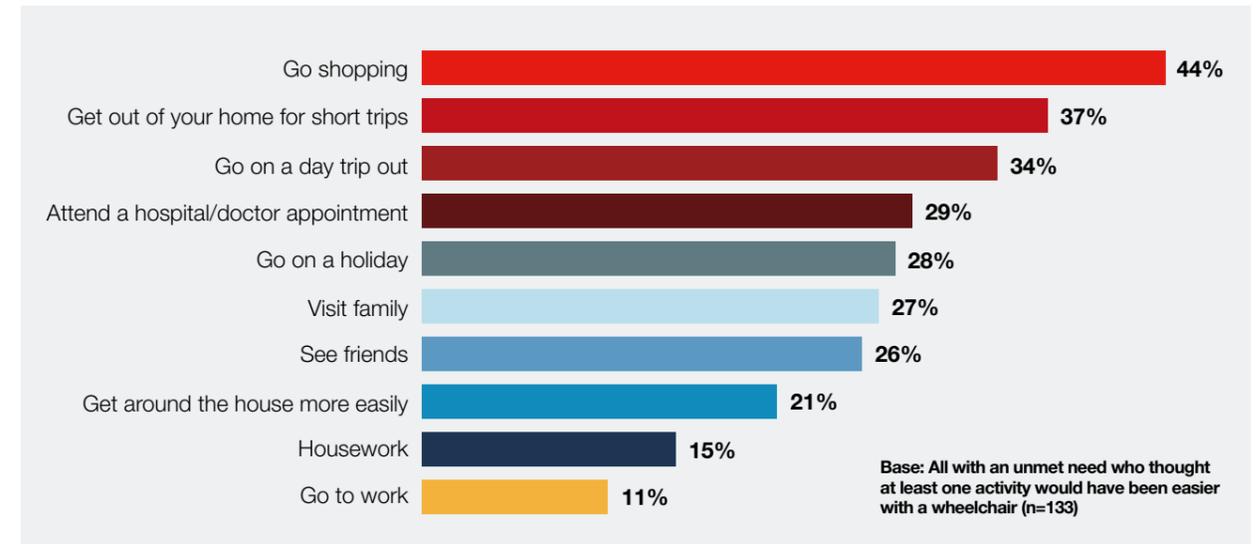


Figure 5. Activities identified by respondents who thought at least one activity would have been easier with a wheelchair

3.5.4 Impact of unmet mobility need on employment

The condition or situation driving the unmet need also had a negative effect on employment. Of those who were employed at the time of the survey, 50 per cent said that their employment was affected in some way. Of those whose employment was affected, 40 per cent found

their responsibilities at work were reduced, and 34 per cent had to leave employment altogether (Figure 6).

"I had no money coming in [due to inability to work] and was surviving off credit cards and loans."

Individual with an unmet need, London

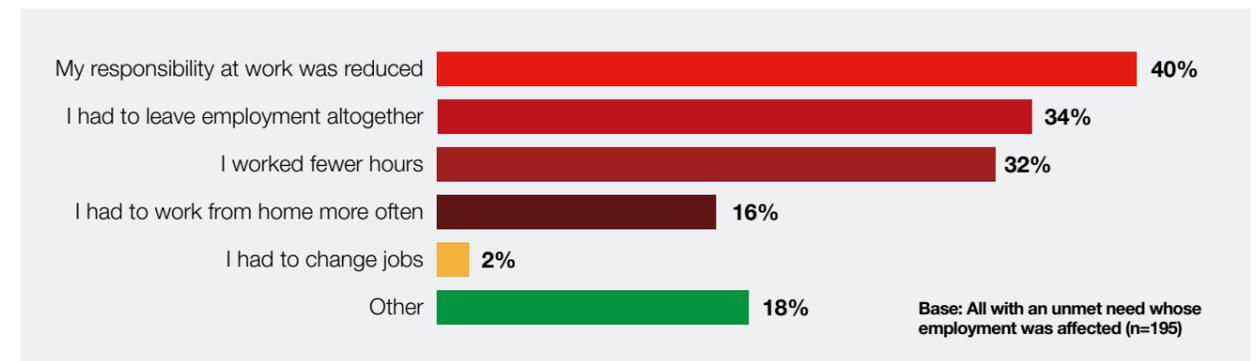


Figure 6. How unmet need affected employment (for those whose employment was affected)

3.5.5 Who considered using a wheelchair?

Although 44 per cent of respondents with an unmet need thought they could have benefited from having access to a wheelchair, only 17 per cent had considered using a wheelchair at the time.

Certain groups were more likely than others to have considered using a wheelchair, with 21 per cent of women considering using a wheelchair compared with 12 per cent of men. Of those who

reported their health was bad or very bad, 28 per cent would have considered using a wheelchair, compared with eight per cent of those who reported their health was good or very good.

When asked where they would have accessed the wheelchair, individuals who had considered using a wheelchair were most likely to select the NHS (39 per cent), followed by buying one privately in a shop (24 per cent) and loaning one from the Red Cross (13 per cent). See Figure 7 for all responses (participants could select more than one option).

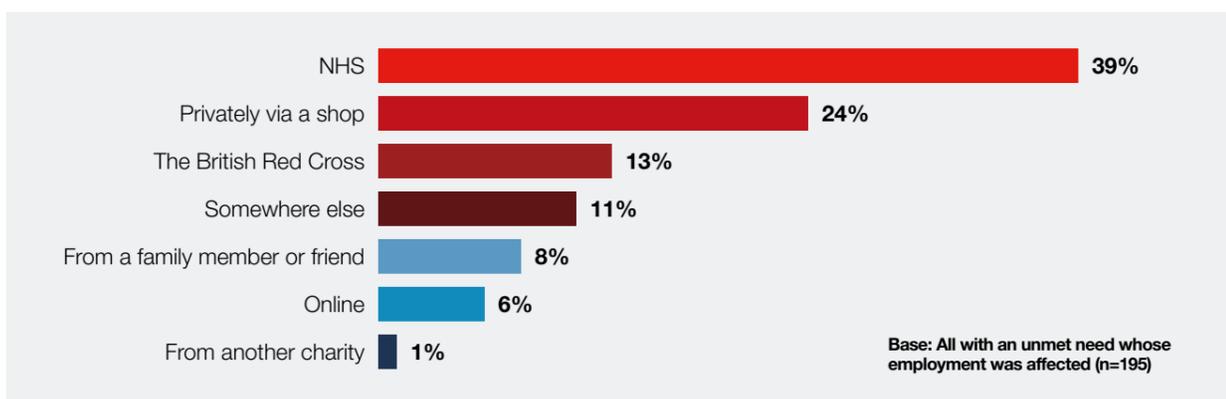


Figure 7. Sources respondents would have tried for access to a wheelchair

While the majority of respondents would have sought to access a wheelchair from the NHS, this organisation has no statutory duty to provide short-term wheelchair use and, as such, the majority of providers cannot offer them.

"I would love to know more about where to go and the criteria for it, and a bit more communication about short-term wheelchair use. I know my colleagues would be extremely keen to find out about it as well."

Healthcare professional, Edinburgh

3.5.6 Who did not consider using a wheelchair?

When prompted, respondents gave the two most common reasons for not using a wheelchair during a period of need as

'I didn't want to use a wheelchair' (38 per cent), and/or 'I didn't think it would be beneficial' (35 per cent).

It is worth mentioning that respondents could choose more than one answer and that only 43 per cent of the respondents who did not consider using a wheelchair indicated this was because they did not want one, or they did not think it would be beneficial. 17 per cent of this group did not use a wheelchair because 'my doctor said it wasn't necessary' (Figure 8).

Interestingly, 21 per cent of respondents who said 'I didn't want to use a wheelchair' agreed that a wheelchair would have helped reduce the risk of further injury. While the survey does not explore why people did not consider using a wheelchair in these circumstances, the qualitative case studies show that stigma around wheelchair use may be a factor, since wheelchairs can be

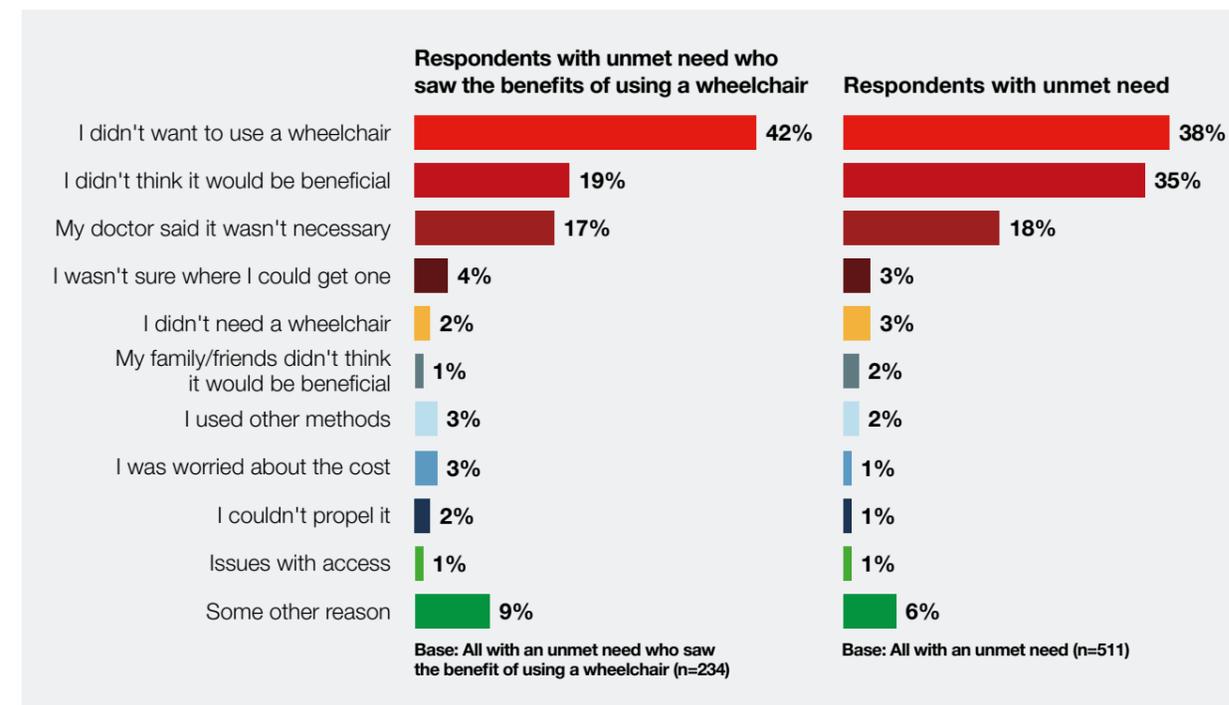


Figure 8. Reasons for not using a wheelchair to meet a short-term need

perceived as a sign of ageing or the end of life (see Section 5, Case studies).

"The media portray it, especially in this country, as getting older and people don't like the thought of getting older."

Individual with unmet need, Manchester

In addition, the qualitative case studies highlighted that wheelchairs can be perceived as a sign of weakness, illness or disability.

"Pride is very important."

Individual with unmet need, Oldham

"The moment you sit in a wheelchair people think you can't do anything."

Individual with unmet need, Newport

3.5.7 Willingness to pay to use a wheelchair

Respondents who did not use a wheelchair for reasons other than 'I didn't think it would be beneficial' (65 per cent) were asked if they would have been happy to pay for, make a donation towards loaning, buy or hire a wheelchair.

Almost half (47 per cent) said they would have been happy to make a payment or donation to use or hire a wheelchair. Individuals who considered using a wheelchair were more likely to be willing to pay or donate (70 per cent, compared with 42 per cent of respondents who had not considered using a wheelchair), although one in five individuals who had not considered using a wheelchair would still have been willing to pay for or donate towards the cost of one.

Individuals whose unmet need was functional (i.e. not due to illness, medical condition, injury or surgery) were more likely to be happy to pay for a wheelchair, with 26 per cent expressing willingness, compared with nine per cent of those who had a weight-bearing unmet need.

Conclusion

The findings of this report reveal a significant unmet need for short-term mobility aids, including wheelchairs. This need is likely to increase as the proportion of older people within the population grows. With an estimated 4.2 million people already likely to have unmet needs for mobility aids, the need for policy and practice change to meet this need and improve the provision of short-term wheelchairs is evident.

The British Red Cross believes that everybody who needs a wheelchair should be entitled to access one, for as long as they need it. Achieving this vision will require changes to regulatory frameworks met with the necessary resources. Improvements will also need to be made in service delivery, needs assessments, and information and advice.



Case studies

The researchers carried out in-depth interviews with a range of individuals having unmet needs. This included interviewing two people in each of the four areas as well as their family members, where possible. Three healthcare professionals were also interviewed in each area. The aim was to illustrate the barriers faced by people when accessing a wheelchair for short-term need, and the impact on their lives when such support is not available. The names of all participants have been changed.

The case studies revealed different reasons for needing a short-term wheelchair loan. All the individuals had a health condition or injury, either chronic or acute and temporary, that affected their mobility. Mobility limitations were caused by hip and knee replacements, weakness due to a heart attack, neurological tremors, leg and ankle fractures, and injury following a leg amputation. In interviews with healthcare professionals, the respondents explained that the need for short-term wheelchair use generally arose following an injury, a medical condition or disease, or during recovery from an operation or fracture.

5.1 Key themes

5.1.1 Barriers to accessing short-term wheelchairs

Awareness levels: A lack of awareness of local provision and eligibility was apparent among healthcare professionals and people with unmet needs.

Cost of wheelchairs: Both healthcare professionals and individuals cited the cost of wheelchairs as a barrier to their use.

Practicalities of wheelchair access: Practical barriers included providers being out of stock, restrictive criteria in accessing wheelchairs, the length of time it takes to get assessed for mobility needs, and the length of time it takes to access a wheelchair once deemed eligible.

Stigma associated with using a wheelchair: Wheelchair use prompted images of frailty, ill-health and being old among some individuals. Many saw themselves as youthful, fit and healthy, and did not want to be seen “in that way”.

5.1.2 Impacts of unmet need for short-term wheelchairs

Impact on system: Not being able to access a wheelchair can put additional strain on the health and social care system. At its most extreme, one individual spent an extra night in the hospital unnecessarily because there was no wheelchair to take him home. Healthcare professionals also spoke about people having to rely on costly home-visits because they could not leave their home; people also missed important medical appointments and, in some situations, experienced a deterioration in their health.

Isolation: Without a wheelchair, individuals lost their independence and became increasingly isolated. Becoming housebound was a common experience and this made it difficult for people to retain a sense of wellbeing and maintain their quality of life.

Dependency: The healthcare professionals and individuals with unmet needs spoke about people becoming dependent on their friends and family. While the wheelchair may not eliminate the need for support from others, it was expected to make things easier.

Emotional wellbeing: Social isolation and dependency on others affected individuals' emotional wellbeing. In more than one case, individuals developed depression and anxiety, and one individual became afraid of going out at all.

Impact on family and friends: In addition to its impacts on individuals, the lack of mobility affected the lives of family and friends. Some had to add the role of carer to their normal day-to-day tasks. Others had their lives disrupted; for example, having the affected individual move in with them or having to defer their studies.

Weakened physical health: Individuals were often advised by healthcare professionals to keep moving to build up their muscle strength and support recovery. However, without a wheelchair, people felt limited in where they could go; they were less motivated to stay active as a result.

5.2 Leanne and Mark, Edinburgh



5.2.1 Background

Edinburgh has steep slopes and many terraced houses with lots of stairs. This can make getting around particularly challenging for people with reduced mobility. In Edinburgh, Leanne and Mark described how they didn't know short-term wheelchair loans were available and, in any case, they felt they couldn't afford one. The impacts of having an unmet need for a wheelchair included being restricted to their homes, becoming dependent on friends and family, and issues with their emotional wellbeing. The views of a physiotherapist, GP and a home-visit nurse, as well as Mark's partner, are also described in this case study.

Leanne is in her late 20s and has recently graduated with a degree in childcare. She lives with her partner and enjoys watching films and crafting. While studying for her final exams, Leanne lost her job. As a result of the stress this caused, she developed neurological tremors. The tremors meant Leanne was unable to walk without support, or climb stairs. She found the tremors lessened when she was lying down and after she took time away from her studies.

Mark is in his late 40s and works full-time running his own engineering company. He lives in a multi-storey new build in the centre of Edinburgh, and enjoys spending time with his family and walking. Mark fractured his ankle in a fall and could not put weight on it. He was given a 'moon boot' by the local hospital so he could return to Edinburgh, where he had pins inserted. He was given crutches but he was not confident using them. Mark had limited mobility for two months while his fracture healed. Because of this he was worried about his business and potential loss of income.

5.2.2 Perceptions of unmet need

The survey revealed that 11 per cent of the adult population in eastern Scotland had an unmet need for short-term mobility aids, including wheelchairs.

Perceptions of unmet need differed among the three healthcare professionals interviewed. The home-visit nurse estimated that about half of the people with a need for short-term wheelchair use were unable to access one. The nurse felt this was due primarily to people failing to receive an assessment or the wheelchair becoming available too late, since the assessment process generally takes longer than the time people need to recover from an acute condition.

On the other hand, the GP assumed that short-term wheelchair need was manageable in Edinburgh and that patients would be referred to the British Red Cross.¹¹ However, neither the GP nor the physiotherapist felt able to comment on the performance of the scheme. They claimed they did not hear from patients after referring them to the Red Cross. The

physiotherapist explained how their role was to give advice and refer to the Red Cross. It was the patient's responsibility to arrange the short-term wheelchair loan.

5.2.3 Barriers to accessing short-term wheelchairs

Awareness

The home-visit nurse described a common lack of awareness about the option to use a wheelchair in the short term:

"They haven't been offered anything or advised of how to go about it."

Home-visit nurse

Leanne was not offered a wheelchair after her tremors began and the uncertainty of not knowing what support was available added to the distress of failing to get an immediate diagnosis of the cause of her tremors:

"You trust the professionals will give you the help that you need. So if they think you will benefit from a wheelchair, you think they'd give you one."

Leanne

Similarly, Mark was not offered a wheelchair. Mark's partner, Suzy, was unsatisfied with the information provided by healthcare professionals:

"There was no support, there was nothing. He wasn't offered a wheelchair."

Suzy

Mark considered asking a neighbour (although he did not know them very well) if he could borrow their wheelchair. He decided against it because he felt "it was a bit cheeky" to take theirs.

¹¹ The Red Cross has a short-term wheelchair loan hub located in Livingston that services Edinburgh.

¹² The cost of wheelchairs varies. The Red Cross buys wheelchairs for around £125.00 but they can also be much more expensive. Light wheelchairs are available for £99.00 in Costco but they are not crash-tested and therefore will not be accepted on public transport. There is no charge to hire a wheelchair from the Red Cross, although they do encourage donations to help provide the service.

Cost

The healthcare professionals we spoke to in Edinburgh felt the cost of purchasing or hiring a wheelchair was likely to be a barrier for many people.¹² Leanne was unable to work while she had tremors, and she did not receive sick pay because of an informal work contract. She considered private wheelchair hire but it was too expensive:

“There are some private-owned disability shops that will provide short-term use but it’s very costly to do that.”

Leanne

Mark runs his own business. He was worried about its viability because he could not work during his recovery. His loss of income meant the cost of a wheelchair was not justifiable. Mark’s partner looked for wheelchair hire options but found nothing that was affordable. Instead, Mark purchased an iWalk 2.0, which he found online. It attaches to the knee, like a stilt, supporting the limb. This allowed Mark to return to work, so he perceived the £150 cost to be reasonable.

Speed of access

Healthcare professionals believed the assessment process for obtaining a wheelchair may be a barrier. They were concerned that, by the time a wheelchair was offered to individuals with a short-term need, they may have already recovered.

“It is not easy to get patients short-term use of wheelchairs.... Everything takes so long for assessments.”

Home-visit nurse

In contrast to the NHS provision of wheelchairs for long-term use, the GP thought the Red Cross provided a much speedier response, and had no patients returning without a wheelchair after being referred.

5.2.4 Impacts on individuals

Isolation

For Leanne, not having a wheelchair meant she lost her ability to move around. The tremors in her arms and legs meant other mobility aids were less effective because they were less stable than a wheelchair. As the tremors became less severe, she began using a walking stick lent to her by a friend. Leanne could use the stick for a few minutes but had to rely on family and friends in case she became tired or slipped, which meant she was not confident leaving her home.

“They haven’t been offered anything or advised of how to go about it.”

Home-visit nurse

Coping with daily life

The hospital had given Mark crutches to help him get around his flat, but he did not like them because he lacked confidence using them. He resorted to crawling on his hands and knees around his home, from one room to another. As a result, Mark’s knees became covered in scabs and scores.

“I would have been able to get around the flat and do bits and bobs, rather than crawling around on my hands and knees... I basically lost all the skin on my knees doing it, which was quite sore.”

Mark

Dependency

Both Leanne and Mark became dependent on others. Leanne’s tremors meant she could not be left alone, and Mark needed support to continue running his business. They both felt a wheelchair would have given them more independence and reduced the impact on the lives of themselves and their families.

Without a wheelchair, Leanne became dependent on her partner and mother. During Leanne’s period of reduced mobility, she passed her degree. It was important to her to attend the

award ceremony in person and celebrate her achievement. Access to a wheelchair would have meant she was less reliant on friends and family to support her throughout the day.

Mark became dependent on his partner, Suzy. Without her support, Mark would not have been able to function in his day-to-day life:

“She was doing everything for me around the house; cooking the dinner, doing all the cleaning, driving me about – doing everything.”

Mark

Emotional wellbeing

Healthcare professionals described the seriousness of the impacts of unmet need on emotional wellbeing. The isolation it causes can lead to feelings of depression.

“We see a lot of older people that are very low, that are probably clinically depressed and a lot of it is because they can’t get out any more, and it must be awful.”

Home-visit nurse

This resonated with Leanne. Her situation made her lonely because she spent most of her time at her mother’s house. She could not go outdoors or participate in activities she used to and this weighed on her mind. The isolation left her feeling low and helpless. Leanne described how her dog was treating her differently; she felt he could sense something was wrong.

“I was just in the house, which was really lonely.”

Leanne

The physiotherapist and the GP warned that having an unmet need for short-term wheelchair use not only affected somebody’s independence and wellbeing, it might also lead to further deterioration of their condition.

“They’re less likely to do anything, they’re less likely to be motivated to do anything – they’re frightened. They become sedentary and [then]

they’re at risk of developing other infections. They become at risk of developing depression.”

Physiotherapist

5.2.5 Impacts on family and the community

Impact on family and friends

Family members often find it challenging to take on the role of carer, and may also become isolated:

“Isolation – that can work for both the person who acquired the wheelchair but also if they have a carer at home, they will feel frustrated and isolated.”

Physiotherapist

Suzy, Mark’s partner, felt the role of caring weighed on her:

“I had to do everything. I literally had to do everything. In the beginning, I had to wash him, I had to prepare all the food, I had to dress him, I had to drive him... a wheelchair wouldn’t have solved everything, but it would have enabled him to get around without me driving.”

Mark’s partner Suzy

It was fortunate that Suzy was a university student and her time was flexible, allowing her to care for him more easily. However, the responsibility left its mark:

“The bottom line for me was that I had to defer my exams. I just deferred them because I couldn’t study.”

Mark’s partner Suzy

Impact on the health service

Healthcare professionals discussed the financial implications of people having unmet needs on the wider system. For example, if people are unable to travel to their appointments, professionals have to make costly home-visits:

“It would impact most on primary care services. If [patients] are not able to get out,

then we are having to visit at home... which is much more time-consuming and much more expensive for the NHS."

GP

5.2.6 Supporting individuals

Information and advice about mobility aid options would have benefited Mark and Leanne. Leanne felt she was left to navigate both her condition and loss of mobility, which was disconcerting. She would have appreciated more help:

"Having a person to talk to that can advise you and make you feel better."

Leanne

Healthcare professionals thought taking a more holistic approach to caring for those with limited mobility would lead to more wheelchair referrals, thus better supporting people in need:

"Let's not always look at things from the health point of view. Let's allow someone to have some independence and some quality of life."

Physiotherapist

A more holistic approach would also allow better access within the community. If museums and public spaces provided wheelchairs, more people might be encouraged to get out of their home, and this would improve their wellbeing. This was the case for Leanne, who occasionally used a supermarket wheelchair.

5.3 Sally and Adrian, Oldham



5.3.1 Background

Oldham is a metropolitan borough of Greater Manchester. In Oldham, Sally described how she was not made aware of the option of accessing a wheelchair early on. Adrian felt there was a certain amount of stigma attached to using a wheelchair. Having an unmet need for short-term wheelchair use had a detrimental effect on their physical health and emotional wellbeing, and both experienced feelings of isolation.

Sally is in her early 70s. She is retired and lives with her husband. Before her surgery, she had an active social life, was interested in health and fitness, and attended a Slimming World group every week. However, after suffering from pain in her knees, Sally had two knee replacement operations, and a further hip replacement for an old sporting injury. During recovery from these surgical procedures, she had difficulty walking and standing. Sally needed a chair in every room of the house, including in the shower, so she could sit down. While the time of most need for a wheelchair was during the first few weeks after her surgery, Sally's wider mobility issues have persisted since her original sporting injury.

Adrian is retired and lives on his own. His wife died a few years ago. He is in his late 70s and typically spends his time with his daughter and grandchildren. He enjoys going for walks, having meals out, going to the theatre and going to church every Sunday. He is a member of several clubs in his neighbourhood, including a French club. In early 2017, Adrian suffered a heart attack. During his recovery period, he had difficulty walking and this limited his mobility for a couple of months.

The researchers also interviewed two district nurses, one physiotherapist and two family members. The healthcare professionals reflected on how Oldham is a former mill town with high levels of deprivation. They noted that the industrial past means the town is associated with a high proportion of respiratory infections, such as fibrosis and occupational lung disease, as well as high levels of cardiac disease. They felt these illnesses contributed to the demand for short-term wheelchair use, alongside other drivers such as post-surgery for hip and knee replacements, and those waiting for specialist equipment.

5.3.2 Perceptions of unmet need

The healthcare professionals felt individuals in need could get a short-term wheelchair loan quickly, either through a local wheelchair centre, the Red Cross¹³ or by buying one themselves. However, while the healthcare professionals presumed there were no barriers to access in Oldham, the survey found that nine per cent of the adult population in Greater Manchester had an unmet need for a short-term mobility aid, including a wheelchair, in the past year.

5.3.3 Barriers to accessing short-term wheelchairs

Awareness

The most significant barrier for Sally and Adrian was that they didn't know they could access a wheelchair for short-term use. While in the hospital and receiving treatment, the option of a short-term wheelchair loan was not suggested to either of them.

"Someone should have said: Do you want a wheelchair for your first six weeks?"

Sally

"I don't know what is available. It seemed difficult enough contacting the district nurses"

Adrian

The musculoskeletal clinic offered Sally mobility aids in the form of crutches and a walking stick. Despite these, she was confined to her house as she felt the walking aids were not enough to support her outside the home. She later learned from a neighbour that a wheelchair could help her to get out and about. However, she didn't know where to find one:

"There was no information about where you could get one from. Nobody knew anything about them."

Sally

Cost

When Sally eventually tried to pursue the option of buying a wheelchair, she was faced with a further barrier: the cost. An online search revealed the cost was prohibitive:

"It was going to be £100 to £200 outlay of money. We haven't got that kind of money to throw around."

Sally

¹³ The Red Cross has a short-term wheelchair loan hub located in Telford that services Oldham.

Eventually, one of Sally's friends gave her the number of a local occupational therapy team in the NHS. However, her discussion with the team did not prove fruitful and she faced another roadblock:

"The occupational therapy team said unless you're using it in the house, you can't have one... It just made me frustrated not being able to get to local places."

Sally

Stigma associated with using a wheelchair

Another barrier (highlighted by Adrian) related to the stigma associated with people who use wheelchairs. Wheelchair use prompted images of frailty, ill-health and old age. Adrian lived a fit and healthy life and he did not want to be perceived in that way. As a result, Adrian felt too proud to ask for help to get a wheelchair:

"People in wheelchairs to me: is that the end of their life? I didn't want to be seen like that."

Adrian

The healthcare professionals echoed Adrian's views:

"There is a bit of stigma with wheelchair users, so they actually don't want to be in a wheelchair, especially someone who is quite young."

District nurse

Individuals may not want to be a burden on the rest of their family and so may attempt to use crutches or other support aids instead, regardless of whether these aids are effective:

"We do find a lot of people not wanting to be a burden. [They] won't bother anybody, and go: Don't worry, I'll manage myself."

District nurse

5.3.4 Impacts on individuals

Isolation

Sally and Adrian both felt isolated and lonely as a result of being housebound:

"When my friends are going out walking and going to do this walk or that walk, sometimes I could cry because I couldn't do it."

Sally

Healthcare professionals reiterated the ripple effect of becoming isolated:

"Some people do get to the point that they get so socially isolated that they don't feel that they could possibly get out of the house, even to see a doctor."

District nurse

Coping with daily life

Sally and Adrian also spoke of the physical impacts on their health that arose as a result of being confined to the house. Both were told by healthcare professionals they needed to keep moving to build up their muscle strength. However, because they did not have a wheelchair, they felt limited in where they could go, and were less motivated to be active.

"The sooner you get out the better. You start to improve. Your physicality builds up. I lost all my muscle strength."

Sally

"I felt very weak. I think being [someone who enjoys walking regularly], it really hit me. You think you're invincible, but it really hits you and really strikes home."

Adrian

Emotional wellbeing

As a knock-on effect of being isolated, Sally started to develop what she described as agoraphobia:

"I also developed this fear of going out as I felt I wasn't fit enough to go out as I hadn't had that step."

Sally

Sally believed that a wheelchair would have prevented her from becoming isolated and anxious about leaving her home. She felt that the use of a wheelchair for a short period of time would have helped her to go on holiday, attend events and see her friends and family.

Adrian's mental wellbeing was also affected; he felt depressed as a result of being "trapped within four walls" and unable to do what he loves to do – getting out and about. He felt that if he had been told about loaning a wheelchair and knew where to get one, he would have been able to go out and get some fresh air, which he felt may have reduced the likelihood of developing depression.

5.3.5 Impacts on family and the community

Impact on friends and family

Being unable to access a wheelchair also had an impact on the lives of Sally and Adrian's friends and families. Sally reported that her inability to leave the house affected her husband emotionally:

"It aggravated him unbearably because we couldn't get out. We tried and it was absolute murder. We went on holiday. We went into the little town. I walked so far I couldn't get any further, I just couldn't do it. That made him think: Well, it's ridiculous. We can't do anything, what are we going to do?"

Sally

Adrian's daughter suggested he could move in with her temporarily so she could look after him. Adrian believed his limited mobility affected his family and friends emotionally and practically. He felt that if he had been offered a wheelchair, he would not have needed to depend on them so much:

"I would have been able to visit the local shops without inconveniencing all the helpful friends and family I have."

Adrian

Impact on the health service

The healthcare professionals suggested that an unmet need for short-term wheelchair use had a wider impact, including putting additional cost and strain on the NHS. The district nurse suggested that, without a wheelchair, patients could miss medical appointments, thereby placing extra pressure on district nurses to make home-visits. They also felt that intervening at crisis points (rather than preventing a crisis from occurring) was a further challenge to the efficient and effective use of resources:

"It's a bigger burden on the NHS because everyone is [all] hands on deck, trying to sort all these different issues out, both health-wise and social-wise."

District nurse

5.3.6 Supporting individuals

Sally and Adrian felt the most important change that needed to be made was to raise awareness of local provision of wheelchairs for short-term use. Sally felt that this needed to come from healthcare professionals initially, when they did a full assessment of a patient's ability, to ensure they were providing the most appropriate mobility aids. If healthcare professionals cannot supply the most suitable support aids, they should provide relevant and up-to-date information on where patients can access them.

They also suggested that wheelchair services should maximise accessibility by offering drop off and collection of wheelchairs for people who do not have friends or family to help:

"Provide the item and retrieve it when its period of use is finished."

Adrian

5.4 Cole and Jeremy, Newport



5.4.1 Background

Newport has historical connections with the coal industry and was formerly the largest coal-exporting port in Wales. In Newport, Cole and Jeremy reported their experiences of having an unmet need for short-term wheelchair use. They described the barriers to wheelchair access as a lack of awareness of availability, service limitations and stigma associated with using a wheelchair. The impacts included isolation and a deterioration in emotional wellbeing and physical health.

The researchers also sought the views of a practice nurse, a district nurse and a senior GP. The healthcare professionals reported seeing high rates of chest problems and septicaemia associated with the local mining and metalwork industries. These illnesses, together with an ageing population, were felt to be driving local demand for short-term wheelchair use. Key drivers of wheelchair need were described as: palliative care; complications of diabetes; amputations, and post-surgery knee and hip replacements; and back surgery.

Cole is in his early 70s and is retired. He lives with his wife and they normally lead an active life. When not volunteering at their local church, they like to walk and take their caravan to Cornwall. Cole also likes spending his time with his family, particularly his grandchildren, as well as with his friends. After suffering pain in his hip, which meant he couldn't walk or stand properly, Cole needed hip replacement surgery. While recovering from the surgery, Cole was out of action and had issues with walking and standing.

Jeremy is semi-retired, working in his family's toy business, which he runs with his sons. He is in his mid-60s and lives with his wife and their dogs. He used to spend his spare time renovating and restoring their house, and enjoyed walking the dogs along a nearby canal. Jeremy developed vascular problems in one of his legs, which meant that he could barely walk or stand. As a result, he had his leg amputated from the knee down. He now has a prosthetic leg. He has regular periods of limited mobility when he injures his stump and cannot use his prosthetic leg. These range from one week to several months, depending on the severity of the injury.

5.4.2 Perceptions of unmet need

The healthcare professionals felt the short-term wheelchair loan service offered by the Red Cross¹⁴ adequately serviced their area. Because the service is based locally, they considered it should be easy for people to access. Unmet need was therefore deemed to be low. However, in the few cases of unmet need for short-term wheelchair use experienced by the district nurse, the main barrier was the cost of the wheelchair.

The survey found that 18 per cent of the adult population in east Wales had an unmet need for short-term mobility aids, including wheelchairs during the past year, suggesting access was still a significant barrier.

5.4.3 Barriers to accessing short-term wheelchairs

Awareness

Jeremy and Cole were aware of the Red Cross service. However, Cole's medical team never mentioned a wheelchair as an option and it never crossed his mind that a wheelchair might help him:

"I would have liked to have someone sit down and explain all the different options, and what was right for me. I wouldn't want a wheelchair if it was going to make my condition worse but I didn't even know."

Cole

The healthcare professionals were unaware of services other than the Red Cross that provided wheelchairs for short-term use. They were also unaware of the processes and criteria used by services, including the Red Cross, to allocate wheelchairs.

Professionals believed people may be unaware of wheelchair loan services for a number of reasons. Older people may be less familiar with the Internet and so less able to search for services. Illiteracy prevents some people from reading service advertisements. Isolation and lack of friends or family to help also limits people's ability to find support.

Speed of access

The healthcare professionals felt the time it took to access a wheelchair would prohibit short-term use:

"The problem with short-term wheelchairs is it can take a long time to get one because of

limited availability, and by the time a person gets one they might not need it anymore."

District nurse

This was an issue for Jeremy. He tried to find a short-term wheelchair loan several times, but was unable to obtain one.

Stigma associated with using a wheelchair

For Cole, pride and a wish to be viewed in a particular way was a barrier to using a wheelchair. For example, he knew Sainsbury's stores were equipped with wheelchairs but he was reluctant to use them:

"There is stigma associated with people in wheelchairs, isn't there? People are in wheelchairs, being invalids, disabled and ill. I was just recovering; this wouldn't last."

Cole

5.4.4 Impacts on individuals

Isolation

Isolation and loneliness was mentioned by healthcare professionals as one of the main impacts of unmet need for short-term wheelchair use. When left unaddressed, isolation and loneliness can lead to depression, adding to an already difficult situation for people with limited mobility.

Jeremy and Cole experienced isolation and it had a profound effect on their quality of life. Limited mobility meant Cole was not able to follow his normal routine, which included shopping, seeing friends, attending church, going to the rifle club and volunteering.

"I felt like I lost my independence. I had to rely on people to help me do things, which I hate. I felt depressed. I couldn't do anything."

Cole

Jeremy mentioned he found it challenging to be restricted to his home, but his wife witnessed the extent of his difficulties:

¹⁴ The Red Cross has a short-term wheelchair loan hub located in Warmley and Crawley that services Newport.

“He was a prisoner. It was upsetting [for him]; he couldn’t get to work, or stay as active as we usually are. With a [wheel]chair, he could have got to his job, done paperwork, been focused and productive. Not destructive.”

Jeremy’s wife Wendy

Coping with daily life

Healthcare professionals described how limited mobility can make it more difficult to recover from a condition or injury. People acquire a sense of purpose when they can get out of the house, and the physical effort of going out was deemed to be important to their physical wellbeing.

Because Jeremy did not have a wheelchair, he used a walking frame instead. A wheelchair would have put less strain on his body, potentially hastening his recovery time.

Emotional wellbeing

Despite the challenges Jeremy described, he felt he was coping. However, his wife Wendy had a different opinion on her husband’s state of mind:

“[He] would rather not have any support. He likes his job, likes building and structuring things in the garden and being active. He gets demoralised, fed up, frustrated.”

Jeremy’s wife Wendy

Cole also struggled emotionally. He did not feel “normal”; he was usually fit, able and independent. His wife explained:

“We used to walk six miles a day. Then ten yards became too much. Jazz – we would go weekly. If he had a wheelchair we could have parked 150 yards away and wheeled him to the jazz club. It would have lifted his spirits.”

Cole’s wife Sarah

Cole felt having a wheelchair would have helped him to “return to life” and reduced his feelings of loneliness and depression.

5.4.5 Impacts on family and the community

Impact on family and friends

Both Jeremy’s and Cole’s wives were physically and emotionally affected by their husbands’ experiences, and spoke about how things might have been better if they had been able to have had periodic access to a wheelchair.

Jeremy’s wife was his sole carer. Having cared for her severely disabled father in the past, she felt able to do what was needed to support her husband. However, she felt the impact on her life from his limited mobility, since she had to prioritise his care over her commitments and cancel meetings with friends and her church group.

Like Cole, his wife was pragmatic. She sought to manage the best she could, knowing her husband’s circumstances were temporary. She felt a wheelchair could have made a difference to both of them:

“While we knew his situation was temporary, it didn’t have to be as difficult as it was. A wheelchair would have been invaluable. If we’d had a wheelchair in the run-up to and after the surgery we could have seen friends for coffee, drive to a park or Cardiff Bay. It would have made our quality of life more pleasant.”

Cole’s wife Sarah

The dramatic shift from an active to a restricted life limited Sarah’s usual lifestyle:

“We went from being an active, young-minded couple to a world narrowed. It was very depressing for us both. I had to make a lot of adjustments in a normally busy life. He couldn’t drive me, couldn’t carry the shopping. I did everything I could to make life as pleasant as possible; made meals, put on films, chatted away... it was hard.”

Cole’s wife Sarah

Impact on the health service

After being taken to hospital for treatment, Jeremy was unable to go home because he couldn’t use his prosthetic limb or crutches, and the hospital did not have a wheelchair he could use in the short term. He tried the Red Cross but it had already rented out all its wheelchairs. In the end, Jeremy had to stay the night in the hospital and was able to get home only once his son found a private wheelchair company in Newport.

“I was disappointed I couldn’t get a chair from the Red Cross and had to hire from a private company. [I] would have rather given that money to a charity to support the work they do. Not to mention, I stayed a night in hospital for no reason.”

Jeremy

5.4.6 Supporting individuals

Awareness

Better awareness of where to access a wheelchair for short-term use, and the benefits of having one, would have helped Cole and Jeremy. Local private and charitable providers could improve their promotion of short-term wheelchair loans and share guidance on the qualification criteria.

“Advice was the biggest thing and knowing what was there, which we didn’t really know about... Everyone needs to know what the provision is and we need to have guidelines of, yes, there’s that provision, what the provision is, how to access it, who qualifies for it and where do we go for it.”

Cole

Healthcare professionals agreed there was a need to increase awareness of the options for short-term wheelchair use. In particular, they felt advertising could be more visible and targeted to key audiences such as district nurses, who are more likely to work with patients that need a wheelchair for short-term use. They also felt a delivery service, either free of charge or with a nominal fee, would help individuals to access a wheelchair for short-term use.

5.5 David and Tom, London



5.5.1 Background

In London, David and Tom described their experiences of having an unmet need for short-term wheelchair use. Barriers included a lack of awareness of the option of accessing a wheelchair for short-term use, and the cost and practicalities of hiring or buying a wheelchair. Impacts of their unmet need included isolation, issues with their emotional wellbeing, dependency on friends and family, and loss of friendships.

David is in his early 50s and runs a building company. He lives alone in a ground-floor flat and has an active social life. David's need for short-term wheelchair use arose when he was recovering from knee replacement surgery. After the surgery, he could not walk and was mobile only when doing his physiotherapy exercises. Unfortunately, his knee did not set properly and he needed further surgery. This prolonged the time for which he needed support with his mobility for several months.

Tom is in his late 30s and is a keen football fan. He enjoys spending time with his mates and watching films. He used to be a gardener but fractured his lower leg in a workplace accident. Following emergency surgery and while recovering, he experienced extreme pain and was unable to bear weight on his leg. Although he recovered after several weeks, the wider impacts of the accident lasted more than a year. The hospital lent him a wheelchair for the first two weeks post-surgery, after which he was asked to return it, despite still having a need for its use.

The researchers also interviewed a GP, a fracture-clinic nurse and an occupational therapist. The healthcare professionals described the key drivers of need for short-term wheelchair use as injuries or diseases, pre- or post-operation mobility, fractures and conditions linked to ageing.

5.5.2 Perceptions of unmet need

The survey found that five per cent of the adult population in London had an unmet need for short-term mobility aids, including a wheelchair during the past year.¹⁵

The healthcare professionals had different opinions as to how often people's needs for short-term wheelchair use were being met in London. The occupational therapist believed need had decreased in recent years because people were more likely to purchase their own wheelchairs. The others felt they did not fully understand the extent of the problem:

"I think it is a big problem but I don't have a huge handle on this... I think often the short-term ones are handled a lot by [other professionals]."

GP

As in other regions, healthcare professionals described signposting patients to other practitioners or services, but had limited knowledge about whether or not patients had accessed a wheelchair as a result.

5.5.3 Barriers to accessing short-term wheelchairs

Awareness

David assumed the people treating him would give him advice on what would help his mobility after surgery. When he was discharged from hospital, he was taken to the car in a hospital wheelchair, but it did not cross his mind what would happen when he got back to his home, and he struggled to get inside his flat. David expected to be given the clinical information and mobility aids he needed for his recovery, but this did not happen. As a result, he did not immediately consider short-term wheelchair use.

"I didn't get anything from the NHS or anything like that to tell me there was any other help out there."

David

Cost

David and Tom both found the cost of short-term wheelchair loans was too expensive. David considered using a private provider but it did not offer a hiring service. He needed the wheelchair only for a limited time and couldn't afford to buy one outright.

Tom was also unable to purchase a wheelchair. His income was limited because his injury meant he was unable to work.

"I looked online, the cheapest was £150. When you've been in hospital for that long, you've not been working and don't have the money."

Tom

Healthcare professionals also emphasised that cost was a barrier to wheelchair access.

Practicalities of access

Tom also talked about the perceived challenges of collecting and returning a hired wheelchair. Like many Londoners, he does not drive and relies on public transport to get around. Without access to a car, he considered the idea of collecting a wheelchair to be impossible.

"I don't know how I would have collected the thing anyway... I don't drive, my mother doesn't drive."

Tom

5.5.4 Impacts on individuals

Isolation

Healthcare professionals acknowledged the sense of isolation and mental health difficulties that may arise when people have an unmet need for short-term wheelchair use. The occupational therapist described how individuals lose their ability to participate in their community:

"They would be isolated in their [own] environment [without a wheelchair]."

Occupational therapist

Both David and Tom became housebound as a result of their unmet need. Without a wheelchair, it was impossible for them to leave their homes. While David was given crutches as a mobility aid, they were inappropriate since he had a condition that meant he struggled to put pressure on his shoulder. This limited his ability to get out of his home.

Dependency

Their limited mobility caused both David and Tom to become dependent on their friends and family. David lives alone, and losing his mobility meant his daughter had to stay with him to do his shopping and pick up his medicine. Like David, Tom felt dependent on others. He described the experience as like becoming a child again and explained how his mum needed to look after him:

¹⁵ From a nationally representative survey that explored the level of unmet need for short-term wheelchair loan and to understand why current needs are not being met.

"[My mum] was bringing me food, coming and doing shopping... I hate it. It's like being a baby again – you can't do anything."

Tom

The negative effects on wellbeing and mental health were clearly recognised by healthcare professionals, who described the serious nature of isolation and dependency. They described how the social and emotional impacts of losing mobility commonly cause people to become depressed:

"People who can't get out because they are not mobile enough get very depressed, very isolated, very dependent."

Fracture-clinic nurse

Emotional wellbeing

Being housebound and feeling isolated had a big effect on both David's and Tom's wellbeing. They both lived active lifestyles and worked in physically demanding jobs; neither was used to spending a lot of time indoors. Tom described how being stuck inside day after day weighed on his mind and led to him feeling depressed:

"It was a very long period of being stuck in bed and feeling hopeless. When you're stuck indoors in bed all day, every day, you really will start to feel depressed. You feel like bursting into tears because you feel like your life has gone down the drain. This was going on for months and months."

Tom

David found himself in a similar situation, unable to leave his home or to do any of his usual daily activities.

For Tom, the main impact of not having short-term use of a wheelchair was that he drifted apart from his friends. He used to spend time with friends in the pub or watching football. When he became housebound, friends visited at first but Tom felt it was not as enjoyable as the time spent going out together. Because he was also feeling

down, Tom became less interested in their visits. Eventually, his friends stopped coming.

Since his work injury, Tom's life changed drastically. He is no longer able to work and, more than a year after the accident, is still recovering psychologically. Although he had wider physical, social, emotional and work-related issues, the lack of access to a wheelchair exacerbated his situation.

5.5.5 Impacts on family and the community

David described how his daughter, who lives outside London, took time off work to care for him when he was first discharged from the hospital. While she wanted to stay longer, she had to return to her young family and could not take extended time off work.

"It's time she should be spending with her family. It's nice, don't get me wrong, but I'd rather that she didn't... I didn't want to be a burden on them and that's what I felt like, a burden."

David

When his daughter had to return home, he relied on a friend, Steve. While he appreciated the company and needed the support, David felt he was a burden on Steve. David felt Steve's wife and children were missing out on time with Steve because of him. David felt that access to a wheelchair would have given him the freedom and independence he needed to get to the shops by himself, and to meet friends in town.

Impacts on the health service

The healthcare professionals felt the main impact of unmet need for short-term wheelchair use was on the healthcare system. NHS home-visit services require additional resources for coordination and time from practitioners than when people can attend clinic or hospital appointments.

"There's a massive impact for us on doing home-visits on people who could potentially get out more. In some cases, they should be able to make it to appointments, but because they don't have a mobility aid they cannot make it. So expensive home-visits are made."

Fracture-clinic nurse

The fracture-clinic nurse and occupational therapist also raised the issue of cost in relation to hospital transport services. Some people using the hospital service could be transported by friends or family if they had access to a wheelchair.

5.5.6 Supporting individuals

David and Tom felt they would have been supported better if they had been given a single source of advice, including information on available services, like wheelchair hire centres:

"I had no one I could phone up... I would need someone I could liaise with, a phone number of a person or a team... When you go to hospitals, there are never pamphlets or information on charities that could help you."

David

Healthcare professionals also recognised that hospitals and GP surgeries could promote mobility aid services more effectively as a means of addressing unmet need for wheelchairs.



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Appendix: Research methodology

Population

The British Red Cross survey measuring the prevalence of need for short-term wheelchair loans was carried out in the UK as part of Kantar TNS's Omnibus survey. The survey aimed to cover adults aged 16 years and over, living in private households.

Interview mode

Interviews were carried out by face-to-face interviewing in people's homes, using Computer Assisted Personal Interviewing (CAPI).

Sample selection

Sample frame

The Kantar TNS Omnibus is carried out using a quota sample, with sample points selected by random location methodology.

The sample points were selected from those determined by Kantar TNS's own sampling system. The Postcode Address File (PAF) and 2001 Census small area statistics were used to define sample points. The sample points are areas of similar population sizes formed by the combination of electoral wards, with the constraint that each sample point must be contained within a single Government Office Region. Geographic systems were used to minimise the travelling time that would be needed by an interviewer to cover each area.

Selection of clusters within sampling points

The sample points in the sampling frame have been divided into two geographically distinct segments, each containing, as far as possible, equal populations. The segments comprise aggregations of complete wards. For the Omnibus, alternate A and B halves are worked in each wave of fieldwork. Each week, different wards are selected in the required half and Census Output Areas selected within those wards. Then, blocks containing an average of 150 addresses are sampled from PAF in the selected Output Areas, and are issued to interviewers.

Interviewing and quota controls

Assignments are conducted over two days of fieldwork and are carried out on weekdays from 2pm to 8pm and at the weekend. Quotas are set by sex (male, female 'housewife', female 'non-housewife', where a 'housewife/househusband' is the person (male or female) responsible for carrying out more than half of the weekly shopping); within female 'housewife', presence of children and working status, and within men, working status, to ensure a balanced sample of adults within contacted addresses. Interviewers are instructed to leave three doors between each successful interview.

Response rates

As this is a quota sample it is not possible to quote response rates for achieved interviews.



Fieldwork

Interviews were carried out by fully trained interviewers from Kantar's field department. Interviewing took place between 31 May and 4 June 2017 and 7–11 June 2017.

The questionnaire

The questionnaire measuring the prevalence of need for a short-term wheelchair loan was developed by Kantar Public and the Red Cross. The survey consisted of the following areas:

- Whether experienced a met need for a short-term wheelchair loan in the last two years.
- Whether experienced an unmet need for a short-term wheelchair loan in the last two years.
- Experience of a met need for a short-term wheelchair loan:
 - Where accessed a wheelchair from.
 - How helpful use of the wheelchair was in the short-term.
 - The impact on quality of life of using the wheelchair in the short term.
 - The impact of using a wheelchair in the short term on recovery and reducing risk of further injury.
 - Activities that using the wheelchair short term allowed individuals to complete that would not have been possible without a wheelchair.
 - The impact of using a wheelchair short term on maintaining independence and everyday life.

- Experience of a unmet need for a short-term wheelchair loan:
 - Whether considered using a wheelchair short term.
 - Where would have considered accessing a wheelchair from.
 - How helpful use of the wheelchair in the short term would have been.
 - The potential impact on quality of life of using a wheelchair in the short term.
 - The potential impact of using a wheelchair short term on recovery and reducing risk of further injury.
 - Activities that could have been possible with a wheelchair that were not possible without one.
 - The potential impact of using a wheelchair short term on maintaining independence and everyday life.
- Demographic details of those who have experienced a need for a short-term wheelchair loan in the last two years:
 - income
 - health.
- In addition, a range of demographic measures are included on the Omnibus:
 - sex
 - age
 - social grade, using the Market Research Society's classification system (AB/C1/C2/DE), based on the occupation of the highest income householder (chief income earner). A description of the social grades is as follows:
 - AB – professional/managerial occupations, C1 – other non-manual occupations, C2 – skilled manual occupations, DE – semi-/unskilled manual occupations and people dependent on state benefits.
 - marital status.

- presence of children aged under 16 in the household
- ethnicity of respondent (White British, White Irish, Any other White background, Mixed White & Black Caribbean, Mixed White & Black African, Mixed White & Asian, Other Mixed background, Indian, Pakistani, Bangladeshi, Other Asian background, Black Caribbean, Black African, Other Black background, Chinese, Other)
- government office region (North East, North West, Yorkshire and Humberside, East Midlands, West Midlands, East of England, London, South East, South West)
- working status.

Validation, editing and imputation

As the interviews are carried out using CAPI, validation is carried out at the point of interview. The CAPI programme ensures that the correct questionnaire routing is followed, and checks for valid ranges on numerical variables such as age. Range and consistency checks are then validated in the post-interview editing process.

Weighting

The unweighted sample profile was compared with population statistics and weighting was applied to compensate for imbalances. Demographic variables were included in the weighting matrix only if they were found to be correlated with the key survey outcomes; the following demographic variables were included within the weighting matrix:

- region
- gender
- age
- marital status
- tenure
- social grade
- number of adults in the household.

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