

## Infrastructure for problem-based collaborative research: Aligning research, policy and practice

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#### **Event details:**

eResearch Australasia 2009 Sydney

#### **Publication Date:**

2009

#### DOI:

https://doi.org/10.26190/unsworks/744

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# Infrastructure for problembased collaborative research

Aligning research, policy and practice

Maude Frances and Joanne Croucher University Library, University of New South Wales

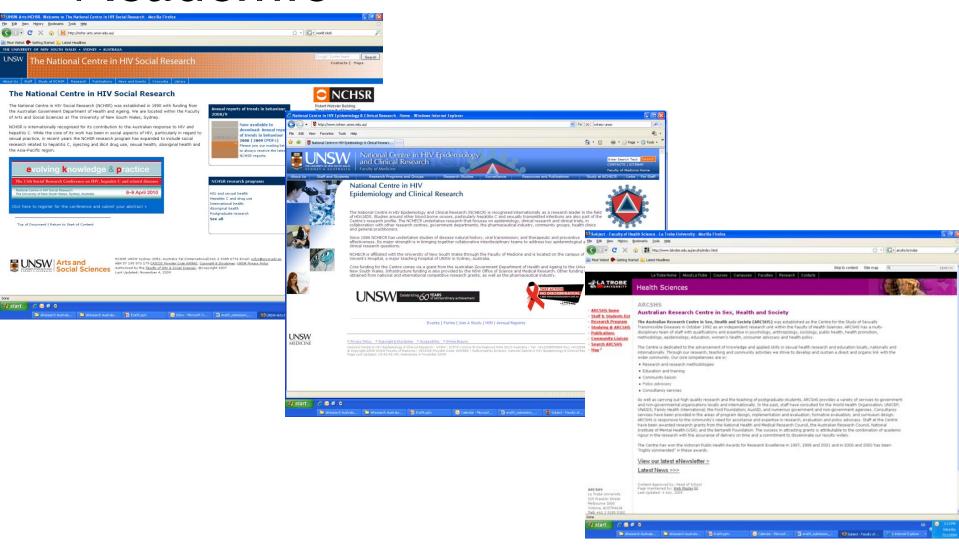


An effective partnership between government, community, researchers and health care practitioners has enabled Australians to substantially modify behaviours that put them at risk of HIV infection and support those with HIV infection from risk of ongoing transmission.

(Bernard, D., Kippax, S. & Baxter, D. (2008). Effective partnership and adequate investment underpin a successful response: Key factors in dealing with HIV increases. *Sexual Health*, *5*, 193–201.)

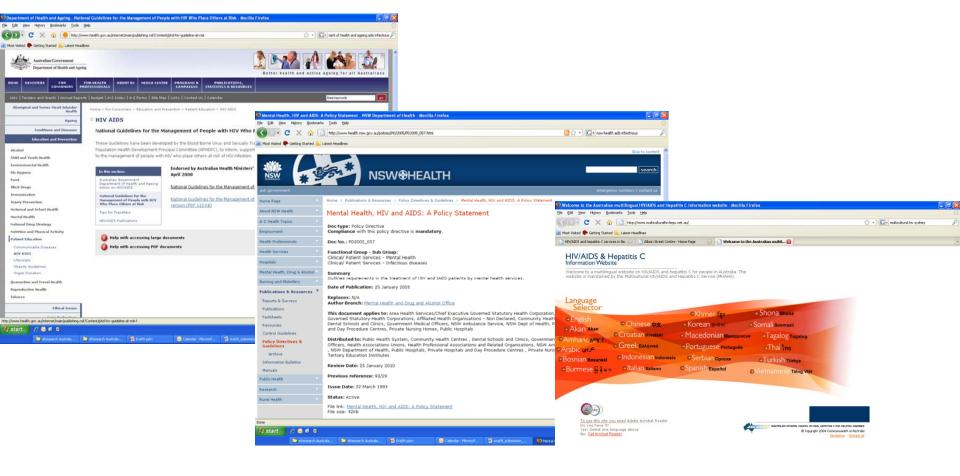
- The research context
  - partners and partnerships
  - existing resources
- Infrastructure for collaboration
  - Fedora-based repository
  - cross sectoral research lifecycle approach
- Social science research
  - Data Documentation Initiative (DDI)

## Academic

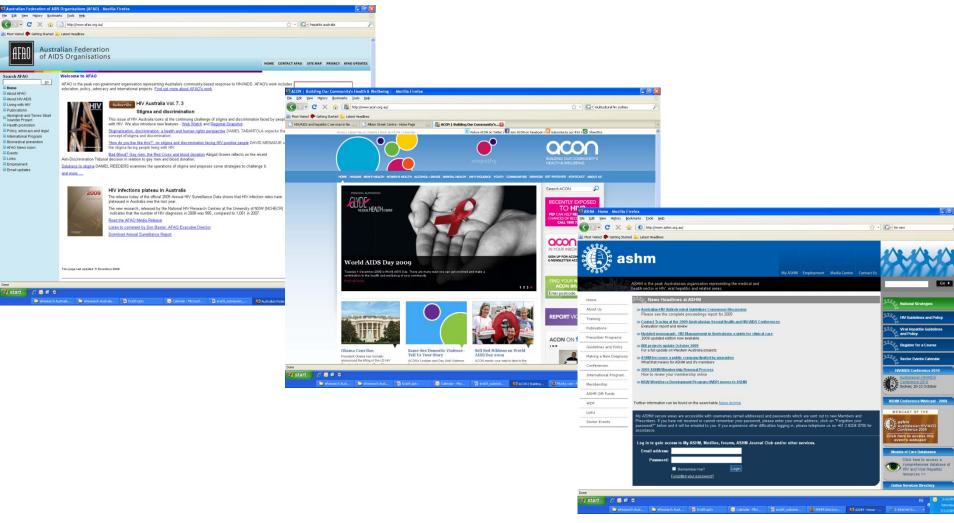


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### Government

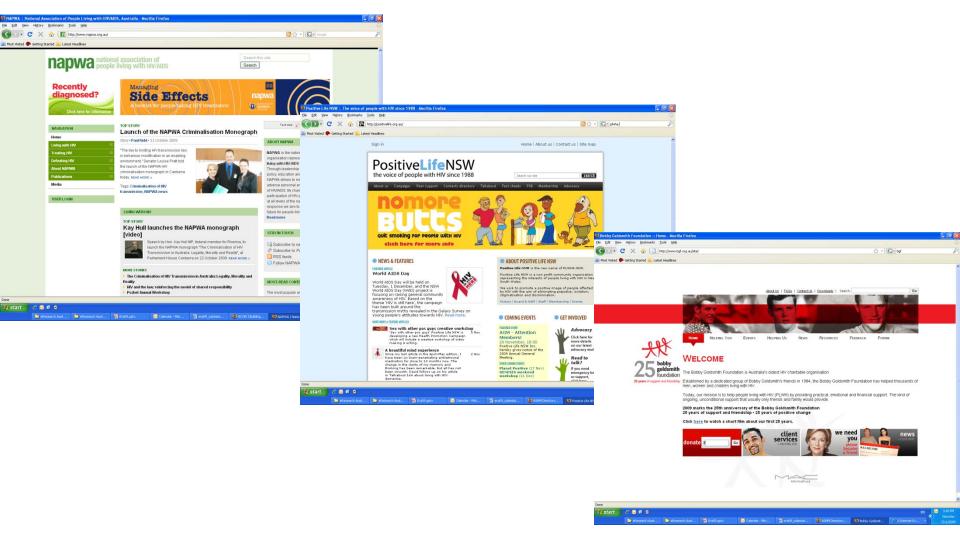


# Non-government



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## Affected communities



# How do partnerships work?

- Twenty five years collaborative research
- Throughout research lifecycle
- Research informs National Strategies
- Strategies inform health promotion campaigns
- Policy and practice inform ongoing research agenda

## Dispersed resources

- Academic multidisciplinary research material
  - Projects
  - Research instruments
  - Data
  - Publications
- Policy documents, guidelines
- Health education material
- Meeting records, conference proceedings and presentations
- News media items



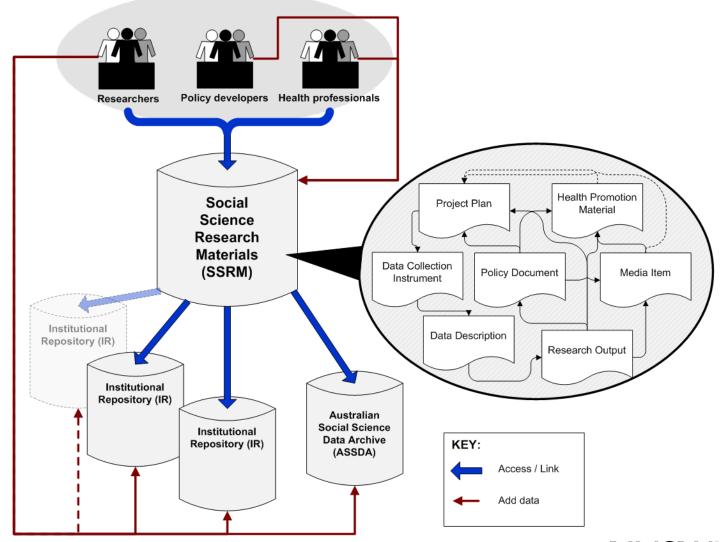
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### Infrastructure for collaboration

- Support for diverse requirements research – policy – practice
- Trust is crucial technology – sustainability - fit
- Fit with existing workflows research – policy – practice

### Social Science Research Materials



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### Metadata Standards

Dublin Core (DC)

- Metadata Object Description Schema (MODS)
  - XML schema for bibliographic data
  - describes digital library projects
  - http://www.loc.gov/standards/mods/
- Data Documentation Initiative (DDI)
  - describes social science research objects
  - http://www.ddialliance.org/





#### Social and Policy Research in HIV, Hepatitis C and Related Diseases

Help



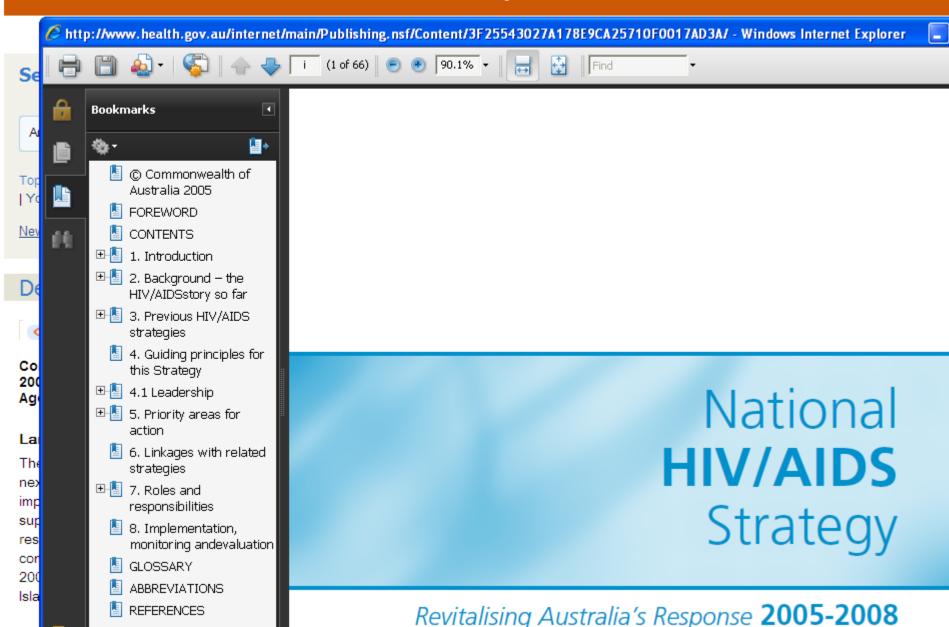
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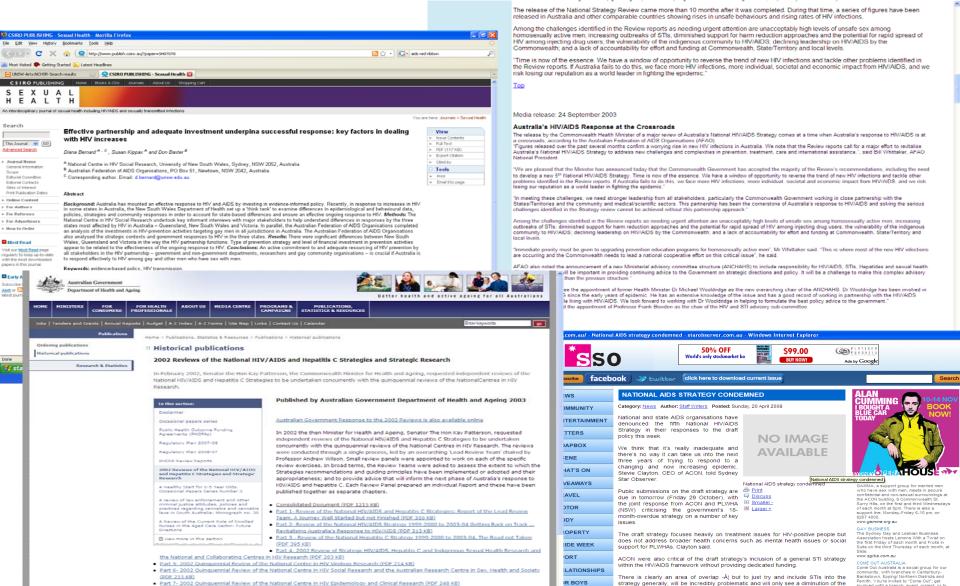
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### Social and Policy Research in HIV, Hepatitis C and Related Diseases

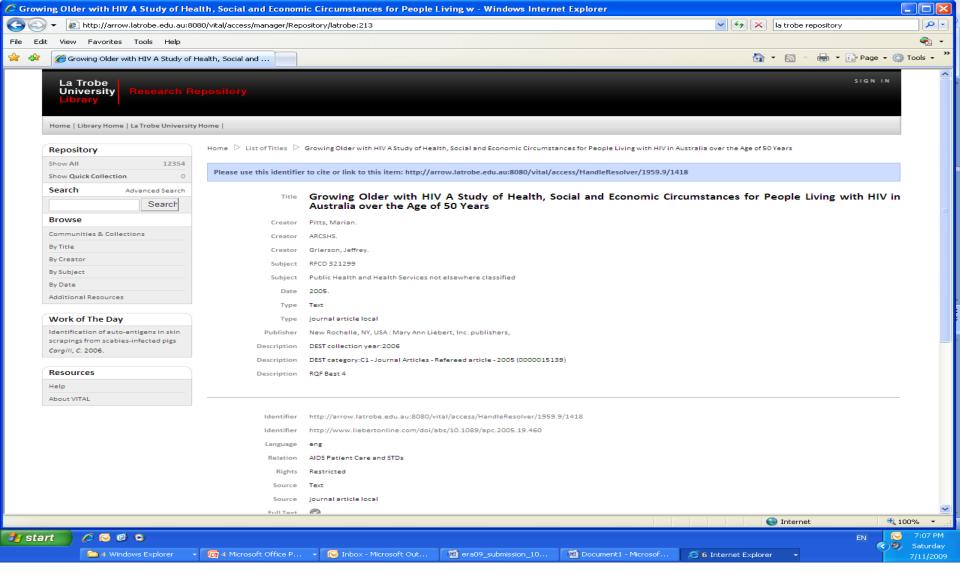


## Related items



# Refine by facets

- Research items
- Policy items
- Health education items
- Media and cultural items



Metadata is harvested from Australian institutional repositories





### Social and Policy Research in HIV, Hepatitis C and Related Diseases

Help

Search for Discrimination GO		Guest e-Shelf	
Topic search: HIV   Hepatitis C   Illicit drug use   Prevention   Treatment, care and support   Living with HIV   Living with hepatitis   Youth   Culturally and linguistically diverse   Gay men   Indigenous  New Search  Advanced Search	C   Discrimination		
New Search Advanced Search			
Details			Back to results list
Result 1	Next >	Keeping this item	
Hopwood, M., & Treloar, C. (2004). The 3D project: Diagnosis, disclosure, discrimination and people living with hepatitis C. Part 1 - diagnosed with hep C. Hep C Review, 45, 41.		<b>⊠ E-mail</b>	
Language: English		<b>⊘</b> Print	
Overview of the 3D research study with extracts from interviews highlighting the fear and frustration that arises when a positive hepatitis c diagnosis is delivered by a doctor without an explanation or referral to sources of information.		Order	
[less] [more]			
Author: Hopwood, Max; National Centre in HIV Social Research, The University of New South Wales; Treloar, Carla; National Centre in HIV Social Research, The University of New South Wales  Topics: Hepatitis C; Living with Hepatitis C; Discrimination  Add to e-Shelf			

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### Social and Policy Research in HIV, **Hepatitis C and Related Diseases**

Help

Search for Discrimination	GO >	Guest e-Shelf
Topic search: HIV   Hepatitis C   Illicit drug use   Prevention   Treatment, o   Youth   Culturally and linguistically diverse   Gay men   Indigenous	care and support   Living with HIV   Living with hepatitis C   Discrimination	
New Search	Advanced Search	
Details		Back to results list
Previous	Result 2	Keeping this item
Hopwood, M., & Treloar, C. (2003). The 3D project: Diagnosis, living with hepatitis C (Monograph 6/2003). Sydney: National	E-mail )	
University of New South Wales.  Language: English		Print
The report explores exigent conditions associated with living with he demands are the effects of stigma and social marginalisation. Many navigate and negotiate daily a field strewn with misinformation, conf relations, often while labouring under significant ill-health and surviv [less] [more]	<b>○ Order</b>	
Author: Hopwood, Max; National Centre in HIV Social Research, 1 NSW; Treloar, Carla; National Centre in HIV Social Research, The Topics: Hepatitis C; Treatment, care and support; Living with Hepatitis C; Discrimination  Link to Resource Add to e-Shelf		

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Home ▷ List Of Titles ▷ The 3D project: Diagnosis, disclosure, discrimination and living with hepatitis C



Title	The 3D project: Diagnosis, disclosure, discrimination and living with hepatitis C		
Author(s)	Hopwood, Max, National Centre in HIV Social Research, Faculty of Arts & Social Sciences, UNSW Treloar, Carla, National Centre in HIV Social Research, Faculty of Arts & Social Sciences, UNSW		
Hepatitis C Disclosure Discrimination Diagnosis Information sources Treatments Health services Australia			
Resource Type	Report		
Publication Details	National Centre in HIV Social Research, The University of New South Wales, Sydney, 2003; ISBN:		
Series No.	Monograph 6/2003		
Description/Abstract	The report explores exigent conditions associated with living with hepatitis C infection. Intersecting these demands are the effects of stigma and social marginalisation. Many people with hepatitis C have to navigate and negotiate daily a field strewn with misinformation, conflicting identities and unequal power relations, often while labouring under significant ill-health and surviving on low incomes.		
Language	EN		
Rights	Please click here to view the rights		
Citation Link	Please use this identifier to cite or link to this item: http://handle.unsw.edu.au/1959.4/10687		
Full Text	◎ 556.9 KB		
Total Attachment(s)	1		

3Dproject.pdf 556.9 kB Adobe Acrobat PDF SOURCE01	Description	Size	Format	Filename
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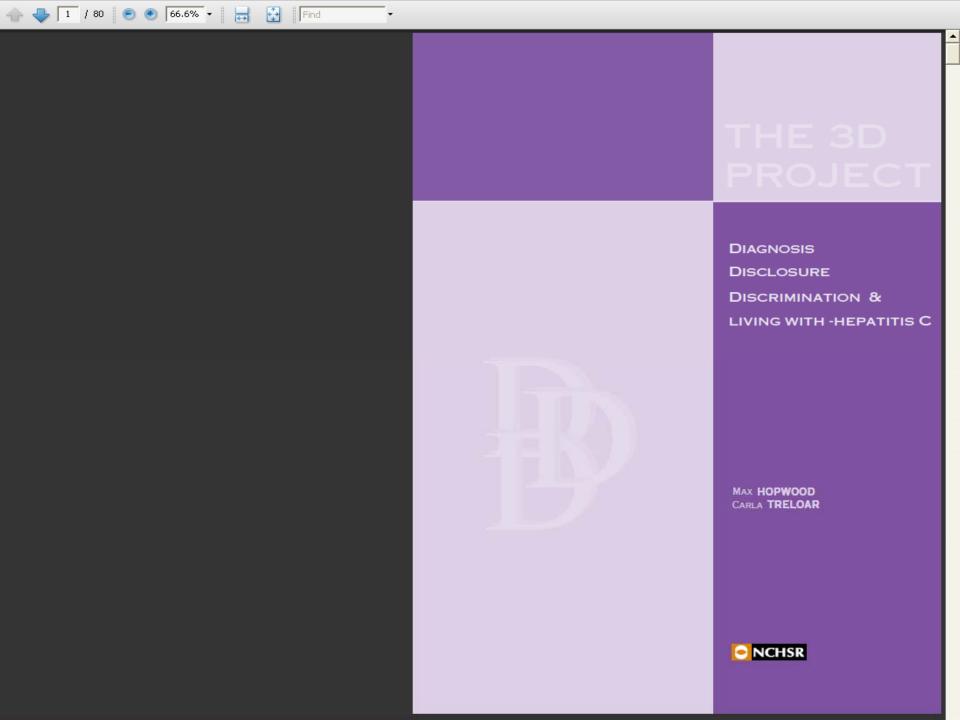
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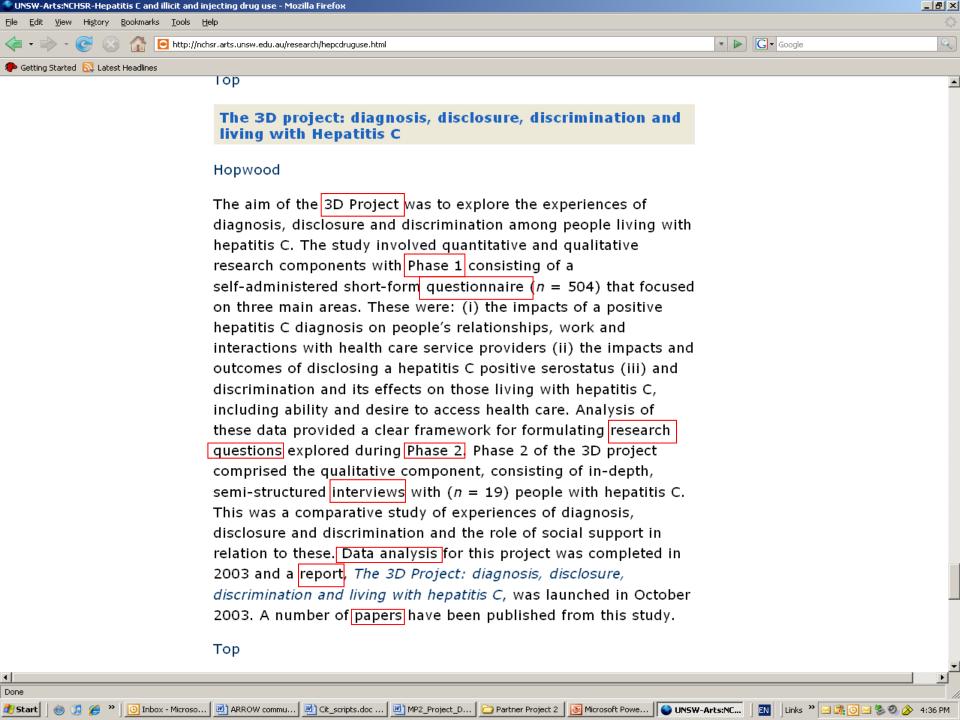












# DDI 3.0 Lifecycle Model

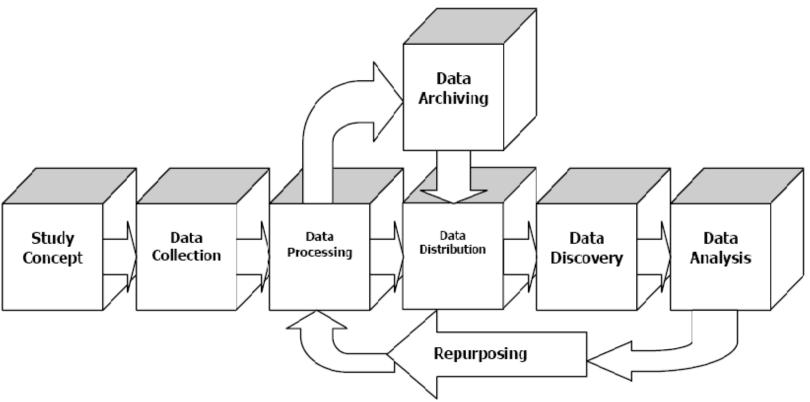
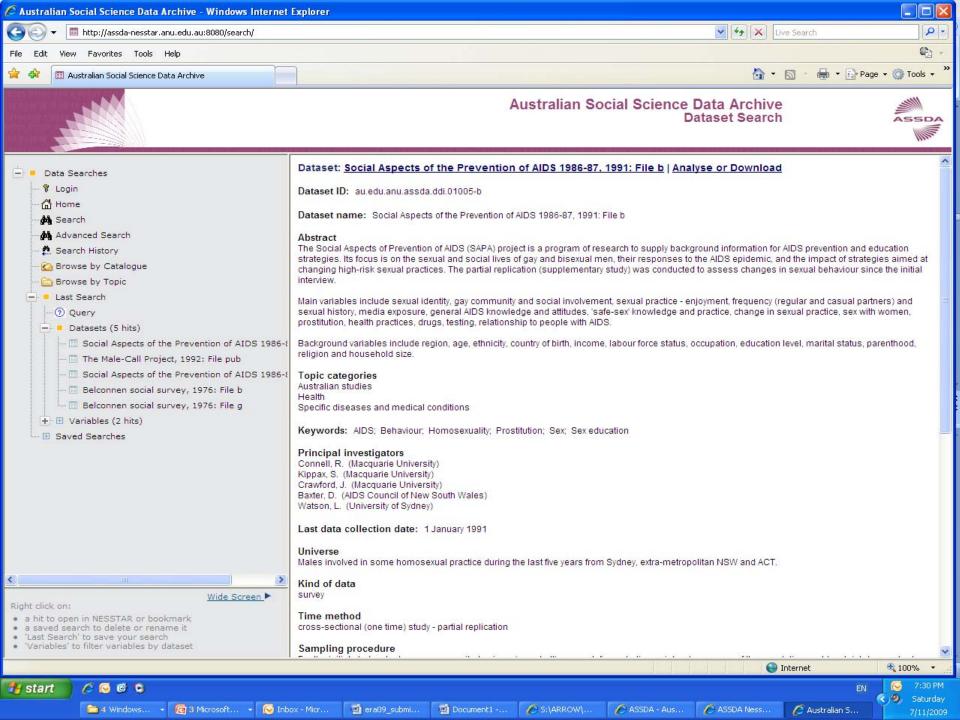
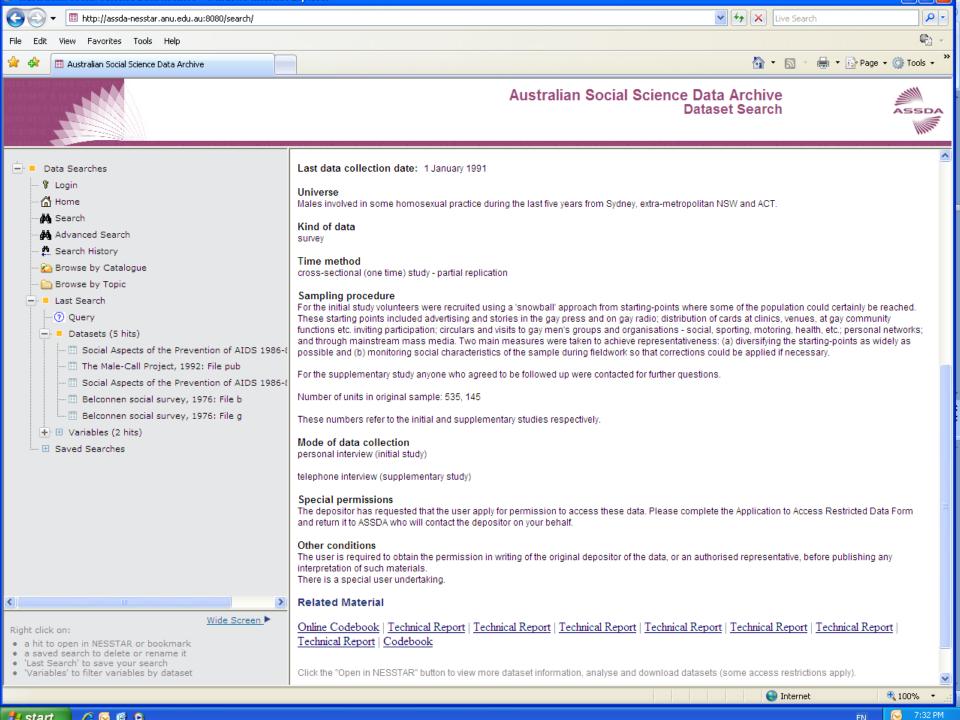


Figure: Combined Life Cycle Model





au.edu.anu.assda.ddi.01005-b Australian Social Science Data Archive Copyright © 2005, The Australian National University. All rights reserved. 25 February 1999 APS Connell, R., et al. Social Aspects of the Prevention of AIDS 1986-87, 1991 [computer file]. Canberra: Australian Social Science Data Archive, The University, . Social Aspects of the Prevention of AIDS 1986-87, 1991: File b au.edu.anu.assda.ddi.01005-b Connell, R. (Macquarie University) Kippax, S. (Macquarie University) Crawford, J. (Macquarie University) Baxter, D. (AIDS Council of New South Wales) Watson, L. (University of Sydney) To maximise rapport as well as to develop the study as a reflexive enterprise of the gay community, it was decided to have most, but not all, interv From applicants responding to advertisements, 27 were selected for training and 25 were employed in the fieldwork. (Some interviews were also described by the fieldwork) and 25 were employed in the fieldwork. ordinator and other members of the core group).

Social Aspects of the Prevention of AIDS 1986-87, 1991: File b

Copyright © 2004, The Australian National University, All rights reserved.

Bibliographic Citation: Connell, R., et al. Social Aspects of the Prevention of AIDS 1986-87, 1991 [computer file]. Canberra: Australian Social Science Data Archive, The Australian National University, .

#### Study Scope

Keywords: AIDS, Behaviour, Homosexuality, Prostitution, Sex, Sex education

Australian studies, Health, Specific diseases and medical conditions Topic Classification:

Abstract: The Social Aspects of Prevention of AIDS (SAPA) project is a program of research to supply background information for AIDS prevention and education strategies. Its focus is on the sexual and social lives of gay and bisexual men, their responses to the AIDS epidemic, and the impact of strategies aimed at changing high-risk sexual practices. The partial replication (supplementary study) was conducted to assess changes in sexual behaviour since the initial interview. Main variables include sexual identity, gay community and social involvement, sexual practice - enjoyment, frequency (regular and casual partners) and sexual history, media exposure, general AIDS knowledge and attitudes, 'safe-sex' knowledge and practice, change in sexual practice, sex with women. prostitution, health practices, drugs, testing, relationship to people with AIDS. Background variables include region, age, ethnicity, country of birth, income. labour force status, occupation, education level, marital status, parenthood, religion and household size.

Date of Collection: First date of data collection, wave 1: 1 September 1986 - Last date of data collection, wave 1: 1 March 1987 First date of data collection, wave 2: 1 January 1991 -

Last date of data collection, wave 2: 1 January 1991

Universe: Males involved in some homosexual practice during the last five years from Sydney, extra-metropolitan NSW and ACT.

Kind of Data: survey

#### Methodology and Processing

Time Method: cross-sectional (one time) study - partial replication

Sampling Procedure: For the initial study volunteers were recruited using a 'snowball' approach from starting-points where some of the population could certainly be reached. These starting points included advertising and stories in the gay press and on gay radio; distribution of cards at clinics, venues, at gay community functions etc. inviting participation; circulars and visits to gay men's groups and organisations - social, sporting, motoring, health, etc.; personal networks; and through mainstream mass media. Two main measures were taken to achieve representativeness: (a) diversifying the starting-points as widely as possible and (b) monitoring social characteristics of the sample during fieldwork so that corrections could be applied if necessary. For the supplementary study anyone who agreed to be followed up

> were contacted for further questions. Number of units in original sample: 535, 145 These numbers refer to the initial and supplementary studies respectively. personal interview (initial study)

Mode of Data telephone interview (supplementary study) Collection:

Class of the Study: Level 2

Mode of Data

Collection:

#### **Data Access**

A copy of the User Undertaking Form must be signed before data may be accessed. Confidentiality Declaration:

Special Permissions: The depositor has requested that the user apply for permission to access these data. Please complete the Application to Access Restricted Data Form and return it to ASSDA who will contact the depositor on your behalf.

Citation Requirement: All manuscripts based in whole or in part on these data should: (i) identify the data, original investigators and data distributors by including the bibliographic reference for the data file given below: Connell, R., et al. Social Aspects of the Prevention of AIDS 1986-87, 1991 [computer file]. Canberra: Australian Social Science Data Archive, The Australian National University, . (ii) declare that those who carried out the original analysis and collection of the data bear no responsibility for the further

analysis or interpretation of them.

Data Archive

Deposit Requirement: In order to assemble essential information about the use of archival resources and to facilitate the exchange of information about users' research activities, individuals are requested to deposit two copies of any completed manuscript, thesis abstract, or reprint incorporating analysis of these data with the Australian Social Science

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Technical Report - 9.89 MB

#### Citation

Codebook

Holdings Information: \_./ASSDAData/codebooks/ASSDA.CODEBOOK.01005-b.rtf.zip

Codebook

### Related Studies

SSDA study d567: National AIDS education campaign benchmark survey 1986-87: gay and bisexual men

SSDA study d990: National Survey of Australian Secondary Students

HIV / AIDS and sexual health, 1997.

Title:

SSDA study d994: Take Control 2: Sexual Behaviour and Attitudes of Gay and Bisexual men in Brisbane, 1992

SSDA study d995: Evaluation of the National Gay / Bisexual Campaign, 1991.

SSDA study d996: Perth AIDS Research Project, 1990

SSDA study d997: Operation Vampire: The impact of AIDS education on sexual behaviour among 1986/8

SSDA study d1004: Victorian Gay and Bisexual Men's Health and Lifestyle Survey, 1986-1989

SSDA study d1007: The Popular People Project, 1994

### SSDA Study d1008: The Male-Call Project, 1992

### Related Publications

Connell, R.W. et al., 'Social Aspects of the Prevention of AIDS Study A Report No.1: Method and Sample'. Sydney: Macquarie University, School of 30 pp.

Connell, R.W. et al, 'Facing the Epidemic: Changes in the Sexual Lives of Gay and Bisexual Men in Australia and their Implications for AIDS Preven 384-402.

Connell, R.W. et al. 'Danger and Context: Unsafe Anal Sexual Practice among Homosexual and Bisexual Men in the AIDS Crisis'. ANZJS 1990, 26:

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### Research models

- Triple helix model
  - Etzkowitz & Leydesdorff (1997)
- Mode 2 research
  - Gibbons et al. (1997)
- Post-normal science
  - Funtowicz & Ravetz (1993)

## Linking research, policy & practice

- Extension of research lifecycle model
- Support for all research partners
- Supports existing and emerging collaborations
- Shared space for working projects
- Storage for past projects

### References

- Bernard, D., Kippax, S. & Baxter, D. (2008). Effective partnership and adequate investment underpin a successful response: Key factors in dealing with HIV increases. *Sexual Health*, *5*, 193–201
- Etzkowitz, H. & Leydesdorff, L. (Eds.), (1997). *Universities in the global economy: A triple helix of university-industry-government relations*. Cassell Academic, London.
- Funtowicz, S. O. & Ravetz. J. R. (1993). Science for the post-normal age. *Futures*, *25*, 735-755.
- Gibbons, M., Limoges, C., Nowotny, H., Schwartzman, S., Scott, P. & Trow, M. (1994). The new production of knowledge: The dynamics of science and research in contemporary societies.
   Sage, London.

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