

# **‘Impact on Participation and Autonomy’**

**(IPA)**

## **Manual to the English version: IPA**

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## AIM AND PATIENT GROUPS

The outcome measure ‘Impact on Participation and Autonomy’ (IPA) was developed in the Netherlands. The English version was adapted for use in English by the Universities of Southampton and Nottingham.

The IPA can be used as part of the assessment procedures in rehabilitation to evaluate the effect of treatments and as part of rehabilitation research. The IPA is unique since it examines autonomy as opposed to dependency. However, rehabilitation is a multi-faceted intervention and the IPA should be used in conjunction with other outcome measures.

The IPA is a generic outcome measure and can be used in populations or with individuals with a range of diagnoses. The IPA is designed to be used with adults with chronic conditions and cannot be used with children.

## DESCRIPTION OF THE IPA

The IPA measures several aspects of participation and autonomy.

1. The IPA quantifies limitations in participation and autonomy. To this extent it contains 32 items, which load on to five participation and autonomy Subscales (Appendix 1):

IPA Subscales	Question numbers
Autonomy indoors (7 items)	1a, 1b, 2a, 2b, 2c, 2d, 2e
Family role (7 items)	3a, 3b, 3c, 3d, 3e, 3f, 4a
Autonomy outdoors (5 items)	1c, 1d, 5a, 6g, 10
Social life and relationships (7 items)	6a, 6b, 6c, 6d, 6e, 6f, 7a*
Work and education (6 items)	8a, 8b, 8c, 8d, 8e, 9a

\* Please note that in articles by Sibley et al. 2006 and Kersten et al. 2007 item 7a was listed in the questionnaire as item 9a. Following publication the developers have requested this item to be moved nearer the section which deals with social life and relationships. This also means that subsequent items have been renumbered (i.e. items 7a-7e have become items 8a-8e and item 8a has become 9a – as listed above).

Each of these 32 items has identical response options, ranging from zero to four with higher scores representing poorer participation and autonomy:

Response options (scoring)	
0	Very good
1	Good
2	Fair
3	Poor
4	Very poor

Autonomy indoors (7 items): chances of looking after yourself, the way you want (washing, dressing, going to bed, eating and drinking), getting around the house when and where you want.

Family role (7 items): the role, tasks, and responsibilities within the family, doing tasks around the house and garden, using your money.

Autonomy outdoors (5 items): activities outdoors such as the frequency of social contacts, possibilities to spend your leisure time and to get around outdoors when and where you want, leading the life you want.

Social life and relationships (7 items): quality of social life and relationships, communication, respect and intimacy, helping and supporting other people.

Work and education (6 items): paid and voluntary work, education and training.

2. The IPA also examines the extent to which these limitations are experienced as problematic. This is evaluated with nine questions, which cover nine different aspects of participation and autonomy:

Questions examining problem experience (question numbers)
1. Mobility: getting around where and when you want
2. Self care
3. Activities in and around the house
4. Looking after your money
5. Leisure
6. Social Life and relationships
7. Helping and supporting other people
8. Paid or voluntary work
9. Education and Training

Each of these nine questions has identical response options, ranging from zero to two with higher scores representing greater problem experience:

Response options (scoring)	
0	No problems
1	Minor problems
2	Major problems

3. Please note that the questions in the IPA are in an order that is logical for patients. Thus, the questions have not been ordered by Subscales. As a result the nine questions that examine the extent to which limitations are experienced as problematic do not refer directly to the Subscales. Rather, these nine questions are useful for clinical decision making.

## **CALCULATING IPA SUBSCALES**

At least 75% of a Subscale needs to be completed. If more than 25% of items are unanswered by a person don't calculate a Subscale score. Since the IPA uses ordinal data it is advised to use median scores when presenting results. A median score of '0' indicates no limitation in autonomy, a median score of '4' indicates very poor autonomy.

## **VALIDITY AND RELIABILITY**

The IPA is valid, reliable and responsive to change. Validation studies have been carried out in the Netherlands (Cardol et al. 1999, 2001, 2002), the UK (Sibley et al. 2006, Kersten et al. in press) and Sweden (Larsson Lund 2004) using factor analysis, confirmatory factor analysis and Rasch analysis.

## **HOW TO USE THE IPA**

The IPA is self-completed by participants and does not require explanation by a clinician or researcher. The IPA can be used as a postal questionnaire. The IPA has not been tested for use in telephone surveys.

## **PERMISSIONS TO USE THE IPA**

The Dutch IPA has been developed by Dr M Cardol and Dr BA de Jong. Copies of the Dutch IPA can be obtained from the website (<http://www.nivel.nl/oc2/page.asp?PageID=5309>) or from:

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The Dutch IPA was adapted and validated for use in English by the Universities of Southampton and Nottingham. Copies of the English IPA can be obtained from the website (<http://www.nivel.nl/oc2/page.asp?PageID=5309>) or from:

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When using the IPA, please quote the original sources listed in the Reference list. These are regularly updated on the IPA website <http://www.nivel.nl/oc2/page.asp?PageID=5309>.

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## APPENDIX 1 SUBSCALES

### **Autonomy indoors**

- 1a. My chances of getting around in my house *where* I want to are
- 1b. My chances of getting around in my house *when* I want to are
- 2a. My chances of getting washed and dressed *the way* I wish are
- 2b. My chances of getting washed and dressed *when* I want to are
- 2c. My chances of getting up and going to bed *when* I want to are
- 2d. My chances of going to the toilet *when* I wish and need to are
- 2e. My chances of eating and drinking *when* I want to are

### **Family role**

- 3a. My chances of contributing to looking after my home *the way* I want to are
- 3b. My chances of getting light tasks done around the house (e.g. making tea or coffee), either by myself or by others, *the way* I want them done are
- 3c. My chances of getting heavy tasks done around the house (e.g. cleaning), either by myself or by others, *the way* I want them done are
- 3d. My chances of getting housework done, either by myself or by others, *when* I want them done are
- 3e. My chances of getting minor repairs and maintenance work done in my house and garden, either by myself or by others, *the way* I want them done are
- 3f. My chances of fulfilling my role at home *as* I would like are
- 4a. My chances of choosing how I spend my own money are

### **Autonomy outdoors**

- 1c. My chances of visiting relatives and friends *when* I want to are
- 1d. My chances of going on the sort of trips and holidays I want to are
- 5a. My chances of using leisure time *the way* I want to are
- 6g. My chances of seeing people as often as I want are
- 10. My chances of living life the way I want to are

### **Social life and relationships**

- 6a. My chances of talking to people close to me on equal terms are
- 6b. The quality of my relationships with people who are close to me
- 6c. The respect I receive from people who are close to me is
- 6d. My relationships with acquaintances are
- 6e. The respect I receive from acquaintances is
- 6f. My chances of having an intimate relationship are
- 7a. My chances of helping or supporting people in any way are (*new item*)

### **Work and education**

- 8a. My chances of getting or keeping a paid or voluntary job that I would like to do are
- 8b. My chances of doing my paid or voluntary work *the way* I want to are
- 8c. My contacts with other people at my paid or voluntary work are
- 8d. My chances of achieving or keeping the position that I want, in my paid or voluntary work are,
- 8e. My chances of getting different paid or voluntary work are,
- 9a. My chances of getting the education or training I want are