“Service users' views on choice in NHS wheelchair and postural seating services”: A Scoping Exercise

Commissioned by

POSTURE & MOBILITY GROUP

Author:

Jo Goodship BA (Hons), MSc

Jo Goodship

Admiralty Consulting Limited

43 Admiralty Tower, Queen Street,
Portsmouth PO1 3GA

"Service users' views on choice in NHS wheelchair and postural seating services" – A Scoping Exercise

Contents

Tables

Boxes

Executive Summary - “Service users' views on choice in NHS wheelchair and postural seating services”: A Scoping Exercise

Since 2010, the Department of Health (DH) has been actively considering reforms to NHS wheelchair and postural seating (WPS) services that will deliver the scale of transformation that, in the DH’s own words, “wheelchair users feel is required”. The precise nature and extent of transformation users feel is required is, however, not entirely clear. This is due in part to perceived difficulties obtaining 'consumer views', not least on what 'choice' means to them. Thus, to help inform discussions with the DH and the current reform agenda, the Posture and Mobility Group (PMG) commissioned an investigation into users’ views on ‘choice’ in NHS WPS services.

In January 2014 PMG approved a Scoping Exercise to identify, in a timely manner, the key issues and themes on ‘choice’ in service provision from the service user perspective. The fieldwork, undertaken by an experienced social research fellow, took place from February to July 2014. User consultants were recruited within four ‘case study’ NHS WPS service areas, and invited to attend a focus group or, if unable or unwilling to attend a group, to submit their views electronically. The qualitative data collected informed the design of a survey instrument, which was subsequently piloted to assess both its user-friendliness and relevance to gathering views on ‘choice’ in service provision on a wider scale. Some recruitment difficulties were experienced resulting in (i) fewer user consultants than anticipated, and (ii) a delay in the timetable for the fieldwork. Nonetheless, the final sample included wheelchair users from a diverse range of geographical locations (from the very rural to a London borough), ethnic backgrounds, ages and physical conditions necessitating a wheelchair for mobility.

User Participation in Scoping Exercise	*Identified by WPS Service Gatekeepers*	*Focus Groups Attendees*	*Submitted Views Electronically*	*Piloted User Survey*
	50	***21 Adults & 2 Children***	***8 Adults & 1 Child***	***7***

Despite this diversity, however, there was a high level of agreement among user consultants as to the main issues relating to ‘choice’ in service provision. At present, users perceived they had little or no choice when it came to their NHS WPS services. This was often linked to a lack of information provided on the chairs and equipment available (either through the NHS or from private providers) suitable to meet their needs. More often than not, following assessment, users were simply told which chair or piece of equipment with which they would be provided. Many commented that ‘choice’ was just policy rhetoric, and that the real agenda was more concerned with reducing costs.

From users’ viewpoint, the most important form of ‘choice’ desired from NHS WPS services was a ‘fit-for-purpose’ chair that met their complex and multifaceted needs. Specifically users wanted a choice of chair/equipment that met both their clinical and social needs (reflecting a social rather than clinical model of disability), and that was of a quality to withstand everyday use. Several examples were cited of unsuitable chairs/equipment firstly aggravating physical conditions and/or actually causing health problems, and secondly, limiting mobility because of problems accommodating a chair in a carer’s car. The chairs/equipment currently prescribed by the NHS were perceived to be of poor quality and they required frequent repairs and maintenance, but this aspect of WPS services was particularly inefficient and often ineffective. Many users had been forced to go without their main wheelchair for several weeks pending its repair. While some users had been provided with a spare manual chair, they pointed out that these were often totally unsuitable for their needs and, in some cases, could even place them at risk of serious harm if they were unable to self-propel.

Very few users had been given information on or knew about the Voucher Scheme, and among the few who did there was a degree of confusion about ongoing responsibility for repair and maintenance of a chair wholly or partly-purchased with a voucher. Even fewer users were aware of AQP, and those who had some knowledge of what AQP involved harboured fears of providers being motivated purely by profit rather than meeting users' needs.

Poor communication and provision of information between WPS services and users was a recurrent theme throughout focus groups, but generally there was very little criticism of WPS service staff who were perceived to be constrained by central policy and budgets, and working under difficult circumstances in the 'Cinderella service of the NHS'. The Government's policy approach to WPS services was the subject of much criticism for being short-sighted and 'cost-ineffective'. Underfunding of WPS services, and bulk purchase of cheaper chairs/equipment, was: exacerbating users' physical deformities and health problems, often leading to the need for additional health and social care services (including lengthy hospital admissions); increasing users' reliance on welfare benefits; and, decreasing their ability to be active in the labour market. Users were unanimous that a more holistic policy approach would not only be more cost-effective for the public purse but would also improve their quality of life.

To improve 'choice' in WPS services users advocated:

- *a more holistic approach to meeting users' needs;*
- *better provision of information to users on the products on the market that would be suitable for them, and on the Voucher Scheme;*
- *separation of the assessment of need, from procurement and provision of chairs and equipment;*
- *the DH, as the major purchaser, to place greater pressure on manufacturers to provide high quality equipment at an affordable price;*
- *recognition that young adults and child users' needs often differed from those of other users (and they were no less 'image conscious' than their able-bodied peers); and,*
- *to address the current inadequacy of repairs and maintenance services.*

It was felt that the DH should consult service users more widely, and suggested that a mixed-methods approach employed by independent researchers would help to maximize the response rate – although it was recognized that not all users were willing and/or able to attend local events or meetings and, consequently, may prefer telephone or face-to-face interviews at home, while many young users would prefer a Skype (or similar) interview. Any survey needed to be user-friendly, carry the DH and NHS logos (to help maximize response rate), and be administered via post, telephone and electronically (via email and online).

Based on the qualitative data collected in the first phase of the Scoping Exercise, a survey instrument was designed and piloted with a small number of user consultants. The feedback was positive, with all users finding it well-presented, the questions clear and easy to understand, and the content suitable to gather quantitative and qualitative data on the extent to which users felt (i) they had 'choice' in their current WPS services, (ii) what was important to them in terms of 'choice', and (iii) how they felt 'choice' could be improved.

The findings from this exercise should help to inform on-going discussions with the DH about the ways in which WPS services can be reformed to improve 'choice' for service users, and the importance of consulting with users before any changes are implemented. Although far from straight forward and demanding the investment of significant resources, it is possible to consult with service users and when they are given an opportunity to voice their views, they are not only pragmatic about what can be achieved given current public sector spending constraints, but also demonstrate a great awareness of the problems facing delivery agencies and the inefficiencies associated with current service delivery policies.

1. Background

Patient choice has been a priority for successive governments since the 1970s. The last Labour Government focused on enabling patients to choose where to receive treatment, creating an entitlement for patients who required referral to a specialist to choose from four or five providers. From 2008 that choice was extended to any eligible NHS or independent sector provider. The present Coalition Government has maintained this emphasis and, like its predecessor, views patient choice not only as a way to improve the patient experience but also as a lever for competition. In theory, patients choose the best services, encouraging poorer quality services to improve in order to compete for patients and funding, thereby driving up standards across the NHS. Competition and choice are now, therefore, inextricably linked.

The 2010 White Paper 'Equity and Excellence: Liberating the NHS' (and its supporting document 'Liberating the NHS: Greater choice and control') clearly signalled the Coalition's intention to provide greater choice for patients in most sections of healthcare. In July 2011, the Department of Health (DH) published 'Operational Guidance to the NHS on Extending Patient Choice of Provider' setting out guidance regarding implementing 'Any Qualified Provider' (AQP) including wheelchair and postural seating (WPS) services as one of the initial service lines to be offered through AQP.

Although identified as a priority service area for an extension of choice through AQP, however, the lack of a sensible tariff for wheelchairs proved to be a barrier to extending patient choice and innovation. The DH has been investigating ways in which to develop a provisional tariff and it is hoped that a non-mandatory tariff for WPS services will be developed through this. This tariff work is part of a wider programme which has led to the DH deciding to de-couple WPS services from AQP implementation. The reasoning behind this is to provide an opportunity to:

- develop robust commissioning guidance (building on the work already done in developing the AQP Implementation Pack for wheelchairs);
- apply concerted pressure on the manufacturers, via the Supply Chain, to improve value for money;
- develop a "good enough" non-mandatory tariff for WPS services.

A brief summary of AQP in set out in Box 1 below.

Box 1: Any Qualified Provider (AQP)

The stated goal of AQP is to enable patients to choose any qualified provider where this will result in better care. Choice of provider is expected to drive up quality, empower patients and enable innovation to support the delivery of Quality, Innovation, Productivity and Prevention (QIPP). Importantly, extending choice of AQP provides a vehicle to improve access, address gaps and inequalities and improve quality of services where patients have identified variable quality in the past. The introduction of AQP began in April 2012, treating 2012/13 as a transitional year. A limited set of community and mental health services covered by national or local tariff pricing were identified as the initial priority areas in which to apply AQP. PCTs were, however, able to choose services not included in the priority list if consultation showed them to be of a higher local priority. By September 2012, PCT clusters had implemented patient choice of AQP for their chosen services. By February 2013 there were 132 unique providers delivering services under approximately 490 contracts, with another 56 contracts already signed. The mix of providers qualifying for AQP is different to that which was expected by the DH, with significantly more small and medium enterprises (SME) and FTs, and fewer large corporate firms.

From 2013/14 local commissioners were expected to decide in which services, if any, they wanted to introduce choice of AQP, reflecting local needs, the quality of existing services and patients' views. Procurement regulations for commissioners, laid before Parliament in February 2013, sought to confirm that local commissioners would have the flexibility to decide whether and how to extend choice in their area, including via AQP.

One stated principle of AQP is that competition is based on quality, not price. Providers are paid a fixed price for a service which is either the national tariff or, where it is not covered by the national tariff, the price set by local commissioners. All providers in the area are paid the same price. Therefore, before AQP can be implemented, commissioners need to identify the price that should be paid for a specific AQP service in their area. The DH has published high level guidance for commissioners on setting prices for AQP services.

In order to be put on the AQP list, providers have to qualify and register to provide services via an assurance process that is designed to test their fitness to offer NHS funded services. The governing principle of qualification is that providers should qualify if they:

- are registered with CQC and licensed by Monitor where required, or meet equivalent assurance requirements;
- will meet the Terms and Conditions of the NHS Standard Contract which includes a requirement to have regard to the NHS Constitution, relevant guidance and law;
- accept NHS prices;
- can provide assurances that they are capable of delivering the agreed service requirements and comply with referral protocols; and
- reach agreement with local commissioners on supporting schedules to the standard contract including any local referral thresholds or patient protocols.

There are four stages of qualification to become an AQP:

- Stage 0 – commissioners determine which services are appropriate for AQP. The offer is made available on Supply2Health and prospective providers apply using the standard qualification questionnaire.
- Stage 1 – the compliance team checks the applying providers' organisation, regulation, IT, financial, commercial and legal details.
- Stage 2 – Qualification Centres of Excellence (QCEs) or local commissioners deal with any outstanding issues from the compliance check and undertake a service delivery assessment. This includes checking that appropriate integrated care pathways have been described and details of clinical governance leads, processes and reporting.
- Stage 3 – the local commissioning body undertakes final checks before declaring a provider qualified or not qualified. Successful applicants are listed in the National Directory of Qualified Providers.
- Stage 4 – Successful providers are offered a contract with a start date and begin to mobilise.

There are five QCEs that cover the eight priority service areas. They are designed to support local commissioners in assessing provider applications, including making sure commissioners and clinicians assess applications fairly and consistently, in line with best practice and regulations.

The DH feels that a cohesive strategy and coordinated package of ongoing activity is needed to deliver the scale of transformation that *"wheelchair users feel is required"*. According to the DH, the new commissioning architecture will be kept in mind when making decisions on next steps, as will recent recommendations to include specialised WPS services as part of Specialised Services commissioned by the NHS Commissioning Board. The AQP team no longer plays an active role in supporting choice and commissioning for wheelchairs, and has handed this work over to tariff and service improvement colleagues in the NHS Commissioning Board. A refreshed Wheelchair Services Implementation Pack is to be made available on the NHS Supply2Health website in due course.

The precise nature and extent of transformation that *users feel is required* was, however, not entirely clear. Indeed, in meetings with representatives of PMG the DH commented on the difficulty in obtaining 'consumer views' to inform WPS service reform – not least how to ascertain what 'choice' in a WPS service context means to service users, as introducing 'choice' is one of the principal issues informing the reform agenda. In the absence of up-to-date data, the DH could only refer to findings from previous consultations undertaken with WPS service users - such as that which formed part of *Moving Forward: Review of NHS Wheelchair and Seating Services in Scotland* (March 2006), and that undertaken by the charity Whizz-Kidz, the findings from which are set out in *My Wheelchair is My Shoes* (2011), a report presented to the All Party Parliamentary Group for Paediatric Wheelchair Reform in 2011.

In light of the dearth of information on consumer views in relation to WPS services, and the DH's plans to transform and modernise these services, PMG identified an urgent need to collect robust data about service users' views, particularly on the concept of choice. Given the DH's admission that it had been unsuccessful in its attempts to collect such data, PMG decided to commission its own investigation into this subject.

2. Investigation Design and Methodology

2.1 PMG Commission

The original invitation to submit a proposal for an investigation of ‘choice’ in service provision in WPS services is encapsulated in the following communication from PMG’s Chair of its Research Committee to the author in December 2013:

> *PMG’s Executive is keen that the piece of work is robust, and stands up to scrutiny. Ideally, the work will include views from a cross-section of age groups (as all have differing agendas and requirements). We are keen that the work captures the whole spectrum of ages, including children. It should include urban and rural dwellers, as well as ethnic spread. We would not specify numbers at this stage, but this is an area of your proposal where you should be explicit … Discussions have revealed that a Mixed Methods approach may be optimal. However, you should propose whatever approach you believe to be optimal; the Executive Group have asked only you to submit a proposal due to your particular experience … With regards to research ethics and governance, again this will be for you to put forward your plans. However, PMG members working in NHS services are clearly well-placed to help facilitate this aspect, if this is the route you choose. So, while the responsibility for undertaking the work would be yours, you can rely on PMG to provide contacts and other reasonable support.*

Based on the author’s experience of research with users of public services, including ‘hard-to-reach’ subjects (including vulnerable adults and looked-after children), she informed PMG that the scope of the proposed research as envisaged was not achievable within the timetable and budget outlined. The key issue was associated with ethical clearance. The author had sought further advice on this aspect of the proposed research from an experienced Chair of a NHS Local Research Ethics Committee [LREC] (who was also the Chair of the University of Portsmouth Ethics Committee, and trained new members of NHS RECs) and he had confirmed that recruitment of users as research participants through NHS-funded WPS services would require prior NHS REC approval. Furthermore, based purely on the geographical coverage desired by PMG, this approval would have to be sought from a Multi Research Ethics Committee [MREC]. Applications to MRECs involving multiple participant categories, are notoriously time-consuming to prepare (and costly if paying a research consultant to make the application), and can take several weeks before they are considered and approved by a MREC.

Another way in which WPS service users could have been recruited would be through non-NHS channels – for example, through local authorities, charities, voluntary organisations and/or by local advertising. However, in many instances ethical approval would still be required prior to fieldwork commencing - for example, recruitment via local authorities through social care registers would require the prior approval of the Association of Directors of Social Services. Not only can such methods of recruitment take a substantial amount of time, but they also offer no guarantee that the final sample of participants would be representative of the wider population of users (or adequately reflect the dimensions of the population considered important by PMG).

Taking into account the background to and aims of this exercise, and further discussions with the Chair of PMG's Research Committee, it was agreed that a proposal for a 'scoping exercise' should be prepared for consideration.

2.2 Why a Scoping Exercise?

A scoping exercise was proposed because it would not require prior NHS REC approval as its primary aim would be to:

i. identify the issues around 'choice' in NHS funded wheelchair and postural seating service provision, as perceived by WPS service users (who are referred to as 'consultants' rather than participants in such an exercise);

ii. identify whether user consultants perceived a need for more research and/or user consultation on 'choice' in WPS services; and if so

iii. identify the best ways, based on user consultants' advice, in which to consult with and gather the views of service users on 'choice' in WPS service provision on a wider (perhaps nationwide) scale.

Such an approach reflected and complied with the DH's agenda on PPI (Patient and Public Involvement) - defined as the active participation of citizens, users and carers and their representatives in the development of health care services and as partners in their own health care.

Thus a scoping exercise would allow 'user consultants' to be recruited via NHS-funded WPS services – in the first instance for focus groups arranged in four different areas of the country, and thereafter for a pilot survey. The main purpose of the focus groups would be to discuss and identify what 'choice' meant to service users, what they felt were the key issues in terms of choice in service provision, and the need for/how best to go about gathering users' views on a wider scale. So, for example, if consultant users at the focus group stage felt that wider consultation was needed, and agreed that one way in which this could be achieved might be through a short survey, then their assistance and advice on that survey's design and question wording would be sought. The production of a survey instrument, and administration of a small-scale pilot, could then form part of the scoping exercise (perhaps to include setting up a database and undertaking some simple analyses of the data collected). Most importantly, it was estimated that this investigation could be achieved both within the £15k budget and the relatively short timetable indicated, and that the findings from this scoping exercise could potentially demonstrate to the DH the need for a wider user consultation exercise (and how that could best be conducted).

The proposal for the scoping exercise was approved by PMG in January 2014 and the fieldwork commenced immediately.

2.3 Approved Design and Methodology

The original proposal for the scoping exercise comprised focus groups conducted with users in four WPS service areas of the country, specifically:

- Birmingham
- Bristol
- Buckinghamshire (Amersham)
- Hampshire (Winchester)

These services/areas were selected because of their location (including the mix of urban/rural areas they covered geographically, and the diversity of local population for whom they provided services), and because of links (direct and indirect) between PMG and the respective service managers. In three of the four areas there had been an indication of ‘agreement in principle’ to help facilitate the scoping exercise should it proceed. As a contingency, however, work to identify potential ‘reserves’ began in case one of the above areas was no longer able to assist in the exercise. It was noted that the Winchester service, which had agreed to be a case study area for the scoping exercise, was one of the few WPS services that had been contracted out to a private provider and its inclusion would allow some comparative analysis of users’ views with those of users of direct NHS providers.

In each area it was proposed to conduct two back-to-back focus groups: the first with N5 WPS user consultants aged 10 to 17 years old, accompanied by one or two parents/legal guardians (maximum total present per focus group = N15); the second with a maximum of N15 adult WPS user consultants. Where possible, a mix of adult user consultants would be invited to focus groups to reflect variations in the population by age, gender, economic status, and ethnicity – but it was noted that this would depend on the level and timeliness of responses to the invitation to participate in a local focus group.

The venue for the focus groups (if there were no suitable facilities within the chosen WPS services) would be centrally-located and fully-accessible; refreshments would be provided; and every consultant would be reimbursed (a minimum of) £20 for expenses associated with attending. In the author’s experience of other similar research undertakings, securing a central and/or convenient location, and advising potential attendees of the venue in advance, the amount they would be reimbursed for expenses, and that refreshments would be provided, enhanced recruitment and increased likelihood of participation.

The researcher was to be accompanied by an assistant who would help to meet and greet users; assist with refreshments and any other user needs; take notes during the focus group (allowing the researcher to concentrate on facilitating and guiding the discussion); and transcribe the digital audio recordings of the focus groups to facilitate subsequent analysis of data.

The agenda for the focus groups would focus on determining what ‘choice’ (in a WPS service context) meant to users and what types/forms of ‘choice’ were important to them. Consultants would also be asked the extent to which service users’ views should influence change to service provision, and whether they felt there should be a wider consultation exercise to inform the current reform agenda. The advice and guidance of consultants would be sought on what they considered were the most effective ways in which to consult service users more widely.

Transcription of the focus group tapes would facilitate analysis of the qualitative data generated, as well as inform the design and wording of a simple, short and user-friendly survey that would subsequently be piloted. It was hoped that this simple, short and user-friendly survey would be piloted with a sample of user consultants recruited and accessed through some of the WPS services across England. Based on a provisional assumption that WPS services would be able/willing to help facilitate the pilot, and recruit a handful of consultants, it was hoped to achieve circa 700 returns. The data collected could then be entered into a pre-prepared SPSS database and some basic analyses undertaken. Without pre-judging the views of user consultants at focus groups, it was anticipated that the pilot survey would comprise both closed, 'tick-box' type questions and at least one open-ended question about choice in service provision – and thus could generate some additional qualitative data, in addition to quantitative data.

Finally, it was proposed that the findings from both the focus groups and the pilot survey would be compiled into a full report for PMG. Digital files for the final report and the SPSS database would also be supplied to PMG on completion of the scoping exercise.

2.4 The Fieldwork – Phase I Focus Groups

The recruitment of user consultants for this exercise was through 'gatekeeper' WPS services. For data protection reasons, this entailed the WPS services first contacting service users from the information on their databases and, having spoken to the individuals, compiling a list of potential user consultants (both adults and parents of children) who had given their consent to their name and contact details to be passed to the author.

The four WPS service managers who had agreed in principle to facilitate the scoping exercise were contacted and asked to begin the process of recruitment of potential user consultants. To aid this process, the service managers were also sent:

- a copy of the full approved proposal for the scoping exercise;
- an adult 'flyer', together with an adapted version for children, which could be given/sent to users explaining why the scoping exercise had been commissioned and why their help was needed (Appendices A and B respectively); and
- a copy of the Information Sheet (Appendix C) that would be sent to those users who, after being contacted by the author, agreed to attend a focus group in their area.

After a number of weeks, however, recruitment of potential user consultants was underway in one case study area only (Winchester) and it became apparent that there were a number of issues in the remaining areas. One manager (Birmingham) had encountered an unusually hostile reaction from service staff to the scoping exercise - something she found rather perplexing, but hoped could be resolved. In the other two areas (Bristol and Buckinghamshire) the managers indicated that they still hoped to help facilitate the scoping exercise, but that recruitment had not commenced due to staffing shortages and/or operational reasons.

In the absence of any progress in the following weeks, and in discussion with the service managers concerned, it was agreed that these three services would formerly withdraw from the scoping exercise and that three alternative case study areas would need to be identified as soon as possible. Unfortunately, the proposed timetable had already been delayed by several weeks, and there was a subsequent delay while new case study areas were identified, the service managers' agreement secured, and the recruitment process started again. So, after nearly two months had elapsed, and it was expected that the focus groups would be well under way, the recruitment process was effectively starting again from scratch.

It was not until the end of March 2014 that three new case study areas were 'signed up'. With the assistance of PMG, approaches were made to the service managers of the Oxfordshire WPS service and Bowley Close Rehabilitation Centre in South London, both of whom eventually agreed to assist with the scoping exercise. Hillingdon in North London became the third new case study area after the author made contact with an elected member of Hillingdon Borough Council. As a former wheelchair user, and the former Chair of a Wheelchair Users Forum, he was keen to assist and secured the assistance of the Borough Council's Community Participation Team in the recruitment of potential user consultants.

Indeed, this Community Participation Team managed to recruit potential adult user consultants relatively quickly in comparison to the experience within WPS services. Due to the everyday pressures on service managers and members of staff with WPS services, recruitment had to be undertaken as an additional task to their clinical and other service duties. There were also problems encountered contacting users both by telephone and/or be email, and sometimes multiple attempts had to be made and messages left before contact was established. Then, after service staff had explained about the scoping exercise, many users declined to attend a focus group – although several indicated they would be prepared to submit comments electronically (via email). Reasons for declining to attend a focus group varied from disinterest through to ill-health and very real, practical difficulties reaching the focus group venue (regardless of reimbursement of the expenses involved). Thus, in each area it was some time before WPS service managers were in a position to supply a very modest list of adult wheelchair users who had given permission for their contact details to be passed on to the author. Furthermore, despite valiant efforts, case study services were unsuccessful in their attempts to recruit child users aged 10-17 years old – although, in June 2014, the Winchester WPS service did manage to recruit three child user consultants (two of whom attended an informal focus group, one of whom submitted comments via email).

It was only when case study services passed on users' contact details that the author was able to establish direct contact with these individuals (encountering difficulties similar to those experienced by WPS service staff) to explain more about the scoping exercise, provide an Information Sheet, and liaise with them on possible dates, times and venues for focus groups. Even at this stage, a small number of these users declined to attend a focus group due to current health problems and/or upcoming hospital admissions, while others - after further consideration - also decided they would prefer to submit comments via email.

Regular contact was maintained with the users who agreed to attend a focus group or to submit comments electronically, and they were provided with detailed information (including confirmation of focus group arrangements) via telephone, post and email. It was also agreed with some users that special transport to and from focus group venues would be arranged and paid for on their behalf, and for several other users the 'Thank You' payment was increased to better reflect the actual travel expenses they would incur in attending a focus group. Despite this, some users withdrew from their focus group on the day of the meeting, or simply did not attend. Indeed, in one focus group area - Bowley Close Rehabilitation Centre – not one of the six confirmed attendees turned up, even though they had received confirmation by email and telephone reminders from both service staff and the author. Furthermore, only a limited number of the service users who indicated that they would submit their views and comments electronically, had actually done so by the end of July 2014 – again despite several friendly reminders and two extensions of submission deadlines. Table 1 below summarises user participation in and timing of focus groups for Phase I of the scoping exercise.

Table 1: Participation User Consultants (UCs) in Scoping Exercise Phase I	UCs Consenting to personal details being provided to researcher	UCs Agreeing in principle to Attend Focus Group	UCs Attending Focus Group/s (+ Carers Present)	UCs Agreeing in principle to Submit Views Electronically	UCs Submitting Views Electronically
Case Study Area 1 (W) *Adult Focus Group* *27 March 2014* *Child Focus Group* *23 June 2014*	12 8	9 3	8 (2) 2 (2)	7 3	6 x Adult UCs 1 x Child UC
Case Study Area 2 (H) *Adult Focus Group* *16 April 2014*	12	10	10 (2)	0	0
Case Study Area 3 (Ox) *Adult Focus Group* *27 May 2014*	8	5	3 (1)	3	0
Case Study Area 4 (BC) *Adult Focus Group* *18 June 2014*	10	6	0	4	2
All Case Study Areas	**50**	**33**	23*(7) *21 Adults 2 Children	**17**	9** ** 8 Adults 1 Child

The difficulties experienced in recruiting service users for Phase I are discussed later in this report, but at this stage it is sufficient to say that their combined impact resulted in:

(i) fewer numbers of adult user consultants than anticipated, and only three child user consultants across the four case study areas;
(ii) focus groups not being completed until June 2014, far later in the Phase I timetable than originally envisaged;
(iii) increased research resources and costs incurred in the recruitment phase than forecast – further explained later in the report.

Despite the early setbacks and recruitment problems, however, a good geographical spread was still achieved in Phase I with user consultants from areas ranging from the very rural and suburban, to large cities (including a densely-populated north London Borough). Furthermore, the final sample of user consultants included a range of ages, ethnicities, and clinical conditions that had rendered individuals reliant on a wheelchair. Phase I included several young adult users in their early to mid-twenties, some in their thirties and forties, and several over 50 years right up to the eldest user consultant who was 83 years of age. Also, the sample included user consultants from Asian, Afro-Caribbean and White British ethnic backgrounds, and while some users had only been reliant on their wheelchair for a few years following diagnosis of conditions such as Multiple Sclerosis, others had been disabled and wheelchair users since birth.

One case study WPS service was provided by a private company under contract to the NHS, although no differences emerged in the views expressed by service users in this area and those by users in areas where services were delivered by NHS institutions.

Three focus groups were held on WPS service premises, one on local authority premises. At focus groups user consultants were welcomed by the researcher and her assistant, provided with refreshments, and meetings started with introductions and informal discussions. The focus group discussion guided by a schedule was, with user consultants' prior permission, tape-recorded and the research assistant made notes. Participants were then thanked for their assistance and given their 'Thank You' payments. The audio tapes were subsequently transcribed for analysis.

The key themes and issues identified within Phase I are set out in Sections 3 and 4 on Findings from adult and child user consultants respectively.

2.5 The Fieldwork – Phase II Pilot User Survey

As originally proposed analysis of the qualitative data collected within focus group discussions was used to inform the design of a simple, user-friendly survey instrument (Appendix D). The difficulties encountered in Phase I (and the associated delays incurred), however, prompted a realisation that the anticipated number of returns outlined in the original proposal was overly-optimistic, and that a review and amendments to the methodology proposed to 'pilot' this research instrument was required. It was felt that the proposal to approach WPS services in England and ask them to secure around 10 returns each would not produce the response desired, and furthermore would only result in further delays to finalising the commission. Experience gained from Phase I suggested that some services would simply not be willing or in a position to assist in this way, and those that were prepared to help would be obliged to adhere to all ethical requirements in the recruitment of user respondents, including explaining the reasons for this work being undertaken and providing an Information Sheet prior to users completing the pilot survey.

Instead, the user consultants who had taken part in Phase I (by attending a focus group or agreeing to submit comments electronically) had also indicated that they would be happy to help pilot the user survey. As these individuals had already been provided with the Information Sheet for the exercise and had consented to participate, this was felt to be the most expedient method to pilot the survey instrument.

Unfortunately, the response was even more disappointing than that encountered in the recruitment process for Phase I. Of the 50 user consultants to whom the pilot survey was sent, only seven had provided a return and feedback by the time of writing this report (August 2014). Four of the pilot respondents had taken part in focus groups, while the remaining three respondents were users who had indicated that they would submit comments electronically but had not done so – but then did respond to the author's further request to help pilot the survey. Given the poor response, analysis of the quantitative data provided was not deemed appropriate but the feedback on the 'user-friendliness' of the pilot survey, together with some additional comments on 'choice' in NHS WPS service provision, is summarised in Findings Section 5.

Without delaying any discussions with the Department of Health on the key findings, it is suggested that PMG may wish to consider seeking the help of its members to undertake a full pilot. Members could be asked to approach users with whom they have contact to see if they would be willing to complete the survey and provide feedback. A SPSS database for the survey instrument has been provided to PMG that would facilitate analysis of any quantitative data (and qualitative data from open-ended questions) collected as part of any extended pilot, and could lead to the inclusion of additional questions, and/or amendments to existing questions within the questionnaire. Should PMG require assistance with the analysis of any additional data collected, the author would be willing to discuss an extension to this commission.

2.6 Ethical Considerations

While this scoping exercise did not require prior NHS Research Ethics Committee approval, it still adhered to good research ethical practice and guidelines. Thus, ethical considerations were taken into account in the planning, design and undertaking of both the focus groups and the pilot survey.

2.6.1 Information Sheets

Although not a formal research undertaking, an information sheet was prepared for WPS services and the author to send to potential user consultants as part of the recruitment process. As can be seen from Appendix C, the Information Sheet included details on:

- the title of the scoping exercise;
- the reason why the exercise was being undertaken;
- who was undertaking the research;
- who was funding the research;
- the timetable for the research;
- why the recipient was being invited to participate & why their participation was important;
- how the data collected would be handled;
- guarantees of confidentiality and anonymity;
- importance of voluntary participation and being based on 'informed consent';
- user consultants' right to withdraw at any stage without explanation;
- Admiralty Consulting Limited's public liability insurance and indemnity against negligence;
- possible advantages and disadvantages of being a user consultant (for example, the findings may help to improve services for wheelchair users and that a disadvantage may be the time it will take them to attend a focus group and/or complete the pilot survey);
- contact details for the author (as main researcher) so that they could get in touch should they have any queries about the scoping exercise or the completion of the survey;
- how to return their pilot survey once completed

2.6.2 Involvement of child wheelchair users

Recruitment of user consultants aged 10-17 years of age had to be negotiated through their parents/legal guardians, who needed to provide formal consent to their child's participation in the scoping exercise. In addition to the main Information Sheet, a simple information sheet or flyer was produced that explained the scoping exercise in language that children would be able to understand, and although parents/legal guardians needed to be in attendance at the focus group or interview with their child, the researcher ensured that the child consultants were given every opportunity to express their views, in their own words.

Unfortunately, despite having clear information in advance of the profile of potential child user consultants, some of the gatekeepers included the names and contact details of parents of children who used wheelchairs who were under 10 years of age. When this became apparent to the author, she thanked parents for their interest but explained that because their child was too young to understand what the exercise was all about and what it involved, for ethical reasons they could not participate.

Through an Occupational Therapist in one WPS service, contact was also made with a number of child wheelchair users all of whom were pupils at a mainstream school within one of the case study areas. Unfortunately the school's welfare officer was reluctant to host a focus group on school premises after the school day had ended, which would have been more convenient for the potential user consultants and their parents/guardians. None of the pupils concerned were willing or able to attend a focus group at an alternative venue, although one young man did agree to submit views electronically. Neither of the two child user consultants who did meet with the author to discuss 'choice' in their WPS services attended the school mentioned above, although one mentioned that she had attended the school and had left because the support she had received had been sadly lacking. This young teenage girl had moved to another mainstream school that had been 'brilliant' in terms of accommodating her needs and making her feel part of the school community.

3. The Findings Phase I – Adult Focus Groups

3.1 Choice? What Choice?

> *We should* ***not*** *just be told this is the wheelchair you can have, that there's no alternative. They give me a new wheelchair every few years, but I don't actually have any choice what it will be. It may be that I need a more robust chair, but I don't get that choice ... I get referred up here just to have a look at how much I've bashed up my old wheelchair, and if I've bashed it up enough I'm offered a new one. But there's no choice.* AFG1

The most important form of 'choice' for users was *real* choice in the wheelchair equipment from which they could select and, in that respect, they felt they had little or no choice at present. Across all case study areas, following assessment the vast majority of users had not received any information from their service about the wheelchairs, adaptations and/or equipment available - neither from the NHS nor from private manufacturers - that would meet their needs.

Instead, they were simply told what chair or piece of equipment with which they would be provided. This was an area in which users felt 'choice' could be easily improved – specifically, information on the options on the market. Even if they personally could not afford, or the NHS could not provide some models/types of equipment, they still would appreciate the information. Indeed, poor communication between WPS services/contractors and users on equipment options is a recurrent theme.

> *I never received any information, on the website, at the assessor's meeting. Choice implies informed choice about anything. You can only make a choice if you know you can choose between a number of options and know why one is better for you. Informed decision implies there is information available about my disabilities and what the service may or may not be able to offer you. You need to know what technology today, if anything, may be able to help you with. You don't want to spend all your day researching.* AFG3

Users felt that the policy rhetoric of 'choice' within the NHS was, in reality, a 'cover' for saving money and cost-cutting. Users mentioned the on-going tightening of eligibility criteria; WPS services offering only basic, bulk-buy models, and often not providing spare wheelchairs as routine (and where they were provided they were often totally unsuitable for the user's needs); and, for those aware of the Voucher Scheme, it was perceived to be a mechanism for the NHS to cover only part of the cost of a superior or better quality chair and to transfer the burden of responsibility for all or part of the on-going costs of repairs and maintenance to users.

> *Choice to me is cost-cutting. Immediately I think [the government] are going to look at how they can make it less expensive. They up their criteria for people that are eligible for electric wheelchairs and are going to offer only a basic model that doesn't necessarily meet their needs ... They go with the bulk order prices, so it's cheaper and can provide wheelchairs en masse rather than on users' specific needs.* AFG2

Generally, users questioned why the increased diversity of wheelchairs and seating available today was NOT reflected in the choice of equipment on offer to NHS wheelchair users – who continued to be offered a limited and often inferior range of chairs/equipment.

3.2 Medical v Social Model

> *Wheelchair services are using a clinical/medical model to prescribe us a chair. But things have moved on. We need the social model of disability to give us the enhanced things in life to go with that chair. We were winning that battle, but because of the cuts that have been made [in public services], they reverted back to the cheaper, clinical/medical model.* AFG2

For some, current WPS services were being operated on a clinical rather than social model of disability – in other words they were only meeting basic clinical needs with no consideration of what users really needed from their wheelchairs in order to participate in normal social activities, and as equal members of their local communities. As one user put it 'Wheelchairs need to work for users' lives and lifestyles'.

> *Eligibility criteria has long been the NHS's way of gatekeeping, of restricting access to the services to make the budget go round, but nowhere does it mention the social model of disability. When people get a wheelchair, they want to be able to know they can take it to enhance their lives, as opposed to further restrict where they go. For example, you want a wheelchair that fits into your car, into all the homes you go in, and you get the right adaptations for your needs.* AFG2

3.3 Choice that really matters …. Fit-for-Purpose Chairs

There was universal agreement among user consultants that any wheelchair provided by the NHS (or through a provider service commissioned by the NHS) should be 'fit-for-purpose'. That is, it should be:

- suitable for a user's needs (often complex and multi-faceted);
- of a quality that could cope with the demands placed on it and withstand every day wear and tear; and,
- of a design and/or adapted to meet users' medical, physical **AND** social needs.

> *Your wheelchair needs to work around you and not the other way round …* AFG2

Users felt that unsuitable wheelchairs failed to prevent, and in some cases even caused, further disability through deterioration in musculoskeletal conditions and/or other health problems. Personal examples cited included inferior quality wheelchair seating causing pressure sores; non-provision of leg supports causing oedema; and, unsuitable back/side support in chairs and the wrong size chair causing and aggravating physical problems – all of which often necessitated additional health and/or social care services or even lengthy stays in hospital. Socially, difficulties in transporting chairs in anything other than a specially adapted vehicle meant that some users were severely limited or confined to their home environment. Often this was associated with financial considerations, for example, in one case study area the author arranged special transport for three elderly users of motorised wheelchairs who lived within a three-mile radius of the focus group venue, with each return journey costing £60.

> *The reason I've been waiting 9 months for [a new chair] is because they told me what the replacement for this chair was. Therefore I assumed that the replacement would do what the original does. So I did have one delivered, but it wouldn't go into my car, wouldn't go up my ramp, it wouldn't fit into my bathroom, it wouldn't fit under my basin, and it wouldn't go under my dining table ... It's not just referral for it, it's adequate assessment. If they don't assess you right, in the situation where it's going to be used, with the people it's going to be used by ...you get in a wheelchair that can't be handled by a carer or a wife, so what use is it?* AFG3

Several young adult users highlighted the increased usage of chairs by themselves and their peers for participation in sporting and leisure activities, and the importance of 'image' for these young people – they did not want the same chairs designed for and used mainly by older people. In any event, the majority of chairs they were offered were simply not suitable for their 'everyday' needs. For example, one young adult female related how she had outgrown her child-sized wheelchair but was still too slight in build for an adult-sized chair – but her NHS WPS service did not offer an intermediate chair. Consequently, she was given a chair too big for her frame which had caused her a number of physical problems, and eventually forced her to self-fund her current intermediate-sized wheelchair. The on-going costs of repair and maintenance for this self-funded wheelchair were, however, a financial burden she could ill afford.

3.4 Choice that really matters … Repairs and Maintenance

Indeed repairs and maintenance was an area of service provision perceived to impact greatly on user 'choice'. When users experienced a breakdown or mechanical problem with their chair, there were often unacceptably long waits for the necessary repairs to be undertaken. There was no equivalent of an emergency 'road-side service' for users when their chairs failed when they were out and about. Several users described personal experiences of chairs breaking down while they were away from home and being left totally stranded, as their local WPS repair service had informed them it was not allowed to attend them at the roadside, only at home. Even then, the length of wait for repairs to be undertaken and/or replacement chairs provided, left some users housebound and reliant on carers (if they had them) for their everyday needs.

> *I got out of a taxi and the whole wheel came off, so luckily enough I had my husband with me so we tried to put it back on without any pieces or tools. I took it into the services and they told me I need a new one. This is only a year old, but all things have fallen off it already – the side, the leg bits, the posture of the legs, one keeps going up and down, the back keeps coming undone. It's basically no good ... they'd rather give me a brand new one, than mend the sides of it or get a new part, because of the cost [of replacement parts]. They'd rather reassess me and give me a brand new chair which I've got to wait a long time for. In the meantime, I've got to sit in this one, while it's falling apart.*
> AFG3

> *Although we all have manual wheelchairs to back-up, wheelchair services need to understand that when we are in our manual wheelchairs, we cannot move. We don't all have 24 hour care. I have to be mobile to get out.* AFG1

In this respect, 'spare' manual wheelchair for users who normally relied on motorised wheelchairs was perceived as simply unacceptable – many users were physically unable to self-propel a manual chair and, consequently, were deprived of their mobility and independence (at worse, if carers could not be organised, users were put at serious risk of harm).

My wheelchair frame broke and they had to give me a replacement. But the replacement was not at all suited to my needs. I'm 6ft, I've got long legs, I need a high back. The wheelchair I was in for about 4 weeks was terrible. I was in a lot more pain. I then found the footplate broken, which stopped me going out on my own. It was over a week before they came out. They came round, looked at the foot plate and took it away, leaving me without a foot plate for another 2 weeks. AFG2

In one case study area, the repairs and maintenance contractor could only be contacted via a 0845 number, while others users reported their service had an answerphone only emergency repair reporting process – neither of which was perceived as acceptable. It was important that users with a problem with their wheelchair could speak to someone to explain the precise nature of the fault, and their personal circumstances, while their chair was out of commission.

While NHS wheelchair repair contracts stipulated that repairs must be carried out within three working days, in the absence of any monitoring, users reported that most failed to meet this obligation. There was general agreement that repair services needed to carry higher levels of better quality spare parts for wheelchairs, and also needed to liaise more closely with OTs and WPS service staff to verify the precise parts needed for a repair (with reference being made to a user's clinical records). Moreover, user consultants felt there was currently a high level of waste due to contractors using inferior spares, and frequent ordering of incorrect parts for chairs. Many users were left stranded for want of a correct inner tube for their tyres, or the correct stabilisers for their model of wheelchair.

3.5 The Voucher Scheme and AQP

Levels of awareness of the Voucher Scheme (VS) across all focus groups was generally low - some users had never heard of this scheme, nor been provided with any information on what it was or how it worked. This may suggest possible communication problems and/or resistance among service staff to the VS at the individual service level. Even in the case study area in which most users were aware of the VS (a small city in a shire county), and among the small handful of users who had actually used a voucher to purchase their wheelchair, it was apparent that there was some confusion about the implications of doing so – not least in relation to responsibility for on-going repairs and maintenance of a chair wholly or part-purchased with a voucher.

As a voucher scheme user from my first wheelchair, the surprise was that … you go back to wheelchair services for something … like changing an inner tube …But once you have the voucher … it doesn't then give you any support even if you knew what support you needed … i.e. physically changing that wheel once you've got the materials … [something] I was incapable of doing. AFG2

If you go to another provider, they're going to show you the top of the range, because they're in the business of making a profit, which is probably more near to what you want as a wheelchair user, but the voucher won't cover the cost at all. AFG2

Users agreed that the VS did not provide increased 'choice' to everyone … only better-off users who could afford to supplement the value of the voucher and/or accept financial responsibility for the future repair, maintenance and adaptation of their wheelchair. Furthermore, some experienced users felt their new and novice wheelchair peers lacked the knowledge and awareness of many aspects of wheelchair design to make the most of the VS and often initially chose unsuitable chairs and equipment.

Indeed, the user consultants who had chosen to privately pay for a new wheelchair, specialist equipment or adaptations to their chair (often due to the ‘excessively’ long waits for and/or inferior quality of equipment being offered to them by their NHS service), conceded that not all users would be in a financial position to be able to exercise ‘choice’ in this way. There were very real financial implications for wheelchair users of taking on board additional responsibility for the upkeep of their chairs. Users pointed out that many users were dependent on welfare services, but faced additional costs in comparison to their able-bodied counterparts also dependent on welfare benefits and assistance. Recent reforms to the welfare system were, in this respect, perceived as only placing wheelchair users (and other disabled individuals) at further disadvantage.

> *It's very simple, patients should be provided with the wheelchair that suits their needs and is the wheelchair of their "choice". They shouldn't be made to fund 50% of it.* EMAFG1

> *But the big problem … with the AQP route, we’re further compounded by the fact there’s a lot of cowboy institutions out there selling wheelchairs who don’t have a faintest idea about giving a good service to disabled people. They just want to sell chairs at whatever cost. The more profit they can make out of it, the better.* AFG2

Only a very few users were aware of AQP within the NHS and they were concerned about its extension to wheelchair services. Specifically, they questioned which contractors would qualify as approved providers; what standards they would need to meet (and how this would be monitored); how eligibility criteria would be set; and, who would decide on what range of wheelchairs would be available and to whom. Some users had concerns of ‘cowboys getting in on the act’.

3.6 Constraints on NHS Wheelchair and Postural Seating Services

The vast majority of user consultants were not critical of WPS service staff, who they perceived to be working under great pressure and centrally-imposed constraints that combined to make their work very difficult at times. Users were well aware of the financial pressures placed on wheelchair services from above – one user described wheelchair services as ‘command rather than demand-led services’.

> *Choice with a wheelchair should not be governed purely by cost. And that is probably the single greatest thing that gets in the way of choice.* AFG1

> *It seems to be a command service from the top down, but it ought to be a demand service. There seems to be a degree of embarrassment when you approach the people here [at the wheelchair service]. When you actually suggest or ask for something, you are supposed to be examined, and they then decide what needs doing. It should be changed round so that we’re able to be more demanding. There are profound problems, like my house is being destroyed by my wheelchair because it lurches all over the place and all the doorways and doors are wrecked.* AFG1

Indeed, there was a great deal of sympathy for service staff members who were constantly constrained by limited budgets and the NHS ‘stock’ of equipment from which they could ‘prescribe’. One user referred to staff being embarrassed when asked about an upgrade or an adaptation to a chair because, while they may agree it was needed, they seldom had the ability to grant such requests.

Wheelchairs are replacing legs, they're not a fashion accessory. Wheelchair users have enough to contend with. The very least we can do as a rich society is enable each wheelchair user to have enough funds to cover the cost of replacing their wheelchair, however much this might be. [Name of son] is now left with a £1500 bill as the chair offered to him was too heavy and unsuitable for his needs. The wheelchair service basically said, "tough", if you want something better, lighter than the wheelchair you've used for the last 10 years, it's too expensive". That is not "choice". EMAFG1

Users indicated that what was perceived by the Department of Health as 'extras' were to them, in fact, essentials. One user suggested wheelchair services had always been under-funded and continued to be the 'Cinderella services in the NHS'. Despite the constraints placed upon WPS services, some users outlined instances of where service staff had gone 'that extra mile' in order to help meet their wheelchair needs – as illustrated in the case study set out in Box 2 below.

Box 2: Case Study of Good Experience of WPS Service in User's Own Words

Wheelchair Services are a vital part of healthcare. The right wheelchair, in essence, means a better quality of life for the service user … I had been in a Harrier Plus standard wheelchair for many years. The WPS Service came to re-assess my needs because the chair no longer fitted me. Being in a wheelchair full time means that I need one to "live" in essentially.
My carer was also having to constantly reposition my feet on the footplates which was tiring for her. We showed the Wheelchair OT and the wheelchair engineer my shower chair as a guideline. This is what is known as a tilt in space chair meaning the back can recline. My criteria for a new chair were: good back support; long levels of comfort; and, no repositioning of feet constantly.

The wheelchair service came up with the Quantum 600 XL. What a difference it has made! I can spend the day in comfort as the chair has a large back support. I can make eye contact. People no longer have to look down at me during conversations. My feet do not require endless repositioning. My head is also supported by a headrest now. The only con is that I am limited in the taxis I can use due to the increased height of the seat. But the pros far outweigh the cons, I can assure you.

Wheelchair Services has been for too long a Cinderella service. [Wheelchairs] are not luxury items, but instead essential for independence and a fulfilled, fully active life. EMAFG1

3.7 False Economies

User consultants felt that following the recent economic recession and associated reductions in public service spending - including to NHS budgets - funding for wheelchair services would continue to be squeezed for the foreseeable future. This was perceived by users to be a very short-sighted policy approach, and very 'cost-ineffective'.

If [the government] doesn't spend the right amount of money on it, people will be getting further disabled, with more money spent on their care and welfare ... the thing to remember is that all wheelchairs from NHS wheelchair services, are as much a prescribed item as antibiotics from a doctor. They'd never turn round and say you can't have antibiotics because of the budget. It's a case of priorities, which is why we need to get wheelchair services funded properly.
AGF2

Having the wrong cushion or the wrong part can do quite bad physical damage to you – damage to your back and hips, bring pressure sore on, whatever. And you could be bed-bound for months and it'll cost more to the NHS if you get admitted. AFG1

User consultants emphasized the urgent requirement for a more holistic approach by central government to meeting their needs – mobility, health, social care and economic needs. Politicians and policy-makers needed to recognise that continued under-funding of wheelchair provision was only leading to increased expenditure on other health and social care for users, and increasing wheelchair users' dependence of welfare benefits.

One user pointed out that the costs of prescription medicines and healthcare treatments for a wheelchair user could quickly exceed those associated with the provision, from the outset, of a ‘fit-for-purpose’ higher specification wheelchair with appropriate adaptations that met a user’s clinical and social needs. One young adult female user related how she had been forced to give up her part-time job because the NHS would not fund an adaptation to her wheelchair. As a consequence, Occupational Health in her workplace could no longer support her continued employment. The consequent reduction in her income had also meant she had been forced to suspend her part-time studies because she could no longer afford the public transport to and from her HE college.

I am someone who can walk around a flat that’s the size of this room, [but who is] not able to self-propel outside, [but] I do not qualify for an electric wheelchair outdoors, when it would allow me to go to work and college and radically reduce the NHS care costs, because I’d be able to contribute something back. I think the qualifying criteria actually discriminates against disabled people. AFG2

3.8 Improving Choice

In terms of the key ways in which user consultants perceived choice in service provision could be improved, there was again universal agreement that the government (through the NHS and WPS services) needed to adopt a more holistic approach to meeting wheelchair users’ needs: medical, physical and social. Rather than individual government departments, and divisions within those departments, operating in silos, looking only at reducing and guarding their individual budgets, there needed to be a much more joined-up approach to meeting users’ needs and recognition, at the highest levels, that savings made in one service area often only led to increased costs in another area … but, after all, it was all public money.

Choice implies informed choice (about anything). You can only make a choice if you know you can choose between a number of options and know why one is better for you. Informed decisions implies there is information available about my disabilities and what the service may or may not be able to offer you.. AF3

Users identified communication between WPS services and the users they assessed as a key area for attention; specifically the need for the provision of better information on equipment, adaptations, spare parts and the VS. This was perceived as a basic step that could go a long way to improving ‘choice’ for service users.

Making the assessment of need independent from the procurement process and provision of equipment; greater investment to improve the quality of the stock of wheelchairs and equipment held and offered by the NHS; and, significant improvements to current arrangements for the repair and maintenance of wheelchairs, were also perceived as pre-requisites to improving ‘choice’.

If professional assessment [of needs] was separate from procurement it would go a long way to increase individual choice. Supposing someone came, a professional team would look at a patient’s conditions and say your condition offers these opportunities. And that session is finished at that stage – they’re not giving you a wheelchair, they’re just explaining your choices. The assessment part is separated from the procurement part, because in the procurement part, you get voucher, additional money, all the rest of it. In this way users may get a better choice. AFG3

On procurement, users felt that the government, through the Department of Health as the major purchaser of equipment, could bring far more pressure to bear on wheelchair manufacturers. Investment in a greater variety and better quality equipment would in the long term be far more cost-effective in terms of public expenditure, as well as having the benefit of improving users' quality of life.

> *I would like to suggest [the introduction of] a preventative maintenance programme for all chairs which, if properly carried out, would actually save money as any breakdowns invariably incur at least 3 call outs due to wrong parts etc. No one would run a car till it breaks and then expect to get it going again.* EMAFG1

The inefficiency and ineffectiveness of current wheelchair repairs and maintenance – by in-house WPS services and private firms under contract to the NHS – needed urgent attention in users' opinion. When wheelchairs failed and were not repaired in a timely manner, and/or a suitable replacement chair was not provided, service users were often left without even the most basic 'choice' of whether or not to be mobile.

3.9 Users' Perspectives on Wider Consultation

In terms of further consultation, users were unanimous that this should be conducted on a wider scale, and suggested that a mixed methods approach should be adopted to give users a choice in terms of:

- attending a focus group - while many users, even when fully recompensed for the expenses involved, may be unable or reluctant to attend such meetings, users felt 'piggy-backing' on existing support and social groups in local areas could be one method in which more face-to-face consultation with users could be achieved;
- a face-to-face, telephone, or Skype interview (the latter was perceived by the young adults and child users who participated in this exercise as the preferred way in which to consult with their peers); and,
- completing a user-friendly questionnaire (postal, with the help of a researcher, or electronically via email or online).

To maximise response rates, users urged that any survey should carry the official Department of Health and NHS logos and be distributed by WPS services, otherwise there was a danger that users would simply not respond. While many users would prefer to complete an electronic version of the survey, it was recognised that others would still prefer face-to-face administration of the survey by a researcher.

User consultants also considered the inclusion of paid and family carers in any wider consultation exercise important, as they had first-hand knowledge of the everyday needs of and problems faced by the wheelchair users for whom they cared. Indeed, some users suggested carers were in many respects 'users' of wheelchairs themselves, as they had to push, manoeuvre and transport them and had to help deal with many of the issues that could arise from unsuitable and faulty features of wheelchairs. Users, however, considered that any wider consultation on behalf of the Department of Health should be undertaken by independent researchers to ensure that the results were not biased or skewed to reflect any official policy preferences, or external constraints placed on service provision by central government.

The focus group discussions on the best ways in which to consult more widely with users prompted some interesting debates about the extent to which users should be involved in running services and in policy-making. Some users were strongly of the view that they should be part of running local services – as part of the assessment process, procurement, and in setting local priorities. With no disrespect to the hard-working staff who worked within wheelchair services, they pointed out that very few were disabled themselves and, therefore, could not fully appreciate everyday life in a wheelchair. Nationally, they felt that users needed to be at the heart of policy-making, perhaps through User Panels, advising politicians and civil servants, and should be more involved in the actual design, manufacture and trials of wheelchairs. However, involvement had to be constructive and meaningful, and users needed good quality training prior to taking on any advisory or participatory role.

> *In theory [user involvement and consultation] would work. There are 2,500 people in [name of shire county] that use a wheelchair, supplied by wheelchair services. A very small proportion actually care a lot about their wheelchair. Getting from that small number, a group that would be sufficiently representative to make sense is hard ... because getting one person with a view on wheelchairs in a room is not a fair representation. But you've got to have people who are capable of representing others and are capable of analyzing situations and are capable of expressing what is needed. And finding those people ... I've been trying to do that for 50 years. Getting disabled people to present a united front, come to a common view on a common goal, is very difficult.* AFG3

Not everyone, however, agreed with this view. Some of the more seasoned users - who between them had a wealth of experience in setting-up and running local user groups, and/or representing users on local authority panels and other disability organisation committees - referred to the difficulties inherent in the recruitment of wheelchair users. Not least they referred to problems ensuring that those users able/willing to sit on local or national bodies were actually representative of users more generally. For example, some users faced very real financial and practical difficulties (transport, health issues and so on) when it came to consultation forums and events, meaning their ability to participate was limited - something perceived to be a nationwide rather than a localised problem.

These experienced and long-term wheelchair users across the case study areas also indicated that the only way in which change in wheelchair service provision could be achieved nationally was for wheelchair users locally to be more vocal and more demanding. In their experience, users only really got involved or made a fuss when they wanted something for themselves and few were willing to put in the time and effort to help influence and shape local and national services. This view was echoed by members of staff at the case study service where no users actually turned up for the focus group.

> *Whilst the change may well take place nationally, and indeed has to, pressure locally is the only place where you're going to get real pressure on wheelchair use ... because wheelchair users, on the whole, aren't broad in their thinking. If you want the real day-to-day wheelchair user, who doesn't care about the system, or being involved in meetings or events ... if you're going to get their input, it's very difficult and can only be done locally.* AFG3

4. The Findings Phase I –Young Users' Focus Group

4.1 Problems Recruiting Young User Consultants

The difficulty in recruiting young (child) users for this exercise was explained, in part, by the two young people who did agree to be interviewed. Basically, they did not want, or like, being identified as disabled or labelled as a wheelchair user. One 16 year-old female said she simply did not like talking about it – and she suspected others may feel the same way.

Some parents of potential child user consultants had experienced frustrations and difficulties securing suitable chairs and/or equipment for their children and, as a result, had decided that they did not want their children to help with the scoping exercise after all. Other parents indicated that they were simply too busy to be able to transport their child to a focus group and, while three indicated instead their child would submit comments via email, only one had responded by both the end of June deadline and the extended deadline of end of July.

4.2 'Choice' in Service Provision

The views of the two children who were willing to attend a focus group are best expressed in the following short case studies based on the researcher's notes of the discussions that took place, together with some direct quotes. Box 3 summarises the views of a 16 year-old female, and Box 4 an 11 year-old male – unfortunately, the latter user spoke very quietly during the discussion and, despite the use of additional background noise-reduction software, his voice was barely audible on the tape and it was not possible to include direct quotes. Due to one child and parent arriving earlier than anticipated (and needing to depart early), and the other child and parent arriving a little late, the discussions with these two children (with respective parents in attendance) actually took place separately.

The views of the only child user consultant (a 16 year-old male) who submitted views via email are set out in full in Box 5.

From these three summaries it can be seen that in many respects the issues raised by these child user consultants reflected, to a great extent, those expressed by the young adults who participated in the adult focus groups, namely:

- more regular review and assessment for changing needs;
- better information on wheelchairs/equipment available through the NHS and other providers that met their particular needs;
- provision of wheelchairs 'fit-for-purpose';
- provision of suitable 'spare' wheelchairs;
- improved repairs and maintenance procedures for main wheelchair;
- greater opportunities to view and 'test drive' wheelchairs and equipment before making a decision on which make/model to accept or purchase;
- increased choice of wheelchair designs geared towards younger people.

Box 3: Young Female Wheelchair User (16 years-old)

AG is a very intelligent, but rather shy and quiet 16 year-old. Initially her mother tended to answer questions on her behalf, but with perseverance I managed to engage directly with AG and she began to be more open in her responses. She had been in her current motorised wheelchair for about 3 years. She had been allocated the chair after her previous chair had developed battery problems. Thinking she was attending the WPS service that day to be fitted for new seating, the OT had brought in her current chair for her to try. Given that it was far superior to her old chair, she was thrilled to accept it as a replacement - but in answer to my question she confirmed that at no stage was she given any choice of chair, nor given any information about other similar models available. Her current chair had proved relatively reliable but AG mentioned that it was meant to tilt but, due to a fault that had not/could not be corrected, this function had never worked. AG did not, however, see this as a huge issue as she felt it made her use her own muscles and prevented her from becoming reliant on the tilt function.

When asked about the Voucher Scheme neither AG nor her mother knew what this was, nor had they received any information about it or how it worked. AG's mother intimated that, even if they had known about the Voucher Scheme, they were not in a financial position to top-up its value to buy a wheelchair.

AG no longer attended (name of previous state secondary school), having decided to leave at the end of Year 7. She related how her previous school had not been helpful or understanding about her needs – *"At lunch, they made me sit away from my friends at a table with all the other wheelchair users because it was the only table high enough. When I was given a detention ... the classroom I had to get to was all the way over from the lift. At the time I was in my manual wheelchair as my electric one was acting up. I got there at the end of lunch and got an after-school detention".* AG indicated that she should also have been provided with LSA support by this school, but it had never been put into place. AG's current school, by contrast, had been brilliant and AG explained that, because there was only one elevator to the classrooms on the first floor, and this was at the far end of the building, the school has timetabled all her classes in ground floor rooms. No issues had ever been raised by her current school about her chair and, on the odd occasion when she was in her manual wheelchair (which she could propel herself, but only with difficulty and for short periods), the school always made sure she was pushed by a member of teaching/school staff (and not reliant on fellow pupils).

Ideally, AG indicated that she wished her current chair *"wasn't so bulky. That's why I don't like it as much as my manual chair. People stare at you more when you're in this one".* She felt that in her current chair she drew attention from other people around her and was more 'obviously' disabled. She was, however, totally unaware of any alternative chairs for which she may be eligible. She felt that a NHS brochure of all types/models of chair available nationwide (not just what may be in stock at the local wheelchair service), together with details of NHS approved chair that could be part-funded through the Voucher Scheme (and how that worked, including the implications for on-going repair and maintenance, additions, adaptation and specialised seating for that chair through the NHS wheelchair service), would be very helpful to users.

AG felt that it must be possible to get the various wheelchair designers and manufacturers to collaborate to produce chairs that were compatible so that various parts/elements were 'universal' i.e. could be fitted to most chairs of a particular type. In that way users, in consultation with their OTs, could almost 'build' their own chair to best meet their personal needs … a 'pick and mix' approach … allowing them to choose the seating, back rest, foot supports, design and so on that best met their physical and social needs. *"I know it sounds silly, but to be able to customize your own chair would be great, picking the features you need from different wheelchairs".*

When asked about how best young people could be consulted about their wheelchair services, AG became a little upset. The interview and tape-recording was halted at this point and some time was spent ensuring that AG was happy to continue. When she had re-composed herself, and the interview recommenced, she explained that she simply disliked talking about her disability and her reliance on a wheelchair – whether that was via a face-to-face interview, in a focus group, or via online communications with a researcher or organisation. Like most young people of her age she just wanted to blend in as best she could and did not like being identified as being 'different'. She did, however, feel that a discussion group organised and run by young wheelchair users, together with able bodied young people, without adult supervision was something in which she would be willing to participate.

At the end of the interview AG reassured me that she had been willing to talk to me and that she just hoped it may result in some change for others like her.

Box 4: Young Male Wheelchair User (11 years-old)

TK is a lovely, intelligent young boy. He has Duchenne Muscular Dystrophy, a progressive neuro-muscular condition. Boys with DMD generally seem to dislike change so getting the powered wheelchair and postural support sorted early on is usually better. TK was first referred to the WPS service in 2010 for a powered wheelchair, and then again in 2012 for a new powered wheelchair and a 'spare' non-powered wheelchair. He was seen earlier in 2014 for a review. He remains under the specialist care of Great Ormond Street Children's Hospital.

TK had an NHS provided manual wheelchair, but due to the unsuitability of chairs available through the NHS, the lack of choice, and the long wait for even a basic model to become available, his parents decided to fund raise the £19k required for a specialized motorized wheelchair fit for TK's needs in 2012. TK and his parents had visited various wheelchair/disability equipment exhibitions (at which TK had test driven a number of models) and researched products available through manufacturers to identify the make/model best suited for TK's needs. They had then set about fund-raising (with help from TK's extended family, friends and school). This had taken about 4 months in total and then, after a home visit by the manufacturer and a delivery wait of approximately another two months, he was able to use his privately-funded motorized chair (the functions of which included elevating him to adult height, totally reclining back, rising leg rests, and tilt function that operated to an upright position to allow TK to stand with support). The chair was even painted in Ferrari Red (genuine Ferrari paint!), with matching red and black upholstery.

When asked if they had used a NHS voucher towards the cost of the chair, TK's mother indicated that they knew nothing about the scheme and had never been given any information about it. I briefly explained how it worked and that, wherever and whenever possible, NHS wheelchair services were keen to collaborate and still provide specialist seating/adaptations and help with some routine repairs/maintenance – although when a chair was not on the NHS approved list, generally the user of a chair purchased privately (or partly purchased with a NHS Voucher) became responsible for the costs associated with their chair's ongoing repair and maintenance. TK's mother confirmed that they still visited the wheelchair service for specialized seating for TK's motorized chair.

TK confirmed that the appearance of his chair was important to him, and could be contrasted with his NHS-provided manual chair that was of the same type used by elderly people. Indeed, TK and his mother related a story which highlighted how unsuitable manual replacements were for users when their motorized chair was being repaired or in the workshop for maintenance. On a recent school trip TK had been forced to use his manual chair as his motorized chair was unavailable while it was being serviced by the manufacturer. His father had been pushing him when the front wheels of the manual chair hit a rut, the chair tipped, and TK ended up on the ground, breaking the femur in both legs. He had been admitted to hospital for a period, and had been in full leg plaster for several weeks and would remain so for a further 6 weeks.

TK thought that it was important that young users had an opportunity to view and try out all the wheelchairs that the NHS could provide, together with all the adaptations and additional features available for each make/model. As individual wheelchair services could only ever carry a limited stock, he suggested exhibitions and/or depots where users could go to see what was on offer and to get more information about the options for part-funding more expensive chairs via the Voucher Scheme.

Although initially rather reticent about talking to a researcher, TK seemed very much at ease (even indicating to his mother in the toilet after the interview had concluded that he'd really enjoyed it!) and suggested that to consult more widely with young users of his age, the Department of Heath should consider interactive online forums and Discussion Boards; facilitating young user groups (led by users themselves); focus groups within schools; and, even home visits by researchers. He did indicate that the 'Thank You' payment on offer to him as part of taking part in the scoping exercise had been an incentive and suggested that young users could be 'tempted' to participate in consultation events and forums with iTunes, Amazon or Game vouchers/gift cards.

Box 5: Young Male Wheelchair User (16 years-old) – Via Email

1. **What does 'choice' mean to you in the context of your wheelchair services?**

- Referral for assessment? I don't feel I am referred for assessment enough especially given the serious, progressive nature of my condition, which means my wheelchair needs are changing all my time. Even when I am referred for assessment it takes quite a long time for alterations to my wheelchair to be made which is obviously no good because my needs are changing all the time.
- Assessment for eligibility? I feel I should be eligible to anything that improves my comfort and support in my wheelchair otherwise this could be detrimental to my health.
- Eligibility criteria? Yes, I am happy with this.
- Equipment provided? I am provided with the right equipment but I do not receive it quickly enough.
- Maintenance, review of needs? Yes, I do receive this but not nearly enough and sometimes I think financial constraints stop me getting what I get when I need it.

2. **What type of 'choice' is most important to wheelchair users?**

- At what stage? Choice is always important to wheelchair users because they are the person that knows the most about their needs, this is even more important when you are growing because your needs are likely to change more quickly.

3. **Bearing in mind the financial constraints faced by NHS funded wheelchair services, how do you feel wheelchair services can be improved?**

- More efficient? – Definitely, I have to wait too long for new equipment,
- More effective? – There needs to be a system in place for people with greater needs.
- Affordable? – Well, it's called NHS which [means] you don't have to pay for [it], so money shouldn't be an issue for the disabled person and their families. I have a privately bought wheelchair [that] is far more comfortable and supportive then my NHS wheelchair but my parents have to pay for the upkeep. I know one boy with my condition who has the same privately funded wheelchair but guess who paid for that, you guys.

4. **To what extent do you feel wheelchair service users should be involved in their services?**

- Commissioning of local services? Yes, this would make life a lot easier because I feel that when it comes to wheelchair needs, a necessity, the wheelchair users along with their family should not have to travel miles because I know with my family this can be stressful.
- Running local services? Please see above.
- Setting eligibility criteria? I think this is quite good at the moment.
- Policy-making? Well there's only one policy, each wheelchair user should receive the right equipment for their needs as soon as possible.

5. **What are the best ways in which to consult with wheelchair users about their services?**

- Locally? I'm not even going to answer that question, obviously local.
- Nationally?

5. The Findings Phase II – The Pilot Survey

As mentioned in Section 2, only seven user consultants provided a return for and/or feedback on the pilot survey instrument.

Three 'respondents' simply sent the author an email to inform her they had found the questionnaire very clear and easy to complete – comments such as *"I found the questionnaire easy to understand and read. The questions were relevant and easy to answer. I liked the blue and black print it makes it easy to read".* Four respondents completed the survey and returned it with comments confirming its 'user-friendliness', together with some additional general comments on 'choice' in service provision. Given this low response, no formal analysis of the quantitative data collected was undertaken, although an SPSS database has been created for potential further use should PMG decide to pursue an extended pilot, possibly facilitated through its own membership.

The additional comments on 'choice' provided by four respondents reiterated and reinforced the key themes and issues raised by their peers within focus groups or in email submissions. For example, one female respondent who had been using a wheelchair for 30 years observed:

> *Wheelchairs and mobility equipment should be about enabling independence. Patients are clients. One size will never fit all. Fact. Limiting access to manufacturers has the potential to be a false economy as the cost and time in adapting one specific make/model may prove unnecessary if an alternative make/model is available in the first place. Listening to the user is fundamental – as someone who has used various wheelchairs for over 30 years I absolutely know my needs and what works and what doesn't work. However, having an engineer or OT who [is] able to work creatively and think outside the box and discuss ideas and alternative solutions, to try things out, can be hugely useful. In a time when technology and engineering of cars, bikes etc is cutting edge and constantly evolving it is vital that staff working in this area are aware of the evolution of wheelchairs and know what else is out there, even if they are unable to supply them via the NHS. This should be an area of expertise. As users we also have a responsibility to consider what is available and what our unique needs are – this should be a two-way conversation.* FR1

One male and one female respondent, who had both been using a wheelchair for 16 years, gave the following reasoning for citing choice of wheelchair and equipment from NHS services as the **most** important aspect of provision.

> *In my view (1) "medical need" should be the 'driver' for the referral; (2) the assessment should be 'professional' and the user should be provided with 'information' on what he/she needs – irrespective of what the NHS can provide; (3) CHOICE is most important in selecting equipment or adaptations.* MR2

> *If you have a wheelchair that immediately meets your needs it is likely it will last longer before needing any alterations or renewal. More time and consideration needs to be spent discussing needs such as fitting in cars etc from both wheelchair user and wheelchair service as, once you have a chair it is too late and, like me, I needed a chair with a folding back as my Mum is the main person to take me out, but as it was it was my Mum's car and did not belong to me (I don't drive now) it was not considered as necessary (I guess it costs more), the Occupational Therapist managed to sort it for me but I could have been left with a chair and be unable to go out with my Mum. I think this sort of criteria they use is wrong and would cause life changing restrictions.* FR2

The same female respondent also added:

> *I think wheelchairs should be chosen for the needs of the user from the start, not changes made from maybe the three chairs that are available as they are bought in bulk cheaply and then alterations made to suit the user. Often the alterations are not satisfactory and users just have to "live with it" rather than having the appropriate chair which is perfect immediately. All chairs should be available within reason, not just three or four.* FR2

On the survey instrument itself, respondents submitted comments such as *'very clear and straight forward'*, and *'very easy to follow and answer, it's well-written and very understandable'*.

6. Timetable and Costs of Exercise

The following factors combined to not only delay the timetable (Table 2), but necessitated adjustments and virement between budget headings to reflect reduced costs of focus groups, and also additional costs associated with the time devoted to the project by the author, whilst still ensuring that the final costs of the exercise were contained within the original approved budget (Table 3):

- three of the original case study WPS services withdrawing from the exercise;
- securing and signing-up new case study WPS services;
- problems (and associated extended timeframe) in the recruitment of user consultants, including contacting potential and actual consultants several times via telephone, email and post;
- less user consultants recruited than envisaged;
- additional main researcher resources invested in the exercise than originally anticipated.

Table 2: Revised to Scoping Exercise Timetable

Scoping Exercise - Stage	**Original Timetable**	**Actual Timetable**
Agreement/signing of contract for scoping exercise	January – February 2014	As anticipated
Preparation, liaison and arrangements for focus groups (including recruitment of consultants)	February 2014	Late March to June 2014
Focus Groups	March 2014	Late March to June 2014
Analysis of Qualitative Data Preparation of Pilot Survey	March – April 2014	May – June/early July 2014
Pilot Survey	April 2014	June – July 2014
Analysis of Quantitative Data	April-May 2014	July 2014
Submission of report to PMG	May 2014	August 2014

Table 3: Revised Costings for Scoping Exercise

Element of Research	**Comment**	**Estimated Cost £**	**Actual Cost £**
Reimbursement of expenses to user consultants attending focus groups	Less consultants, but some reimbursed actual expenses or special transport arranged	1,600.00	670.00
Venue hire	All focus groups held within WPS service premises	300.00	0
Refreshments	Less consultants and researcher & assistant provided catering	1,200.00	378.29
Travel Expenses for focus groups: mileage and parking	Researcher and assistant had to travel separately to Focus group venues, but fewer miles travelled to case study areas	425.00	360.50
Accommodation	No overnight stays required	320.00	0
Office Costs	Additional printing and postage costs	250.00	423.45
Transcription of Focus Group Audio Tapes	Fewer focus group recordings to transcribe	500.00	240.00
Sub Total		**4,595.00**	**2,072.24**
Jo Goodship, Research Services	Additional research time invested due to issues outlined in report	8,000.00	10,772.76
Research Assistance for Focus Groups	Less focus groups and Research Assistant not able to attend all focus groups	400.00	150.00
Sub-Total		**12, 995**	**12,995.00**
VAT @ 20%		2,599	2.599.00
TOTAL		**£15,594**	**£15,594**

In addition, PMG agreed to reimburse the author for expenses incurred in attending and presenting at the National Training Event on 9th July 2014, in Cardiff: a total of £134.95 (separate claim submitted).

7. Conclusion

This has been a rewarding, if at times, challenging commission. I have to conclude the Department of Health's suggestion to PMG that it is not easy to consult with wheelchair users, something about which I was initially very sceptical, is probably a fair assessment of the situation. Recruiting user consultants for this scoping exercise proved difficult and resource-hungry, not least in terms of the time and effort needed by both WPS services and the author just to get to the point at which a service user could be contacted to ascertain whether or not they would be willing to take part in the consultation, either by attending a focus group or submitting comments in writing. Considerable follow-up action and reminders were also necessary and, even then, some users simply did not attend their focus group or submit comments as agreed.

Despite the problems, however, it is not impossible to engage with users and, as demonstrated by the findings outlined in this report, when given the opportunity to voice their perspective on service policy and delivery, they can offer useful insights to the ways in which services can be made to work more efficiently and effectively. The service users who helped with this exercise were wonderful people with a genuine desire to help improve NHS wheelchair and postural seating services. They were also grateful for an opportunity to express some of their frustrations about the false economies they observe within current service policy and practice.

When it comes to 'choice' one seasoned service user pointed out *'that wheelchair users, like everyone else, should be allowed to make their own personal choices about the wheelchair and equipment they use, even if those choices are perceived by others to be bad ones'* … which raises the question of whether 'consumer choice' in public services is realistic and anything other than rhetoric when there are insufficient resources available to meet the healthcare and social care needs of an ever-growing and increasingly ageing population.

Acknowledgements

I would like to thank all the wheelchair service users who assisted in this Scoping Exercise by attending a focus group, submitting comments by email and/or commenting on the pilot survey; the wheelchair service managers within the case study areas and the Community Participation Team at Hillingdon Borough Council, for facilitating the recruitment of user consultants and providing focus group venues; Aaron Levitt, the research assistant; and, last but far from least, Olwen Ellis for being an invaluable source of advice, information and support throughout this commission.

Appendix A

WPS SERVICE TO INSERT ITS LOGO, NAME, ADDRESS AND CONTACT NO.S HERE

POSTURE & MOBILITY GROUP

ADMIRALTY CONSULTING
Company No: 7819082 VAT Reg No: 129945280
43 Admiralty Tower, Queen Street, Portsmouth PO1 3GA
Email: jo.goodship@googlemail.com or jo@admiraltyconsulting.co.uk

Your Wheelchair & Postural Seating (WPS) Services – Your Choices

- Do you care about and have views about the wheelchair and postural seating (WPS) services you receive on the NHS?
- Did you know that the Department of Health is intending to reform WPS services across the country?
- Would you like your views, and those of other service users, to be heard before those changes take place?

If the answer to all these questions is 'YES' then we need your help !

The Posture and Mobility Group (PMG) - a charity that aims to advance professional expertise and practice relating to the posture and wheeled mobility needs of people with physical disabilities, in particular the equipment and services those needs require - has commissioned Jo Goodship, a Senior Social Researcher from Admiralty Consulting Limited, to explore what 'choice' means to users of NHS WPS services. As part of this exercise Jo will be trying to find out whether service users feel that the Department of Health needs to consult with them more widely before any decisions are made of how WPS services should be changed.

Four case study areas have been identified, one of which is based around (name of area/WPS service). Jo will be talking to small group of service users in each of the case study areas over the next couple of months at a special meeting (called a focus group) to find out what they think. Would you be willing to be one of the user consultants and come along to tell Jo what you think? It will only take an hour, Jo will provide some refreshments, and give each service user who attends a minimum of £20 towards their expenses.

If you are over 18 years of age and you are interested in being one of the user consultants for this area, please ask your Wheelchair Service to pass on your contact details to Jo and she will be in touch as soon as possible. Once Jo has made contact with you will be able to ask her any questions you may have about this exercise, and if you agree to take part, she will send you an Information Sheet all about the work that is taking place for PMG. In due course, Jo will be in touch with details on the date, time and venue of the focus group in your area. Also, if you are a parent or guardian of a wheelchair user aged between 10 and 17 years old, and they would like to attend a local focus group especially for young wheelchair users (accompanied by you), then please also get in touch with the Wheelchair Service and it will pass on your details to Jo and she will be able to tell you more.

THANK YOU FOR TAKING THE TIME TO READ THIS!

Appendix B

PMG POSTURE & MOBILITY GROUP	**ADMIRALTY CONSULTING**	**43 Admiralty Tower,** **Queen Street,** **Portsmouth,** **Hampshire PO1 3GA**

What do you think about the choice you get in your wheelchair and postural seating services?

We need to know what you think about your wheelchair and postural seating services – would you like to have more say, or choice, in what you get and where you have to go to get things sorted?

The Government is thinking about changing wheelchair services all over the country, but a group of people called the Posture Mobility Group thinks it is very important that people like you, who actually use wheelchairs and postural seating services, have a chance to talk about those changes before they take place.

So the Posture and Mobility Group has asked Jo and Aaron from Admiralty Consulting to talk to people who use wheelchairs and postural seating services, in four different parts of England, to hear what they think. Jo and Aaron will be talking to adults in groups, but they also want to talk to some young people, in small groups. Although your parents and guardians will come to these meetings with you, we really want to hear from young wheelchair users what they think about their services.

So, please talk about this with your parents or guardians (we have sent them some more information all about the focus groups) and if you think you would like to become one of our special consultants, we will get in touch to make the arrangements for you to come along. We will give you £20 to help cover your expenses, and we will also provide something for everyone to drink and eat. The focus group meeting will not take long, an hour at the most.

Appendix C

PMG POSTURE & MOBILITY GROUP ADMIRALTY CONSULTING

43 Admiralty Tower,
Queen Street,
Portsmouth,
Hampshire PO1 3GA

Scoping Exercise:
Service Users' Views on ' Choice' in Wheelchair and Postural Seating Services

1. Invitation We are writing to you to invite you to take part in a scoping exercise as a service user 'consultant'. Before you decide it is important for you to understand what this exercise involves and why it is being undertaken. Please take time to read the following information and discuss it with your family and friends if you wish. Please do ask us if anything is not clear to you, or you need more information. Thank you for reading this.

2. What is the purpose of the scoping exercise?

The project is being led by Jo Goodship. Jo is a Senior Social Research Fellow, who has worked for many years for the University of Portsmouth but who also works for the independent consultancy company, Admiralty Consulting Limited. The charity the Posture and Mobility Group (PMG) is funding this research.

Over the last 15 years, Jo has managed and undertaken a wide range of social research projects funded by government departments, non-departmental government organisations, local authorities, charities and higher education institutions. She will be assisted in this work by Mr Aaron Levitt, a recent graduate from Bristol University.

As part of the scoping exercise, the team will be talking to:

- young people, aged 10 to 17 years old, who use wheelchair and postural seating services in England; and

- adults who use wheelchair and postural seating services in England.

Also, after listening to the views of service user consultants at focus groups, the team will also ask a number of service users to pilot a short questionnaire on ‘choice’ in service provision, with a view to a much larger survey of service users on this subject at some point in the future.

The main aim of the exercise is to find out what ‘choice’ means to users of NHS funded wheelchair and postural seating services in England; to identify the issues involved as far as users are concerned when it comes to choice in their services; and, whether users feel that further research is needed in this area before the Department of Health implements changes and reforms to these services.

3. Why have I been chosen? You have been chosen because you are a user of the wheelchair and postural seating services (or the parent/legal guardian of a young person who uses those services), and you live in one of the areas chosen for the scoping exercise.

In the first part of the scoping exercise, the team will be conducting focus groups in four ‘case study’ service areas in England - including your area. We hope to hold two focus groups in each area – the first group will be with a small number of young people aged 10 to 17 years old, who will be accompanied by their parents or legal guardians; the second group in each area will be with a mix of adult service users. A maximum of 15 people will be involved in each focus group.

We are interested in the views of people who use wheelchair and postural seating services on the issue of ‘choice’ in service provision – specifically what this means to them, the issues they feel are linked to choice in service provision, and whether they feel that further consultation is needed with service users before the Department of Health implements changes and reforms to wheelchair and postural seating services in England.

4. Do I have to take part? No, you do not have to take part – it is entirely up to you whether or not you volunteer to be one of our service user consultants. If, after reading this information, you decide that you would like to help us, we should be grateful if you would either ring Jo or send her an email and she will then talk to you about the arrangements for the focus group in your area. (See contact details at the end of this Information Sheet).

If you do decide to help us by becoming a service user consultant, you can still change your mind at any point. A decision to withdraw at any time, or a decision not to take part, **will not** affect the services you receive in any way.

5. What will happen if I do become a service user consultant and what do I have to do? All you will have to do is attend a focus group, and talk to us about what 'choice' means to you in terms of the wheelchair and postural seating services you receive. This will be in a small group with other people in the same position as you, at a local venue. In some areas we may be able to arrange the focus group at the venue of your wheelchair and postural seating service BUT nobody from that service will be in attendance at the focus group, so you will be able to talk freely. The focus group should not take longer than an hour at most. With your permission, the group discussion will be tape-recorded.

The research team appreciates that attending a focus group can involve personal expense for you – for example, your fuel costs or taxi fares to get to the venue – and so we will give all service user consultants a minimum of £20 to cover those costs. In addition, we will also provide free refreshments for everyone at the meeting (including parents/legal guardians accompanying their children).

6. What are the possible disadvantages and risks of taking part? The possible disadvantages of taking part are the time you give up, the slight inconvenience, and the personal effort on your part to attend a focus group.

We also appreciate that discussion of wheelchair and postural seating services generally may raise some sensitive issues, such as questions about eligibility and other queries. We are very sorry but as completely independent researchers we will not be able to deal with individual problems or answer individual questions, but we will be able to give you the contact details of people who will be able to advise and help you with any specific problems and questions you may have about your services.

7. What are the possible benefits of participation? There may be no immediate benefit to you personally if you do decide to become a service user consultant and take part in a focus group, but the findings will help the Posture and Mobility Group (PMG) to hold discussions with and make recommendations to the Department of Health about how it can consult service users on a wider scale about what they want and need in terms of 'choice' in wheelchair and postural seating services – especially before the Government implements any changes and reforms to the way in which these services are provided.

8. What happens if the scoping exercise is stopped before completion? If, for any reason, it is not possible to complete the scoping exercise, you will be informed.

9. What if something goes wrong? It is most unlikely that you would suffer any harm as a result of taking part in the scoping exercise, although Admiralty Consulting Limited will investigate any complaints about the conduct of one of its researchers or the use/handling/storage of data collected from user consultants. The Company is indemnified against negligent harm and non-negligent harm caused by a member of its staff.

10. Will my taking part in this scoping exercise be kept confidential? As a matter of routine the collection, handling and use of information relating to all individuals who take part in the scoping exercise will be treated as confidential at all times (and in accordance with the legal requirements of the Data Protection Act). All information (including audio tapes of focus groups) will be stored securely and will not be made available to anyone outside the research team. We shall also make sure that your name is never mentioned in any report or document we prepare about the scoping exercise. Any comments you make will be anonymous.

There is, however, one exception to our guarantee of confidentiality. If, during the course of a focus group, a service user or a parent/legal guardian reveals to a researcher that they or their child/ward, has been abused or is currently at risk of abuse, then we would be not be able to treat that information as confidential as we do have a duty to protect our user consultants from harm, and we would have to report the abuse or risk of abuse to the relevant local authority social services department.

11. What will happen to the findings of the scoping exercise? A report will be submitted to the Posture and Mobility Group (PMG) on the overall findings of the scoping exercise, who will then discuss those findings with the Department of Health.

12. Who is funding this research? The research is being funded by the Posture and Mobility Group (PMG). PMG is a registered charity that aims to advance the education of the public in all matters relating to the posture and wheeled mobility needs of people with disabilities and about the equipment and services those needs require within a framework which recognises the rights and dignity of such people, through all or any of the following means:

1. developing an interdisciplinary forum for continuing education, research and debate in the interests of the general public and of people with disabilities in particular;
2. providing an umbrella organisation linking members of voluntary and statutory agencies, representatives of users' bodies and representatives of manufacturers;
3. maintaining a register of members to enable efficient communication;
4. encouraging the establishment and maintenance of high standards of service delivery.

Although the research is being funded by PMG, the team from Admiralty Consulting Limited is completely independent of the charity, the Department of Health, and the NHS.

12. Contact for further information Should you require any further information before deciding whether or not to take part in the scoping exercise, please do not hesitate to contact Jo Goodship:

Telephone: 023 9273 7628 or *Mob:* 07854104880

E.mail: jo.goodship@googlemail.com or jo@admiraltyconsulting.co.uk

Thank you for your time in reading this information. If you are willing to become a service user consultant and would like to take part in the scoping exercise, please either ring Jo on the above telephone number, or email her, and she will contact you to talk about the arrangements for the focus groups in your area.

Yours sincerely,

Jo Goodship

Jo Goodship, Research Fellow
Admiralty Consulting Limited

Appendix D

NHS WHEELCHAIR SERVICES - IMPROVING USER CHOICE

Please take a few minutes to fill out this pilot questionnaire on ‘choice’ for users of NHS Wheelchair Services. It is part of an exercise funded by the Posture and Mobility Group (PMG), and may be used for a wider survey of NHS wheelchair users across the country. All the information you provide is confidential and anonymous.

Thank you for your help.

Section A: Your experience as a wheelchair user?

How long have you been using a wheelchair?

Please indicate approximate number of years. ----------------------years

Your MAIN wheelchair - Please indicate what type of wheelchair is the one you use most of the time (not old or spare wheelchairs you may also have). Please tick one box only.

☐ Attendant propelled manual wheelchair (i.e. pushed by someone else)
☐ Self-propelled manual wheelchair (i.e. large wheels propelled by the person in the chair)
☐ Powered wheelchair

Your MAIN wheelchair - Please indicate who provided the wheelchair you currently use most of the time. Please tick one box only.

☐ Purchased privately with user’s own funds.
☐ Provided by NHS Wheelchair Service at no cost.
☐ Provided by a supplier through NHS Voucher Scheme at no cost.
☐ Provided by a supplier through the NHS Voucher Scheme, but with financial contribution by user.

Section B: Your NHS Wheelchair Service?

How satisfied are you with the process of being provided with a wheelchair by the NHS? Please tick **one box only** for each stage listed.

Stages in the Process of Being Provided with a NHS Wheelchair	***Very Dissatisfied***	***Dissatisfied***	***Satisfied***	***Very Satisfied***
Referral by a GP for Assessment (of Eligibility/Need)				
Assessment (of Eligibility/Need) by NHS Wheelchair Service				
Selection of Wheelchair (and equipment) from NHS Wheelchair Service				
Repairs and Maintenance to Wheelchair				
Annual Review of Wheelchair Needs				
For users who have received a NHS Voucher only Selection of Wheelchair (and equipment) from provider using NHS Voucher				

To what extent do you feel you had 'choice' in the process of being provided with a wheelchair by the NHS? Please tick **one box only** for each stage listed.

Stages in the Process of Being Provided with a NHS Wheelchair	***Excellent Choice***	***Good Choice***	***Poor Choice***	***No Choice At All***
Referral by a GP for Assessment (of Eligibility/Need)				
Assessment (of Eligibility/Need) by NHS Wheelchair Service				
Selection of Wheelchair (and equipment) from NHS Wheelchair Service				
Repairs and Maintenance to Wheelchair				
Annual Review of Wheelchair Needs				
For users who have received a NHS Voucher only Selection of Wheelchair (and equipment) from provider using NHS Voucher				

In which area of NHS wheelchair services do you feel it is **MOST** important for users to have more choice? Please tick **one box only**.

☐ Initial referral to NHS Wheelchair Service
☐ Assessment for NHS Wheelchair
☐ Selection of wheelchairs/equipment from NHS services
☐ Repairs and maintenance of wheelchair
☐ Adaptations to NHS wheelchair
☐ NHS Voucher Scheme

Please give brief reasons for your answer:

Please rate the performance of your NHS wheelchair service overall. Please tick one box only.

☐ Outstanding ☐ Good ☐ Adequate
☐ Needs improvement ☐ Poor

Section C: About You? Finally, a little bit more about you ….

How old are you? Please tick one box only.

☐ Under 18 years old ☐ 18 to 30 years ☐ 31 to 50 years
☐ 51 to 60 years ☐ 60+ years

Gender? Please tick one box only.

☐ Female ☐ Male ☐ Prefer not to say

Additional Feedback

Please let us have any other comments you wish to make about

(i) improving choice for users of NHS wheelchair services, and
(ii) the wording, presentation and content of this questionnaire.

Please continue on page 4 if necessary

If you are happy for Jo Goodship, the researcher, to contact you to discuss your responses, please give your name, a contact number and/or an email address below (all personal information will be treated confidentially).

Name (please print):
Daytime Contact Number:
Email:

Thank you for taking the time to fill out our survey. Your feedback could help to improve NHS wheelchair services across the UK and your input is greatly appreciated. If you have any questions about the questionnaire, please contact **Jo Goodship –** either on her mobile number 07854104880 or by email to jo.goodship@googlemail.com.

Please return your completed form in the envelope provided, or by email, by (insert date).

PMG
POSTURE & MOBILITY GROUP

NB A Continuation Sheet (page 4) was attached