

Malcolm Masso

Alan Owen

Tara Stevermuer

Kate Williams

Louise Ramsey

Rob Gordon

Kathy Eagar

Suggested citation

Masso M et al (2005) ***PADP Assessment and Priority Setting based on Need and Capacity to Benefit.*** Centre for Health Service Development, University of Wollongong.

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Main messages

The purpose of this research was to develop a common state-wide approach to the assessment of applicants for PADP using standardised data elements and a priority rating system. Initial consultation identified support for 'need' and 'capacity to benefit' as the twin pillars of this approach. The results of the project support the use of these basic concepts to assess and prioritise PADP applications.

For the purposes of this project, 'need' has been equated with a global measure of function. This is not necessarily appropriate for all applicants. Implementation of a state-wide assessment system should recognise this and develop appropriate criteria for identifying those who might be disadvantaged by such an approach.

The project has confirmed the anticipated difficulties of achieving a uniform approach, reflecting the complex decision making that is currently undertaken by PADP managers and PADP committees in approving applications. While full uniformity may not be possible, a common and more standardised system is clearly feasible.

There were insufficient data collected in the field trial to make detailed recommendations about a state-wide system for those under the age of 16 (who constitute 15% of applications). Establishing a common system for adult applications will create a platform for work to establish a system for children at a later stage.

A common state-wide assessment system is a necessary, but not sufficient, condition for improving equity and consistency in the process of PADP approvals. The results show that the number of items in the adult assessment tool can be reduced while maintaining its usefulness as a decision-support tool. On that basis it is recommended that a common system for adult applications be implemented, based on the results of this project.

A common system for adult applications should still allow for the writing of narrative reports to provide the necessary context for applications to be considered. These reports should be standardised and avoid duplication with the assessment process suggested by this report.

The use of common item-specific assessments for high-cost items should be considered to augment the person-centred assessments developed as part of this project.

The results of the project show a common approach across the system is feasible, but indicate the inherent difficulties in building a more uniform approach, especially for priority rating. It is preferable to first implement a common assessment system and allow it to operate for a reasonable period of time (one year is recommended) and then address the issue of priority rating, using the considerable amount of data that can be collected.

Applications to PADP are rarely rejected and many approved applications are not purchased for a period of time. The issue is largely one of managing a waiting list but this is not formally acknowledged in setting priorities for applications. Consideration should be given to whether a factor in priority rating should be a judgement about how long applicants can afford to wait for equipment, and how a suitable 'weighting for waiting' can be applied.

Applicants for incontinence items typically have a severe level of incontinence. Priority setting for incontinence items was not incorporated into this project and no reasons have emerged to warrant changing this approach. It may be worth incorporating severity of incontinence in the eligibility criteria for incontinence items.

Executive summary

This project to develop an assessment and priority system for PADP in New South Wales has been undertaken in three stages involving an initial process of review and consultation, followed by development and pilot testing of a suite of tools, and concluding with field testing the revised tools at four sites. It was unclear at project commencement whether it would simply involve development of assessment tools or whether it would be possible to also establish thresholds for setting priorities. The project aimed to deliver assessment tools that could be used to assess need in a consistent way across NSW and that were acceptable to key stakeholders, based on evidence and consistent with current policy.

Initial review indicated that the tools should cater for the needs of all age groups and take a person-centred rather than an equipment-centred approach. The consultation process demonstrated strong support for basing assessment and subsequent consideration of priority on the twin concepts of 'need' (as measured by function) and the capacity of the applicant to benefit from the provision of the equipment requested from PADP. Domains to measure capacity to benefit were initially canvassed as part of the consultation, trialed in a pilot test, modified and then tested in the field.

Five tools were developed for adult assessment, adult priority rating, child/youth assessment, child/youth priority rating and adult incontinence. For the purposes of PADP applications an adult is defined as anyone 16 years of age or older.

Pilot testing was undertaken in late 2004 and resulted in many changes to the assessment and priority rating tools. Many useful ideas for training staff in use of the tools were also generated during pilot testing.

Pilot testing resulted in many changes to the assessment and priority rating tools, including the addition of items to assess safety and health status. No evidence was generated during the project to suggest the addition of any more items, over and above those used in the field test.

Invitations to participate in field testing were sent to area health services after pilot testing and resulted in four areas being selected to participate. One area subsequently withdrew but was replaced with another area, the final list of sites being Central Sydney, Central Coast, Illawarra and the Southern Area Health Service (using the names of area health services at that time).

Each site participating in field testing collected data for two months, with each site choosing to test the tools 'in parallel' to their existing system for PADP applications and to use a database developed for the purpose.

Data collection proved to be more difficult than originally anticipated, at both the level of prescribers completing individual applications and PADP managers and committees making decisions based on the applications. The field trial yielded a total of 164 applications using the new tools, 106 adult assessments, 35 child/youth assessments and 23 adult incontinence assessments. This was less than the number expected at commencement of the field trial. The number of assessments at one site was particularly low.

Prescribers were provided with a mechanism to provide feedback on individual assessments but few took up this opportunity. Despite this there is some evidence that there was a reasonable degree of acceptance of the tools. Occupational therapists (who complete the bulk of assessments for PADP) appeared to be comfortable with the basic structure and content of the tools.

The use of need and capacity to benefit as the basic constructs underpinning assessment of PADP applications was supported at each stage of the project, albeit to varying degrees. One

field test site had reservations about what they saw as the subjective nature of the assessment and had concerns about the particular needs of young people with disabilities and the elderly.

The results of the field trial indicate that the number of expected benefits in the adult assessment tool could be reduced to six:

- improvement in self care function
- change in hours of care and assistance
- sustainability of care/self care arrangements
- likelihood of remaining in community/own residence
- improvement in applicant's participation in social or community activities
- overall effect on applicant's health status

Based on feedback during the project and our own observations of how current systems operate we favour inclusion of safety items, for both applicant and carer, as expected benefits. This is essential for face validity of the assessment tools, enhancing their credibility with PADP committees and prescribers.

These results accord with the views of those involved in the pilot test. This would exclude the domestic functioning assessment (with eight items), reduce the adult assessment from 35 items to 20 items and result in need being based solely on the applicant's self care assessment. Some concerns were raised during the project regarding the suitability of the assessment tools for particular client groups such as those with lymphoedema and sensory impairments.

The low number of child/youth assessments in the field trial prevented a determination of whether any of the expected benefit items could be removed from the assessment process. Very few changes were noted on the functional assessment, particularly for cognition items. It is recommended that implementation of any decision to proceed with a common state-wide system for PADP applications based on the work reported here should focus initially on adult assessments (which constitute the majority of applications) and leave the issue of a common system for child/youth applications to a later date, when the success of a new format for adult applications can be properly gauged.

There is a strong attachment by all those involved in dealing with PADP applications to the narrative reports currently used by prescribers. Prime importance is given in deciding priority to the applicant's 'story', which principally revolves around how the requested equipment fits with the applicant's disability and their personal circumstances. Some details of the applicant's story (essentially the clinical justification for the equipment) are essential and should be retained, preferably using a standard format. Any decision to implement tools similar to those developed as part of this project should incorporate a review of existing reports used by prescribers to avoid duplication.

The existing systems of priority setting at each field test site use 3-4 levels of priority, but the majority of applications are typically assigned to one level of priority. This meant that it was not possible to make a meaningful comparison between the priority assigned by existing systems and the priority assigned using the results of the adult and child/youth assessments from the field trial.

A priority rating exercise was developed to try and determine the extent to which the adult priority rating tool could be used to establish relative priority between applications. The results of this exercise were disappointing, with low level of agreement between the four sites involved. We conclude that it was overly optimistic to expect people to meaningfully use a totally different system of assigning priority within such a short space of time, particularly when the existing system continues to be used.

Current systems for PADP applications are effectively systems for managing a waiting list. Most applications are approved but few are funded immediately. Applicants on the waiting lists receive their items when funds become available, or when their circumstances change and their prescriber negotiates successfully with the PADP coordinator for a change in priority status. Consideration should be given to whether this should be more formally acknowledged by assigning priority based on an assessment of how long the applicant might reasonably wait to receive the equipment requested. This would make the concept of urgency explicit in the setting of priorities, thus standardising the way PADP currently operates. It would create clear performance indicators, which could be monitored, and provide guidelines to PADP coordinators on the order in which waiting list items should be funded. It would also give applicants some indication of how long they can expect to wait for their requested items.

The results of the field test indicate that thresholds for determining priority cannot be assigned with any degree of confidence. It is recommended that the first step would be to get agreement to adopt a common assessment system state-wide, then collect data for a reasonable period of time (say one year), then use the results to establish indicative thresholds, not forgetting that these tools are designed to assist in decision making, rather than serve as a complete substitute for the current decision making by PADP managers and PADP committees.

1 Context

The Program of Appliances for Disabled People (PADP) assists eligible residents of NSW who have a life-long or long-term disability to live and participate within their community by the provision of appropriate equipment, aids and appliances. Approximately \$16 million per year is allocated by the NSW government to provide this support. Though relatively small in the context of the overall health budget, the program has the capacity to make a significant impact on the quality of life of individuals receiving assistance, and on the well-being of carers and family.

Under current policies, the Department and each area health service is required to establish one or more PADP advisory committees with responsibility for planning, funds management, determining the priority of applicants on the basis of need, and implementation of system improvements. There is no uniform method of assessing the needs of those applying for assistance or for determining the priority of applicants on the basis of need across NSW.

The NSW Health Department commissioned the Centre for Health Service Development (CHSD) to develop a PADP assessment tool that will assist in determining priority of funding and the equitable allocation of equipment, aids and appliances based on clinical need.

A key reason for undertaking the project is to achieve equity in the way that PADP resources are allocated. The desired outcome is an assessment system that can assist providers, health professionals and program managers to ensure that:

- people with equal needs receive equal assistance
- people with different levels of need are provided with assistance that is related to their level of need
- those with greatest needs get highest priority in receiving assistance.

The project aimed to produce assessment tools that:

- can be used across NSW to assess the needs of clients in a uniform way
- are acceptable to key stakeholders
- are based on principles of best practice
- achieve equity of PADP resource allocation
- are consistent with NSW PADP Policy
- take into account tools already in use.

The project was conducted in three stages:

Stage 1 consisted of reviewing PADP data, existing practices and the literature on assessment and priority setting. This formed the basis for a consultation paper distributed to PADP services in NSW. Stage 1 included analysis of the responses to the consultation paper.

Stage 2 involved the selection of tools for testing at one pilot site. The purpose of the pilot was to identify training requirements, test whether instructions for use of the tools were clear and whether the forms were well designed and understood. Stage 2 included analysis of data and feedback from pilot testing.

Stage 3 consisted of modifying the tools on the basis of the pilot test and field testing the tools in four sites.

It was unclear at the beginning of the project whether it would simply involve the development of an assessment tool or whether it would also be possible to establish thresholds that could be used to determine a priority rating for each applicant.

The project was approved by the University of Wollongong and Illawarra Area Health Service Human Research Ethics Committee. Individual patient consent was not required because the research involved assessment staff and PADP committees giving feedback on a new system that will operate in parallel with routine practice. Each PADP lodgement centre consented to involvement in the project on behalf of their staff. Assessors from outside the host organisation participated with the consent of their agency. Individual PADP lodgement centres were free to withdraw participation at any time.

This report includes material from our two previous reports on this project, together with the results from field testing.

2 Initial review and consultation process

2.1 Review of data

Data were reviewed for items issued under the program in 2000/2001 and 2001/2002. Incontinence aids constitute over a quarter of items issued. Mobility aids represent a further quarter of items issued (manual wheelchairs about 4%, electric wheelchairs about 1%, and other mobility aids about 20%). Bathing aids account for about 14-16% of items, while aids related to pressure care, beds and sleeping represent account for another 11-12%. The remaining quarter is comprised of 11 different categories of aids and equipment. The data indicate that the assessment process should include measures of self-care ability and continence management.

About 35% of applicants are 75 years or over. The age groups 46-64 years, 65-74 years and young people aged 0-15 years each represent about 15% of applicants. The age groups 16-30 and 30-45 each represent about 6% of applicants. This suggests that the assessment process needs to be sensitive to the needs of all age groups.

A critical issue is whether the primary focus of assessment should be the person or the item requested. The assessment could focus on applicants (one assessment for each applicant, irrespective of the number of items requested) or an assessment could be triggered for each separate item requested. Some individuals may need a group of items to gain benefit from any one item while others may have a set of separate needs, each of which can be satisfied by one item.

2.2 Existing practice and literature review

A review of several application forms in use in NSW was undertaken, as well as a literature and website search (using search engines for occupational therapy and physiotherapy - OTseeker and PEDro, with keywords of aids and appliances, medical aids, functional needs). The results indicated that assessment for aids and equipment is similar to those used in functional assessment in health and community care. It was concluded that the key feature to be assessed in this project was the functional status of applicants and the extent to which the provision of an aid or appliance would assist them in undertaking everyday self care and domestic tasks. Criteria were identified for selection of suitable instruments – reliability, validity, applicability, practicability, compatibility and efficiency.

Eagar et al (2001) reviewed many of the currently used measures to assess both self care activities of daily living (ADL) and domestic (instrumental) activities of daily living (IADL). ADL measures usually cover basic physical functions and fundamental abilities that underlie normal living and are required for an independent life. IADL may be defined as those activities needed for

continued community residence and include activities such as shopping, preparing meals, cleaning the house and using the telephone.

2.3 Consultation process

At the beginning of the project a consultation paper was prepared for the many stakeholders involved in the PADP program. Issues canvassed in the consultation paper fell broadly into four groups:

- ideas (concepts)
- value judgements (for example, about what's important to include in a PADP assessment)
- practical issues (for example, about who should do the assessment)
- technical details (for example, the psychometric properties of various assessment tools).

Included in the consultation paper was a discussion about the concept of 'need', drawing on the work of Bradshaw (1972) who distinguished four types – normative need, comparative need, expressed need and felt need.

The consultation paper also included discussion of the concept of 'capacity to benefit' and how this might be incorporated in to the assessment process. It was suggested that, using the concepts of need and capacity to benefit, seven domains appeared to be key aspects to incorporate into the assessment process – safety, ability to manage activities of daily living, quality of life, availability of family and carers, dependency on family and carers and the risk of residential care.

A total of 31 responses were received from a diverse range of respondents - 24 from individuals or groups directly involved with the provision of health and/or welfare services, six from consumer advocates and one from a health professional working for a supplier of high cost equipment of the type provided by PADP.

There was strong support for the assessment process proposed in the consultation paper, although some respondents highlighted potential difficulties in assessing 'capacity to benefit'. A number of respondents, both consumer and health professional, highlighted the need to make the assessments 'practical' – citing the time required of both consumer and therapist if the tools were complex, and the high training needs for complex tools.

3 Development of initial set of tools

Taking into account the responses to the consultation process a suite of tools consistent with the assessment model described in the consultation paper was developed. Five tools were developed for adult assessment, adult priority rating, child/youth assessment, child/youth priority rating and adult incontinence. For the purposes of PADP applications an adult is defined as anyone 16 years of age or older.

3.1 Adult assessment

The initial adult assessment tool had four components:

- Self care functional assessment, based on the 50 point modified Barthel Index.
- Domestic functioning assessment based on the 30 point Lawton Instrumental Activities of Daily Living (IADL) scale.
- Information on care and assistance received by the applicant and an assessment of the impact of providing the requested item(s) on those providing the care and assistance.
- An assessment of the expected benefits to the applicant of providing the requested item(s).

For the self care functioning and IADL assessments function is recorded with and without the requested item(s). This gives an overall measure of need and a measure of the increase in function expected to result from providing the requested item(s).

The Barthel Index originally included three levels of rating for most functional skills (Collin et al, 1988). There was concern that this would not be sensitive enough to discriminate levels of need amongst people with disabilities. It also needed to work easily in an algorithm to create a priority scoring system. The original Index was therefore modified by the CHSD to allow for five levels of rating (1 = total dependence, 2 = moderate assistance, 3 = small degree of assistance, 4 = independent but takes a longer time or there are safety concerns, 5 = independent).

The original domestic functioning assessment developed by Lawton and Brody (1969) has been found to perform well as a generic tool in other assessment situations. The version included in the adult assessment tool has previously been used in studies on Home and Community Care clients, modified to include four levels of rating for some items (Eagar et al, 2002). It assesses how a person gets around and what they can do in their domestic environment and includes eight areas – use of telephone, shopping, food preparation, housekeeping, laundry, outdoor mobility, responsibility for medications and ability to manage finances. Each item is scored in the direction of dependent (1) to independent (3 or 4).

The various aspects of care arrangements and how these might be influenced by provision of the requested equipment were captured with a series of items:

- Three questions on ‘need for a carer’, ‘carer availability’ and ‘carer residency status’ that do not form part of the formal assessment and priority rating process. This was considered to be useful information to include in an application for PADP equipment.
- An item on hours of care and assistance based on an assumption that some items of equipment will reduce the hours of care and assistance provided to the applicant.
- An item to assess the sustainability of the current care arrangements.
- Five items to assess the impact on people who provide care and assistance to the applicant - impact on time providing support, impact on physical effort, impact on emotional well being, impact on independence and impact on quality of life. These items used a four point scale - (1) no change, (2) slight improvement, (3) moderate improvement, (4) significant improvement.

Expected benefits to the applicant were assessed with items on:

- the likelihood that the applicant will remain in the community
- quality of life
- participation in social and/or community activities.

3.2 Child/youth assessment

The initial child/youth assessment tool also had four components:

- Functional assessment, based on the Functional Independence Rating Scale for Children (FIRSC). Function is recorded with and without the requested item(s).
- Bladder and bowel management
- Information on hours of care and assistance received by the child and an assessment of the impact of providing the requested item(s) on those providing the care and assistance.
- An assessment of the expected benefits to the child of providing the requested item(s).

To develop the assessment tool a large range of currently used measures for health-related quality of life (HRQOL) and functional status of children were examined. Most of these were too long and

contained dimensions that are not really relevant to the need for an aid or an appliance. In many scales there is relatively little focus on functional skills. It was decided that a checklist/rating scale rather than a self report form would be best to use with children.

After reviewing the literature, discarding those instruments with too many items, and further review, the WeeFIM (UDSMR – see reference list) was identified as one of the more relevant scales to assess need for appliances/aids. However, while it is good for rating what a child can or cannot do it was unclear how this related to age appropriateness. It was decided to develop a simplified, 20-item, 5 point, rating scale based on the functional dimensions from the WeeFIM and subscales relating to functional skills from a range of other child assessment instruments. It includes items on all WeeFIM dimensions but also includes items on problem solving, memory and mental function.

The Child/Youth Functional Assessment includes items on bowel and bladder management but additional questions were added to assess continence and the need for continence aids, although these items were not incorporated in to the Child/Youth Priority Rating. These additional items were modified from the pad use items in the Adult Incontinence Tool.

The various aspects of care arrangements and how these might be influenced by provision of the requested equipment were captured with a series of items similar to those included in the adult assessment:

- An item on hours of care and assistance.
- An item to assess the sustainability of the current care arrangements.
- Five items (the same as those included in the adult assessment) to assess the impact on people who provide care and assistance to the child.

Expected benefits to the child were assessed with items on quality of life and participation in social and/or community activities.

3.3 Adult incontinence

Adults requesting incontinence aids only are assessed using the Adult Incontinence Assessment Form. For assessment of adult faecal incontinence the five-item Wexner Scale was included (Jorge and Wexner, 1993). For urinary incontinence the Incontinence Severity Index (Sandvik et al, 1993) was selected as it gives good information on frequency and amount. These items do not differentiate the type of urinary incontinence.

3.4 Priority rating

The priority setting approach in adult and child assessments is based on a 'data driven method' developed during work for Home and Community Care (Stevermuer et al, 2003). The priority rating tools assign priority based on a combination of consumer need and expected benefit. The assumption is that the highest priority ranking should go to applicants who have a high need (measured as equivalent to low level of function) and who are expected to achieve high benefits. The lowest priority should be assigned to applicants who have low need (measured by a high function score) and who are expected to receive few benefits from the provision of the requested item.

It is not intended that the priority rating tools alone determine an applicant's priority. The actual priority ranking will always be determined by the PADP Manager or PADP Committee. The priority rating tool is a decision support tool.

For the purposes of testing the priority rating it was decided to include ranges for classifying need as low, medium and high and expected benefits as low, medium and high. These ranges were not based on any evidence, merely serving as useful starting points for determining priority.

4 Pilot testing and finalisation of the tools

Staff from the Illawarra Area Health Service (IAHS) had indicated a willingness to be involved in pilot testing the tools and this was confirmed in a meeting with the research team in August 2004. Pilot testing took place in September and October 2004 and consisted of using the assessment and priority rating tools on a small number of clients. Feedback was sought on individual assessments with provision of a form for this purpose and a meeting was held with key staff at the conclusion of the pilot test to brainstorm ideas and suggestions for improving the forms. Twenty assessments were undertaken in the pilot study. Feedback on individual assessments included comments that:

- The item seeking to identify expected changes in quality of life from provision of the requested equipment was too subjective.
- The section in the adult and child/youth assessments on expected benefits for applicants and carers was 'messy and confusing' with some of the items difficult to understand.
- Instructions on scoring some items were not clear.

Within the adult assessment tool the self care functioning assessment was considered to be far more relevant than the domestic functioning assessment. It was also pointed out that for some clients function will never improve regardless of equipment provided. There were several comments that the issue of safety had not been included in the assessment process. It was estimated that the adult assessment tool required approximately half an hour longer to complete than the tools currently in use.

It was agreed that a 'how and why' training manual should be developed for the field trial and that this should include brief explanations about why the various items in the tools had been included as well as instructions about how to score the items (in addition to the instructions already included on the forms). Many useful ideas were generated by the pilot test and incorporated into the training manual.

The project team considered a number of issues arising from the pilot study, resulting in the following changes to the tools:

- Inclusion of an item for outdoor mobility on the adult assessment form.
- Inclusion of safety (for both applicant and carer) as a 'capacity to benefit' item in both the adult and child assessments.
- Inclusion of a capacity to benefit item for 'overall impact on health status' to pick up improvements to health status that had not previously been incorporated in the tools. This is applicable for some items of beds and sleeping equipment, monitoring equipment and pain management aids.
- For some applicants the hours of care required will increase with the provision of the requested item and this was included in the scoring of the relevant item in the adult and child assessments.
- The item on the adult assessment form for 'increase in likelihood of remaining in community/own residence' was simplified from one based on the aggregate of three questions to one based on a four point scale of risk of institutionalisation.
- The sections on the adult and child/youth assessment forms for capacity to benefit items were re-formatted to improve clarity and understanding. Items were also numbered to facilitate feedback in the field trial.

- Changes to the layout and ordering of items on the priority rating tools to make them more user-friendly and consistent with the assessment tools.

In addition, many small changes were made to simplify wording, ensure consistency in wording between the different tools and remove any redundancy. All changes to the assessment and priority rating tools since development of the initial set of tools were logged. The pilot test and subsequent review of the assessment and priority rating tools resulted in a total of 50 changes to the tools, although the basic format remained unchanged. Copies of the final set of forms used in the field trial are attached as a separate document.

Another factor influencing development of the tools was the new circular for PADP issued by the NSW Health Department on 22 September 2004 that lists PADP items in 16 categories. The tools were reviewed to identify the extent to which modification to reflect these different categories of equipment might be possible.

5 Field testing of tools

5.1 Introduction

The NSW Health Department sought expressions of interest from area health services for participation in field testing the tools and four sites were selected – Central Sydney, Central Coast, Illawarra and Greater Western (using the names of area health services as constituted at that time). Greater Western subsequently withdrew and was replaced by the Southern Area Health Service.

The field trial sought to answer a number of questions:

- What is the best mix of assessments of consumer need and expected benefits that result in a reliable relative priority rating?
- Are the logistics of administering the tools acceptable to those undertaking the assessments?
- Is the burden of data collection acceptable to those undertaking the assessments and staff of the lodgement centre?
- Are the assessment tools 'user friendly'?
- How well do the assessment tools fit with current professional practice?
- Are the assessment tools culturally and age appropriate?
- Are the assessment tools sensitive enough to identify functional status with and without the requested item?
- What are the optimal thresholds for the priority rating tools?
- How do the tool-based recommendations accord with clinician recommendations?
- What is the cost difference of administering the assessment and priority rating tools compared with existing tools?
- How do the proposed assessment and priority rating tools compare with the existing system in each lodgement centre?
- Are any items in the assessment tools redundant?
- Should any items be added to the assessment tools?

Site visits were conducted to meet with key staff and explain the requirements of the field test. Review of the monthly workload at each of the field test sites and consideration of the number of completed forms required for an adequate sample resulted in a decision that data would be collected for two months.

5.2 *Training in use of tools*

A 'How and Why Manual' was developed, including information about development of the various tools, together with instructions about how to complete the tools. The Manual is underpinned by an assumption that health professionals completing the tools have well developed assessment skills. Hence, sufficient information was included to facilitate completion of the tools but not too much information that those completing the tools would find it professionally insulting. The Manual was distributed at training sessions and each site provided with an electronic copy to distribute to PADP prescribers.

Training sessions were conducted at each site to explain the background to the project and use of the assessment and priority rating tools. The main points emphasised during training about how to complete the assessments were:

- Rate what the person is capable of doing rather than what they do.
- Where an item is not relevant (eg, client does not use medicine), rate what the person would be capable of doing if the item were relevant to their situation.
- Make sure the ratings, especially of items regarding standards of cleanliness, are based on the person's own social or cultural context, not that of the assessor.

Instructions for assessing these items stated that it should be done in consultation with the applicant and their carers and any other relevant information. In cases of disagreement between the professional judgement of the prescriber and the assessment of the client and/or their carer the instruction was to use the scoring that did not disadvantage the applicant.

5.3 *Data collection*

Each site was given the option of using the tools 'in parallel' with their existing system or replacing their system with the new tools for the duration of the field trial. All four sites chose the first option. To collect basic information about each applicant (e.g. age, gender, disability, items requested) a PADP Cover Sheet was developed.

Sites were given the option of using a totally paper-based system for the field trial or completing forms for the assessments and entering the data in to a database developed for the field trial. Each site chose to use the database. The database automatically generated a priority rating for each application based on the new tools. This information was available to the PADP manager and PADP committee in each lodgement centre to assist with decision making for each application. On completion of the trial a copy of the database was sent to the research team, with all data de-identified.

A feedback form was developed to allow prescribers to provide comments on individual applications. The form was included in the PADP database developed for the field trial. Members of the project team attended PADP committee meetings to observe their discussions and gather qualitative data about use of the assessment and priority rating tools. To facilitate data gathering, a set of questions was written (see Appendix 1).

In September 2005 the research team made a presentation to the NSW PADP Advisory Committee at which copies of the assessment and priority rating tools were distributed. Subsequent to the meeting the adult assessment tool was trialed by Vision Australia service providers with seven current and past PADP applicants to examine its suitability to people who have a sensory deficit. This provided useful feedback on use of the tools for a very specific client group and the results have been included in this report.

5.4 Priority rating exercise

As the field trial drew to a close completed applications from the sites were used as the basis for constructing a sample of 10 'dummy' adult applications to PADP. The aim was to examine the usefulness of the adult assessment and priority rating tools in determining relative priority between applications. The adult assessment tool rather than the child/youth assessment tool was used because of the greater number of adult applications at each site and hence greater familiarity with that tool.

Each application was based on one or more 'real life' applications and consisted of a cover sheet and the page from the adult priority rating tool that summarised the results of the assessment for that application. Background information was included on each cover sheet to provide some context for the application. The information was fictitious but written in such a way as to be consistent with the assessment results.

The applications included different levels of function and expected benefits (see Table 1).

Table 1 *Function and capacity to benefit for each application in priority rating exercise*

Case number	Self care score	Domestic score	Total expected benefits
1	46	27	19.4
2	28	12	26.8
3	32	14	22.4
4	20	10	31.2
5	35	12	17.4
6	39	16	16.8
7	37	21	29.8
8	18	12	17.4
9	44	24	20
10	20	14	24.4

The net effect of constructing the sample in this way was to distribute the sample amongst the nine cells in the adult priority rating tool used in the field trial, as shown in Table 2.

Table 2 *Distribution of cases according to matrix on adult priority rating form*

Consumer need	Expected benefits		
	High	Medium	Low
Low function	Case 4	Case 10	Case 8
Medium function	Case 2	Case 3	Case 5
High function	Case 7	Cases 1 and 9	Case 6

The sample of applications was sent to each site with a set of written instructions on how to complete the exercise. The PADP manager was requested to complete the exercise in collaboration with at least one member of their PADP advisory committee. The exercise required each site to:

- Identify the three applications with the highest priority for funding.
- Identify the three applications with the lowest priority for funding.

- Place each of the remaining four applications either in the group with highest priority for funding, or the group with lowest priority for funding, or in an intermediate group (intermediate priority for funding).

For the purposes of the exercise it was assumed that all applications would be approved.

6 Field testing results

This section presents the most important results and summary data (a more detailed analysis is included in Appendix 2). All correlations are Spearman's rho as the data are ordinal.

6.1 Summary details

A total of 168 assessments were received from the four sites, as detailed in Table 3.

Table 3 Data received by PADP centre

PADP Centre	Cover sheet	Adult Assessments	Child/Youth Assessments	Incontinence Assessments
Site 1*	48	37	1	6
Site 2	19	15	0	4
Site 3	48	29	17	2
Site 4	53	25	17	11
Total	168	106	35	23

* Four cover sheets had no assessments

6.2 Adult assessments

Adult applicants were typically aged between 65 and 73 years old, with almost equal numbers of males and females. For 56.7% of applicants this was their first PADP application and for 54.7% of applications the cost of the requested items was less than \$800. For each applicant their disabilities were grouped into function or body system involved using the International Classification of Functioning, Disability and Health (Table 4). Disability related to neuromusculoskeletal and mental function accounted for three-quarters of all applicants. Most applicants reported two or three disabilities. Female applicants were a little older than male applicants, as were those applying for the first time or requesting items less than \$800.

Table 4 Disabilities of adult applicants

Function or body system involved – determined using the International Classification of Functioning, Disability and Health (ICF)	Number (%) of applications		Average age of applicant	Average number of disabilities listed	Proportion of male applicants
Neuromusculoskeletal and movement-related functions or involvement of structures related to movement	49	(46.2%)	73.8	3.0	43.8%
Mental functions or involvement of structures of the nervous system	29	(27.4%)	55.9	2.0	62.1%
Functions or structures of the cardiovascular, haematological, immunological and respiratory systems	19	(17.9%)	71.5	3.9	52.6%
Functions or structures of the digestive, metabolic and endocrine systems	3	(2.8%)	75.0	4.0	66.7%
Genitourinary and reproductive functions	1	(0.9%)	60.0	5.0	0.0%
Voice and speech functions	1	(0.9%)	n.a.	2.0	100.0%
Unable to be assigned	4	(3.8%)	70.0	1.8	0.0%
All disabilities	106	(100.0%)	69.3	2.9	50.5%

Approximately 2.5 items of equipment were requested by each adult. No items were requested in 7 of the 16 categories of equipment currently specified in the NSW PADP policy. Applications for beds and sleeping equipment, seating equipment, and equipment to assist with mobility, toileting, showering and transfers accounted for 94.2% of all items requested (Table 5).

Table 5 *Items requested by adults from PADP (excluding incontinence items)*

Category of equipment	No. of items	Percentage of total
Aids to nutrition	1	0.4%
Alarms	0	0.0%
Beds and sleeping equipment	45	18.8%
Communication aids	0	0.0%
Environmental control aids	0	0.0%
Mobility aids	73	30.4%
Monitoring equipment	0	0.0%
Orthoses and footwear	4	1.7%
Pain management devices	0	0.0%
Pressure garments and pressure relief equipment	8	3.3%
Prostheses	0	0.0%
Seating equipment	20	8.3%
Technological aids to inclusion	1	0.4%
Toileting and showering aids	75	31.3%
Transfer aids	13	5.4%
Total	240	100%

6.2.1 Impact on function

Adult assessment required each applicant for PADP to be assessed for self care and domestic function, without the requested equipment and then with the requested equipment. Between 103 and 106 assessments were completed for each item on the self care functional assessment. All items saw some change, ranging from 1.9% (stairs) to 41.5% (bathing). The results are summarised in Table 6 including the mean change in score for each item for all assessments and for only those assessments that changed. The amount of change overall was small (all assessments considered). However, when considering only those assessments with change, the amount of change was typically more than one point (the smallest change possible).

Slightly fewer domestic functioning assessments were completed. All items saw some change (Table 6), ranging from 1.0% (telephone) to 27.5% (shopping). The amount of change was small, across all assessments. When considering only those assessments with change, the amount of change was typically more than one point.

Table 6 *Functional assessment – without requested equipment and expected change with requested equipment*

Item name	Number of assessments	Mean score without equipment	Number of assessments registering change		Mean change in score for each item	
			n	%	All assessments	Assessments with change
Self care functional assessment						
Bowels	103	3.99	11	10.7%	0.17	1.64
Bladder	103	3.48	15	14.6%	0.26	1.80
Grooming	104	3.37	11	10.6%	0.16	1.55
Toilet use	105	3.08	33	31.4%	0.56	1.79
Feeding	104	3.86	5	4.8%	0.08	1.60
Transfer	105	2.94	40	38.1%	0.72	1.90
Indoor mobility	104	2.87	37	35.6%	0.85	2.38
Dressing	106	2.99	8	7.5%	0.08	1.00
Stairs	105	2.19	2	1.9%	0.02	1.00
Bathing	106	2.52	44	41.5%	0.66	1.59
Domestic functioning assessment						
Telephone	103	3.17	1	1.0%	0.03	3.00
Shopping	102	1.75	28	27.5%	0.33	1.21
Food preparation	101	1.86	9	8.9%	0.14	1.56
Housekeeping	101	1.73	12	11.9%	0.17	1.42
Laundry	101	1.60	11	10.9%	0.17	1.55
Outdoor mobility	102	1.88	23	22.5%	0.33	1.48
Medications	101	2.04	1	1.0%	0.01	1.00
Finances	101	2.03	3	3.0%	0.03	1.00

Of the total 106 assessments four had at least one missing self care data item and five had at least one missing domestic item. Table 7 details the correlation of each item with the overall improvement (change) in the assessment and the domain (scale 1-4), and the variation in the domain explained by that item.

Table 7 *Domain review by items in self care and domestic functioning assessments*

Item name	Number of assessments	Mean change	Correlation		Variation in domain explained by individual item
			Improvement	Domain	
Change in self care functional assessment					
Bowels	102	0.18	0.434**	0.361**	13.0%
Bladder	102	0.26	0.436**	0.350**	12.2%
Grooming	102	0.17	0.471**	0.448**	20.1%
Toilet use	102	0.56	0.729**	0.695**	48.3%
Feeding	102	0.08	0.224**	0.206**	4.2%
Transfer	102	0.67	0.649*	0.654**	42.7%
Indoor mobility	102	0.80	0.708**	0.685*	47.0%
Dressing	102	0.07	0.351**	0.339**	11.5%

Item name	Number of assessments	Mean change	Correlation		Variation in domain explained by individual item
			Improvement	Domain	
Stairs	102	0.04	0.131	0.135	1.8%
Bathing	102	0.65	0.690**	0.644**	41.4%
Change in domestic functioning assessment					
Telephone	101	0.03	0.158	0.151	2.3%
Shopping	101	0.34	0.808**	0.821**	67.5%
Food preparation	101	0.14	0.542**	0.546**	29.8%
Housekeeping	101	0.17	0.620**	0.612**	37.4%
Laundry	101	0.17	0.574**	0.558**	31.2%
Outdoor mobility	101	0.34	0.754**	0.726**	52.7%
Medications	101	0.01	0.158	0.151	2.3%
Finances	101	0.03	0.251*	0.264**	7.0%

* Correlation is significant at the 0.05 level (2-tailed)

** Correlation is significant at the 0.01 level (2-tailed)

Regression analysis was used to determine which, if any, items could be dropped from the assessments of self care and domestic function. In determining this there is a trade-off between the need to explain variation to a satisfactory degree (by including more items) and the need to develop an assessment tool that is easy to administer (by including less items). The aim is to get the best result, in terms of variation explained, for the least effort in collecting data. For the purposes of this analysis it was assumed that inclusion of sufficient items to explain at least 90% of the variation would represent the best option, with 2nd and 3rd best options including more items, and hence explaining more variation. In order (with variation explained in parentheses), the options are:

- 1 bladder, toilet use, indoor mobility (90.5%)
- 2 bladder, toilet use, transfer, indoor mobility (93.1%)
- 3 bladder, toilet use, transfer, indoor mobility, bathing (95.0%).

Put another way, the self care domain can be reduced to five items with the loss of only 5% in the amount of variation explained and the minimal number of items (accounting for 90.5% of the variation in the self care domain) is three - bladder, toilet use and indoor mobility.

Taking a similar approach with the assessments of domestic functioning results in the following best options (in order, with variation explained in parentheses):

- 1 shopping, housekeeping, outdoor mobility (94.1%)
- 2 shopping, housekeeping, laundry, outdoor mobility (96.4%)
- 3 shopping, food preparation, housekeeping, laundry, outdoor mobility (98.0%).

Further details of this analysis are included in Appendix 2.

6.2.2 Impact on carers

In one third of the applications it was expected that provision of the requested item would result in a change in the hours of care provided to the applicant each week by the primary carer (5½ hours). Although greater changes in time were seen in the hours of care provided informally (8 hours) and formally (25½ hours), only a few applicants changed (see Table 8 for details). Four applicants had an expected increase in the hours of care per week. Most applicants were able to be left alone and had a co-resident carer. Only one in four of all care and assistance

arrangements were sustainable, with one in three likely to breakdown in either the short term (within six months) or long term (greater than six months). For further details of these results see Appendix 2.

Table 8 Hours of care per week – without requested equipment and expected change with requested equipment

Item name	No. of assessments	Mean hours of care without equipment	No. of assessments registering change		Mean change in hours of care	
			n	%	All assessments	Assessments with change
Primary carer	96	33.84	30	31.3%	1.68	5.37
Informal care	96	1.84	6	6.3%	0.50	8.00
Formal care	96	6.42	7	7.3%	1.86	25.57

Provision of the requested item(s) was expected to have greatest impact on the physical effort and safety of the carer. It was least likely to affect the independence and emotional wellbeing of the carer (Figure 1). The range of responses to each of the five ‘impacts on carer’ suggests that each is capable of discriminating between applicants to varying degrees.

Figure 1 Impact of provision of requested item(s) on carers

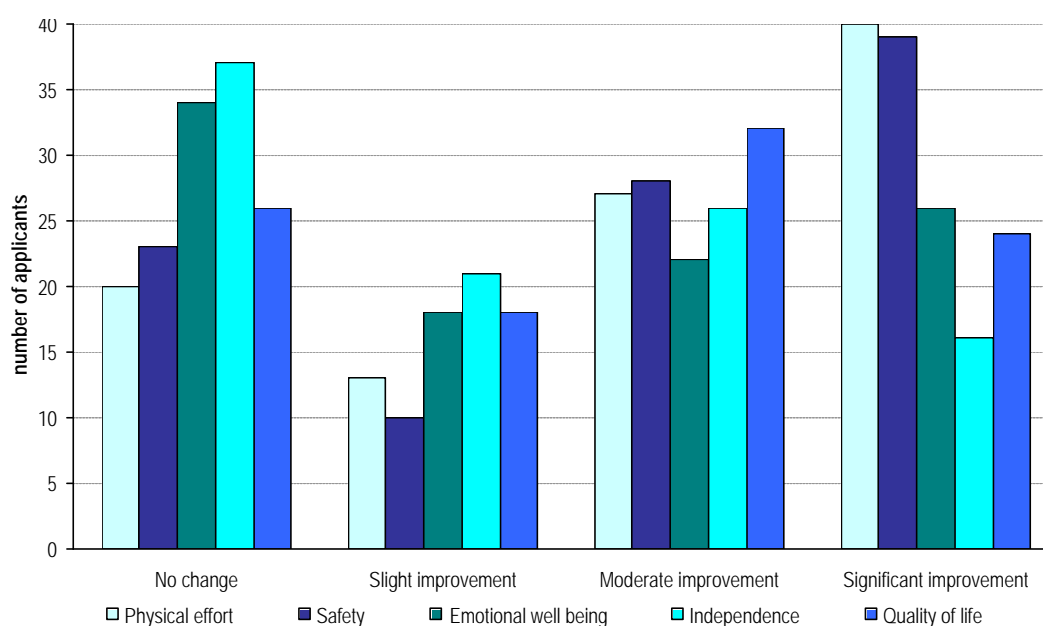


Table 9 details the correlation of each item assessing impact on carers with the domain (scale 1-4), and the variation in the domain explained by that item.

Table 9 Domain review by impact on carers

Item name	No. of assessments	Mean change	Correlation with domain*	Variation in domain explained by individual item
Physical	100	2.87	0.816	66.6%
Safety	100	2.83	0.843	71.1%
Emotional	100	2.40	0.821	67.4%
Independence	100	2.21	0.773	59.8%
Quality of life	100	2.54	0.897	80.5%

* Correlation is significant at the 0.01 level (2-tailed)

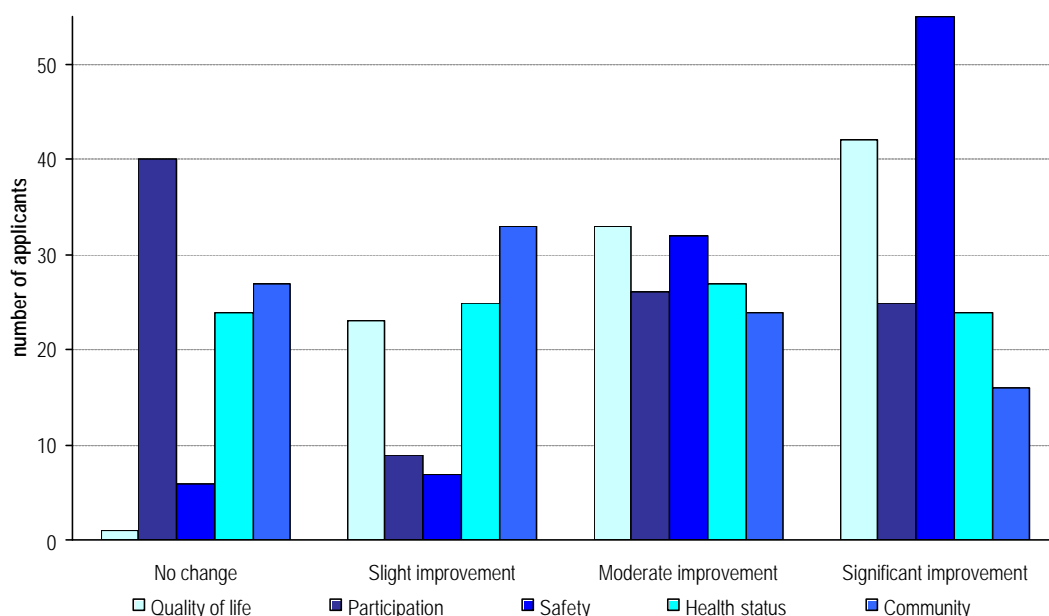
Regression analysis to identify which, if any, items could be dropped from the assessment of impact on carers resulted in the following options (in order, with variation explained in parentheses):

- physical effort, independence, quality of life (96.2%)
- physical effort, quality of life (92.0%)
- physical effort, emotional well being, independence, quality of life (98.0%).

6.2.3 Expected benefits

Provision of the requested item(s) was expected to have the greatest benefit for the applicant in the domains of safety and quality of life. (see Figure 2).

Figure 2 Impact of provision of item(s) on applicant



The adult assessment tool includes 10 expected benefits:

- improvement in self care function
- improvement in domestic function
- change in hours of care and assistance
- impact on people who provide care and assistance
- sustainability of care/self care arrangements
- likelihood of remaining in community/own residence
- improvement in applicant's quality of life
- improvement in applicant's participation in social or community activities
- overall effect on applicant's safety
- overall effect on applicant's health status

Regression analysis was used to determine which, if any, of these domains could be dropped from the scoring of expected benefits. The mean, correlation and variation explained for each domain is shown in Table 10. The table includes the results from using a modified version of the self care functional assessment, domestic functioning assessment and assessment of the impact on carers based on the previous analysis, namely:

- self care - bladder, toilet use, indoor mobility
- domestic - shopping, housekeeping, outdoor mobility
- impact on carers - physical effort, independence, quality of life.

Table 10 Review of expected benefits by domain

Domain	N	Mean	Correlation*	Variation in expected benefits explained by individual domain
Self care	93	2.3	0.599	35.9%
Self care – modified	93	2.1	0.573	32.8%
Domestic	93	1.6	0.588	34.6%
Domestic – modified	93	1.7	0.610	37.2%
Hours of care	93	1.7	0.405	16.4%
Impact on carers	93	2.6	0.543	29.5%
Impact on carers – modified	93	2.6	0.521	27.1%
Sustainability	93	2.4	0.588	34.6%
Community	93	2.3	0.646	41.7%
Quality of life	93	3.2	0.630	39.7%
Participation	93	2.4	0.569	32.4%
Safety	93	3.4	0.470	22.1%
Health status	93	2.5	0.550	30.3%

* All correlations significant at the 0.01 level (2-tailed)

The best model (in terms of the trade-off between number of items included and variation explained) would see the ten domains reduced to six:

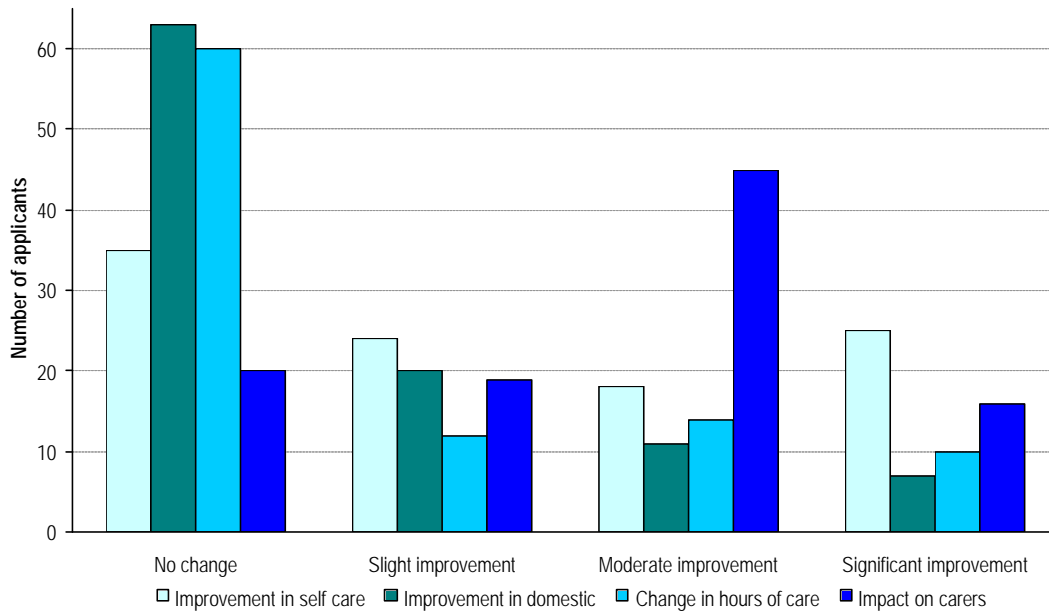
- improvement in self care function
- change in hours of care and assistance
- sustainability of care/self care arrangements
- likelihood of remaining in community/own residence
- improvement in applicant's participation in social or community activities
- overall effect on applicant's health status

This would account for 93.2% of the variation in expected benefits (see Appendix 2).

6.2.4 Review of expected benefits, applicant need and priority

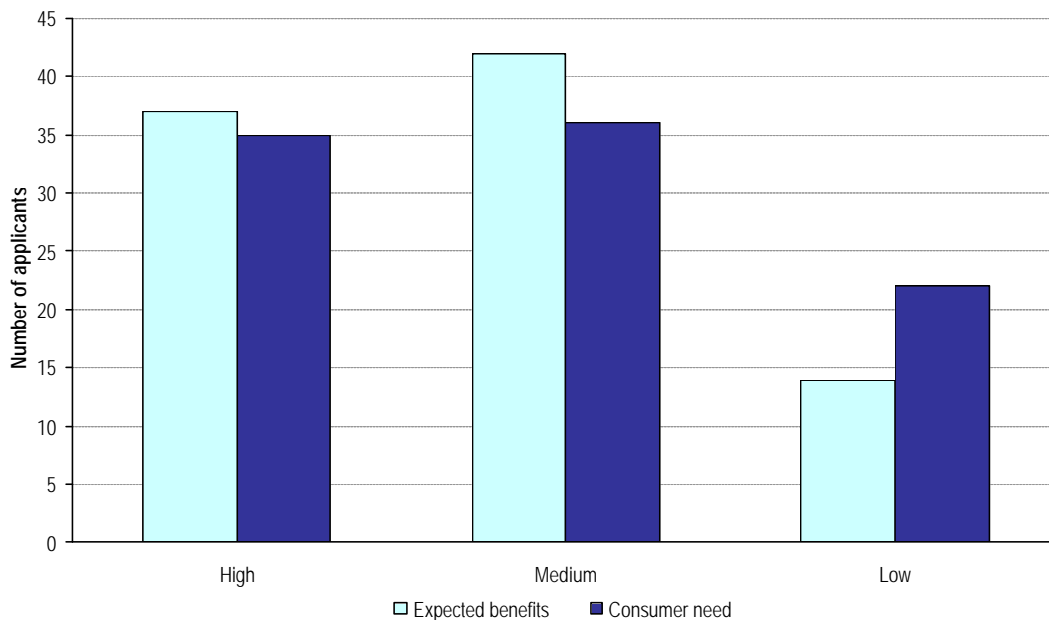
Of the 106 assessments 13 had at least one missing data item resulting in 93 assessments having all items for expected benefits, applicant need and priority assigned. Most applicants had no change in domestic function or hours of care (Figure 3). The largest expected benefit was in the domain of impact on carers, where provision of the requested item was expected to result in a moderate improvement.

Figure 3 Expected benefits 1, 2, 3.1 and 3.2



The results in Figure 4 show that most applicants had medium to high expected benefits and need (medium to low function). Based on the data collected expected benefits and need could be used to distribute the assessments more evenly with recalibration. Given the small number of assessments this was not done.

Figure 4 Expected benefit and need



Most applicants (43.0%) were assigned a priority of four, and the smallest group (5.4%) were assigned a priority of five. With the calculation of expected benefits changed, and the recalibration of both expected benefits and consumer need it is expected the distribution of priority could improve further.

6.2.5 Impact of disability on assessment results

Applicants with 'neuromusculoskeletal and movement-related functions or involvement of structures related to movement' had significantly higher self-care assessment scores without the requested item, slightly higher domestic assessment scores without the requested item, and were more likely to improve in both of these assessments than applicants with other disabilities. More details can be found in Appendix 2.

Significant improvement in carer safety and physical effort were reported more often by carers of applicants with 'mental functions or involvement of structures of the nervous system' than by carers of applicants with other disabilities. Carers of applicants with 'functions or structures of the cardiovascular, haematological, immunological and respiratory systems' were more likely to report significant to moderate improvement in well being and quality of life than other carers.

Despite these differences, all the classifications of disability were similar with regard to expected benefits, need and assigned priority.

6.2.6 Redundant items on the adult assessment form

The adult assessment form used in the field trial has 35 items. If the expected benefits domain were reduced from ten domains to six (self care, hours of care, sustainability, likelihood of remaining in community/own residence, community participation, health status) this would have the effect of reducing the adult assessment by 15 items. Eight of these 15 items are the domestic functioning assessment, which is currently also used in the calculation of the applicant's need for equipment. It is possible to remove these items and base need only on the applicant's self care score.

6.3 Child/youth assessments

Child/youth applicants were typically aged between 7 and 10 years old and were just as likely to be male as female. For most applicants (76.5%) this was not their first PADP application, with most applications (60.0%) for new item(s) costing greater than \$800. For each applicant their disabilities were grouped into function or body system involved using the International Classification of Functioning, Disability and Health. Three out of four child applicants had disabilities related to mental function; these were generally the older children (Table 11). Child applicants typically reported one or two disabilities, with those not listing mental function reporting three or more disabilities. With regard to the nature of the items requested there was a similar pattern to adults with the categories beds and sleeping equipment, seating equipment, and equipment to assist with mobility, toileting, showering and transfers accounting for 84% of all items requested.

Table 11 *Disabilities of child applicants*

Function or body system involved – determined using the International Classification of Functioning, Disability and Health (ICF)	Number (%) of applications		Average age of applicant	Average number of disabilities listed	Proportion of male applicants
Mental functions or involvement of structures of the nervous system	30	(76.9%)	10.0	1.6	53.3%
Functions or structures of the cardiovascular, haematological, immunological and respiratory systems	3	(7.7%)	n.a.	3.0	100.0%
Neuromusculoskeletal and movement-related functions or involvement of structures related to movement	2	(5.1%)	n.a.	3.0	0.0%
Genitourinary and reproductive functions	1	(2.6%)	5.0	5.0	0.0%

Function or body system involved – determined using the International Classification of Functioning, Disability and Health (ICF)	Number (%) of applications	Average age of applicant	Average number of disabilities listed	Proportion of male applicants
Unable to be assigned	3 (7.7%)	4.0	2.0	50.0%
All disabilities	39 (100.0%)	9.4	1.9	52.6%

Among the 35 functional assessments completed, five of the 20 items were missing one or two assessments. Only nine items saw any change. Six of these nine items changed for only one applicant, one item changed for two applicants and two items changed for three applicants. There was no change in any of the cognition components of the Wee-FIM (items 14 to 20). See Table 12 for details.

Table 12 Child/youth assessment – review of functional assessment

Functional assessment item name	N	Mean	Changed	
		without	n	%
Eating	35	1.80	1	2.9%
Grooming	35	1.29	0	—
Bathing	35	1.14	1	2.9%
Dressing – Upper	35	1.26	1	2.9%
Dressing – Lower	35	1.17	1	2.9%
Toileting	35	1.26	0	—
Bladder management	35	1.77	0	—
Bowel management	35	2.06	0	—
Transfers – Chair or wheelchair	34	1.44	1	2.9%
Transfers – Toilet	33	1.27	2	6.0%
Transfers – Bath or shower	35	1.29	3	8.6%
Locomotion	35	1.86	3	8.6%
Stairs	35	1.34	1	2.9%
Comprehension*	35	2.57	0	—
Expression*	35	2.51	0	—
Communication*	35	2.34	0	—
Social interaction*	35	2.11	0	—
Problem solving*	33	2.39	0	—
Memory*	34	2.56	0	—
Mental function*	34	2.88	0	—

* Cognition items

In one quarter of applications, provision of the requested item was expected to change the hours of care provided to the applicant each week in primary care (reduced by an average of 4½ hours) and formal care (increased by an average of 6 hours).

Most applicants were always incontinent. The provision of the requested item(s) had the greatest impact on safety, physical effort and quality of life of the carer. There was mostly no change in the independence of the carer (Figure 5). Half (51.5%) of all care and assistance arrangements were sustainable, however nearly one in five (18.2%) were likely to breakdown in the short term (within 6 months). The greatest expected improvements for the carer were in the domain of safety (Figure 6).

Figure 5 Impact of provision of equipment on carer

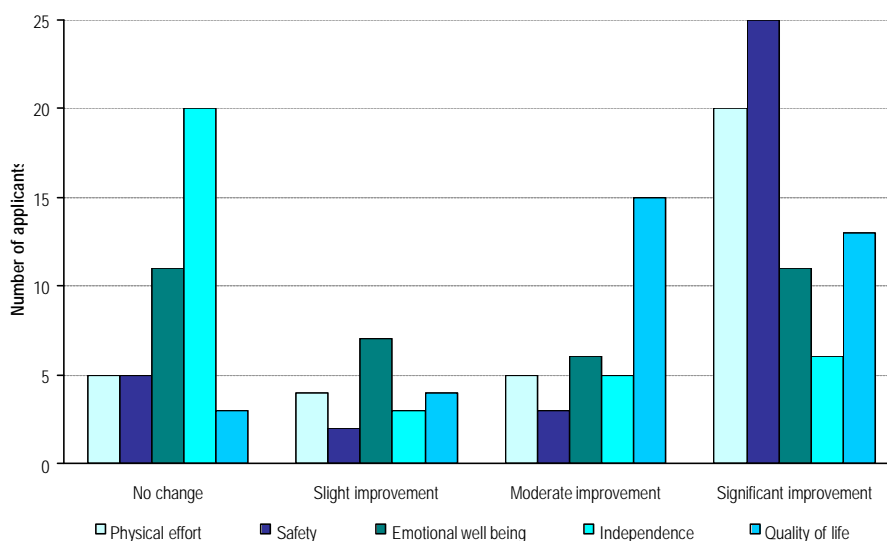
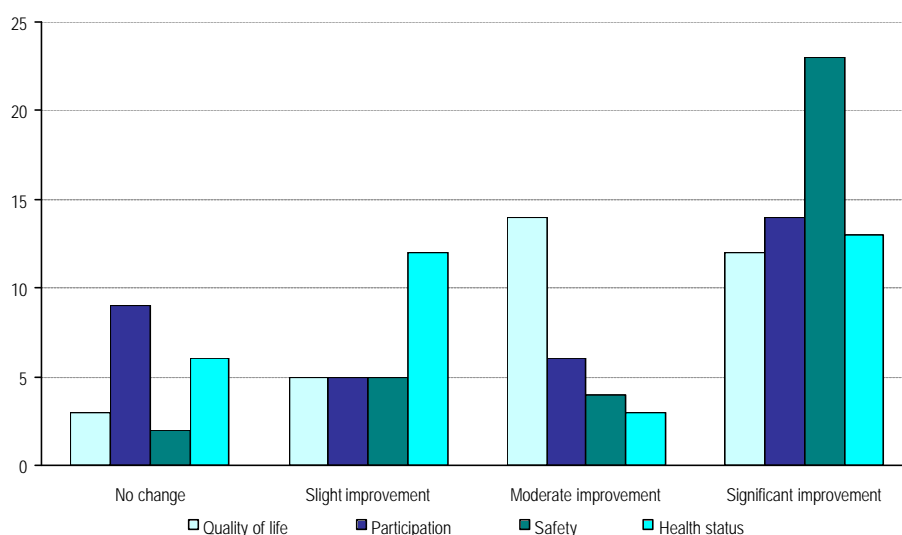


Figure 6 Expected impact on child of providing equipment



6.3.1 Review of expected benefits, applicant need and priority

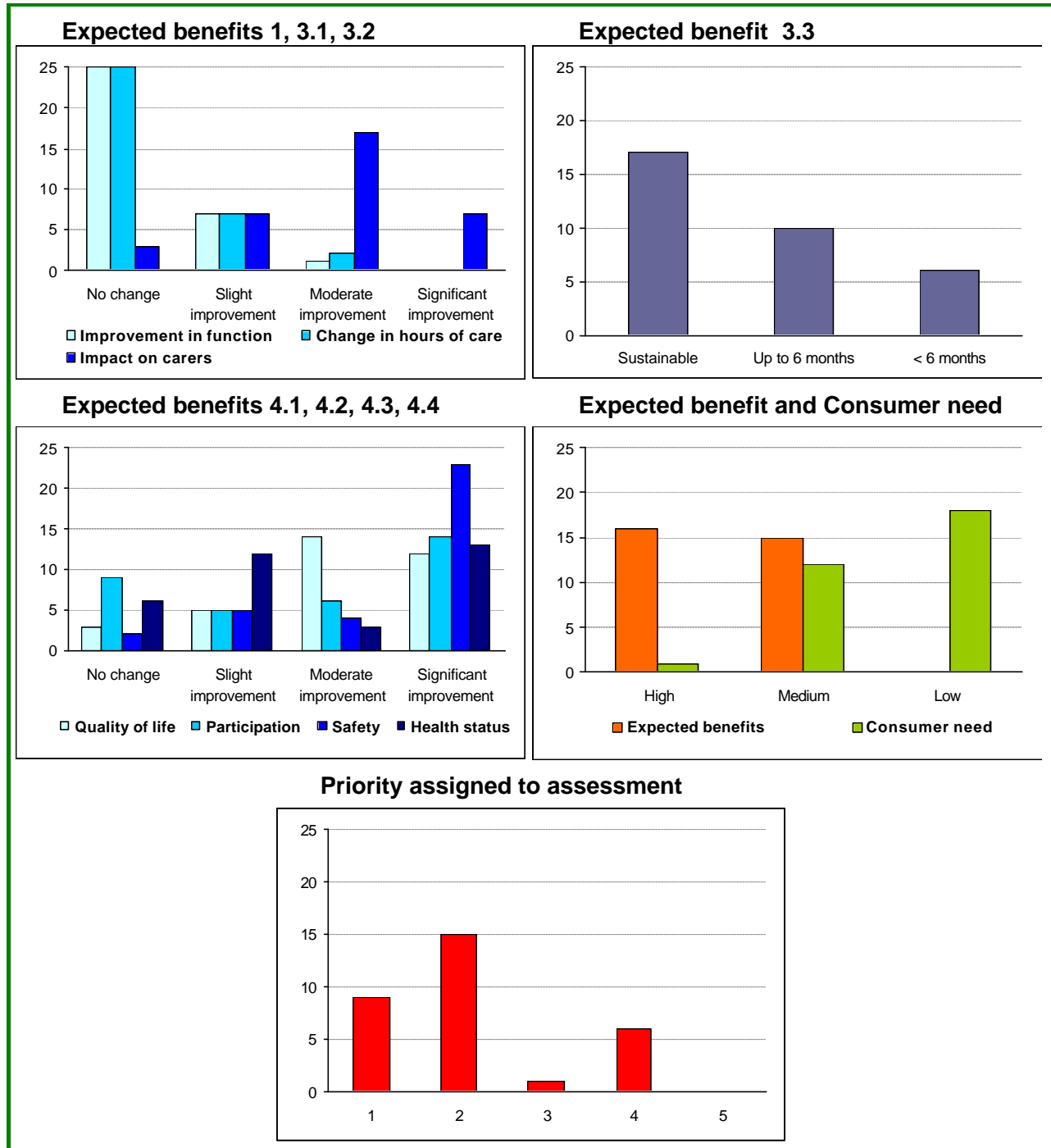
Four assessments had at least one missing data item resulting in only 31 of 35 assessments having an expected benefit, consumer need and priority assigned. Review of the eight domains that create expected benefit found that improvement in function (domain 1), change in hours of care and assistance (domain 3.1), sustainability of care arrangements (domain 3.3) and overall effect on child’s health status (domain 4.4) were not very useful in discriminating between consumers (Figure 7). This could be due to the small number of assessments or the casemix of consumers assessed.

Most children assessed had high expected benefit and/or low consumer need (high function). Based on the data collected both expected benefits and consumer needs require recalibration to distribute the assessments more evenly. However, given there were so few assessments this has not been done.

Most children (77.4%) were assigned a priority of 1 or 2, there were no priority 5s assigned. With the calculation of expected benefits changed, and the recalibration of both expected benefits and

consumer need the distribution of priority would improve. A larger and more representative sample size would be required to do this.

Figure 7 Child/youth assessment – expected benefits, need and priority



6.3.2 Redundant items on the child/youth assessment form

The current child/youth assessment form has 36 items. Due to the small number of assessment collected it was not possible to determine if the number of expected benefit domains could be reduced or if the number of items within a domain could be reduced. The three items on bladder

and bowel management were highly correlated with items 7 (bladder management) and 8 (bowel management) on the functional screen and could be considered redundant.

6.4 Adult incontinence assessments

Among the 23 adult incontinence assessments collected, 14 had urinary incontinence only, one had faecal incontinence only and eight had both urinary and faecal incontinence. Those with faecal incontinence were slightly younger, generally female, and were less likely to be applying to PADP for the first time than those with urinary incontinence (Table 13).

Table 13 Summary of incontinence applicants

Assessment type	Urinary	Faecal	Total
Number of assessments	22	9	23
Gender (%male)	50.0%	22.2%	47.8%
Median age (range)	74 (33-91)	69 (33-84)	74 (33-91)
First application (%yes)	63.6%	44.4%	65.2%
Both assessments	8(36.4%)	8 (88.9%)	8 (34.8%)

The provision the requested incontinence aids had a greater impact on the applicant than on their carer (Figure 8). Applicants typically experienced moderate to significant impact on their independence, quality of life and participation in social and/or community activities, regardless of the type of incontinence. The impact on carers was more varied.

6.4.1 Urinary incontinence

The assessment of urinary incontinence is based on measures of frequency and amount of urine lost each time. Frequency ranges from 'never' to 'every day and/or night'. Of the 21 applicants for which this question was answered 17 (81%) recorded the highest frequency, with two applicants recording '1 to several times a week', one applicant 'less than once a month' and one applicant 'never'. Despite the small number of assessments this accords with comments by staff at the sites participating in the field trial that only people with frequent incontinence generally apply to PADP for assistance with incontinence aids.

The same pattern is evident with the amount of urine lost. On the three point scale from 'a few drops' to 'more' 17 applicants (81%) recorded the greatest amount of urine lost each time. These applicants always had to wear protective underwear. One assessment recorded no score for urinary incontinence.

Given the extremes reported in this data for frequency and amount, the severity index (frequency x amount) was not very good at discriminating between applicants. Most applicants (15 out of 21) had the maximum severity index score of 12. No alternate calculation of the severity index was possible. The amount of urine lost each time accounted for most of the variation in the severity index, and was completely independent of whether protection needed to be worn. Those applicants that experienced leakage every day and/or night were most likely to wear protection always.

The amount of urine lost each time is the most important of the three urinary incontinence questions. If only one question measured urinary incontinence it would be this question. The need for protection is potentially a redundant question. It is not used in the calculation of the severity index and due to its similar responses to the frequency of leakage it is unlikely to be used in future calculations.

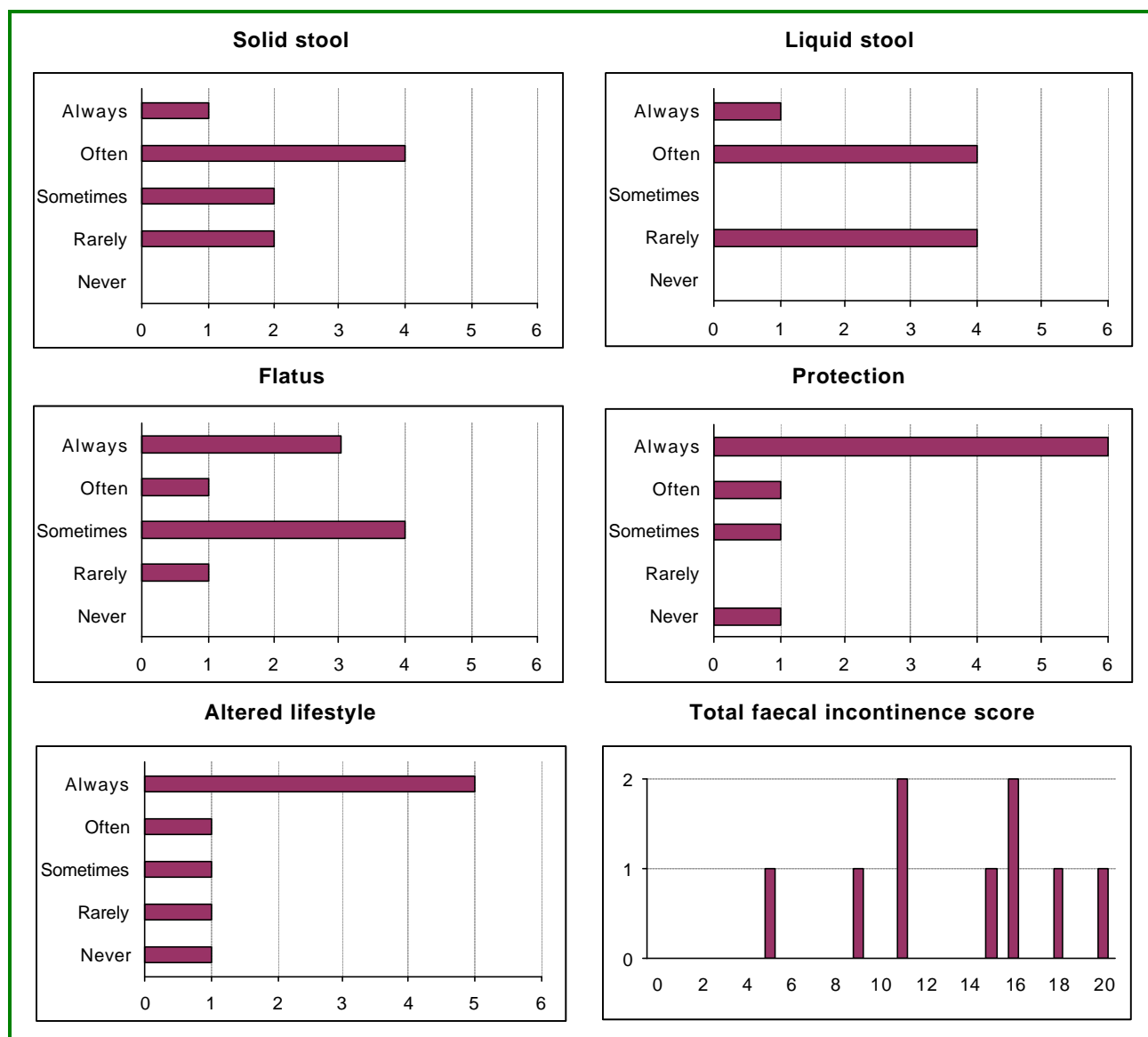
Figure 8 Impact of aids on applicants and their carers by type of incontinence



6.4.2 Faecal incontinence

Most applicants with faecal incontinence always had to wear protective underwear and always had to alter their lifestyle (Figure 9). They were more likely to leak solid stools and least likely to leak flatus.

Figure 9 Summary of faecal incontinence results



The total faecal incontinence score (TFIS) was better at discriminating between applicants than the urinary severity index, with a median of 15 and scores ranging from 5 to 20. Leaking liquid stools and the need for protection were the main predictors of the TFIS (Table 14). The items concerning flatus and solid stool were the least useful. The item on flatus is potentially redundant, accounting for only 1.8% of the variation in the TFIS. Modifying the TFIS to exclude the item on flatus results in a median of 9 and a range of 0 to 16.

Table 14 Correlation between faecal incontinence items and TFIS

	Solid stool	Liquid stool	Flatus	Protection	TFIS
Solid stool					0.656
Liquid stool	0.731*				0.921**
Flatus	0.168	0.457			0.568
Protection	0.412	0.732*	0.290		0.814**
Lifestyle	0.192	0.660	0.233	0.618	0.746*

* Correlation is significant at the 0.05 level (2-tailed).

** Correlation is significant at the 0.01 level (2-tailed).

6.4.3 Redundant items on the adult incontinence assessment form

The current adult incontinence assessment form has 14 items. Due to the small number of assessments collected it was not possible to determine if the number of items could be reduced. The need for protection (urinary) and flatus (faecal) could be considered redundant items.

6.5 Feedback on individual assessments

Although efforts were made to keep the feedback form short and approachable, response rates were very low, particularly on the child/youth assessments. This was probably because the feedback forms were completed after respondents had already spent considerable time completing the assessment forms. The feedback is summarised below.

6.5.1 Adult assessment

A total of 37 adult assessments had completed feedback sheets attached to them (response rate 34.9%). Site 1 supplied feedback for 13 clients, Site 2 for 5 clients, Site 3 for 15 clients and Site 4 for 4 clients. Most of those who completed the feedback sheets for the adult assessments gave their job title as 'occupational therapist' (26, 70.3%). Feedback was also received from two podiatrists and one respondent from each of the following professions: allied health manager, physiotherapist, registered nurse, speech pathologist. Five respondents did not specify their job titles.

Twelve people indicated that they had found some of the assessment questions not useful. Three said none of the questions were redundant, and the remaining 22 left this question blank, although some of these added comments on some aspects of the assessment.

A number of respondents expressed concern that specific issues relating to particular types of items or disabilities - namely, lymphoedema, safety, communication and feeding - were not addressed in the assessment and therefore not reflected in the priority rating. Several others felt that the assessments failed to capture the complexity of the client's situation. One pointed out that many of the questions were addressed in an accompanying report from the occupational therapist, reflecting the fact that sites used both systems in parallel during the trial. Another commented that 'it would be easier to give a brief description of client and carers needs – how the equipment would be beneficial'. Two criticised the wording of some of the questions as subjective or unclear.

For eight clients, health care professionals indicated that the assessment forms had missed some important information. Only one said nothing had been missed, and the remaining 28 left this question blank. Again, respondents highlighted several specific issues that were not covered, including lymphoedema and the distinction between outdoor mobility and ability to use public transport. One felt that questions relating to interactions with family and friends would be useful, and that quality of life impacts were addressed in a 'minimal' way compared with other sections of the assessment. Others described complex interactions between clients' disabilities and their environments which they felt should affect priority. For example, providing a new mattress could conceivably increase a client's safety if she was in danger of self harm due to pain and fatigue. In another case, the client was primary carer for his partner, who had dementia, so increasing his ability to function safely would also improve safety for her. An intellectually disabled man with poorly controlled epilepsy had a high level of function, but only with constant supervision and support. In contrast, one respondent commented that the assessment contained 'too much detail rather than not enough', and specifically highlighted the difficulty of estimating impacts of the requested equipment on carers' time.

Ten respondents made comments criticising the instructions given in the cover sheet (2) or assessment forms (8). On the cover sheet, there was some confusion about how to complete the section on existing equipment; specifically, whether loan equipment or items in the current

application should be included in the list. There were three suggestions for improving the layout of the assessment forms:

- the totals for the Self Care Assessment columns should be on the same page if possible
- better labelling/definition of the columns 'With requested item' and 'Without requested item'
- better flow between questions on the page so that it is clear that sections on the right hand side also have to be completed.

Most of the remaining comments referred to the section on carers. Two made the point that the applicant was also a carer and that the item applied for would affect his/her ability to perform this role. Another said it was difficult to identify the number of hours per week of care required and it would be easier just to state the change in hours with the new equipment. Some impacts on carers, such as quality of life and emotional wellbeing, were seen as not particularly relevant to paid carers. One respondent took issue with the narrow definition of 'transfers' in Q6 of the Self Care Assessment, arguing that this should include not just bed-to-chair but also transfers to the toilet and shower.

Table 15 presents respondents' views on the difficulty of making the ratings and their confidence that the ratings they had made were accurate. Almost half of the professionals who completed the feedback sheets (18, 48.6%) said they found the assessments moderately or very difficult to make. Nevertheless, most (23, 62%) were very or fairly confident about the accuracy of their ratings. Three people declined to answer either of these questions.

Twelve respondents (32.4%) took up the invitation to add further comments at the end of the form. All but two were occupational therapists. Seven comments related to the length of the assessment process, which was described as 'time consuming', 'cumbersome' and 'not user friendly'. Two said the assessment had taken over an hour to complete. One criticised the layout of the forms and also stated that some of the information requested (about when other items of equipment were received) was not relevant and difficult to obtain. In contrast, one respondent said the 'only hard question was hours of care per week'. Two others also commented that carers' hours were hard to determine, particularly in informal or group home care settings. One respondent felt that the impact of pain relief from supportive equipment should be included in the assessment, and another commented that the form did not accurately reflect the benefits of outdoor mobility aids. Clients with complex needs were said to be difficult to assess.

Table 15 Respondents' views about the difficulty of making the ratings and their confidence in the accuracy of the ratings

How difficult was it to make the ratings? Tick one box only.						
Assessment type	N (%)	Very easy	Moderately easy	Neither easy nor difficult	Moderately difficult	Very difficult
Adult	34 (32.1)	3	10	3	14	4
Child/youth	4 (11.4)	0	2	1	1	0
Adult incontinence	6 (25.0)	4	1	1	0	0
How confident do you feel that the ratings you have recorded are accurate? Tick one box only						
	N (%)	Very confident	Moderately confident	Neither confident nor otherwise	Not very confident	Not at all confident
Adult	32 (30.2)	1	22	3	4	2
Child/youth	3 (8.6)	2	1	0	0	0
Adult incontinence	5 (20.8)	1	4	0	0	0

Percentages are based on the total number of assessments received in each category

6.5.2 Child/youth assessment

Only six feedback reports were received on child/youth assessments (response rate 17.1%). Five of these were from Site 3 and one from Site 4. Four respondents gave their job titles; of these, two were occupational therapists and two were clinical nurse specialists.

One respondent felt that the question on current equipment required too much detail about when this was supplied and by whom, and it was difficult and time consuming to track down this information. The other respondents did not highlight any redundant questions.

The forms did not miss any important information, according to the six health professionals who provided feedback. One remarked on the amount of detail collected. Another suggested that the information was not particularly relevant to children and young people with continence problems.

There was just one comment on the instructions, and that respondent declared that 'instructions were good'. Feedback on the difficulty of making the ratings and confidence in their accuracy is provided in Table 15. The few who responded to this question appeared to find the rating exercise reasonably easy and were confident the ratings were accurate. Three respondents provided further comments at the bottom of the form. These comments related to the time taken to complete the forms and their relevance to children with disabilities.

'The questions on incontinence and impact on client and carer are not relevant as assistance in changing and cleaning are nearly always needed with disabled children.'

'Lengthy and time consuming. The applicant currently has a tilting wheelchair. The scores reflect an expected improvement from the features of that chair (which she has currently outgrown).'

'It was time consuming to write my details at the bottom of every page.'

6.5.3 Adult incontinence assessment

Feedback forms on the adult incontinence assessment were received for 10 clients (response rate 41.7%). Two of the feedback forms, however, contained no information other than the client ID number and another included only the ID number, service name and job title. Of the six respondents who gave their job titles, there were two community nurses, one clinical nurse consultant, one continence clinical nurse consultant, one registered nurse and one continence advisor.

No respondents highlighted questions they felt were not useful. One asked whether a paid carer should be classified as 'no carer'. Two respondents raised questions not addressed in the assessment:

- How long have symptoms been present?
- Is surgery an option?
- How many pads are currently used?

They also raised the issue of how to answer questions if a catheter was already in place, and suggested that a space for extra comments should be provided on the form.

Two respondents raised concerns about the instructions. One felt that the impact question did not allow for impacts on convenience and finances. The other suggested changes to the severity index:

'SEVERITY INDEX CONFUSING. HEADINGS SHOULD BE Frequency (for how often leakage occurs) and Amount for (how much urine is lost)'

Table 15 shows that most respondents found the rating system easy to use and were confident that the ratings they had recorded were accurate.

Just one additional comment was made:

'Cover sheet and severity index, if to be used, should be incorporated into PADP application.'

6.5.4 Vision Australia trial

In addition to the trials at the four PADP centres, Vision Australia conducted a trial to determine the suitability of the adult and child/youth assessments for people with sensory impairment. Since September 2004, equipment relevant to people with sensory impairment has been included under the NSW Health PADP scheme. Both adult and child/youth assessments were used with each of seven applicants, all aged over 15 years. Six applicants were seeking equipment specific to people with sensory impairment, such as video magnifiers, braille equipment, a talking glucometer and a vibrating paging system. The forms were found to be straightforward to use, but they omitted important domains of function which are particularly relevant to people with sensory impairments.

The Vision Australia trial found that the adult self care and domestic functioning scales appeared strongly oriented towards clients with physical impairments. Some areas in which people with sensory impairments could benefit from equipment, such as gaining access to written communication and print information, were not covered. Other questions were not relevant, including those relating to bowel and bladder function, toileting, feeding, transfer and bathing. The domestic functioning form contained more relevant items than the self care assessment, but did not highlight areas in which the requested equipment could have a positive impact, such as reading and writing.

In the child/youth assessment, the question on 'locomotion' focused on physical ability and distances clients could travel, not taking into account the ability to orient themselves and negotiate the environment, avoiding obstacles and finding their way. Nevertheless, the child/youth assessment did contain some questions more relevant to people with sensory impairments. These included comprehension, expression, communication and social interaction. One deafblind client scored a higher priority on the child/youth assessment than on the adult assessment due to the inclusion of these items.

Overall, most applicants scored well on the functional assessments and their scores were similar with and without the requested equipment. This is to their disadvantage, as relatively low scores on both consumer need and capacity to benefit would place them in a low priority group. Vision Australia recommended that the functional assessments should include questions on reading/writing and environmental awareness (e.g., ability to detect alarms). Areas such as communication, expression, social interaction and comprehension may need to be included in the adult assessment as well as in the child/youth assessment.

6.6 Feedback from PADP committees

Feedback on a set of questions written for the trial (see Appendix 1) was received from PADP committees at three of the four sites in the trial. At the fourth site no applications using the tools being tested were sent to the local PADP Committee and hence no feedback was sought from that committee. This was in accordance with standard practice at that site where very few applications are submitted to the PADP Committee. This site was also distinguished by the fact that all items requested using the assessment tools being tested were not only approved but supplied immediately, with no need to place requests for equipment on a waiting list.

6.6.1 Time taken to complete the tools

Estimates of the time taken to complete the tools ranged from 40 minutes to over one hour. Therapists who had completed only one or two assessments and were unfamiliar with the process took the longest. There was some acknowledgment (from both the committee and individual feedback) that speed would increase with practice. During the trial, therapists used the pilot tools in addition to their usual application process, which represented a considerable burden of time and effort.

6.6.2 Validity of this approach to assessment

Committee members at two sites were very comfortable with the idea of using need and capacity to benefit as the dimensions for assigning priority. There was some concern about whether the tools were sensitive enough to pick up changes in function for some clients, particularly those with low function. Nevertheless, the range of items assessed was considered appropriate and there were no relevant areas they felt needed to be added to the assessment.

The PADP Committee at one site, however, had some serious reservations. Assessment of both need and capacity to benefit was seen as rather subjective, and the committee also pointed out that there would be different issues for young disabled people and aged people. It was felt that the pilot tools may disadvantage elderly people applying for items for safety reasons. Under the current ranking system used by that committee, such items are supplied as a top priority because of the emphasis on keeping applicants in their own homes and out of institutions.

There was some confusion over how the capacity to benefit questions should be answered if the client had loan or rental equipment. (This confusion was also apparent in the individual feedback on some applications).

6.6.3 Determining priority

Safety issues were considered of prime importance by all three committees. Items designed to address occupational health and safety problems for carers or prevent injury to applicants tended to be funded immediately. Committee members from two sites felt that safety issues should therefore be given greater importance when determining priority. One PADP coordinator explained:

If items are delayed then clients are at risk of representing into hospital. For the elderly the risk of representing ... may be a lot higher and the effect of a fall due to not having the equipment could be quite dramatic in terms of recovery and returning to previous levels of independence. Equipment is put in place as a preventative measure.

One of the committees commented that issues such as quality of life should be given less weight in determining priority. It was, however, pointed out by a committee member from another site that quality of life may be particularly relevant for child applicants. This person felt that the impact of the requested items on the child's ability to socialise and interact with other children and adults was not given sufficient weight. For children about to start school, the item(s) might make the difference between attending school or not attending school.

Occupational therapists had raised concerns with one committee that the tools were unsuitable for people with lymphoedema. Such people would receive a low priority rating, partly because they could function independently with no carer. Despite this, they required their equipment immediately because they could not do without it.

Differences in the makeup of committees in different areas may affect the reliability of the pilot assessment tools. It was pointed out that committees vary widely in terms of their composition of consumer and provider representatives. The discussion that takes place during meetings may be as or more influential in the decision-making process than the assessment tools used.

6.6.4 Information that could be added to the assessment

One committee named several items of information routinely used in their existing system that were not captured on the pilot assessment forms. These were:

- carers' health and functional ability
- carers' ability to sustain care arrangements
- social supports and extended family
- an assessment of the risk to the applicant and/or carer if funding is delayed beyond the time when loan equipment has to be returned
- an estimate of the financial burden of the withdrawal of loan equipment and whether the client can bear these costs

PADP committees, with their focus on meeting needs within a limited budget, sometimes consider alternatives to the more expensive equipment requested in applications. The years of experience and the different perspectives represented on PADP committees enable them to suggest other options, whereas the prescribers and applicants may be 'fixed' on a particular solution to the problem. This expert prompting role of the committee could potentially be built into the assessment tools if they were interactive and web based. The tools could prompt applicants to trial a set of simpler solutions where possible. This would work best for straightforward requests. It would be more time consuming to trial alternatives for clients with complex needs and care situations.

All three committees were keen to see some way of including an applicant's 'story' in the assessment process. The story is a description of how the requested items fit with the applicant's diagnosis and his/her personal circumstances. The committees rely heavily on these descriptions, particularly in complex cases, and there was some concern that the pilot assessment 'is reducing clients to a number' and 'does not give the information we need'. Without the accompanying narrative report, the assessment process was seen as narrow and incomplete.

6.6.5 Comparison with existing systems

The priority rating systems currently in use at these three sites differ in their details but all are essentially based on a waiting list system. In this respect they differ markedly from the pilot assessment system, which divides applicants into groups according to need and capacity to benefit, rather than when items are required.

Under the current system, few applications (if any) are rejected outright, but applications tend to be divided into those that must be funded immediately and others, which go onto a waiting list. The length of the wait is not defined in terms of months, but different levels of urgency are implied. For example, the criteria for prioritisation at one site are:

Immediate purchase

- Life sustaining / life threatening
- Tracheostomy
- Kangaroo pump
- Suction pump

Priority 1

- Risk of injury
- Institutional admission will result if aid not supplied
- OH&S of carer / service at risk

Priority 2

- Client managing with difficulty

Priority 3

- Aids solely for leisure
- Marginal clinical benefit

At this site, applications rated as Priority 1, 2 or 3 go on the waiting list and are purchased as funds become available. At another site, more weight is given to clients reapplying for funding as there is an implicit assumption that the priority should be higher if the person has already waited some time. Equipment that will mainly benefit the carer receives a lower rating than equipment that directly affects the applicant. Equipment that addresses safety concerns tends to receive the highest priority rating.

At the third site, applications are rated very high (fund immediately), very high (waiting list), high (waiting list) and medium (waiting list), although in practice few are assigned to medium priority. The PADP coordinator chooses individual items from approved packages of items for particular clients as funds become available. This is done in consultation with prescribers. Applications for incontinence items that are approved have to wait until someone currently receiving incontinence items dies. When that happens, one of the approved applications is chosen from the waiting list and funded.

No sites appear to specify how long an applicant can expect to wait for an item given a particular priority rating. At least one of the sites, the process by which applications are chosen from the waiting list for funding is a combination of the priority assigned to the application and lobbying by the therapist who prescribed the item. This takes the form of direct communication between the prescriber and the PADP coordinator, in which the prescriber explains why the applicant is now in dire need of the item (for example, because safety concerns have arisen).

One committee acknowledged that, to some extent, the priority categories set down in the pilot tools may be 'translated' into urgency rather than need. Given that this may occur, the committee recommended that the pilot tools should include more detailed information to help committees assess the urgency of applications and classify them, for example, into those that should be funded now versus those that should wait or be followed up for more information.

At one site, no priority is assigned to some applications if the items are held in stock and can be supplied immediately. This site holds a considerable stock of equipment including many high-cost items. The need to set priorities for these items is likely to arise, however, when this existing stock of items runs low. Many items in stock have been accumulated from clients of the Department of Veterans Affairs but since applications from this client group are no longer processed through PADP committees this source of stock has now ceased.

Another issue raised by one site was the need to distinguish between desirable and necessary features on customised equipment. Many of the committee's debates centred on the cost of additional features and whether these were 'a clinical need or a want of the client'. Each request was considered on its individual merits, allowing for customised features that were clinically warranted and applying the DOH policy that basic equipment is provided to meet need. Some

price capping was applied in order to keep the waiting lists manageable. Under the existing system, applications for items such as complex wheelchairs, custom seating systems and specialised showering equipment were accompanied by reports outlining relevant information and justifying why a particular model was required. The committee felt that the pilot assessment system did not capture the level of detail needed to make decisions on expensive, complex, customised equipment. It could, however, be useful to speed up the application process for basic items.

The adult and child/youth assessment tools include a question asking prescribers to describe why they have requested equipment that is more expensive than the base model. It was suggested that the emphasis of this question could be changed, so that it asked for justification of customised features. Again, the key point was the need for a narrative 'story' providing a more complete explanation.

6.7 Priority Rating Exercise

Two sites (Site 2 and Site 3) followed the instructions for the priority rating exercise and categorised three applications as 'highest' and three applications as 'lowest'. One site (Site 1) was unable to prioritise three applications because of lack of information and then proceeded to prioritise one application as 'lowest' and all other applications as 'highest'. When asked for a reason for doing so the response was that no applicant should be disadvantaged because of lack of funds. Site 4 also only rated one application as 'lowest'. The results are summarised in Table 16.

Table 16 Results of priority rating exercise

Case no.	CHSD priority *	Site 1	Site 2	Site 3	Site 4
1	4	Lowest	Highest	Lowest	Intermediate
2	2	Highest	Highest	Highest	Highest
3	4	More info	Intermediate	Intermediate	Intermediate
4	1	Highest	Highest	Intermediate	Highest
5	4	Highest	Lowest	Lowest	Intermediate
6	5	Highest	Lowest	Intermediate	Intermediate
7	3	More info	Highest	Highest	Highest
8	3	More info	Lowest	Lowest	Intermediate
9	4	Highest	Intermediate	Highest	Highest
10	2	Highest	Intermediate	Intermediate	Lowest

* CHSD priority is the priority assigned by the adult priority rating tool used in the field trial where '1' represents the highest priority and '5' represents the lowest priority.

Excluding those instances where a priority could not be assigned due to the need for more information there were three cases (cases 2, 3 and 7) where there was agreement amongst the sites on the level of priority. At the other extreme there were four cases (cases 1, 5, 6 and 10) where all three priority options were assigned by different sites. Given the reluctance at two sites to assign the lowest level of priority to any application this discrepancy might have been greater if the instructions for the priority rating exercise had been followed.

7 Discussion

7.1 General comments

Based on feedback from the four sites participating in the field trial it was anticipated that a two month field trial would yield approximately 300 applications using the adult, child/youth or adult incontinence tools. The number actually obtained in the field trial (164) is therefore disappointing, although in part this was due to the very low response from one site. If the yield from the site with the low response had approximated that of the other three sites the total number of assessments would have been about 200. The number of child/youth assessments appears low (with two sites only yielding one assessment each) but at 21% across the four sites is actually more than the 15% of applications in the 0-15 age group seen across NSW.

Data collection in the field trial proved to be much more difficult than originally anticipated. All sites chose to run the trial 'in parallel' with their existing systems, with each assessment taking up to one hour, over and above the normal work requirements of prescribers. Sites were all keen to use the database developed for the field trial but this also proved to be more time consuming than anticipated. This prevented one site from entering any of the data themselves and the research team entered the data.

Few prescribers took the opportunity to provide feedback on individual assessments. It is highly speculative to make judgements about the reasons for not using this opportunity more but there were some comments during the field trial along the lines of 'if the therapists were unhappy with the tools they would tell you so', suggesting that at least in some cases non-response equated to some measure of satisfaction with the tools. Certainly there was a positive response from prescribers (primarily occupational therapists) during the training sessions for the field trial. The only suggestion that the tools did not fit with current professional practice was the comment by some occupational therapists that the tools would be more difficult to use for health professionals other than occupational therapists who would be less familiar with instruments that assessed function.

It is interesting to note what appears to be a considerable variation in PADP resources across the four field test sites. One site approved all applications included in the field trial and had sufficient resources to purchase all items immediately. At the other extreme another site likewise approved all applications but only 12% were approved for immediate purchase.

The design of this project assumed that applications for high cost items would require item-specific assessments to augment the person-specific assessments developed as part of the project. We did not see a lot of evidence of systematic use of item-specific assessments, although much detail was included in narrative form as part of reports by prescribers.

7.2 Need and capacity to benefit

The consultation process, comments by prescribers at training sessions for the field trial and feedback from the field trial all support use of the concepts of need and capacity to benefit to assign priority for PADP with the exception of one field test site. That site had reservations about what they saw as the subjective nature of this assessment process and concerns about the particular needs of the young disabled and the elderly.

The results of the field trial indicate that the number of expected benefits in the adult assessment tool could be reduced to six:

- improvement in self care function
- change in hours of care and assistance

- sustainability of care/self care arrangements
- likelihood of remaining in community/own residence
- improvement in applicant's participation in social or community activities
- overall effect on applicant's health status

These results accord with the views of those involved in the pilot test who considered the self care functioning assessment to be more useful than the domestic functioning assessment. This would reduce the adult assessment from 35 items to 20 items. The major change would be exclusion of the eight items in the domestic functioning assessment, which is currently also used in the calculation of an applicant's need for equipment. If this was done need would be based solely on the applicant's self care score.

The results of the field trial suggest that the self care domain (as a means of assessing expected benefits) could be reduced from ten items to three. However, removal of the domestic functioning assessment from the adult assessment (and hence from the calculation of applicant need) indicates that the self care functioning assessment should be retained in its entirety, given that it is used in many other areas of assessment, rather than reduced to just three items as suggested by the statistical analysis.

Concerns have been raised at various stages of this project regarding the suitability of the assessment tools for particular client groups. One such example is applicants with lymphoedema. The impromptu trial of the tools with a group of clients with sensory impairment suggests that the tools would not be suitable for that group.

Based on the pilot study many changes were made to the assessment and priority rating tools, including the addition of items to assess safety and health status. No evidence was generated during the project to suggest the addition of any more items, over and above those used in the field test.

One caveat regarding these results concerns the inclusion of items for safety, for both applicant and carer. Although statistical analysis suggests not including safety because it does not discriminate well between applicants it is an issue that was mentioned frequently during pilot testing and the field trial, and was strongly supported by PADP advisory committees. It was clear from the committees that applications addressing safety issues are most likely to be funded immediately. This may have contributed to the lack of variability in this item in the assessments as prescribers are aware that raising safety issues will increase their client's chance of receiving the item quickly. Our considered opinion is that any assessment tool for PADP applications that did not incorporate safety would not have credibility with prescribers or PADP committees. Based on the results from this study, we would expect most applicants to have high expected benefits in the domain of safety, but it would be the other items highlighted in the statistical analysis which would discriminate between them in establishing priority.

The item on hours of care and assistance involves three steps – assessing the number of hours required by the applicant without the equipment requested, estimating the number of hours required by the applicant with the equipment, and then using the difference in these two values to assign a score ranging from 1 (no change or increase in hours) to 4 (significant change in hours). The first two steps are means to the third step but proved difficult for prescribers to assess. We suggest that the item be simplified to include only the third step i.e. an estimate by prescribers of the change in hours, based on a range of four options. The three items on the adult assessment form regarding care and assistance issues are not used in the calculation of priority, and therefore might also be considered for removal.

The low number of child/youth assessments in the field trial prevented a determination of whether any of the expected benefit items could be removed from the assessment. Very few changes were noted on the functional assessment, particularly the cognition items for which there were no

changes recorded for any application. PADP applications represent only 15% of the total and if the field test results are any guide the majority are for high cost items, which were not the focus of this project. If introducing a common assessment system is more of a priority for adult rather than child/youth applications it may be worth introducing the former and delaying the introduction of the latter until the success of a new format for adult applications can be properly gauged.

It is very clear from informal feedback, observations by the research team, and the feedback specifically sought for this project that prescribers, PADP managers and PADP committees are very attached to the current systems in place that rely heavily on the narrative reports by prescribers. Prime importance is given to the applicant's 'story', which principally revolves around how the requested equipment fits with the applicant's disability and their personal circumstances. It is our understanding that a state-wide working party is to be convened to establish a standard format for this type of report.

During the field trial the assessment and priority rating tools being tested were an 'add-on' to existing systems, including the narrative reports. Serious consideration needs to be given to the extent to which the tools tested for this project can substitute for the content of the current reports completed by prescribers. It is our view that some details of the applicant's story (essentially the clinical justification for the equipment) are essential and should be retained, preferably using a standard format. However, introducing a suite of assessment tools similar to those developed for this project and leaving current systems unchanged would result in unnecessary duplication.

7.3 Priority setting

The existing systems of priority setting at each field test site use 3-4 levels of priority, but the majority of applications are typically assigned to one level of priority. For example, at one PADP advisory committee meeting attended by the research team 22 out of 25 applications were assigned the same priority. It was originally intended that the priority assigned using the 1-5 levels of priority incorporated in the adult and child/youth assessments would be compared with the priority assigned using existing systems. However, this was not possible due to the nature of the existing systems and the fact that a high number of adult applications (43%) ended up being assigned one level of priority (priority 4) by the adult priority rating tool used in the field trial. The number of child/youth assessments was too small to make such a comparison and the incontinence tool does not include priority setting.

Because of these difficulties the priority rating exercise was developed to try and determine the extent to which the adult priority rating tool could be used to establish relative priority between applications. The results of this exercise were disappointing, with low level of agreement between the four sites involved. These results, and our own observations and interaction with staff at the four field test sites, leave us to conclude that it was overly optimistic to expect people to meaningfully use a totally different system of assigning priority within such a short space of time, particularly when the existing system continues to be used.

For three of the four field test sites not only is it rare to reject applications but few items are approved for immediate purchase. The current systems are effectively systems for managing a waiting list of PADP applications. Consideration should be given to whether this should be more formally acknowledged in any new tools implemented state-wide. We did not incorporate any 'weighting for waiting' in the tools we developed although we did consider doing so. There may be some parallels with the system used to prioritise elective surgery. For example, priority 1 PADP applications could be approved for purchase within (say) one month, priority 2 within three months and priority 3 within six months. Targets could be set and performance monitored using such measures.

At the commencement of the project it was unclear whether it would be possible to establish thresholds that could be used to determine a priority rating for each applicant. The results of the field test indicate that such thresholds cannot be assigned with any degree of confidence,

particularly given the options for removing items from the assessment canvassed in this report. It is recommended that the first step would be to get agreement to adopt a common assessment system state-wide, then collect data for a reasonable period of time (say one year), then use the results to establish indicative thresholds, not forgetting that these tools are designed to assist in decision making, rather than serve as a complete substitute for the current decision making by PADP managers and PADP committees.

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Appendix 1 Questions for PADP committees and coordinators

Approximately how long did it take prescribers in your area to complete the assessment tools?

Do you have any comments on the use of 'need' and 'capacity to benefit' to decide the priority of PADP applications?

Are the range of items on the adult and child assessment forms (functional status, hours of care and assistance, impact on carers, sustainability of care / self care arrangements, likelihood of remaining in community/own residence, quality of life, participation in social or community activities, safety and health status) appropriate to determine priority? Invite comments on any particular item.

Should any of these items be given greater importance when determining priority? Why?

Are there any items of information not captured on the assessment forms that you routinely use in your existing assessment of PADP applications?

How do the assessment and priority rating tools compare with your existing system?

Can you suggest any improvements to either the assessment tools or the priority rating tools?

Any other comments?

Appendix 2 Additional results from field testing

Handling of incomplete and inaccurate data

Where data were incomplete or incorrect it was sent back to the PADP centre for review. Subsequent to this, where missing data could be derived (Table 17) they were. Where data remained missing, those assessments were excluded from expected benefit, consumer need and priority calculations but, where possible, were included in validating individual items.

Table 17 Treatment of missing data

ITEM(S)	IF...	THEN...
All items	blank or out of range	follow-up
Hours of care	one NEW = blank and other NEW > 0 OR one CURRENT = blank and other CURRENT > 0	follow-up
Hours of care type, self care, domestic	CURRENT = 0 and NEW = blank	NEW = CURRENT
Hours of care type	NEW = 0 and CURRENT = blank	CURRENT = 0
Self care, domestic	NEW > 0 and CURRENT = blank	CURRENT = NEW
Hours of care	any CURRENT/NEW = 0 and other CURRENT/NEW = blank	other CURRENT/NEW = 0
Impact on carer (adult only)	ITEM = blank and Carer availability = 3	ITEM = 1

Additional results from adult assessments

Table 18 and Table 19 provide extra summary information about adult applicants.

Table 18 Summary of applicants

Summary	N	Statistic	Value
Gender	103	Proportion of males	50.5%
Age	71	Mean (95% CI)	69.3 (65.4-73.3)
		Median (range)	75 (23-96)
First Application	104	Yes	56.7%
Reason for assessment	75	<\$800	54.7%

Table 19 Age distribution of applicants

Summary of age by:	N	Mean (95% CI)	Median (range)
GENDER	Female	51 71.1 (65.6-76.7)	76 (34-96)
	Male	52 67.3 (61.2-73.4)	72 (23-93)
FIRST APPLICATION	Yes	59 73.1 (68.8-77.4)	76 (34-96)
	No	40 61.9 (53.7-70.1)	64 (23-86)
	Not sure	5 77.7 (57.0-98.4)	75 (71-87)
REASON FOR ASSESSMENT	<\$800	41 74.5 (69.0-80.0)	78 (35-96)
	\$800+	34 63.3 (53.0-73.6)	63 (23-94)

Figure 10 and Figure 11 provide details about care arrangements.

Figure 10 Care and assistance issues

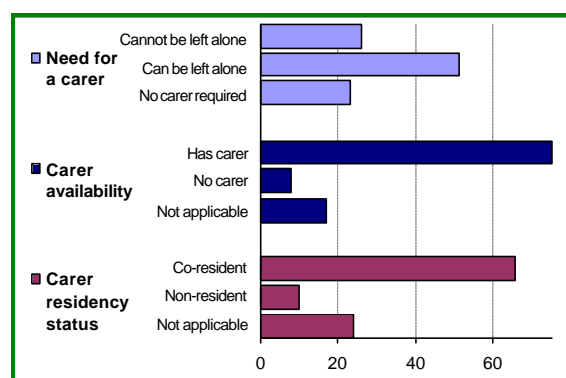


Figure 11 Sustainability of care arrangements

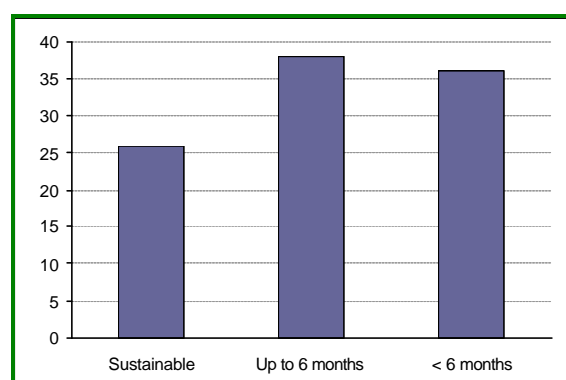


Table 20 shows the results from the regression analyses used to determine which, if any, items could be dropped from the self care, domestic and impact domains. Table 21 shows the high correlation between the new domains for self care, domestic and impact (each based on three items) with the original domain for each.

Table 20 Regression results – item reduction in self care, domestic and impact domains

Items considered in the new domain	Correlation with current domain total	Variation explained	Items selected for new domain
SELF CARE DOMAIN (was 10 items)			
Bathing, Bladder, Transfer, In-Mobility, Toileting	0.975	95.0%	3rd best
Bathing, Transfer, In-Mobility, Toileting	0.944	89.1%	-
Bladder, Transfer, In-Mobility, Toileting	0.965	93.1%	2nd best
Transfer, In-Mobility, Toileting	0.934	87.3%	-
Bladder, In-Mobility, Toileting	0.951	90.5%	Best
In-Mobility, Toileting	0.917	83.7%	-
DOMESTIC DOMAIN (was 8 items)			
Shopping, Food prep., Housework, Laundry, Out-Mobility	0.990	98.0%	3rd best
Shopping, Housework, Laundry, Out-Mobility	0.982	96.4%	2nd best
Shopping, Housework, Out-Mobility	0.970	94.1%	Best
Shopping, Housework	0.944	89.0%	-

Items considered in the new domain	Correlation with current domain total	Variation explained	Items selected for new domain
IMPACT DOMAIN (was 5 items)			
Physical, Emotional, Independence, Quality of life	0.990	98.0%	3rd best
Physical, Independence, Quality of life	0.981	96.2%	Best
Physical, Quality of life	0.959	92.0%	2nd best
Quality of life	0.897	80.5%	-

Table 21 Current domains compared with new domains – self care, domestic and impact

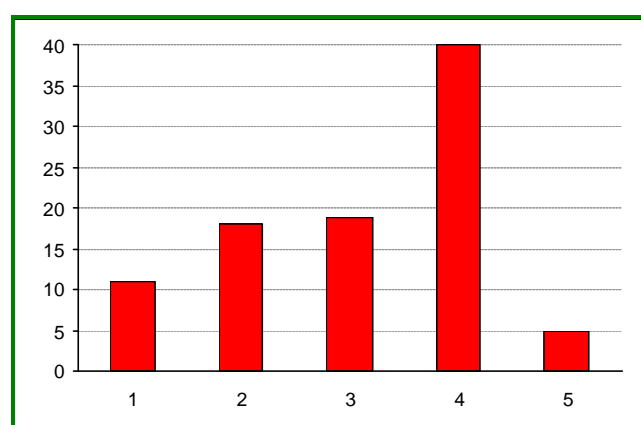
Domain	Number of items		Correlation	Items in new domain
	Current	New		
Self care	10	3	0.878*	Bladder, In-Mobility, Toileting
Domestic	8	3	0.988*	Shopping, Housework, Out-Mobility
Impact	5	3	0.961*	Physical, Independence, Quality of life

* All correlations significant at the 0.01 level (2-tailed)

Table 22 shows the regression results for the reduction of domains in the calculation of expected benefit. The distribution of priority based on current expected benefit and consumer need are shown in Figure 12. Differences in outcome measures by function / body system involved are summarised in Table 23.

Table 22 Reduction of domains in expected benefits

Domains considered in expected benefits	Correlation with total expected benefits	Variation explained	Domains selected
Community, Participation, Self care, Health status	0.922	85.1%	-
Community, Participation, Self care, Health status, Hours of care	0.951	90.4%	-
Community, Participation, Self care, Health status, Hours of care, Sustainability	0.965	93.2%	Best
Community, Participation, Self care, Health status, Hours of care, Sustainability, Impact on carer	0.979	95.8%	2nd best
Community, Participation, Self care, Health status, Hours of care, Sustainability, Impact on carer, Safety	0.983	96.7%	-
Community, Participation, Self care, Health status, Hours of care, Sustainability, Impact on carer, Safety, Domestic	0.989	97.8%	-

Figure 12 Distribution of priority assigned to adult assessments**Table 23 Differences in outcome by function / body system involved**

Outcome	Function or body system involved*	Mean	(95% CI)	Min	Median	Max
Self Care score without requested item	Neuromusculoskeletal and movement-related functions or involvement of structures related to movement	35.5	(32.3-38.8)	10	38	50
	Mental functions or involvement of structures of the nervous system	26.4	(21.8-30.9)	10	26	50
	Functions or structures of the cardiovascular, haematological, immunological and respiratory systems	26.8	(21.7-31.9)	11	27.5	47
Self Care score improvement	Neuromusculoskeletal and movement-related functions or involvement of structures related to movement	3.9	(2.3-5.5)	-1	2	22
	Mental functions or involvement of structures of the nervous system	2.5	(1.0-3.9)	-2	1	16
	Functions or structures of the cardiovascular, haematological, immunological and respiratory systems	3.5	(1.6-5.4)	0	2	12
Domestic score without requested item	Neuromusculoskeletal and movement-related functions or involvement of structures related to movement	17.8	(15.9-19.6)	8	16	30
	Mental functions or involvement of structures of the nervous system	15.1	(12.3-17.9)	8	12	30
	Functions or structures of the cardiovascular, haematological, immunological and respiratory systems	13.8	(11.1-16.6)	8	13	29
Domestic score improvement	Neuromusculoskeletal and movement-related functions or involvement of structures related to movement	1.6	(0.7-2.4)	0	0	15
	Mental functions or involvement of structures of the nervous system	1.2	(0.3-2.1)	0	0	10
	Functions or structures of the cardiovascular, haematological, immunological and respiratory systems	0.5	(0.1-0.9)	0	0	3
Change in hours of care required	Neuromusculoskeletal and movement-related functions or involvement of structures related to movement	1.7	(-0.6-4.0)	-28	0	35
	Mental functions or involvement of structures of the nervous system	2.1	(0.4-3.7)	-2	0	16

Outcome	Function or body system involved*	Mean	(95% CI)	Min	Median	Max
Total Expected Benefits	Functions or structures of the cardiovascular, haematological, immunological and respiratory systems	11.5	(-8.0-30.9)	-20	0	168
	Neuromusculoskeletal and movement-related functions or involvement of structures related to movement	24.0	(22.2-25.9)	12.6	23	35
	Mental functions or involvement of structures of the nervous system	24.4	(22.0-26.9)	13.8	25.4	35.6
	Functions or structures of the cardiovascular, haematological, immunological and respiratory systems	25.3	(22.8-27.8)	16.4	25.7	34.2
Expected Benefits Domain	Neuromusculoskeletal and movement-related functions or involvement of structures related to movement	2.2	(2.0-2.4)	1	2	3
	Mental functions or involvement of structures of the nervous system	2.2	(1.9-2.6)	1	2	3
	Functions or structures of the cardiovascular, haematological, immunological and respiratory systems	2.4	(2.1-2.8)	1	2.5	3
Consumer Need Domain	Neuromusculoskeletal and movement-related functions or involvement of structures related to movement	2.3	(2.1-2.6)	1	2	3
	Mental functions or involvement of structures of the nervous system	2.0	(1.6-2.3)	1	2	3
	Functions or structures of the cardiovascular, haematological, immunological and respiratory systems	1.9	(1.5-2.3)	1	2	3
Priority assigned	Neuromusculoskeletal and movement-related functions or involvement of structures related to movement	3.4	(3.1-3.7)	1	4	5
	Mental functions or involvement of structures of the nervous system	2.8	(2.4-3.3)	1	3	5
	Functions or structures of the cardiovascular, haematological, immunological and respiratory systems	2.7	(2.1-3.2)	1	2.5	4

Additional results from child/youth assessments

Table 24, Figure 13 and Figure 14 provide extra details about child/youth applicants.

Table 24 Summary of child/youth applicants

Summary	Number of assessments	Statistic	Value
Gender	35	Male	51.4%
Age	35	Mean (95% CI)	8.7 (7.0-10.4)
		Median (range)	9 (1-19)
First Application	34	Yes	23.5%
Reason for assessment	25	New item >\$800	60.0%

Figure 13 Bladder and bowel management

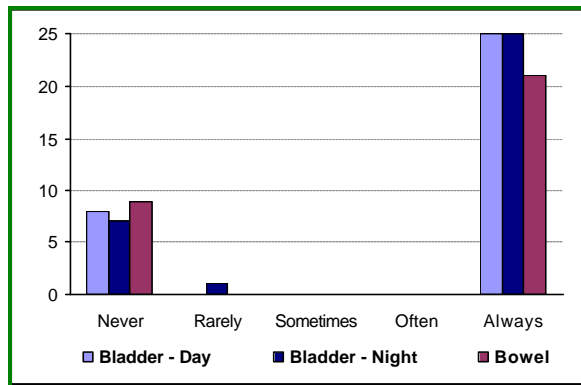
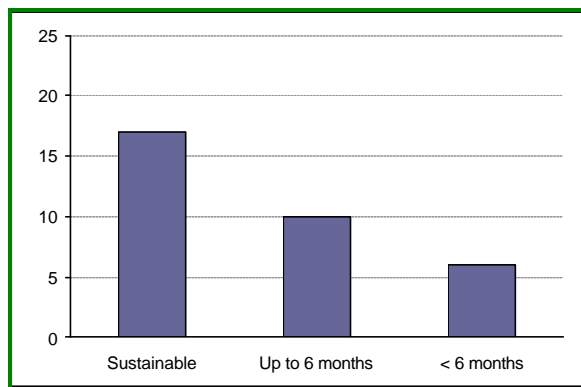


Figure 14 Sustainability of care arrangements



Additional results from adult incontinence assessments

Figure 15 and Table 25 provide extra details about urinary incontinence.

Figure 15 Summary of urinary incontinence results

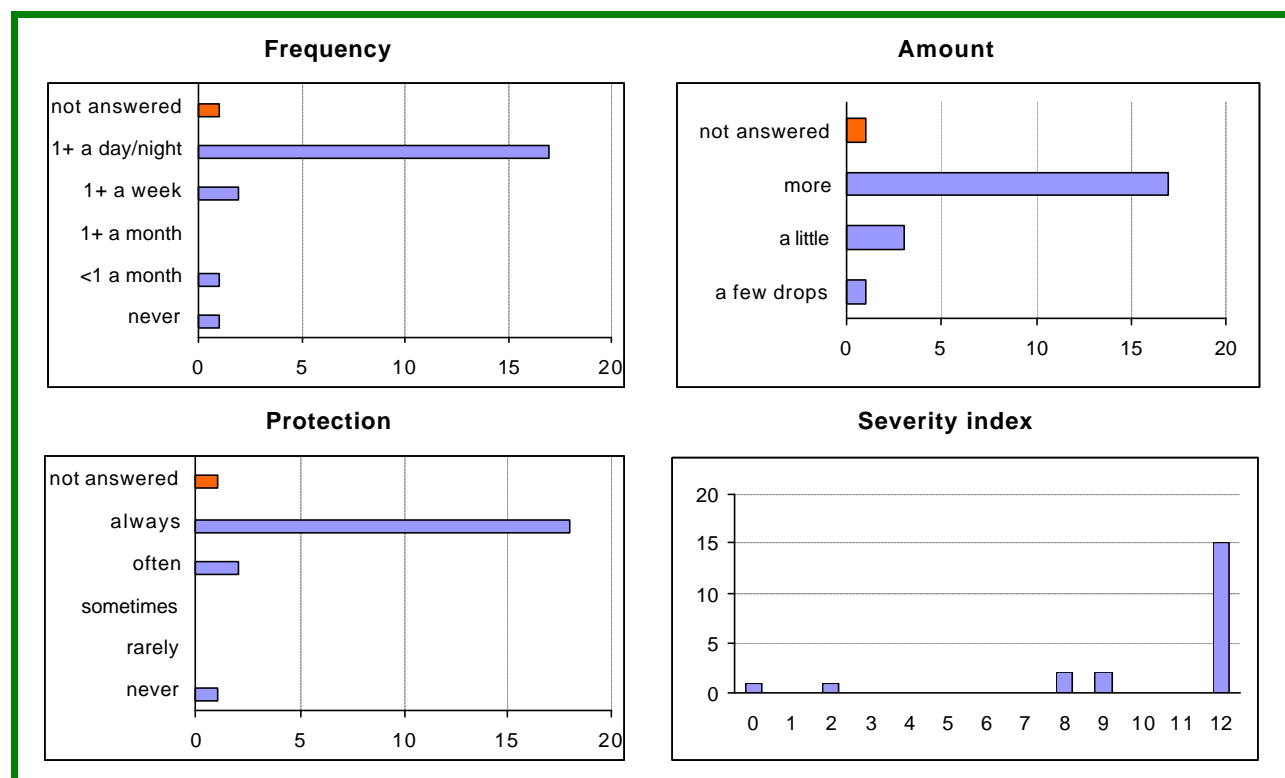


Table 25 Correlation between urinary incontinence items and severity index

	Frequency	Amount	Severity Index
Frequency			0.769**
Amount	0.471*		0.858**
Protection	0.530*	0.234	0.375

* Correlation is significant at the 0.05 level (2-tailed).

** Correlation is significant at the 0.01 level (2-tailed).