ESRC End of Award Report

For awards ending on or after 1 November 2009

This End of Award Report should be completed and submitted using the grant reference as the email subject, to reportsofficer@esrc.ac.uk on or before the due date.

The final instalment of the grant will not be paid until an End of Award Report is completed in full and accepted by ESRC.

Grant holders whose End of Award Report is overdue or incomplete will not be eligible for further ESRC funding until the Report is accepted. We reserve the right to recover a sum of the expenditure incurred on the grant if the End of Award Report is overdue. (Please see the ESRC Research Funding Guide for details.)

Please refer to the Guidance notes when completing this End of Award Report.

<table>
<thead>
<tr>
<th>Grant Reference</th>
<th>RES-062-23-2663</th>
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</thead>
<tbody>
<tr>
<td>Grant Title</td>
<td>Life on Antiretroviral therapy: People’s adaptive coping and adjustment to living with HIV as a chronic condition in Wakiso District, Uganda</td>
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<tr>
<td>Grant Start Date</td>
<td>1st Nov 2010</td>
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<tr>
<td>Grant End Date</td>
<td>31st Aug 2013</td>
</tr>
<tr>
<td>Total Amount Expended:</td>
<td>£178,145.15</td>
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<tr>
<td>Grant holding Institution</td>
<td>University of East Anglia</td>
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<tr>
<td>Grant Holder</td>
<td>Dr Steve Russell</td>
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<tr>
<td>Grant Holder’s Contact Details</td>
<td>Address</td>
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<td>School of International Development</td>
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<td>University of East Anglia</td>
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<td>Norwich, NR4 7TJ, UK</td>
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<tr>
<td>Institution</td>
<td>University of East Anglia</td>
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<tr>
<td>Co-Investigators (as per project application):</td>
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<tr>
<td>Prof Janet Seeley</td>
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<td>Institution</td>
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<td>University of East Anglia</td>
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1. Non-technical summary

For people living with HIV (PLWH) in places like Uganda, availability of effective treatment means that HIV has become a manageable condition, not a death sentence. This treatment is known as antiretroviral therapy (ART). ART has restored people’s health, but challenges remain, such as taking medicine every day for the rest of their lives, and living in harsh economic conditions. The broad aims of this study were to:

- build understanding of how people manage their health and their daily lives
- analyse factors that enable or hinder people’s effective self-management of the condition
- measure the quality of life and mental health of PLWH, to see whether they are coping and building new meaningful lives.

The study was based in the Wakiso district of Uganda.

In-depth interviews were conducted with 38 PLWH recruited from three types of HIV care facility. They told the story of their illness and how they are getting on now. Quantitative data were collected from 260 people living with HIV, randomly selected from the same HIV facilities, and from a comparison group of 160 people living in nearby communities. With these data the study measured people’s quality of life and mental health.

Our findings show that PLWH’s quality of life and mental health are better than in the comparison group, and various factors can explain this surprising finding. PLWH on ART have adjusted well to living with HIV on ART, have hope for the future and are working hard to rebuild their lives. Several important things have helped them on their journey of recovery, notably family support, advice and counselling from health workers, and decreasing levels of discrimination in communities.

2. Project overview

a) Objectives

Please state the aims and objectives of your project as outlined in your proposal to us. [Max 200 words]

The research objectives outlined in the proposal were as follows:

1. To document patient pathways to accessing ART at three contrasting service delivery sites, and their self-management processes and reported adherence levels.
2. To analyse the changes in ART patients’ lives and their self-management strategies since
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becoming HIV positive and starting ART.
3. To analyse the factors explaining a more radical transformation in people’s identity, activities and outlook since becoming HIV positive and starting ART.
4. To examine people’s feelings of achievement (or disappointment) and self-esteem arising from their efforts.
5. Through qualitative data analysis, to examine the implications of the above changes in life, strategies and achievements on processes of transition or transformation:
6. Through quantitative analysis, to measure outcomes indicative of transition or transformation, notably mental health, physical health, and economic outcomes (asset portfolios and a food security index).
7. To evaluate the factors influencing people’s transition processes and outcomes through qualitative and quantitative data analysis.
8. To assess whether ART and the better health of PLHIV modify community-wide constructions of HIV and processes of stigmatisation.

b) Project Changes
Please describe any changes made to the original aims and objectives, and confirm that these were agreed with us. Please also detail any changes to the grant holder’s institutional affiliation, project staffing or funding. [Max 200 words]

No changes were made to the original aims and objectives. Some small changes were made to the details of the research design and methodology (e.g. sample groups and sizes), due to the actual situation for sampling on the ground once the project started.

c) Methodology
Please describe the methodology that you employed in the project. Please also note any ethical issues that arose during the course of the work, the effects of this and any action taken. [Max 500 words]

Study sites
Data were collected between January 2011 and March 2012. Three types of ART delivery site in Wakiso District were selected to recruit study participants:

- the HIV clinic at the government hospital in Entebbe;
- three government health centres (level 3) that have referral links to Entebbe

Wakiso District, which encircles the capital city Kampala, was selected as the site for ease of access to the study population (the research project and team were based at the Medical Research Council/Uganda Virus Research Institute (MRC/UVRI), Entebbe) and
because of the presence of governmental and non-governmental treatment providers. Ethical approval for the study was obtained from the Uganda Virus Research Institute and the University of East Anglia, UK. Overall approval was granted by the Uganda National Council for Science and Technology.

**Qualitative component of the study**

Eligible patients for the study were those who had been on ART for more than one year. A list of eligible patients was compiled for each facility. Thirty-eight participants were purposively sampled to ensure an equal gender balance, an age mix and participants (n=3) on a second-line ART regimen. Of the 38, there were 18 male and 20 female. 13 were from Entebbe government hospital, 11 from the three referral health centres, and 14 from TASO Entebbe.

There were two types of qualitative interview: The first was an unstructured life history interview about participants’ experience of illness, treatment and recovery. This first interview was not taped, but notes were taken and detailed life and illness history narratives were written up after the interview. The second interview was semi-structured and examined issues around HIV self-management in more depth. This interview was taped, transcribed and translated into English.

The qualitative interviews explored changes in ART patients’ lives and their self-management strategies since becoming HIV positive and starting ART, for example with respect to disclosure and management of identity, their work and daily activities, relationships, reflective and spiritual endeavours, links with civil society organisations and mobilisation of support. The effects of these processes were examined in terms of how people felt about their activities and achievements (or disappointments), whether they were fulfilling important roles expected of them, their future outlook, hope and motivation.

**Quantitative component of the study**

A questionnaire survey was undertaken with 263 PLWH and a community control group of 160 (total n= 423). A list of eligible patients (all those on ART for at least one year) was compiled at each facility using patient files. 263 people living with HIV (PLWH) taking ART were randomly selected. The 160 control participants were randomly recruited from the general population in nearby villages, first stratified by gender, using resident lists from communities which had been part of an earlier MRC/UVRI study.

The quantitative instrument measured socio-economic and demographic characteristics, illness perceptions, mental adjustment to HIV, quality of life and depression.

No ethical issues arose during the conduct of the research.
d) Project Findings
Please summarise the findings of the project, referring where appropriate to outputs recorded on the ESRC website. Any future research plans should also be identified. [Max 500 words]

Quality of life (QOL)
QOL among PLWH is an indicator of how well they are self-managing their condition on ART. A satisfactory QOL is also an important motivator for people to go on self-managing a disease and adhering to treatment in the long term. The first output from the research is the validation of the Luganda version of the QOL instrument used (the WHO QUAL BREF), found at http://www.uea.ac.uk/documents/439774/542576/wp46+final.pdf/ad7405dd-2dc6-4f20-bbd6-bba96574912c.

Our quantitative data show that QOL among PLWH was significantly higher than for the community control sample. Although socio-economic status was slightly higher among PLWH, this accounted for only 6% of variance in QOL scores. Mean depression scores and number of people reaching a threshold for possible depression diagnosis were lower for PLWH on ART, compared to the community sample.

Qualitative data show the positive impact of treatment, recovery and a new chance at life across the four domains of QOL and depression, and reveal psychological adjustment mechanisms operating, noted elsewhere in the health psychology literature (e.g. response shift), for example:

- The benefits of access to a dedicated HIV service provision infrastructure, and the positive effects of counselling, advice and treatment
- Improved physical functioning, and the ability to pursue normal work and social activities, combined with a ‘before and after treatment’ comparison generating an additional level of appreciation of health, strength, and ability to work hard.
- Improved psychological well-being, derived from counselling which positively re-framed HIV as a manageable disease, with a much better prognosis, giving hope for the future and motivation to carry on. Positive psychological adjustment mechanisms were the recovery of a ‘normal’ or new identity, self-esteem and confidence to go out again ‘like a normal person’. PLWH also find meaning from the new chance at life on ART: they value each day, and have new purpose. A dramatic recovery was seen as a gift from God, and with it came a new purpose in life.

These QOL effects are highly gendered. Women with HIV on ART reported much better QOL and lower depression compared to women in the control sample, whereas the differences men was less stark.

Self-management strategies
Narratives reveal a range of cognitive, emotional and behavioural self-management processes. These can be categorised into managing the illness (e.g. learning about it, adhering to treatment, monitoring the body); managing daily life (work routines, planning, disclosure, finding meaning) and mobilising resources (from health providers, and social, spiritual, psychological, material resources). Factors that have enabled or hindered effective self-management are emerging, and some of these are different for men and
women (e.g. support (or not) from intimate partners and the role of children).

The role of health workers / counsellors
A key finding was the positive effect of health workers’ advice and encouragement on PLWH’s adjustment and well-being, and we analyse this using framing theory. Acting as framing agents, health workers/counsellors gave people the hope and strength to carry on after diagnosis. They helped PLWH reconstruct a more optimistic conceptualisation of the illness and self-management skills.

Stigma after ART
A recovery of health and a healthy body appearance improved self-esteem and reduced levels of experienced and self-stigma. But underlying processes of stigmatisation, based on moral discourses that label and discriminate, remained in the narratives, and we examine this through sociological and anthropological theories of stigma, e.g. an underlying moral discourse of blame and fear remains.

e) Contributions to wider ESRC initiatives (eg Research Programmes or Networks)
If your project was part of a wider ESRC initiative, please describe your contributions to the initiative’s objectives and activities and note any effect on your project resulting from participation. [Max. 200 words]

Na
3. Early and anticipated impacts

a) Summary of Impacts to date

Please summarise any impacts of the project to date, referring where appropriate to associated outputs recorded on the Research Outcomes System (ROS). This should include both scientific impacts (relevant to the academic community) and economic and societal impacts (relevant to broader society). The impact can be relevant to any organisation, community or individual. [Max. 400 words]

<table>
<thead>
<tr>
<th>Academic impacts</th>
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<tr>
<td>Analysis is now generating empirical and theoretical insights which will make a contribution to knowledge and understanding, in line with the objectives identified above. The PI was Head of Department during the project, hence a delay to publishing outputs, but is now on study leave, with one paper finalised for submission and others being written. The written paper (on QOL) was presented at the 2nd ASSHH conference in Paris in July 2013, triggering debate among academics because of the counter-intuitive findings about QOL. The paper will shortly be submitted to PLoS Medicine.</td>
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Data collection was undertaken by a Ugandan research team comprised of four field workers and a project leader. Research capacity among the team at MRC has been developed, through the work itself and by training workshops on: in-depth interviewing skills; theoretical frameworks and applying them to data; qualitative data analysis skills.

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<thead>
<tr>
<th>Engagement with research users and economic and societal impacts</th>
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<tr>
<td>Engagement with The AIDS Support Organisation (TASO) in Uganda, a collaborator in the project, has taken place throughout, and with different health service delivery levels. Prof Janet Seeley is currently seconded to MRC in Uganda and is ideally situated to coordinate our user engagement meetings. A presentation of the research design was made to TASO at the start of the project in December 2010, where useful feedback was obtained. In 2012 Steve Russell presented to TASO Entebbe some of the key research findings emerging from the qualitative data.</td>
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So far it is too early to demonstrate concrete non-academic impacts, as defined by ESRC and HEFCE. However in August the project completed a documentary film, based on the research findings, which will be used in 2013 and 2014 to disseminate the findings to a wide range of non-academic users. We anticipate this film to generate impact in the UK, Uganda and internationally. The film was made by a Ugandan film-maker and TASO have contributed to the film’s final production.

The documentary reveals how ART has transformed the lives of PLWH, from being bedridden at home to walking proudly in the street. The film us called *The Mango Tree: Living with HIV in Uganda*, inspired by the words of one of the research participants: “I can now plant a mango tree and live to eats its fruits”.

The film is booked to be first shown on World AIDS Day, 1st December 2013, at Norwich Cinema City, and then at the University of East Anglia. It will be publically available on the internet (at [http://youtu.be/9zFaKNPL2OQ](http://youtu.be/9zFaKNPL2OQ) now).
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UEA have prepared a press release for Nov 2013 based on the film and the research which may generate further media interest.

b) Anticipated/Potential Future Impacts
Please outline any anticipated or potential impacts (scientific or economic and societal) that you believe your project might have in future. [Max. 200 words]

**Anticipated Academic Impacts**
Publications will come out over the next 12 months. Journal articles are being written and we anticipate publication in high quality journals reflecting the key findings discussed above, for example:

- Gender effects and differences for increased quality of life and mental health on ART (quantitative and qualitative data combined)
- The role of health workers and counsellors as framing agents
- The changing nature of stigma due to ART
- Self-management strategies of PLWH in resource-limited settings

We anticipate that some of these papers will be presented at national university fora (workshops, seminars), including a public lecture at UEA London in 2014, and at international conferences during 2014, including a submission to the Melbourne 2014 World AIDS Conference.

The documentary film (see above) will generate academic impacts, as the target audience includes academics and students.

**Engagement with research users and economic and societal impacts**
Following the development of papers, a workshop to disseminate and discuss key findings with TASO in Uganda will be organised for 2014.

The documentary film will generate impact in Uganda and the UK. An English and a Luganda version were made. In Uganda, we anticipate that TASO will distribute the film across its district centres, and also take it to rural communities, to support its HIV awareness campaigns and inspire and encourage people to get tested or to start taking ART.

You will be asked to complete an ESRC Impact Report 12 months after the end date of your award. The Impact Report will ask for details of any impacts that have arisen since the completion of the End of Award Report.
4. Declarations

Please ensure that sections A, B and C below are completed and signed by the appropriate individuals. The End of Award Report will not be accepted unless all sections are signed. Please note hard copies are not required; electronic signatures are accepted and should be used.

A: To be completed by Grant Holder

Please read the following statements. Tick one statement under ii) and iii), then sign with an electronic signature at the end of the section (this should be an image of your actual signature).

i) The Project

This Report is an accurate overview of the project, its findings and impacts. All co-investigators named in the proposal to ESRC or appointed subsequently have seen and approved the Report. ☒

ii) Submissions to the Research Outcomes System (ROS)

Output and impact information has been submitted to the Research Outcomes System. Details of any future outputs and impacts will be submitted as soon as they become available. ☐
or
This grant has not yet produced any outputs or impacts. Details of any future outputs and impacts will be submitted to the Research Outcomes System as soon as they become available. ☒

iii) Submission of Data

Data arising from this grant have been offered for deposit with the UK Data Service. ☒
or
Data that were anticipated in the grant proposal have not been produced and the UK Data Service has been notified. ☐
or
No datasets were proposed or produced from this grant. ☐