

Innovative approach to encourage women with an intellectual disability to present for cancer screening

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Victorian Population Health survey of people with an intellectual disability 2009 (VPH- ID 2009)

- **Less** likely to have a Pap test compared to general population (14.8% compared with 71.1%)
- **Less** likely to have a mammogram compared to general population (55.2% compared with 75.9%)
- **Similar** screening rates for bowel cancer screening (24.5% compared with 25.6%)



Government response:

Minister for Disability Services and Reform and Community Services, Hon Mary Wooldridge MP (Department of Human Services) announced funding a project to address:

- Current barriers to breast, cervical and bowel screening participation for women with an Intellectual disability
- Ways existing systems can be improved to ensure better access
- Hence, a DHS funded joint project between Cancer Council Victoria, PapScreen Victoria and BreastScreen Victoria, coordinated through Cancer Council Victoria



Advisory Group:

Representation from

- Yooralla
- SCOPE
- Women with Disabilities Victoria (WDV)
- Victorian Advocacy League for individuals with a disability (VALID)
- Centre for Developmental Disabilities Health Victoria (CDDHV)
- DHS
- Family Planning Victoria (FPV)
- DHS – Northern region Representatives



Activities:

State- wide:

- **Invitational Letter to all women with an ID on DHS database**
- **Health Professional resources**
- Online audio / visual short clip on all cancer screening

Demonstration Sites: (Banyule & Whitehorse)

- **Training and education workshops for support staff / carers**
- **Distribution of Bowel cancer screening tests**
- Cancer Screening clinics



Invitational Letters Campaign

Aim:

To stimulate a conversation between the women and her support person (family member, friend, carer, GP, Nurse etc) to consider if screening is right for them.



Invitational Letters Campaign

Considerations:

- Addressed to the woman
- In easy English
- Size of envelope and look of resources
- Give her the option to seek assistance
- Assurances of privacy maintained
- Language reflects choice



Supporting Communications strategy

- GPs / Nurse Cervical Screening Providers
- House supervisors
- Disability peak bodies
- Community Services including women's health
- BreastScreen services



Invitation Letters Campaign

Over 5110 packs sent to women aged 20 – 49

Pack A - Pap test information only

- Cover Letter
- Invite 1 (Pap test only)
- Pap test the Plain Facts



Invitation Letters Campaign

Over 1900 packs sent to women aged 50 – 69

Pack B- all screening information

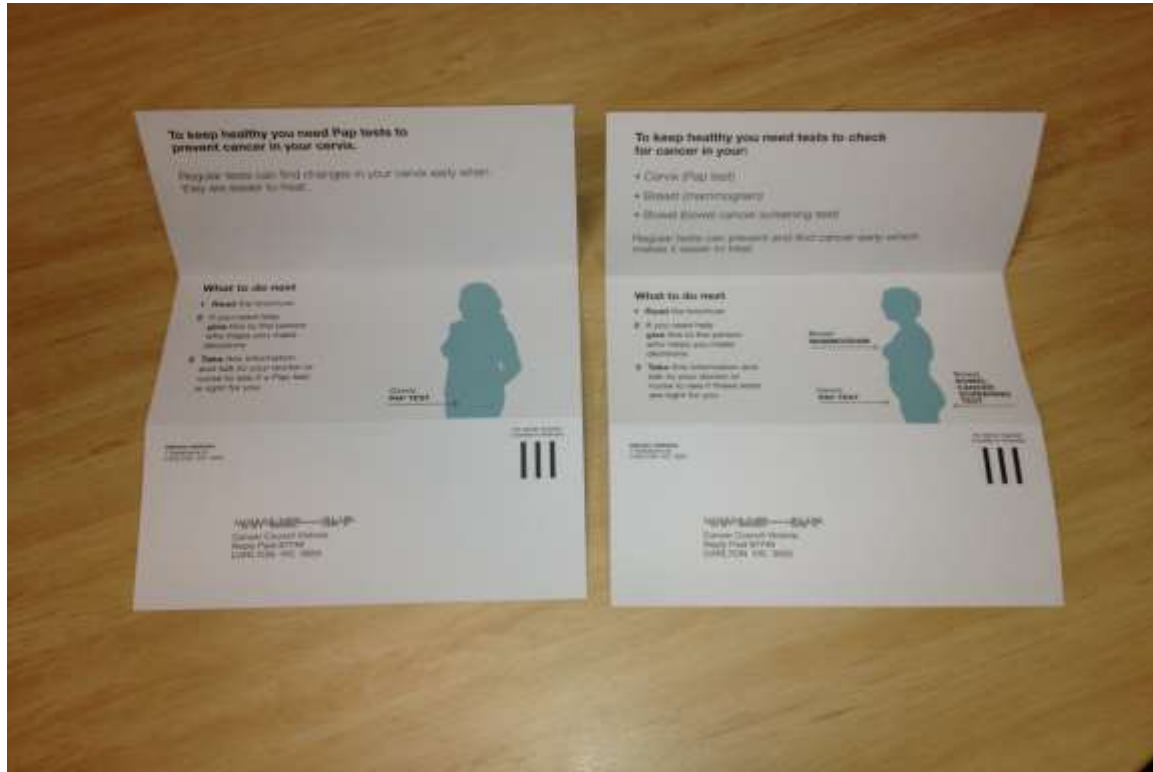
- Cover letter
- Invite 2
- Brochure
- Information sheet



Invitation Letters Campaign



Invitation Letters Campaign



Evaluation - Returnable Discussion cards

INFORMATION ABOUT THIS INVITATION

This project aims to increase awareness of the need for cancer screening. You can help by:

- 1) Having a conversation about the need for screening tests
- 2) Determining if the woman is eligible for these tests
- 3) Completing the section to the right and returning it to Cancer Council Victoria

Completing this information does not breach privacy guidelines

Completed by GP Nurse Family/Staff Other _____

Date / / Woman's postcode

Together we have discussed: Mammogram Pap test FOBT

The woman is up to date with: Mammogram Pap test FOBT

The woman wishes to think about having: Mammogram Pap test FOBT

Appointments have been made to have a: Mammogram Pap test

This woman was given an FOBT: Yes No

The woman has chosen not to have a: Mammogram Pap test FOBT

Reason No consent given Did not understand

Or

Test not needed, because: _____



Returnable Discussion cards

| | Discussion cards returned | Returned to sender -address unknown |
|----------------------|---------------------------|-------------------------------------|
| Pack A Pap | 70 (1.4%) | 329 (6.4%) |
| Pack B All screening | 29 (1.6%) | 136 (7.1%) |
| Total | 99 (1.5%) | 465 (6.6%) |



Evaluation – preliminary results

Pap tests

- A quarter of women were up to date with Pap tests
- Over a third had chosen not to have a Pap test with over half of those reported that they are 'not sexually active'
- 10% Pap tests 'too distressing, did not feel comfortable or woman not compliant
- Six appointments made, seven women wished to think about it.

Mammograms

- 41% were up to date with Mammograms
- Seven women wished to think about it and 3 respondents indicated appointments were made.
- Seven women chose not to screen



Evaluation – preliminary results

Bowel Cancer screening tests

- Only 14.8% were up to date with bowel tests
- Over 30% wished to think about it
- Half the respondents indicated they had been given a test, either through GP or National Bowel Cancer Screening Program (NBCSP)



Health Professional resources

Assisting patients with intellectual disabilities to access cancer screening in the GP setting

| Resources for Health Professionals | | |
|--|---|---|
| Management Guidelines: Developmental Disability 3 | These management guidelines available as a booklet or print are to help a busy general practitioner care for people with developmental disability. | http://www.sj.org.au/doctor.php?section=63 |
| Centre for Developmental Disability Health Victoria (CDDHV) - A Guide to Better Primary Health Care of Patients with an Intellectual Disability | This resource is aimed at supporting GPs in their vital role and highlights some of the challenges in this work as well as some initiatives aimed at assisting GPs. | http://www.cddhv.vic.gov.au/better-primary-health-care-gps.html |
| Guidelines for preventive activities in general practice (the red book) | The red book provides a single entry point to common conditions seen in Australian general practice and offers practical advice on the kind of screening and services that should be provided to the general population. Available as a PDF download. | http://www.racgp.org.au/australian-documents/guidelines/redbook/redbook08.pdf |
| The Intellectual Disability Health Assessment | Medicare item numbers for health assessment for people with intellectual disability. | http://www.cddhv.vic.gov.au/disability-health-assessment.html |
| Articles and reports | | |
| Preventative women's health care for women with a disability: Background and literature | These guidelines are designed to assist general practitioners to provide preventative health care to women with disabilities, including accessing cancer screening. | http://www.cip.rmit.edu.au/information-and-resources-for-health-professionals/publications/preventative-womens-health-care-for-women-with-disabilities |



Developed a central hub for all links to

- Resources for Health Professionals
- Articles and Reports
- Learning and Development opportunities
- Resources for patients

Promoting the hub link directly to GPs via email lists, and inserting hub link into various communication activities including newsletters, Friday faxes and through Medicare Locals.



Training and education – Overcoming the Barriers workshops

- Held two workshops in cities of Banyule & Whitehorse
- Attended by 36 support staff from Community residential services and day program providers
- Addressed barriers people with an ID face when considering attending cancer screening, including Bowel, Breast and Cervical
- Practical solutions and encouraging support staff to normalise screening for clients

'Bowel screening week'

'celebrate being a woman'

'reward with lunch/ outing'



Distribution of Bowel Cancer Screening tests

- Over 170 bowel cancer screening tests sent to house supervisors
- DHS group home in Cities of Whitehorse & Banyule
- For eligible men and women in the group home
- Included translation of informed consent statement in easy English
- Demonstration sessions for staff offered.
- Data on the outcomes of the tests will be provided in the coming weeks.



Unintended outcomes

- Other city councils requesting workshops – PapScreen running additional two workshops.
- Bowel Cancer Screening tests supplier (Enterix – Insure) are redeveloping their forms to improve readability and accessibility.



Recommendations

- Repeat mail out and consider
 - Interval, dataset, key messages around sexual activity, languages other than English
- Workshops in each city council area
- Strategies to inform parents and support people



Next Steps

- Alternative pathways into screening
- Final Report
- Current VPH – ID 2013 in the field now
- Project completion in June 2013



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