

The P15 – a multinational assessment battery for collecting data on health indicators relevant to adults with intellectual disabilities

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Abstract

Background Health disparities between adults with intellectual disabilities (ID) and the general population have been well documented but, to date, no dedicated assessment battery for measuring health disparity has been available. This paper reports on the development and testing of a multinational assessment battery for collecting data on a range of health indicators relevant to adults with ID.

Methods An assessment battery (the P15) was developed following piloting, and administered to samples of adults with ID, in 14 EU countries. Samples were neither random, nor representative of the countries from which they were drawn. However, within the local health administration areas selected in each country, efforts were made to

ensure samples were broadly representative of the typical living circumstances, ages and ability levels of the administrative population of adults with ID. The total sample comprised 1269 adults with ID, of whom 49% were female. The mean age was 41 years (range 19 to 90).

Results Overall, feasibility, internal consistency and face validity of the P15 was acceptable.

Conclusions With some refinement the P15 could be useful for collecting data on health indicators known to be particularly important for adults with ID. It is useable in a range of countries and has the potential to highlight health inequity for adults with ID at a national or local level. Larger scale epidemiological studies are needed to exploit the potential of the P15 to address health inequity in this group.

Keywords health indicators, health inequity, health disparity, health survey, intellectual disabilities

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Introduction

Health disparities between people with intellectual disabilities (ID) and the general population have been well documented (van Schrojenstein Lantman-de Valk & Walsh 2008). For example, people with ID have health conditions such as epilepsy, sensory impairment, respiratory problems, dental problems and incontinence more often or more seriously than the general population (Beange *et al.* 1995; Turner & Moss 1996; Kapell *et al.* 1998; Sutherland *et al.* 2002; Ouellette-Kuntz 2005). Analyses of predictors of psychotropic medication receipt amongst people with ID suggest that the receipt of both antipsychotics and hypnotics/anxiolytics is predicted by variables related to challenging behaviour rather than by symptoms of mental ill health (Robertson *et al.* 2000a). Given the lack of evidence to support the use of antipsychotics in the treatment of challenging behaviour (Brylewski & Duggan 1999) and the serious side effects known to be associated with the use of antipsychotics (Emerson 1995; Baumeister *et al.* 1998), the over-prescription of antipsychotic medication is a systemic factor associated with increased risk of poor health. People with ID are also at significant risk of deviating from normal weight and are more likely to lead sedentary lives (Emerson 2005). Although life expectancy of people with ID is longer than in the past, it is shorter than in the general population (Beange *et al.* 1995; Bittles *et al.* 2002).

The disparities in health between people with ID and the general population extend to their health care. People with ID are more likely to have untreated morbidity (Howells 1986; Wilson & Haire 1990; Beange & Bauman 1991; Webb & Rogers 1999) and they are less likely to experience health promotion and disease prevention activities (Rimmer *et al.* 1993; Sullivan *et al.* 2003). When people with ID access primary care, they may encounter barriers to high-quality care including communication difficulties (Wilson & Haire 1990; Beange *et al.* 1995), behavioural difficulties (Minihan & Dean 1990), and lack of specialist general practitioner training (Lennox *et al.* 1997).

To the extent that these disparities are avoidable and unjust, they amount to health inequities (Ouellette-Kuntz 2005). This is inconsistent with

World Health Organization and European Union (EU) policies aimed at ensuring equal opportunities for health (Crombie *et al.* 2004; European Union 2007). Ouellette-Kuntz (2005) proposes the development of explanatory models for health inequities. Recognising that causal pathways will differ for specific health outcomes, she advocates the targeting of specific health indicators and the consideration of modifiable variables such as lifestyle factors, behaviours, social networks and living conditions.

The P15 is an assessment battery which was developed to gather data that could be used to highlight health inequity for adults with ID and, potentially, to generate explanatory models of inequity. To a large extent this was a feasibility study. Of more interest than the data collected *per se* was the development and testing of an assessment battery which could be used across Europe to see if it could be used in future epidemiological research. The purpose was not to compare countries on particular health indicators, so data are presented in aggregated form rather than at the level of individual member states.

Method

Measure

Development of the P15 was a two-stage process. In the first stage (2002–2004) a partnership representing 13 EU member states derived a set of 18 health indicators through an extensive literature search and a multistep consultation between project partners all of whom had extensive experience in the field of health issues relating to people with ID. The indicators were categorised under four broad headings using a framework applied in the European Community Health Indicators project, an EU initiative aimed at determining health indicators for the general population (Table 1).

The procedure for the first stage is described fully elsewhere (van Schrojenstein Lantman-de Valk *et al.* 2007). Selection of indicators was guided by the quality and quantity of supportive literature, the capacity to operationalise it and the value of the indicator for advancing knowledge about the health of adults with ID.

Table 1 Indicator Domains identified at Stage 1

Demographics	Prevalence; living arrangements; daily occupation; income/socio-economic status; life expectancy
Health status	Epilepsy; oral health; body mass index; mental health; sensory; mobility
Determinants	Physical activity; challenging behaviour; psychotropic medication use
Health systems	Hospitalisation & contact with health care professionals; health check; health promotion; specific training for physicians

The second stage of development (2005–2008) was funded separately by the European Community Action Programme. Fourteen EU countries participated in the second stage, the primary aim of which was to address the feasibility of gathering data in each country pertaining to the 18 indicator domains identified above. Indicators were classified as relating to either ‘country level’ or ‘individual level’ data. Country level data were required to address three of the 18 indicator domains, ‘prevalence of intellectual disability’, ‘life expectancy’ and ‘training of physicians’. These data, where available, were gathered by project participants via desk research. Individual level data relating to the remaining 15 indicator domains were addressed via a survey of adults with ID in each country. Two of these survey indicators were measured using standardised ID specific measures. Mental health was assessed using the Psychiatric Assessment Schedule for Adults with a Developmental Disability Checklist (Moss *et al.* 1998), which is an ID specific measure of symptoms associated with mental problems; and challenging behaviour was assessed using the Aberrant Behaviour Checklist (Aman & Singh 1986) which is an ID specific measure of challenging behaviour. The remaining 13 indicators were living arrangements, daily occupation, income (including hardship), epilepsy, oral health, body mass index, sensory impairment, mobility, physical activity, medication use, health promotion activity, hospitalisation and contact with health professionals. The specific items used to measure these indicator domains were largely taken from existing European Health Interview surveys. The project provided an opportunity to determine whether the use of these ‘generic’ items was appropriate for a sample of adults with

ID (e.g. whether the majority would score at ceiling or floor levels) with a view to highlight disparity with general population data.

The P15 survey instrument, translated into and back-translated from 13 languages, is administered as a semi-structured interview either directly with the person with an ID, or if this is not possible, with a person who knows the individual well. Ethical approval for its administration to samples of adults with ID was sought and received in all countries which required approval for survey research (13/14). The survey instrument was piloted amongst 84 adults across 13 countries and modified accordingly.

Feasibility study

When data collection was complete in all 14 countries, each interviewer was asked to complete a questionnaire to assess the feasibility of the P15 in terms of: (1) face reliability, i.e. apparent accuracy of responses according to type of respondents (person with ID, family carer, non-family carer); (2) social and psychological acceptability, i.e. whether items were acceptable to respondents (judged mainly by whether respondents refused to answer particular items); (3) user-friendliness, i.e. whether respondents had difficulty understanding and/or responding to particular items, the extent of additional explanation required, training requirements and time taken to administer; and (4) practicality, i.e. how useful the item might be in routine practice and monitoring, whether it would be useable in general health surveys/databases, and whether interviewers required additional training/experience to administer particular items. Respondents were asked to address these issues on a section-by-section basis, and to identify items which proved problematic on one or more of these areas for 25% or more of the P15 interviews administered. For example, if an interviewer found that one in four interviewees had difficulty responding to the item which requested the frequency of visits to and from their general practitioner, that item would be flagged and rated on each of the feasibility criteria. Responses from interviewers who had conducted at least four P15s were analysed. This amounted to 23 interviewers who had conducted 674 P15s between them. Considering the P15 as a whole, the feasibil-

ity questionnaire also asked individual country project leaders or principal interviewers for ratings on (1) to (4) above plus applicability (whether the content seemed appropriate for the assessment of the health of adults with ID), efficiency (the value of the information derived from the P15 in relation to the effort required to solicit it), coding complexity and cultural transferability. Each of these was rated from 1 to 4, where lower ratings indicated greater feasibility in each respect.

Sampling

The final version of the P15 was administered to samples in each of the 14 participating countries by local researchers. Researchers from each country selected a 'health area' large enough to ensure that, as far as possible, samples were representative of typical living circumstances for adults with ID in their respective health areas. In addition, the intention was for samples to represent a broad range of ages (18+) and ability levels and to ascertain the usability of the P15 across a range of participant characteristics and countries. The final sample comprised 1269 adults resident in 14 EU countries. Forty-nine per cent of participants were female and 51% were male. The mean age was 41 years (range 19 to 90); 36% were aged between 20 and 34, 42% were between 35 and 54, and 22% were 55 or older. Categorisation of ability level was available for 80% of the current sample. Proportions in the mild, moderate, severe and profound categories were 27%, 34%, 25% and 14%, respectively.

Despite being a convenience sample it is useful to know how, at an aggregated level, participants' characteristics compare with the administrative population of adults with ID. National ID databases are rare but the Irish National Intellectual Disability Database (NIDD) includes data which allows such a comparison (Kelly *et al.* 2009), at least, for the Irish subset of the current sample. The most recent NIDD data summary describes people who were receiving ID services or who were in need of these services in 2008. The Irish sample comprised 70 adults of whom 59% were female and 41% were male. This compares with a 43%/57% female/male split in the NIDD. The mean age was 38 years (range 20 to 74). Unlike in the current sample, the NIDD includes children. If these are excluded from

the NIDD, 37% were aged between 20 and 34, 45% were between 35 and 54, and 18% were 55 or older. Corresponding proportions in the current Irish subsample were 48%, 39% and 13%. Categorisation of ability level was available for 92% of the NIDD sample and 77% of the current Irish subsample. Proportions of the NIDD sample in the mild, moderate, severe and profound categories were 36%, 43%, 17% and 4%, respectively. Corresponding proportions in the current sample were 43%, 41%, 13% and 3%.

Interviews were conducted either with the person with ID alone (14%), with the person with ID together with another person (52%), or with a proxy respondent alone (34%). There were three main categories of proxy respondents: paid carers (39%), parents or guardians (24%) and health professionals (20%). Proxies had known the person with ID on whose behalf they were responding for an average of 15.8 years (range 1 to 79 years).

Although not an indicator *per se*, the Support Needs Scale (SNS) (Emerson *et al.* 2005) was incorporated into the P15 survey as a demographic measure of independence to allow investigation of indicator data by level of ability. Internal consistency on the SNS in this study was 0.91 (Cronbach's alpha). SNS scores averaged 46.5% across the whole sample (range 0–100, SD 30.2). One third of the sample had SNS scores (% of scale maximum) in the lower quartile of the range, one fifth had scores in the upper quartile and 46% had scores in the range between 30% and 75% where higher scores indicate greater independence.

Psychometric properties

The P15 may be best described as an assessment battery which complements an indicator set.

Despite incorporating some assessment instruments (the SNS, the Aberrant Behavior Checklist and the PAS-ADD Checklist), the P15 is not an assessment instrument *per se*. As such, it is not possible to explore its psychometric properties in detail; and furthermore, such exploration might not be appropriate (Salvador-Carulla and Gonzalez-Caballero, 2010). Nevertheless, where possible, internal consistency and inter-rater reliability were explored.

Regarding the former, Cronbach's alpha was computed for scale type items where the items analysed

were coded in the same direction, i.e. with higher scores equating to better health. Items were omitted if the 'direction' was unclear. For example, items concerning the number of visits to health professionals were excluded because more visits could indicate poorer health, better access to health care, or a combination of the two. Similarly, items were excluded if they had mutually exclusive response options which were arbitrarily assigned a code, such as living arrangement and daily occupation. Single items such as Body Mass Index score and income were also excluded from internal consistency analyses, and finally, items which elicited qualitative data such as the name and type of medication used were excluded. The Kuder-Richardson 20 statistic was used with binary data. This resulted in internal consistency being analysed for 9 of the 15 indicators. To assess inter-rater reliability the intention was to conduct an interview with a second respondent for a subsample of 10% of participants for the two scales which relied on third party responses and were not designed for completion by adults with ID themselves (i.e. the ABC and the PAS-ADD Checklist). The 10% target was not achieved but interviews with second respondents were conducted for 43 ABCs and 42 PAS-ADD Checklists across nine countries.

Results

Three subsections follow. First, the results of the feasibility study are presented. Second, basic psychometric data are presented. Third, a number of bivariate analyses are described which explore the validity of the P15 in terms of consistency with the literature on known risk factors for poor health. Complete results for subsection one are published in the full Pomona project report (Walsh *et al.* 2008).

Feasibility

A feasibility questionnaire was only included in the analysis if the interviewer who completed it had administered four or more P15s. Across the 14 participating countries 23 interviewers met this criterion. Between them they had conducted 674 interviews. Twenty-four per cent of interviewers had

previous experience of working with adults with ID and 48% had previous experience in structured interviewing. Only 41% of interviewers received specific training in using the P15. On average, the interview took an hour to conduct with adults with ID and 45 minutes when administered to carers.

A P15 item was deemed to be problematic if it was flagged in two or more of the feasibility questionnaires. Table 2 shows the items that met this criterion. Of the 313 P15 items 64 were problematic for some interviewers. Several of these 'items' were, in fact, response options. If response options are excluded, 26 items proved to be problematic.

Eleven of the 14 project leaders or principal interviewers completed the section of the feasibility questionnaire which included the more comprehensive set of ratings referring to the P15 as a whole as opposed to individual items within the P15. Their ratings are summarised in Table 3. Although certain project leaders rated the P15 as having poor feasibility in terms of user-friendliness, training requirements, administration time and usability in routine practice and general health surveys, median scores on these and all other dimensions indicated that, overall, the P15 was deemed to have good feasibility.

Psychometrics

Internal consistency

Table 4 shows the internal consistency of nine of the P15 indicators. High internal consistency was found for the established scales incorporated within the P15 (the ABC, the PAS-ADD and the SNS) and for the epilepsy and mobility indicators. The internal consistency of the physical activity and oral health domains was low; and alpha coefficients on the remaining domains were reasonable.

Inter-rater reliability

The mean Kappa value of the PAS-ADD Checklist and the ABC in all countries was 0.73 and 0.48, respectively.

Bivariate analyses using known risk factors for poor health

As an indication of face validity a selection of bivariate analyses were performed using well estab-

Table 2 Items* which were problematic for 25% or greater of the interviews conducted by two or more interviewers. (Based on responses from 23 interviewers who completed a total of 674 P15s)

Number of items causing problems	Item content	Problematic feasibility issue
1	Living conditions Do you have the support of paid staff in your house?	Problem with accuracy, especially when the question was answered by family members or caregivers.
1	Social relationships and social support How often do you communicate with anyone who is not a member of your family?	Problem with accuracy: there are different sources needed to get this information. Problem with acceptability of the question. Some people refused to answer the question. Problem with difficulty in understanding the question.
9	Finance and money handling In the last year have you always had enough money for these items when you wanted them? (9 items listed)	Problem with accuracy: there are different sources needed to get this information. Difficulty in coding the item for the interviewer. Practicality was rated low.
3	Support needs How much help do you need to (1) drink a cup of tea, (2) make a sandwich, (3) find out what is on TV?	Problem with accuracy: there are different sources needed to get this information. Problem with acceptability for the PwID. Problems with difficulty in understanding the question for the respondent and in coding the question. Practicality was rated low.
15	Medical conditions For each condition listed below, can you tell me whether you have ever had the condition in the past and also whether you currently (in the last 12 months) have the condition?	PwID do not provide accurate information to this question. Problems with difficulty in understanding the question for the respondent and in coding the question.
1	Oral health During the past 12 months about how many times have you visited a dentist?	Problem with accuracy: there are different sources needed to get this information. Problem with practicality. This item was rated to be unusable for routine practice, monitoring or in general health surveys.
1	Vision Are you normally able to read ordinary newspaper print?	Problem with accuracy: there are different sources needed to get this information. Not suitable, because a lot of PwID can't read. Problem with difficulty of the item.
1	Can you see well enough to recognise a friend at a distance of one metre?	Problem with accuracy: too abstract. It was difficult to explain what 'a metre' is. Problem with practicality. This item was rated to be unusable for routine practice, monitoring or in general health surveys.
1	Can you see well enough to recognise a friend at a distance of four metres?	Problem with accuracy: too abstract. It was difficult to explain what 'a metre' is. Problem with practicality. This item was rated not to be usable for routine practice, monitoring or in general health surveys.
1	Mobility How far can you walk on a flat ground without a pause or feeling discomfort?	Problem with accuracy, especially when the question was answered by the PwID. Difficulty: too many response categories for PwID. One needed to rephrase question or ask caregiver.
1	Physical activity At least once a week do you engage in any regular activity, such as jogging, cycling, etc., long enough to work up a sweat?	Problem with accuracy. Formulation of question was not suitable: e.g. overweight people sweat a lot.

Table 2 Continued

Number of items causing problems	Item content	Problematic feasibility issue
15	Do you experience any difficulties in engaging in physical activity because of the following reasons? (15 reasons listed)	Problem with accuracy: there are different sources needed to get this information. Problem with acceptability: Too many alternatives to answer. Refusal by respondents to answer all of them. Too difficult. Problem with practicality. This item was rated not to be usable for routine practice, monitoring or in general health surveys.
1	Outpatient visits to health professionals During the past 12 months, about how many times have you visited or received a visit from a doctor?	Problem with accuracy, especially when the question was answered by the PwID. There are different sources needed to get this information.
4	During the past 12 months, about how many times have you visited (1) a mental health professional, (2) a physiotherapist, (3) an occupational therapist, (4) a speech therapist?	Problem with accuracy, especially when the question was answered by the PwID. There are different sources needed to get this information.
1	Health prevention During the past 12 months, about how many times have you had a full physical medical examination?	Problem with accuracy: there are different sources needed to get this information.
3	Have you been vaccinated against (1) influenza, (2) tetanus, (3) hepatitis B in the last 10 years?	Problem with accuracy, especially when the question was answered by the PwID. Practicality was rated low.
1	Have you had your blood pressure measured in the past 5 years?	Problem with accuracy and difficulty of the question
1	Have you had your cholesterol measured in the last 5 years?	Problem with accuracy and difficulty of the question: explanation of cholesterol.
1	Have you had a breast examination (excluding a mammogram) by a doctor or nurse in the past year? (women)	Problem with accuracy, especially when the question was answered by the PwID. Difficulty in understanding the question for the respondent. Practicality was rated low.
1	When was the last time you had a mammogram? (women)	Problem with accuracy, especially when the question was answered by the PwID. Difficulty in understanding the question for the respondent. Practicality was rated low.
1	Have you had testicular cancer screening in the past 3 years? (men)	Problem with accuracy, especially when the question was answered by the PwID. Difficulty in understanding the question for the respondent. Practicality was rated low.

* Some items have been paraphrased or grouped together to simplify the table. Actual items were 'closed-format' questions. PwID, person with intellectual disabilities.

lished risk factors for poor health in adults with ID. In their study of lifestyle-related risk factors for poor health in residential settings for adults with ID, Robertson *et al.* (2000b) reported higher obesity, less physical activity and higher rates of smoking amongst more able people; a positive association between inactivity and age; a positive association between obesity and being female; and a negative association between being female and smoking. Men and people with lower levels of adaptive behaviour are reportedly more likely to exhibit higher levels of challenging behaviour (Emerson & Bromley 1995; Emerson *et al.* 2001). Epilepsy is also more common amongst people who have lower

levels of adaptive behaviour (Shepherd & Hoskins 1989; Goulden *et al.* 1991; McGrother *et al.* 1996).

To perform bivariate analyses in the current study, groups were created using the following criteria. To compare groups based on ability level, two groups were created based on SNS scores. The mean SNS score for the lower ability group was 20% (range 0–45, $n = 578$) and the mean score for the higher ability group was 72% (range 50–100, $n = 593$). Comparisons on the basis of age were achieved by two age groups based on a median age split (median age = 40 years). People younger than 40 constituted one group, and those aged over 40 constituted the other. In a similar vein, higher and

	Median	Minimum	Maximum
Applicability	2	1	3
Accuracy	2	2	5
Psychosocial acceptability	1.5	1	2
User-friendliness	2	1	4
Level of training	2	1	4
Administration time	2	2	4
Coding complexity	2	1	3
Data management	2	1	3
Practicality	2	1	3
Usability for routine practice	2	1	4
Usability in general health surveys	2	1	4
Efficiency	2	1	3
Cultural transferability	2	1	2

Table 3 Overall feasibility of the P15 ($n = 11$)

Scale: 1–4. 1 = very high feasibility; 4 = very low feasibility.

Table 4 Cronbach's alpha and Kuder-Richardson 20 Values for P15 scales and sub-scales

Scale/sub-scale	Coefficient used	No. of items	No. of response categories	Mean coefficient*
PAS-ADD Checklist	Cronbach's alpha	24	3	0.73
ABC	Cronbach's alpha	58	4	0.95
Epilepsy	KR20	4	2-2-5-2	0.80
Oral health	KR20	2	3-2	0.28
Sensory difficulty	KR20	8	2-4-4-4-2-4-2-2	0.61
Mobility difficulty	KR20	2	4-2	0.80
Physical activity	KR20	3	4-2-1-1	0.45
Hospitalisation	KR20	3	2-2-2	0.54
Health promotion	KR20	6	2-2-2-2-2-4	0.56

* The reported coefficients are the mean of coefficients calculated for each country.

PAS-ADD, Psychiatric Assessment Schedule for Adults with a Developmental Disability; ABC, Aberrant Behavior Checklist.

lower challenging behaviour groups were based on a median split of ABC scores (median = 7).

Results of the bivariate tests using data from the current sample were consistent with findings reported in the wider literature in the case of six out of nine comparisons (Table 5). Obesity was significantly more common in the higher ability group (28% vs. 15%, chi-square = 21.2, $P < 0.001$). SNS scores also correlated significantly with BMI ($R = 0.27$, $P < 0.001$). Although high for both groups, activity was described as predominantly sedentary for significantly more of the lower ability group (59% vs. 44%, chi-square = 21.3, $P < 0.001$). Smoking was more common amongst more able

participants (16% vs. 4%, chi-square = 48.4, $P < 0.001$) and men (14% vs. 6%, chi-square = 20.3, $P < 0.001$). More women than men were obese (25% and 19%, respectively, chi-square = 5.52, $P < 0.05$). The proportion of people who had experienced an epileptic seizure in the preceding 5 years was greater for less able people (29% vs. 12%, chi-square = 50.3, $P < 0.001$). Levels of sedentary activity were similar in both age groups (older group = 53%, younger group = 51%) as were levels of obesity (older group = 30%, younger group = 27%). Half of the people in the higher challenging behaviour group were men, so being male was not associated with higher challenging

Table 5 Bivariate analyses using risk factors for poor health

Significant association reported in wider literature	Significant association found in current study
Higher ability and greater obesity	✓
Higher ability and less physical activity	×
Higher ability and more smoking	✓
Lower ability and having greater challenging behaviour	✓
Lower ability and epilepsy	✓
Being female and being obese	✓
Being male and smoking	✓
Being male and having greater challenging behaviour	×
Being older and being less physically active	×

behaviour. However, significantly more people in the higher challenging behaviour group were also in the lower ability group (chi-square = 30.8, $P < 0.001$).

Discussion

The aim of the study was to develop and test an assessment battery to assess health indicators known to be particularly salient to adults with ID. The P15 assesses 15 health indicators and can be administered easily and relatively quickly with minimal training. In this study it was used in 14 countries with people who had a range of levels of ID. In terms of applicability, accuracy, acceptability, user-friendliness, level of training, administration time, coding complexity, data management, practicality, usability, efficiency and cultural transferability, the P15 was considered to be acceptable. Although some items require refinement, administration of the vast majority of items was problem free.

Inter-rater reliability on the two established assessment instruments included in the P15 was substantial for the PAS-ADD Checklist and moderate for the ABC according to the criteria set out by Landis & Koch (1977) for interpreting Kappa values. Exploration of the psychometric properties of the P15 as a whole is not necessary because it is

not a scale *per se*. Nevertheless, where possible, internal consistency of items was assessed and found to be satisfactory.

The purpose of this study was to report on the utility of the P15 rather than the data it yielded *per se*, and the current sample was not intended to be representative of the administrative population from which it was drawn. With respect to the Irish subsample, the gender profile was dissimilar from the NIDD sample which had a higher proportion of men. Although there was a trend towards the current Irish sample being younger and more able than the NIDD sample, the age and ability profiles of the two samples were broadly similar. Given the well-established association between age and level of ID on the one hand, and many health indicators on the other, however, it is possible that the health problems found in the current study are under-representative of the wider Irish population of adults with ID. The extent to which subsamples from the other countries in this study are representative of the wider population of adults with ID in those countries is unknown. Given this, descriptive data collected in the study should not be extrapolated beyond the current sample. These data have not been described here because they could detract from the validity and feasibility study. However, the descriptive data on health indicator outcomes do illustrate the breadth of data that the P15 can be used to collect and they are presented by Walsh *et al.* (2008).

The results of the bivariate analyses performed using known indicators for poor health were generally consistent with what would be expected according to existing research. This adds some weight to the face validity of the P15. In addition, the P15 was found to provide a useful way of exposing regional variation, and by implication, inequity, on some indicators. In this respect, the P15 could be useful in public health. For example, data on vaccinations could be compared with standard vaccination schedules for the relevant country and benchmarked against agreed standards for people with ID. Data could also be used to monitor trends in health and lifestyle to inform service planning. For example, examination of residential provision by age might reveal typical 'living arrangement pathways' which could be used to predict future residential support needs.

The P15 needs refinement which should be based on further research using larger epidemiological samples. In refining the P15 there should be consideration of concordance between the responses of adults with ID and those of proxy respondents. In the context of quality of life outcome data it has been reported that concordance tends to be high for items relating to objective data and low for subjective data (Perry & Felce 1995). The vast majority of P15 items are objective. However, further investigation may be warranted to assess whether proxy responses are appropriate for the handful of subjective items in the P15 such as satisfaction with health and dental pain. Future research might also investigate social desirability bias between cultures when using the P15. A finalised version of the P15 might facilitate the investigation of relations between indicators. For example, by dividing into high and low ability groups one could look at the differences on indicators such as access to healthcare provision, sedentary lifestyles and so on. In a similar vein, several of the P15 items relate to comorbidities, which permits the exploration of relationships between these and the various health indicators. Lifestyle indicators are also incorporated into the P15 and the relationship between these and health indicators could be investigated. In these respects, the P15 facilitates the collection of data of potential value in explanatory models of health inequity. The health disparity which adults with ID experience on many health indicators is unacceptable, and the P15 might contribute to addressing it.

Since 2003, considerable resources have been invested by the European Commission to develop a health monitoring system – the European Health Survey System (EHSS) (European Commission Health and Consumer Protection Directorate-General 2004). This includes the European Health Interview Survey (EHIS) which aims to measure the health status, lifestyle (health determinants) and healthcare services use of the EU citizens in a harmonised and highly comparable way. Integration of the EHIS within national surveys will become compulsory by 2013; however, currently this system is likely to exclude adults with ID as they are not identified in population based surveys, and their specific health needs are not addressed in the typical survey items included in national health interview/examination surveys (Linehan *et al.* 2009).

As a mainstream public health monitoring system, the EHSS could provide an ideal vehicle for the collection of survey data on adults with ID in European countries using the P15.

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