

‘NOT LEAVING DATA IN THE DARK’

Naydene de Lange

HIV and AIDS Education Research Chair

Faculty of Education

IN THE BEGINNING...

In the age of AIDS ...

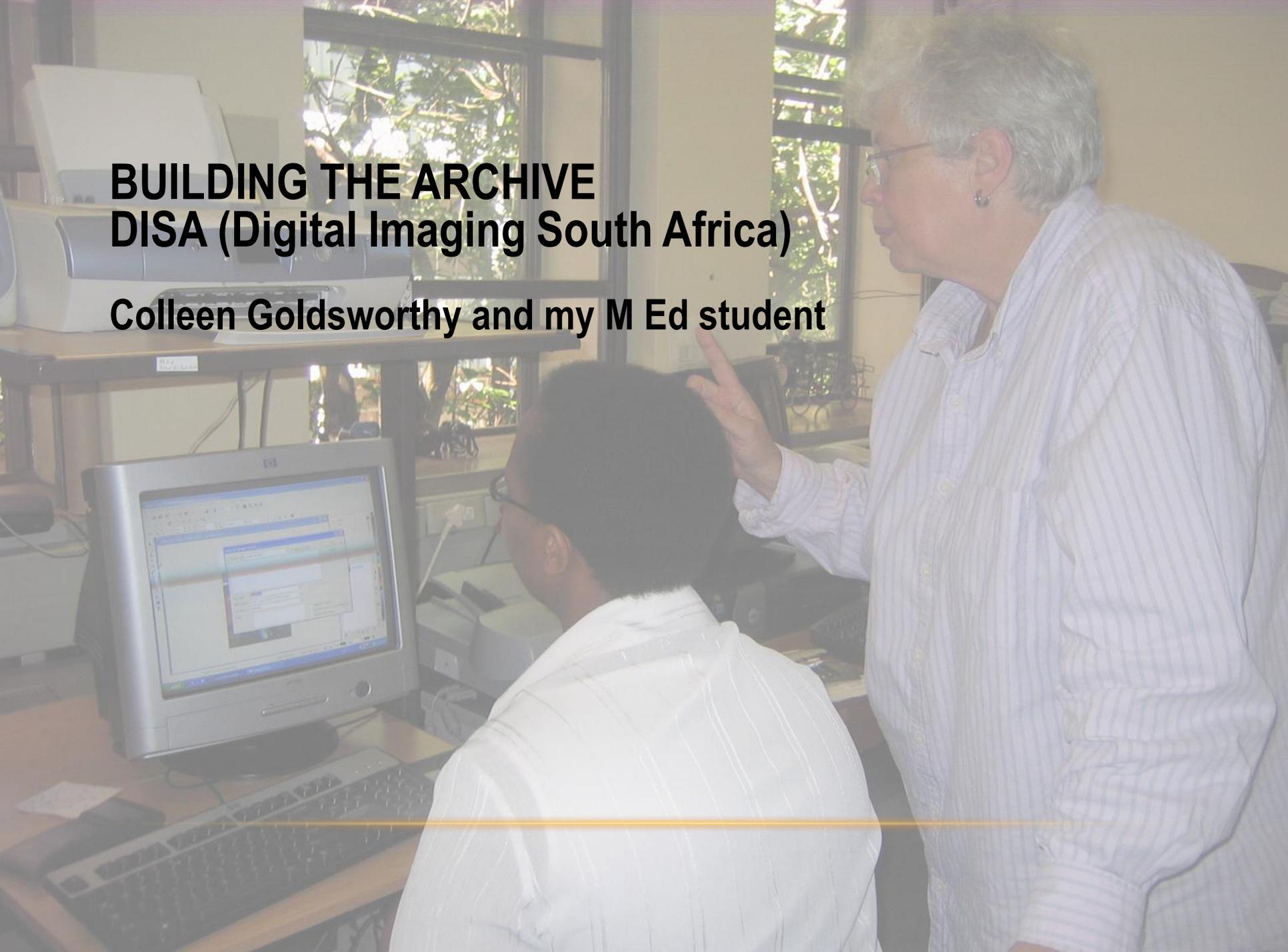
- prevention and awareness education
 - visual arts-based approaches to research
 - engaging people (young and old) in playing an active role in addressing gender-based violence and HIV and AIDS
-

2004-2007 (NRF): Learning Together: Towards an integrated participatory approach to youth, gender and HIV and AIDS interventions in rural KwaZulu-Natal

- Large collections of visual data
- Challenges : effective management and storage of data, accessing data across two continents

**2008-2011 (NRF):
WORKING WITH DIGITAL ARCHIVES: GIVING LIFE
(TO DATA) TO SAVE LIVES (IN THE AGE OF AIDS))**





**BUILDING THE ARCHIVE
DISA (Digital Imaging South Africa)**

Colleen Goldsworthy and my M Ed student

PHOTOVOICE (Photographs)

- Prompt: “Create representations of stigma around HIV&AIDS

It025



Metadata

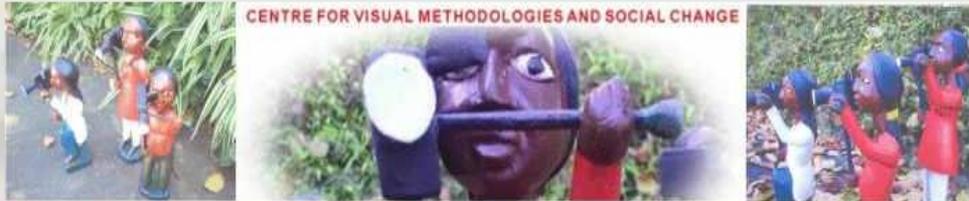
The screenshot shows the Greenstone Librarian Interface v2.72. The main window displays a list of files on the left and a metadata table on the right. The file 'ltph025.jpg' is selected. The metadata table contains the following information:

dc.Title	Untitled photograph
dc.Creator	Anonymous student from a male/female group of partici...
dc.Subject and Keyw...	
dc.Description	A staged photograph of a young male student beating a y...
dc.Publisher	
dc.Contributor	
dc.Date	2005-04-00
dc.Resource Type	Photograph
dc.Format	10x15cm
dc.Format	Colour photograph
dc.Resource Identifier	ltph025
dc.Source	Centre for Visual Methodologies for Social Change, Learn...
dc.Language	
dc.Relation	
dc.Coverage	South Africa, KwaZulu-Natal, Vulindlela district
dc.Rights Management	CVMSC, UKZN

At the bottom of the interface, a message states: "No Metadata Element Selected".

Caption: (Facilitator Prompt) : “Create representations of stigma around HIV&AIDS”

Caption: (Photographer Narrative) He could not accept that he is HIV positive he decided to beat the female to silence her because the girl is willing to reveal their HIV status



CENTRE FOR VISUAL METHODOLOGIES AND SOCIAL CHANGE

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Learning Together

Towards an integrated participatory approach to youth, gender and HIV/AIDS interventions in rural KwaZulu-Natal Schools . Despite the many efforts in South Africa to reduce the rate of transmission of HIV/AIDS, certain populations, most particularly youth - and within the youth population, young women between the ages of 15 and 19 - continue to be the most vulnerable.

It is estimated that over 60% of all new infections occur in youth between the ages of 15 and 25, with young women being infected earlier and at higher rates. Young women between the ages of 15 and 19 are acquiring 24% of all new infections. What is apparent is that no one intervention or 'sector' can address all of the central factors - poverty, high rates of gender-based violence, cultural attitudes, and so on.

If communities are to play an effective role amongst youth in AIDS prevention and care, there is a need to consider ways of integrating the efforts of those working in the various sectors (health, community development, education).

However, while an inter-sectoral integrated approach to HIV/AIDS intervention may be key, community, school, and health care workers often lack a space in which to explore strategies and lessons learned.

This project therefore asks two main questions: (1) how might participatory methodologies bring together the various sectors and partners working in the area of gender, youth and HIV/AIDS prevention and care in rural areas?

This particular collection of photographs emanates from working with youth in grades 8 and 9 at a senior secondary school in the Vulindlela district.

The teachers in the school realised that stigma around HIV & AIDS was an issue that had to be addressed in school.

This created the opportunity to use visual participatory methodologies, in this instance photovoice, to engage the learners with stigma issues around HIV&AIDS.

Most of the photographs (staged as a representation of situations depicting stigma) were taken by youths, while some are photographs of the process of using photovoice.

Project leader : Naydene de Lange delanqen@ukzn.ac.za

Team members: Claudia Mitchell, Relebohile Moletsane, Jean Stuart, Thabisile Buthelezi, Myra Taylor, Fikile Mazibuko
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The team gratefully acknowledge the funding and support of the NRF.



Centre for Visual Methodologies for Social Change

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HOW CAN WE 'GIVE LIFE TO DATA TO SAVE LIVES (IN THE AGE OF AIDS)?



In our research over the past few years our research team has generated vast amounts of data through visual participatory methodologies in addressing HIV & AIDS. Building on our current research, we are asking how can we create, position and maintain a (digital) knowledge base that can empower researchers (nationally and internationally) and ordinary people (as producers of knowledge) to generate opportunities and solutions to ease the HIV & AIDS pandemic?

In this work the focus has been on involving groups of teachers, community health workers and young people in one rural district in taking pictures of 'problems and solutions in addressing HIV&AIDS' as well as 'stigma', and making video documentaries on 'issues affecting their daily lives'. Our work with visual methodologies has been in response to the failure of HIV & AIDS prevention programmes for youth as a particularly vulnerable population in the AIDS crisis (Campbell, 2003). It has highlighted the significance of visual arts-based approaches both to engaging young people in becoming protagonists in addressing the issues, and to stemming what we have described elsewhere as a "sick of AIDS" phenomenon (Mitchell and Smith, 2003), but also to deepening our understanding of the contribution of such methodologies to obtaining an 'insider view' of the issues. We have found that when children and young people, teachers and community health care workers have had a 'visual voice' in identifying the issues, there has been more engagement with the issues and more ownership in seeking solutions. As might be imagined, the participatory visual methodology interventions have generated (and continue to generate) vast quantities of visual data -- and many questions. The challenge, however, is to find effective ways of working with the ever expanding collections of photographs and other visual data in ways that go beyond the techniques that we have used so far, and that can deepen our understanding of the interplay between and amongst modes of inquiry, modes of representation and modes of dissemination.

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The objective of the NRF is to support and promote research through funding, human resource development, and the provision of the necessary research facilities, in order to facilitate the creation of knowledge, innovation and development in all fields of the natural and social sciences, humanities and technology.



The main goal of CAPRISA is to undertake globally relevant and locally responsive research that contributes to understanding HIV pathogenesis, prevention and epidemiology as well as the links between tuberculosis and AIDS care.

Not leaving data in the dark: Use with teachers



Not leaving data in the dark: Use with community health workers



Not leaving data in the dark: Use with children



2012-2014 (NRF): NOT LEAVING DATA IN THE DARK¹: PARTICIPATORY ARCHIVING AND VISUAL DATA TO ADDRESS HIV AND AIDS

**Naydene de Lange, Claudia Mitchell,
Relebohile Moletsane, Myra Taylor**

The title is drawn from Linden and Green's (2006) work around digitizing statistical data, Linden, J. & Green, A. (2006). Don't leave the data in the dark: Issues in digitizing print statistical publications. D-Lib magazine, 12, 1

WHY THIS RESEARCH?

- Social Science research in a South Africa - ravaged by various socio-economic ills, but in particular by HIV and AIDS - should be pushing **innovation** in search of ways in which **research could make a difference**

(See Andrews & Pouris, 2010; DHET, 2011)

- One key way of doing this is by **fully engaging participants themselves** throughout the research process in new ways as

knowledge producers

knowledge users

and disseminators of new knowledge

Keeping in mind that research data have

- a **limited life**
- that published research findings have a **limited audience** (mostly academic)
- **seldom reach the community**

this project is organized around the idea of “not leaving data in the ‘dark”, but rather making it accessible to communities.

NLDD explores this in two ways:

- through extending the data in an already existing digital archive by linking it to other data sets to make 'big data' (social science researchers often hear that large scale studies are more important than smaller studies); and
 - through extending the community engagement with an already existing digital archive through such practices as participatory archiving, participatory analysis and re-use and re-mix of data, in addressing HIV and AIDS.
-

RESEARCH QUESTIONS

- How might a digital archive be extended to include multiple digital archives by linking it to collections of visual data generated by other research teams to enable “big data” in the age of AIDS, enabling analysis across data sets?
 - How might teachers, youth and community health workers become agents in the construction of knowledge through participatory archiving and participatory analysis in a community-based digital archive? And how might this help towards making participants agents of community empowerment in the age of AIDS?
 - How might youth as a particularly critical group in the AIDS pandemic become engaged in a media approach (through re-mixing and re-using) to visual data within a participatory cultures framework in order to contribute to knowledge production and youth empowerment?
-

A. Community health workers as cultural producers in addressing gender-based violence in rural South Africa



Making the data



**Having sex with elderly women (gogos)
does not cure AIDS and it affects gogo's
health**



**Ukuya ocansini nogogo akusilaphi isifo
sengculazi kodwa kukhubaza impilo yogogo**

Concept and Design by Songonzima Clinic Community Health Workers @2013

Owning a set
of media
posters to use
in their
community



B. *“Building a future without gender violence”*

Rural teachers and youth leading community dialogue





What do you not like about it?

01:26



YOUTH-LED COMMUNITY DIALOGUE ON SEXUAL VIOLENCE IN THE AGE OF AIDS



Directed by

Nonhlanhla Gasa
Hamilton Shelembe
Styles Colvel

05

28:52

3:55 AM 2014/01/12

C. ADDRESSING GENDER-BASED VIOLENCE IN THE AGE OF AIDS: RURAL YOUTH EDUCATING PEERS THROUGH SOCIAL MEDIA



- This 'research as intervention' demonstrates some of the ways in which the role of rural teachers, youth, community health workers, could be transformed so that they see themselves as agents of change..
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