

Victorian population health survey for people with an intellectual disability 2009



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Purpose of the session

- Provide background information about the Victorian population health survey for people with an intellectual disability 2009 (VPHS-ID 2009)
- Report on progress to date
- Future directions



Victorian policy context

A Fairer Victoria

- Reduce health inequalities
- Promote health for all
- Providing quality services and support people to live in the community



Victorian Population Health Survey

- established in 1998 to provide State and regional information about the health of Victorians and determinants of that health.
- an established method to collect relevant, timely and valid health information to be applied to policy development and strategic planning.



Contents of the VPHS

20 minute interview about:

Health and lifestyle

Obesity among adults

Asthma & Diabetes

Psychological distress

Social support, community participation
and attitudes

Chronic disease

Social inequalities in health



The VPHS and people with an intellectual disability

- VPHS for the general community excludes people with an intellectual disability due to methodology
- Some people with ID may be included but not identified
- Lack of robust evidence about Victorians with intellectual disability to inform decisions about public health priorities.



The 'drivers' for the VPHS-ID

Health disparities are evident when people with intellectual disabilities are compared with people who do not have intellectual disabilities.

Health information systems are necessary for identifying and understanding health inequities.

Pomona-I group

*Journal of Applied Research in Intellectual Disabilities 2009, 22,
409–420*

International Journal of
Epidemiology 2007;36:139–146

'People with intellectual disability ... die prematurely, and often have a number of unrecognized or poorly managed medical conditions as well as **inadequate health promotion** and disease prevention'.

Nicholas Lennox et al



Benefits of doing VPHS-ID 2009

- Reliable local evidence about health of people with an intellectual disability can be compared to the general population to draw attention to the public health needs of people with an intellectual disability
- Health agencies respond to sound evidence
- Treasury responds to sound evidence
- Health status trends tracked over time.

History to the VPHS-ID project

2005- 2006 previous attempt to include some questions about intellectual disability to the general VPHS.

2007-8 pilot project by CDDHV, Monash University and RMIT validated a tool to gather data from a 'proxy' on behalf of PWID.



Why use a proxy?

- Information is gathered by interviewing a person who knows the person with an ID well (called a proxy).
- Ensures that people with a profound ID can participate.



Use of proxy



- Reliance on proxy respondents is expected when surveying the health of respondents who have intellectual disabilities’.
- The use of proxy respondents is considered a valid method for data collection in all Health Interview Surveys (HIS) and Health Examination Surveys (HES) for a range of respondent groups’.

Validation of the survey tool

- Questions in the pilot study were validated by comparison with health records or by direct measurement e.g. weight and height



VPHS-ID 2009

- Rural, regional and metropolitan areas
- People with an intellectual disability
- Aged 18 years and over



- An epidemiologist is a crucial member of the team

Sampling

Victorian population	~ 5,000,000	100%
Victorian population with an ID	~ 100,000 to 150,000	2-3%
Expected people with ID in administrative database	~ 20,000 to 25,000	0.4-0.5%
people with an ID aged 18 years and older in administrative database	21,279	0.4%
Recruitment packages Opt ins Completed interviews	6000 > 890 so far... > 175 so far... (aiming for 900)	0.12%

Methodology of the VPHS-ID 2009

- Recruitment packages sent
- People 'opt in'



Respecting rights

- Ethics approval

Input from:

- Legal services
- Advocacy services
- Disability services



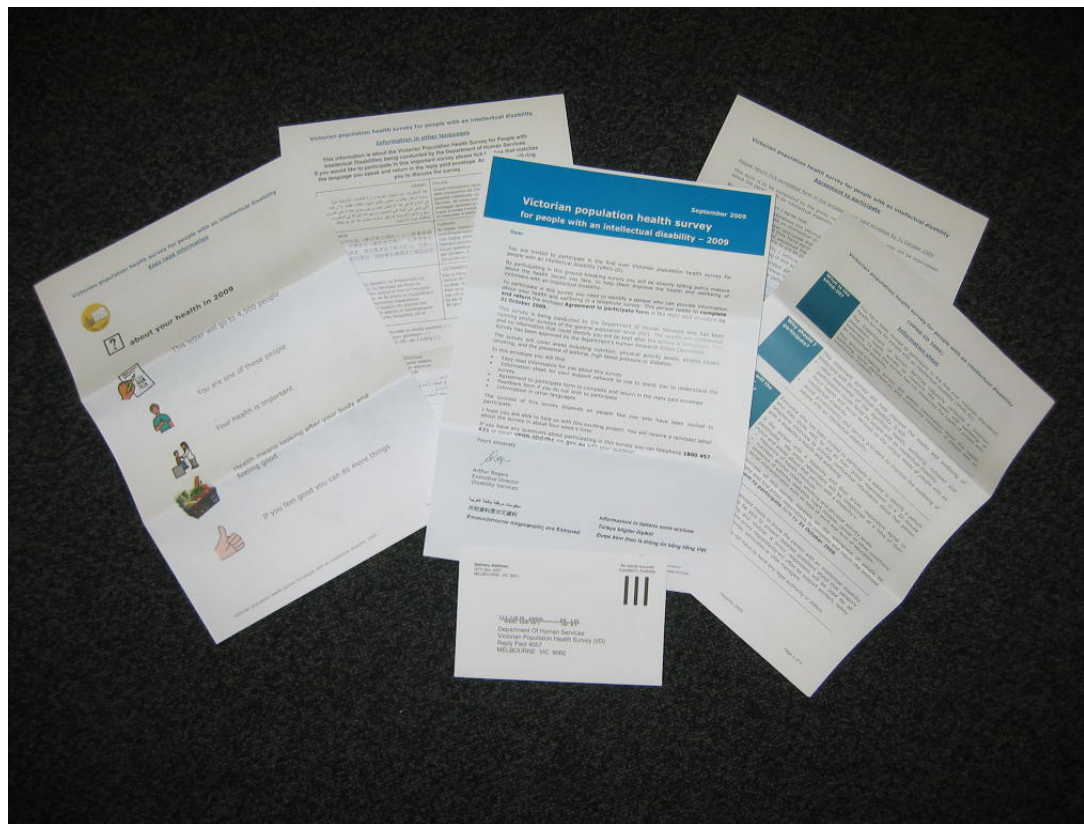
Information sent to the person with an intellectual disability

The recruitment package contained:

- Easy read information
- Information for the person's support network
- Information in 6 languages
- *Agreement to participate* form
- Reply paid envelope



Recruitment package



Role of support network... (if needed)...

- Explain the information sent in the letter
- Assist the person to make a decision about participating or not
- Inform support network
- Identify the best proxy
- Be available to be interviewed

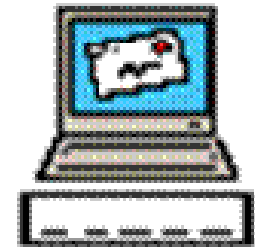


Communication

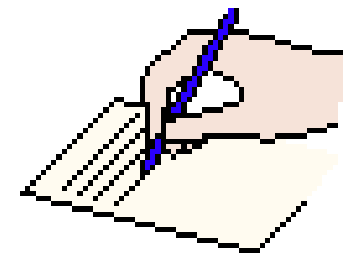
- VPHS-ID hot line



- VPHS-ID email

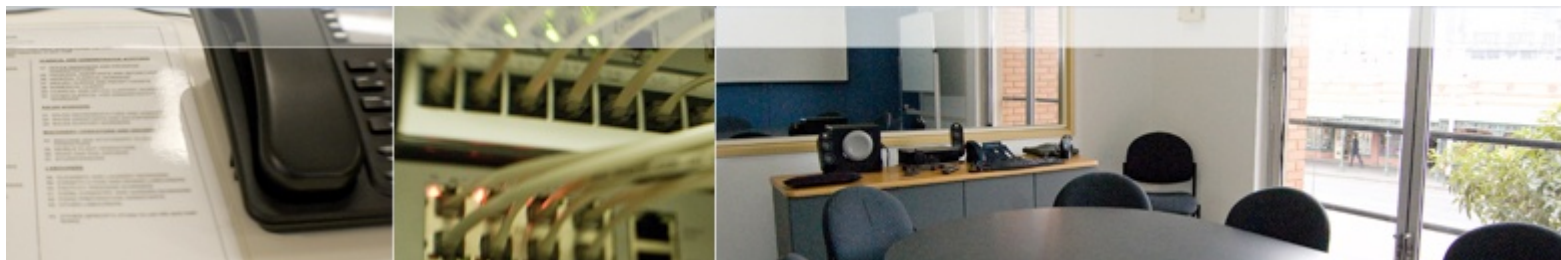


- Letters to all registered disability services providers



Computer assisted telephone interviews

- The Social Research Centre (SRC) conducted the interviews
- The SRC conducted the previous 4 VPHS and has experience of conducting surveys with carers
- Small team of trained interviewers



Response rate

- The response rate for the pilot was 13%
- The response rate for the VPHS-ID 2009 so far is 13%



Where to from here

- Social Research Centre complete the interviews
- The de-identified aggregate data will be analysed and compared to the general Victorian population
- The report will be made available (Feb 2010) on the VPHS-ID website at <http://www.health.vic.gov.au/healthstatus/vphs.htm>



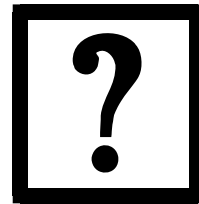
Goal

- By February 2010 the Department of Human Services will have the same robust evidence as the Department of Health to inform public health policy and strategic planning for people with ID so we can tackle the health disparities.



Thank you for listening

- Thoughts
- Questions
- Reflections
- Comments



For more information

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