Making a feature length documentary film linked to the Programme for Improving Mental health carE (PRIME) in Nepal and South Africa: process and ethical challenges

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COMPULSORY DECLARATION

This work has not been previously submitted in whole, or in part, for the award of any degree. It is my own work. Each significant contribution to, and quotation in, this dissertation from the work, or works, of other people have been attributed, and has been cited and referenced.

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ABSTRACT

Globally mental health is widely regarded by scholars as a neglected public health issue. Documentary film is recognised as an approriate medium for addressing social and political issues, and mental health is both of these. Country comparative documentary films on mental health, set in low and middle-income countries, appear to be lacking. Prorgramme for Improving Mental health carE (PRIME) works in five low and middle-income countries, two of which were selected for the film (Nepal and South Africa). This was motivated by across continent comparisons, financial and logistical viability within a one year timeframe, global interest and appeal and the support of PRIME colleagues and local country partners.

Based on qualitative research including a literature review and 40 indepth interviews with stakeholders, this essay reports on, and critically assesses the ethical and production processes involved in making the documentary film. The essay includes several elements.

Firstly, it considers the power relationship between the filmmaker and the subject. Whilst Nichols, Aufderheide and colleagues present useful ethical considerations for making a documentary film, both from the subject and audience perspectives, more care is required when making a film with persons living with mental illness. This is particularly because the subject may not have the mental capacity to consent, and if they do, participating in the media production process could potentially exacerbate their condition. Having weighed these risks up with the benefits of representing persons living with mental illness, and giving them a voice, the decision was made to give persons living with mental illness the opportunity to represent themselves.

Secondly, and having made the decision to allow for representation, the various documentary modes (expository, performative, poetic, observational, reflexive, participatory) conceived by Nichols were explored, in an attempt to identify a conceptual framework for the film. The performative mode was most appropriate for telling deeply personal stories, and providing patients with an opportunity to be represented. However, this mode was ideally complemented with elements of the expository (verbal commentary of experts), poetic (use of rhythm, emotion and music), observational (footage of patients in their daily routines, and of their environment for cutaways) and participatory (through direct engagement between filmmaker and subject) modes.

Having identified a conceptual framework, the third element involved the institutional research ethics processes. These processes contributed to a more ethically sensitive film production. This included a check for mental health service users to ensure that they do have the capacity to consent. The process of developing a research protocol highlighted the synergistic benefits of integrating a qualitative research method in the form of in-depth interviews into the film production process (and vice versa), whilst remaining cognisant of not compromising research findings for more visually appealing footage. Following a research process for the production also contributed to a more robust discussion guide after translating communication objectives into research objectives.

Finally, the process of implementing the film's production, and post-production, was assessed. A host of steps were identified, which included securing the funding for the filmmaking, establishing stakeholders support, briefing the crew on the vision and purpose of the documentary and having access to equipment and translators. During the post production process, a systematic approach to editing using a script outline was helpful in identifying main themes, and to ensure the narrative flow. Despite its typical use in fictional filmmaking, the three-act structure was fitting as a framework for the narrative. Time-coding during translation and transcription was found to be particularly expedient for inserting English sub-titles. The country comparative approach revealed similaries and differences, and developing and implementing stakeholder specific distribution strategies (including conferences, symposia, film festivals and broadcasters) was identified as critical to the public dissemination and reach of the film.

Documentary film, and the performative mode complemented by other modes, has shown to be an advantageous means of representing persons living with mental illness, and their families. However, the paper calls for more evaluation research regarding the impact of the film on the main patient characters, amongst other stakeholders such as health workers and policy makers. The paper also proposes the integration of media production into a research process for researchers interested in using this medium to visually communicate their research findings, emphasising the value of systematically using the research findings to develop a narrative script in the context of a typical three act structure. A distribution strategy was also identified as necessary to maximise the research and stakeholder impact of the film.

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GLOSSARY

BREC	Biomedial Research Ethics Committee (of the University of KwaZulu Natal)
CFMS	Centre for Film and Media Studies (Department of the University of Cape Town)
HREC	Human Research Ethics Committee (of the Faculty of Health Science, University of Cape Town)
LMIC	Low and Middle-Income Country
NCDs	Non-Communicable Diseases
NGO	Non-Governmental Organisation
NHRC	Nepal Health Research Council
PI	Principal Investigator
PRIME	Programme for Improving Mental health carE
TPO	Transcultural Psychosocial Organisation
UCT	University of Cape Town
UKZN	University of KwaZulu Natal
WHO	World Health Organisation

CHAPTER 1

INTRODUCTION: BACKGROUND AND MOTIVATION

The aim of this paper is to report on, and critically assess the process involved in making a feature length documentary film linked to the Programme for Improving Mental health carE (PRIME) in Nepal and South Africa.

1.1. Structure of the research essay

The paper explores the motivation for choosing the topic and medium of documentary film (Chapter 1); the ethical issues of representation in film, including the intricacies of producing documentary films amongst persons living with mental illness, their families and stakeholders involved in providing mental health care (Chapter 2); developing the film idea further by exploring the 'modes' of documentary through a Nichols (2001, 2010) lens, and selecting a suitable mode for the film (Chapter 3); the research ethics processes required by various partner institutions, and the development of a research methodology (Chapter 4); the process of executing the film project, including production and post-production processes (Chapter 5); limitations of the project (Chapter 6) and concluding remarks (Chapter 7).

1.2 Why the choice of topic 'mental health'?

Mental health is a neglected public health issue

More than a decade ago, the World Health Organisation (WHO) reported that between 12 and 47% of people (approximately 1 in every 5) will experience a mental disorder in their lifetime (WHO 2000). Despite this knowledge, most scholars within the mental health fraternity are of the view that mental health does not get the attention in deserves, particularly in low and middle-income countries (Tomlinson & Lund, 2012; Bird et al 2010). Aside from a lack of public attention, much has been published regarding the stigma and discrimination that exists against people living with mental illness amongst different groups in society, not excluding the media (Hendersen et al 2013; Lund et al 2012; Thornicroft et al 2010; Benbow 2007).

In response to the above situation, and in an attempt to destigmatise persons and families living with mental illness, the film intended to explore the perspectives of a range of stakeholders, including mental health patients (commonly referred to as 'service users'), within the field of global mental health for the express purpose of producing a documentary film for dissemination and communication in mainstream media. That the

media has a key role to play in shaping public opinions about mental health and mental illness has also been recognised (Benbow 2007).

Rosenthal (2010) maintains that the filmmakers choice of topic is largely driven by a passion for a particular subject. In this case, the choice of topic was not only driven by passion, but also driven by evidence and funding.

1.2. Why documentary film as a medium?

The choice of medium to communicate the complexities of this subject matter is never an easy one. Having researched the issues relating to the topic, documentary film seemed a feasible way of communicating a broad range of research evidence and questions relating to mental health.

Suitable medium to address social and political issues

Documentary film has been identified as a suitable medium to address social and political issues (Nichols 2010). Mental health is both of these. At a social level, people living with mental illness are often stigmatised, negatively affecting their lives and those of their families and communities; and at a political level, mental health is a neglected public health policy issue with many scholars calling for increased attention to the issue.

Nichols (2010) articulates the rationale for making documentary films in the context of social and political issues:

> *"We need explanations to get things done. If we know what causes poverty or sexual abuse, pollution or war we can then take measures to address the issue. We need understanding, with its qualities of empathy and insight, to grasp the implications and consequences of what we do. Actions rely on values, and values are subject to question. Lives are at stake. Understanding, like critical perspective, leavens explanations, policies, solutions. Social actors are not pawns, but people."*
>
> *(Nichols, 2010)*

It is exactly this that the documentary film medium aims to do: provide the target audiences with empathy, insight and understanding about the complex issues relating to mental health in the hope of inspiring some kind of action. These actions might include better care and sensitivity of families and health workers towards people with mental

illness, or increased political will or budgetary allocation for mental health amongst policy makers.

Few films set in low and middle-income countries (LMIC) appear available

Although not a strong indicator, an elementary Google search of documentary films on mental health, set in LMIC, reveals that only three films ('Go Away Evil'; 'Breaking the Chains'; and 'Still We Rise') have been promoted, perhaps indicating the limited production of such films.

The search terms used were firstly "mental health documentary film" only; followed by "mental health documentary film" AND "low and middle income countries".

The following documentary films were revealed from the Google search (Jan 2015):

- 'Bedlam' – mental health in Britain
- 'Sick' – mental health institutionalisation of youth, USA
- 'A New State of Mind' – ending the stigma of mental illness, California, USA
- 'Back from the Edge' – Borderline Personality Disorder, USA
- 'The Marketing of Madness' – The Truth about Psychotropic Drugs, USA
- 'Go Away Evil' – by Delaney Ruston set in South Africa (Grand Challenges funded)
- 'Breaking the Chains' – by Dr Erminia Colucci set in Indonesia
- 'Still We Rise' – Molly Raskin, set in Liberia

None of these film titles identified online were comparative, across countries.

Thus, the rationale for making a documentary film is driven primarily by three factors: its suitability as a medium for drawing attention and increasing understanding of social and political issues; the dearth of films that appear to be available on the subject in LMIC and the absence of a cross-country, comparative film, on the subject.

1.3 Why the choice of countries?

PRIME is working in three African countries (Ethiopia, South Africa and Uganda) and two Asian countries (Nepal and India).

The decision to produce the film in two countries, one in Asia (Nepal) and one in Africa (South Africa) was a function of a) global interest and appeal; b) feasibility and c) relationships. Firstly, it was projected that a two country film, in two different settings (one African and one Asian), would likely have a greater interest and appeal internationally due to its comparative nature. Secondly, the time frame required to complete the film and the timing in relation to PRIME's research activities made it feasible, financially and logistically. Thirdly, the fact that PRIME has good, collaborative working relationships with its partners in the countries that it works with, including Nepal and South Africa, made it uncomplicated to secure the 'buy in' and support amongst the country project partners. Furthermore, at a country level, access to people working in the health system at different levels was also made possible by the positive working relationships PRIME has established domestically. The process of securing stakeholder support is discussed in depth in Chapter 5.

CHAPTER 2:

TO REPRESENT OR NOT? AN ETHICAL DILEMMA

The question of ethics, and the relationship between the filmmaker and the subject are not new phenomena. Nichols (2001,2010) and Aufderheide et al (2009) have been amongst the scholars to have reflected in-depth on the ethical challenges facing documentary filmmakers. Both authors' theoretical frameworks for the ethics of documentary filmmaking are presented below, and considered for the making of a documentary film on mental health. In addition, specific ethical issues relating to the representation of those with mental illness are raised by scholars of global mental health, which are also considered in making ethical decisions for the film production.

2.1 Considering ethical issues for the film through a Nichols lens

In his chapter on ethical issues being central to documentary filmmaking, Nichols (2010) argues that documentaries engage with the world by representing it in three ways:

(1) by 'offering a likeness or depiction of the world that bears a recognisable reality'. This is explained by the fact that audio and visual recordings of people, places, situation and events often form the basis for belief;
(2) by acting as public representatives in representing the interests of others, both for individuals who are represented in the film, and for the institution or agency that supports the filmmaking activity; and
(3) by making a case for a particular interpretation of the evidence before the audience to win consent or influence opinion.

The ethics of a documentary film on mental health can be assessed in relation to each of these depictions. In the first ethical caution of representation, Nichols (2010) reminds us that what we do or show can influence audiences' belief. In the case of this film, this is an important concern as part of the aim is to change the beliefs of audiences, and to contribute to removing the stigma of mental illness.

With regards to the second point, the film consciously acts as a public representative in representing the interests of the characters, and the programme (PRIME), which supports and funds the filmmaking activity. In order to minimise the filmmaker 'representing' the characters, a voice-over is intentionally not used in an attempt to give the typically vulnerable subjects more power, and greater representation. Thus, the use of a narrator, commonly referred to as a 'voice of God' or 'voice of authority' is absent in the film. For the same reason, people are represented in their own preferred language of choice, with the

use of English subtitles rather than an English voice over, which would have the effect of drowning out the local (Nepali and Setswana) languages, and diminishing their power of representation. On the issue of representing the interests of an institution or agency (PRIME), the film declares upfront, at the appropriate time in the narrative, that the film is about the work of PRIME, and its interventions to integrate mental health into public health systems. This may have a limitation in that it could be perceived as a promotional film, rather than a documentary. However, every effort was made not to bias this film by balancing the successes of the programme's interventions, with its challenges.

On the third point, the filmmaker intends to influence opinion based on its own research evidence. To ensure that the influence has integrity and is based on evidence, the film attempts to draw on the voices and opinions of its participants and was peer-reviewed amongst scholars of global mental health at cross-country, and country levels.

2.2 Considering ethical issues for the film through an Aufderheide-Jaszi-Chandra lens

Scholars at the American University's School of Communication published a study amongst 41 filmmakers regarding the ethical challenges in producing documentary films. The authors (Aufderheide et al, 2009) identified two types of ethical challenges faced by the filmmaker: those relating to the *subject*, and those relating to the *audience*.

Challenges relating to the Subject

The authors identified six key points of discussion that they managed to crystallise from their research. Each of these will be considered in relation to the mental health documentary:

(1) ***Pre-emptively protecting the subject***, referring to the intentional omission of material by the filmmaker as an act of empathy for the subject.

In the case of the film, this was a consideration for only one scene: where the mother of a boy cries, for quite a few seconds, as she conveys the plight of the family in having to care for a son with mental health challenges. The initial thought was that she might find it offensive, if she saw herself crying on the screen. Having consulted with supervisors of the film, and members of the production team, most of them considered it from an audience perspective, and were of the view that it conveyed a strong sense of emotion. No doubt, that would make it more powerful, and may have the effect of making mental health more recognised, potentially increasing its attention amongst policymakers. Thus, it was decided to include the crying scene. However, the best indicator would be to gain a perspective from the mother herself, after seeing the film. Unfortunately this was challenging to achieve within the scope of this film project, given that the subject is located in a fairly remote village in Nepal, which made her difficult to access again after the editing process. This points to future research opportunities to test the film amongst the main characters who participated, particularly the marginalised, before distributing it publicly.

(2) ***Preventing resale of images***, which happens when filmmakers prevent material featuring their subjects from being reused in ways that might misrepresent them in

new contexts. The study revealed that this choice had to be balanced with the commercial imperative, and the need for them to earn a living.

In the case of this film, which is fully funded by PRIME and the University of Cape Town's Television Studio, the reuse of footage needs careful consideration so as not to misrepresent the characters in the film, particularly persons living with mental illness due to their vulnerablity. Whilst the film is not produced with any intended commercial imperative, how to deal with unintended proceeds which may accrue from interested broadcasters should be carefully considered, taking into account the main subjects of the film, the funder and the intellectual property policies of the respective institutional partners.

(3) ***Sharing decision making*** about the film refers to a choice sometimes made by filmmakers to share decision making power with some subjects in order to balance power differentials that may exist between the filmmaker and the subject. Whilst the idea seems similar to that of participatory filmmaking, in which groups or communities create their own film, this idea appears to be intended to allow the filmmaker and subject to have a more equitable power relationship.

In the case of persons living with mental illness, and in the context of the vulnerability of the population discussed in the background, it is very important to share some decisions regarding the film with participants. Doing this was not within the scope of this research project. The distance of the filmmaker to the participants, both physically and from a language perspective, and budget limitations did not make it feasible. Having said this, one such instance of sharing the footage did occur due to the relationship of one PRIME counsellor with a particular family. A short film clip containing the Nepali main character's interviews and cutaways was shared with him and his family. Based on the feedback report received from the counsellor via email, the family were very supportive of the use their interviews and footage in the film, and in her view, they also felt a sense of empowerment by being involved in the media production. It has been documented that people living with mental illness', who participate in mental health policy making processes, are supported in their their recovery process through such involvement. This may also be the case for people with mental illness who participate in media production processes, such as that of documentary film. This is another potential avenue for future research, which can be linked to the testing of the film amongst main characters, referred to in (1) above.

(4) ***Sharing control of fine cut****,* where filmmakers give subjects the right to decide whether or not their material should be included in the film. The reasons for doing so include the need to demonstrate a relationship of trust with the subject, and the need to make a film that was responsible to the subjects perspectives.

As with the choice to share the decision making, the feasibility of this may be difficult given the distance of the filmmaker to the participants described above, however, and for the reasons discussed below (*2.3 Ethical issues of representing those with mental illness*), it is important to at least give the main participants the opportunity to see themselves, and the filmmakers selection of their interviews on the screen. This is to ensure that they are satisfied with their representation, and most importantly, that it does not contribute to their further stigmatisation in the community or become a reason for their relapse. This has been discussed in depth under the risks associated with filming persons living with mental illness.

(5) ***Paying subjects****,* a concept which is reportedly forbidden in journalistic practice, was believed to be an acceptable, and reasonable way to address the power differential between the filmmaker and the subject.

In the case of this film, providing vulnerable participants with a small stipend to cover costs and time of participation was the preferred choice. In Nepal, this was agreed to by the local PRIME team collaborating on the project, whilst in South Africa, it was not suggested as it was believed to cause a conflict of interest with other participants from the PRIME research cohort who were not being filmed. Thus, in the case of Nepal, US$50 was suggested for each of the two vulnerable families, who consented for us to spend at least a whole day with them. One family invited us to spend a second day without any expectation, which was accepted. The incentive fee was intentionally not mentioned upfront to the subjects during the recruitment process in order to ensure that this was not the motivation for participation. In the case of South Africa, whilst a fee was not provided, it was difficult to spend time in the home of the two participants without any token of appreciation for their time. Hence, it was decided that a bag of groceries (fruit and vegetables) would be a reasonable offering as a token of appreciation, without causing any conflict of interest. The average value of each bag was approximately R150. As in the case of Nepal, the token was not mentioned during the recruitment process, and only mentioned and provided after the interview.

(6) ***Deception,*** a strategy which some filmmakers have admitted to using with subjects, and gatekeepers who kept them from subjects, arguing that 'the end justified the means'.

In the case of the film produced, sincere engagement with participants was sought, and no deception was intended or necessary. Specifically, ethical approvals were obtained from the participating institutions, including the University of Cape Town (HREC REF 139/2014), University of KwaZulu Natal (BREC REF BE333/14) and the Nepal Health Research Council (REF 1179). Informed consent was also obtained from the participants (see Appendix 4), and in the case of people living with mental illness, a declaration was signed by a mental health worker (e.g. counsellor or psychologist) stating that, in their professional opinion, the subject did have the mental capacity to consent (see Appendix 5).

Challenges relating to the Audience

Three audience-related points of discussion were identified by Aufderheide et al (2009) from their research with filmmakers.

(1) ***Framing and editing***, referring to the choices that filmmakers make to tell a story one way or another. It was believed that narrative structure does sometimes mandate manipulation, which filmmakers sometimes felt uncomfortable about.

In the case of this film, the film was approached from a research perspective in order to explore a range of issues identified in mental health arena. Indeed, when developing the narrative, some information might have been excluded. However, this was more a function of not being able to include everything, and identifying the key issues from analysis of the transcript to construct the narrative. Thus, none of the key issues identified from interviews with the subjects, particularly the vulnerable, were intentionally withheld.

(2) ***Staging, restaging and effects,*** such as restaging routine or trivial events, such as walking through the door, was believed to be very much part of the filmmaking process, and not "what makes the story honest".

The only 'staging' that the film did do was to request four of the characters to go about their daily lives by doing their daily chores, after seeking their permission. They were also requested to ignore the camera, which seemed difficult for people to do. Two situations did arise where the subjects sought guidance regarding what they were expected to do, eager to please the filmmaker. In such situations, members of the production team would advise them to either walk in or out the house, around their homes, or around the clinic. No doubt, this did help to add to the variety of images portraying them, and did little to change the truth in the overall storyline.

(3) ***Use of archival material,*** particularly still and motion photographic material, and its treatment was widely recognised as a point of ethical concern. Whilst some filmmakers are adamant that only precisely accurate images of the people, place and time should be used, the authors reveal that filmmaker Ken Burns, well reknowned for his style of using archival footage and photographs, often chose

material that communicated the message more rapidly. His yardstick was ‘whether it compromises the ultimate truth’.

In the case of this film, some archival material was used from the University of Cape Town’s Television Studio (Stepping Stone project), from a TED Talk, a stills photographer, newspaper cuttings from a local NGO, and website screen recordings. All of these were appropriate as they were actual materials of the subjects, and not unrelated archival footage which, in the view of the author, did not compromise the ultimate truth. The motivation to use the available archival materials was to give context in the form of cutaways during the interviews, and to provide a variety of visuals, which could potentially reduce the boredom factor and increase the appeal.

2.3 Ethical issues of representing those with mental illness

In addition to the general ethical issues of representing the world pointed out by Nichols (2010) and the subject and audience challenges identified by Aufderheide et al (2009), making a documentary film amongst persons living with mental illness, and their families, added another layer of complexity in considering this film.

Having screened a short version of the film consisting of one patient subject to research audiences at two conferences, and based on consultations with local PRIME teams in Nepal and South Africa, the issue and sensitivity of interviewing mental health subjects encouraged lively debate, and was a point of concern. One ethics committee during the early stages of enquiry even suggested that the images of people living with mental illness should be silhouetted or not revealed to the audience.

In light of the evidence on the stigmatisation of the mentally ill, it was argued that such an approach of silhouetting persons is effectively not representing them, and could contribute to the further stigmatisation and disempowerment of people and families living with mental illness.

In presenting the ethical argument, the risks and benefits of the project were carefully considered at the stage of formulating research protocols for respective ethics committees. This is mostly attributable to rigorous ethical protocols that were required by respective institutions involved (discussed in Chapter 4), highlighting the value of the research ethics process.

Risks

The first risk identified was that the person with mental illness participating in the interview, after consenting, could be intimidated or may develop anxiety by the presence of the camera. The second risk identified was that the person could experience further stigmatisation from peers or social groups within the community, if they become exposed to the film. In order to guard against such risks, the consent form included a line about the subject being allowed to change his mind within one month after providing consent. The reason for not keeping the change of mind open-ended is to ensure that no post-production time is wasted in processing the subject's footage. Furthermore, a decision was made to have the counsellor present, whose ethical duty it would be to stop the interview should he or she detect any such anxiety. With regards to the second risk, the screening of the film could be limited to exclude the community in question, or it could be removed should any reports of further stigmatisation be received from the family.

Benefits

Turning to the benefits, many scholars working in the field of global mental health hold the view that the benefits of showing visual images and film facilitates the destigmatisation of long held misconceptions of societies regarding people living with mental illness, and contributes to raising the awareness of human rights violations amongst public health researchers and advocates (Patel et al 2012: 362).

Another benefit may relate to the recovery of the service user. Tait and Lester (2005) have identified a host of benefits of service user involvement:

- Users are experts about their own illness and need for care
- Users may have different but equally important perspectives about their illness and care
- User involvement may increase the existing limited understanding of mental distress
- Users are able to develop alternative approaches to mental health and illness
- User involvement may be therapeutic in itself
- User involvement may encourage greater social inclusion

Furthermore, Saraceno and colleagues (2007) emphasize the power of consumer movements, and the unmet potential represented by the mobilization of service users to ensure that decision makers hear their concerns.

Finally, it has also been shown that involving people affected with mental illness in mental health policy development and implementation is not only useful for the recovery process of the mentally ill, but can also have a positive impact by making mental health policy development and implementation more relevant (Kleintjes et al 2010; Nelson et al 2008; Tait and Lester 2005). Perhaps the same may be true for persons affected by mental illness who are involved in the making of a media product such as this documentary film. Their involvement and participation could help their recovery process, and if also screened to policy makers, may potentially have an impact on the further development of mental health policy.

Useful ethical considerations have been identified by Nichols (2010) and Aufderheide et al (2009) for producing a documentary film. Whilst these are generally useful, more careful treatment is required for producing a film amongst people living with mental illness. The decision was made by the filmmaker to represent, rather than to not represent. Whilst efforts were made to minimise the risks and identify them early, these need to be carefully weighed up against the benefits, and empirically tested through further research.

CHAPTER 3

TOWARDS A CONCEPTUAL FRAMEWORK: IDENTIFYING THE MODES OF THE FILM

This chapter seeks to explore the various documentary modes, and assess with modes with which the film was executed.

Nichols (2001, 2010) is well known for classifying the different types of documentary that may be possible; he identifies six 'modes of documentary', namely:

(1) ***Expository mode:*** Dubbed as the 'voice of God' due to the frequent use of narration, this mode emphasises verbal commentary. It intends to address the spectator directly, using titles or voices that propose a perspective, advance an argument or recount history. Expository mode is most associated with television or broadcast media. Natusch and Hawkins (2014) add that this mode is ideal for disseminating information, or for persuasion.

For the ethical reasons discussed in Chapter 2, narration through the use of a 'voice over' was not regarded as the best way of empowering, and giving a voice to the vulnerable. Instead voices of the main character subjects, and verbal commentary from experts were employed. Hence, the expository mode was only partially used through the verbal commentary of expert voices, which were intercut with main character voices.

(2) ***Poetic mode:*** Intended to be a subjective, artistic expression, this mode stresses the lyrical, rhythmic and emotional aspect of history.

The film did attempt to use this mode by emphasising the emotions that are characteristic of people living with mental illness, and their family members. Music was also carefully selected, and used in an attempt to convey the rhythm and emotion.

(3) Observational mode: Regarded as a window into the world, this mode is an attempt to observe aspects of the historical world as they happen. Typically, this mode does not feature voice over commentary, supplementary music, sound, interviews or any re-enactments. Social actors are expected to behave as if no cameras were present. Natusch and Hawkins (2014) point out that this mode seeks objectivity, with the unobtrusive camera taking on the role of audience, watching and observing the action.

Although not completely observational, the film did have elements of this mode to the extent that subjects with mental health problems would allow. At times,

subjects (families) who were being observed seemed to be under the impression that the production team wanted them to act. However, after some time of not receiving any direction from us, and a request to try to ignore the cameras and go about their daily routines, they seemed to do so, whilst occasionally looking at the camera, appearing cognisant of it at times. Also, the observational mode was employed through the use of cutaways of the location and surrounding environment, to give context to participant interviews.

(4) Participatory mode: Natusch and Hawkins (2014) simply assert that this mode relies on interviews, considering them to be a credible source of knowledge about the subject. However, Nichols (2001) is more specific, maintaining that this mode involves an interview with the filmmaker and the subject, allowing the filmmaker to address people who appear in the film formally, as opposed to addressing the audience through voice-over commentary. He further adds that it also involves participation from the filmmaker, as well as social actors, giving the audience a sense of what it is like for the filmmaker to be in a given situation, and how the situation alters as a result.

Whilst this film did not include participation in the film by the filmmaker, it does have participatory elements in that it does involve interviews with the filmmaker and subject, albeit through a translator, and does allow the subjects to address the public formally through their interviews, without voice over commentary.

(5) Reflexive mode: In this mode, the processes of negotiation between the filmmaker and viewer become the focus of attention. Rather than following the filmmaker's engagement with other social actors, the filmmaker engages with the audience by speaking not only about the events that have occurred, but about the problems and issues of representing it as well. This mode is said to draw attention to the filmmaking process, and take into critical consideration implications for representation.

Based on the context, and the accessibility and availability of the social actors, the film did not employ this mode. The film did not revolve around any specific historical, past events. Rather, the film intended to provide people and families affected with mental illness an opportunity to voice and share their personal experiences in the present.

(6) Performative mode: Often regarded as deeply personal, this mode is said to be ideal for filmmakers from marginalised groups to tell their own, personal stories. The mode is said to offer the filmmaker a chance to air unique perspectives,

without having to argue the validity of their experiences.

The film did employ much of this mode, as it explored the deeply personal experiences of people living with mental illness, and their families. As discussed in the background, these groups are typically marginalised. Hence, the film provided these groups an opportunity to share their experiences without having to justify anything.

Thus, from all of the documentary modes reviewed, the film can be regarded as being Performative (deeply personal stories told by a marginalised group), with elements of Expository (verbal commentary of main characters and expert voices), Poetic (through the emphasis of rhythm and emotion through the personal stories and music), Observational (by using cutaways of main characters home environment, village environment and health system to provide context) and Participatory (through the direct engagement between the filmmaker and subject) modes.

A purely 'observational' approach may have been ideal, revealing more information about how people and families experience mental illness day to day, but would not have been appropriate amongst mental health patients for ethical reasons, and far less feasible from a logistics and budget point of view. Such an approach would require much more time in the personal environment of the participants, which may be emotionally or mentally distressing to the participant, potentially exacerbating their condition. Nevertheless, where the respondents did allow the time and space, the Performative-Expository-Poetic-Participatory approach was complemented with an Observational approach.

In conclusion, the documentary modes conceptualised by Nichols (2010) provides a helpful framework for filmmakers to think about approaches, and decide on a theoretical approach. Whilst the Performative mode can be regarded as the primary approach that the film adopted, the filmmaker's intent was not restricted to this mode only, but rather adopted a hybrid approach, including elements from Expository, Poetic, Participatory and Observational modes. Testing the impact of the dominant Performative approach for films on mental health can contribute to future research, and affirm whether this can be proposed as an ideal approach for films on the subject.

CHAPTER 4

THE RESEARCH ETHICS PROCESS: DEVELOPING A METHODOLOGY

Given the ethically sensitive nature of the subject area, and its link to the PRIME research project, a research protocol needed to be developed and adapted for a range of research ethics committees, identifying the specific research objectives and study design.

4.1 Producing 'research protocols' for Research Ethics Committees

Given the sensitive nature of producing media amongst persons living with mental illness, and the institutional context within which the documentary film was approached, a number of research ethics committees were required to consent to the film production. PRIME (cross country) is led from the University of Cape Town (UCT). The University of KwaZulu-Natal (UKZN) leads the PRIME South African research, and a non-governmental organisation (NGO), TPO Nepal, leads the PRIME Nepal research activities. Hence, the following institutional review boards were recommended by the respective PRIME team members: UCT's Faculty of Health Sciences Human Research Ethics Committee (at a cross country level), UKZN's Biomedical Research Ethics Committee (BREC) for the South African research and the Nepal Health Research Committee (NHRC) for the Nepal research.

Research ethics protocols were developed and adapted for each of the committees, consistent with their particular format and template. Approval was received from UCT's HREC, UKZN's BREC and the NHRC.

Most research ethics protocol templates were framed with research questions in mind, requiring the lead investigator to identify research objectives, and methodologies. Communication objectives were identified for the film, which were translated into research objectives for the purposes of the research ethics process.

4.2 Identifying communication objectives

Communication objectives were identified for the documentary film. The primary purpose was to produce a film as a means of documenting the experiences of people living with mental illness, and people involved with PRIME. In so doing, the film intended to educate and demystify misconceptions of people living with mental illness, and to illustrate

progress regarding the integration of mental health into primary health care in Nepal and South Africa.

The following secondary communication objectives were identified to support the primary objective:

- To share personal experiences of living with mental illness (showing African/Asian cross-country perspectives)
- To unpack the experiences of living with common mental disorders (such as alcohol abuse / depression) and severe mental disorders (such as schizophrenia)
- To explore the factors which have been responsible for mental illness (biological, psychological & environmental e.g. poverty)
- To explore patients' and family members' perspectives on stigma as it relates to mental illness
- To depict how LMIC's are responding to challenges of mental health care (e.g. task sharing), and highlight any tensions within public health (e.g. funding, NCDs).

4.3 Translating communication objectives into research objectives

The above communication objectives were adapted into research objectives prior to proceeding with the production, in order to satisfy the requirements of the ethics committees. Whilst it was made explicity clear in the ethics application that the project was intended for producing a documentary film, it is possible that the findings can be regarded as research findings too.

Stakeholder specific discussion guides (see Appendix 6) were developed based on the research objectives, and in order to attain them.

4.4 Study design

The documentary film study was qualitative in nature. Face-to-face, indepth interviews were be to conducted with a broad range of stakeholders who have perspectives on mental health.

Using the infrastructure and support of the Principal Investigators and project teams of PRIME in Nepal and South Africa respectively, interviews were conducted with stakeholders in local languages of Nepali and Setswana, which were audio and video recorded by the UCT documentary film team.

'Buy-in' from the PRIME Management Team (UCT), the PRIME South African team (UKZN) and the PRIME Nepal team (TPO Nepal) and the UCT Centre for Film and Media Studies was obtained in support of this research film project.

4.4.1 Characteristics of the study populations

The study population included adults living in Nepal (the capital, Kathmandu, and Chitwan, where the PRIME pilot is taking place) and South Africa (Cape Town, Pretoria and the Kanana township near Klerksdorp, where the PRIME pilot is taking place).

More specifically, the following broad sample design for interviews was developed with the respective PRIME country teams.

4.4.2 Sample Design

The sample design was informed by PRIME's cross country 'Research Uptake Strategy', which was formulated in consultation and collaboration with all PRIME countries, including Nepal and South Africa.

The documentary project endeavoured to attain the following desired sample of participants for Nepal and South Africa respectively. The idea was to try to obtain a broad range of opinions from as broad a range of stakeholders as it was possible to identify.

- Mental health service user & family member 2
- Service User Organisation representatives 2
- Mental health specialist (Psychiatrist / Psychologist public and private) 2
- General Primary Heath Care Staff / Health Workers 2
- Local PRIME country representatives 2
- Policy Makers 2
  - o Ministry of Health representatives
  - o Primary Health Care workers
  - o Mental Hospital coordinators
- Academic or University representative (e.g. from Psychology department) 2
- Local NGOs 2
- Traditional Healer 1
- Media Organisations involved in mental health communication 1
- International Organisations / NGOs 2

TOTAL: 20

A convenience sampling approach was used to seek candidates from each of the above groups. Thus, interviewees will be selected on the basis of the close proximity of the local PRIME recruiter to stakeholder networks.

In the case of Nepal, the desired sample was attained and exceeded due to an enthusiastic local recruiter and coordinator. However, in the case of South Africa, interviews with all the stakeholders was not attained due to the lack of availability of some stakeholders, time and resource constraints. In particular, a psychiatrist or psychologist working at the facility level was not available during the production week, nor were traditional healers, a media stakeholder or members of an NGO. Nevertheless, having reviewed all of the footage, it is believed that enough material was available to construct a relatively balanced, patient-centred narrative.

4.4.3 Recruitment and enrolment

Where possible, stakeholders were recruited by local country coordinators in advance of the scheduled film shoot. Some were only recruited after arrival of the documentary film crew to the Kanana Township, due to the limited capacity of the PRIME intervention coordinator supporting the process. Prior to enrolment, local recruiters followed the informed consent procedure detailed below (See 4.4.7 Informed consent process).

4.4.4 Research procedures and data collection methods

The qualitative responses from face-to-face interviews were captured electronically on audio and video recording devices.

4.4.5 Data safety and monitoring

The audio and video footage captured on a memory cards were backed up (duplicated) on an external hard drives once full (after a few interviews).

4.4.6 Data analysis

Analysis of the film footage collected took the form of a qualitative review of audio recordings and video footage. Selected scenes were extracted for the formulation of a narrative arc, consistent with the communication objectives of the documentary.

The following systematic steps were followed in order to analyse the data:

- Producing English transcripts of interviews, which were viewed alongside the synced video and audio footage on video editing timeline

- Analysis of the four main character (mental health service users) interview transcripts, and footage, and identification of common themes.

4.4.7 Informed consent process

All stakeholders (listed in Sample Design above) were briefed about the research prior to recruitment, and consented to participate in writing, including consenting to having their audio and video footage used for dissemination to a wide audience.

In the case of mental health service users, and consistent with Paragraph 30 of the Helsinki Declaration (2013), a mental health professional overseeing care for the patient confirmed in writing that the patient, in their professional opinion, did have the capacity to consent. This responds to the ethical concerns raised that a person with mental illness may not have the capacity to consent.

4.4.8 Privacy and confidentiality

Whilst participants, particularly mental health service users, may not have as much privacy and confidentiality in the field regarding the informed consent process, they were recruited prior to the start of the film shoot and the informed consent process happened in the local language. These conditions would have increased the likelihood that they would express themselves should they no longer wish to participate.

Participants who agreed to participate in the documentary film were explicitly advised that any pictures or videos taken were for public use and dissemination, and would not remain confidential. However, participants' did have a choice to maintain a degree of anonymity (to use a pseudonym) or to use their real name in the film. If participants' preferred not to have their names used, every effort was made to ensure that it was kept confidential, and that the real name and contact details would be seen by members of the production team only.

In conclusion, the research ethics processes amongst institutional partners provided a helpful mechanism with which to clarify the objectives and interview questions for the film, and carefully evaluate the production process. The translation of communication objectives into research objectives brought to the fore the synergistic nature of conducting research and producing communication products, such as film, in one process. However, there are some limitations associated with the adaptation of the ethics application into a research protocol. Whilst the information gathered from interviews can be qualitatively analysed and written up for research purposes, the inverse is not true: documentary film,

even though evidence-based, may not necessarily communicate all of the research findings in the construction of the narrative story.

CHAPTER 5**:**

FROM IDEA TO IMPLEMENTATION

5.1 Seeking approval and support for the film

Aside from a host of websites such as Wikihow, Wikipedia and Desktop-Documentaries, little has been published regarding some of the production processes that a filmmaker traverses. These include the challenge of obtaining funding, and a strategic communication process in order to obtain support for the film amongst a wide variety of stakeholders.

5.1.1 Securing the budget

A number of stakeholders needed to be consulted in order to obtain conceptual, and financial support for the film. Firstly, a presentation of the idea and budget was made to the PRIME CEO and Management Team, and UCT's Centre for Film and Media Studies (CFMS). Input and critique was received from both groups, who positively supported the process in principle, and approved the budget.

5.1.2 Obtain local, country level support

Secondly, the presentation was adapted for each country, and local country support was obtained from the PRIME Principal Investigators (PIs) and Project Coordinators in Nepal and South Africa respectively. This was done by sharing the presentation idea via email, talking it through with team members via phone calls and face to face meetings, where possible. The goal was to obtain support through a simultaneous bottom up, and top down process in order to ensure that country Project Coordinators and country PIs were supportive, and minimise any resistance. All cross country partners were also informed of the proposed project through a monthly teleconference, to which no objections were raised.

5.1.3 Identifying the crew

Once the local level support was obtained, and dates were scheduled, a call for a camera and sound crew was distributed through UCT's CFMS current student and alumni networks. Postgraduate and undergraduate students were interviewed, and selected to join the crew. Funding was available for their flights, accommodation and a daily subsistence allowance was provided for the duration of the film shoot. Presentations were made to the crew members regarding the vision of the film, and members of the crew were

invited to provide any input or suggestions. Whilst the camera person remained constant for both country film shoots, the sound recorder did change due to her lack of availability for the second country shoot. The advantage of having the same camera person shooting in both countries was that a consistent style was used, which is likely to have contributed to better consistency for the feature film. Whilst the lack of consistency in the sound recorder was not ideal, efforts were made in the post production edit to ensure sound levels were consistent.

5.1.4 Scheduling the production

Once the support was obtained from country teams, the production needed to be scheduled. The crew, flights and equipment needed to be booked, interview schedules needed to be finalised and ethics applications needed to be followed up on. In the case of Nepal, a dedicated project manager was recruited on our behalf by the local PRIME country team as they identified that their capacity would be limited. In the case of South Africa, support for the recruitment and scheduling was received from the PRIME South African project site coordinator and counsellor. The former appeared to work more effectively, as the person had more time to identify people and secure interviews, and location shoots.

5.2 Post Production

Having completed a week of footage in Nepal (April 2014) and a week of footage in South Africa (November 2014), the process of post production began.

Interviews and cutaway footage was systematically organised in the editing software. The footage was reviewed in order to identify potential main character interviews. The process of sound syncing began with the main characters identified.

5.2.1 Choice of editing software

The editing software, Adobe Premiere Pro, was chosen based on two factors: cost and adaptability. Firstly, the University of Cape Town as an educational institution makes available Adobe software at a signficantly reduced cost. Secondly, the availability of the software for both Windows and Apple operating systems made it adaptable for members of the post production team using either operating system.

5.2.2 Translation and sub-titling

A process of translation and transcription took place after each film shoot. English transcripts were produced for all Nepali and Setswana interviews. In the case of Nepal, the transcripts were produced without time coding, making it challenging to align translation with character voices. A Nepali translator was recruited in Cape Town to assist to resolve this and ensure accuracy of the translation. Having learnt from this experience, the Setswana interviews were time coded, making it easier to align with character voices.

5.2.3 Producing the final narrative and edit

Although a script outline was produced based on the anticipated footage that was hoped for, the final story turned out to be quite different from the script that was formulated at the project inception, as it the case in non-fiction filmmaking. Nevertheless, the script did provide a useful outline of what the filmmakers intention and vision for the film was, even if the expected outcome differed slightly.

Given the mass of interviews and cutaways that were available during post production, and the multicountry scenario, a systematic mechanism was necessary to document the narrative story, and to monitor its flow and timing.

Thus, an Excel spreadsheet (see Appendix 7: Script Outline) was developed which tracked the character voices, the key message that the sequence intended to communicate, location and key themes whilst maintaining a classic three act structure (Setup, Confrontation and Resolution) used in screenwriting. Although typically used for fictional films, the three-act structure seemed fitting for this particular film.

In the Setup (Act I), the main characters, their locations and their families were established (exposition). The inciting incidents and problems were also introduced: *Sani* admits that he used to drink alcohol all day and night; *Narayan* introduces himself (with slurred speech); *MaAgnes* speaks of her trauma of losing her children; *MaPule* speaks of her 'hearing voices' and the community referring to her as 'crazy'; *Seth*, husband of *MaPule*, speaks of his unemployed status and caregiving responsibility. This is followed by the familys' experiences of stigma, and the personal impact that mental illness has on them, including the suicidal thoughts that two mothers' experience as a result of their childrens' mental problems.

The rising action is developed in the Confrontation (Act II), where the families begin to challenging task of seeking help for their mental health problems, including consulting a traditional healer and people working in the public health system.

The Resolution (Act III) features the resolution of the story, where the familys' finally obtain help, and share their experiences after receiving help (revealing the change or development of the characters), including any ongoing challenges associated with the help that they have received.

The comparative approach was useful in demonstrating the commonalities that people living with mental illness experience despite the heterogenous African (South Africa) and Asian (Nepal) settings. For instance, the issue of stigma against people living with mental illness was applicable in both countries. Not only was the approach useful for illustrating similaries, but also differences. For example, the more rural study community in Nepal appeared to consult traditional or faith healers more routinely than the more urbanised Kanana township dwellers in South Africa.

Once the filmmaker was satisfied with the narrative flow in the offline edit (the process of copying and editing raw footage, without affecting camera original film stock), the process of online editing (the process of adapting the original camera footage for the screen, including adding visual effects, formatting titles, colour grading and sound mixing) was completed by an experienced student supporting the project.

5.2.4 What happens after the film is completed? Towards a distribution strategy

The question of what happens after the film is produced is a very important one, especially if the goal is to disseminate and communicate the film as widely as possible. Questions of the target audience are fundamental in developing the distribution strategy.

In a review of the media's impact on public perceptions of mental illness, Baun (2009) points out a number of authors that have found television to be the most powerful medium for framing public consciousness. This makes the case for pitching the film to festivals and television broadcasters in the distribution strategy. A more detailed distribution strategy for the film should be developed to ensure that its impact, and reach amongst stakeholder audiences can be maximised.

Issues of production, and post-production have been touched on in this chapter. Processes such as funding, securing stakeholder support, briefing the crew, having access to equipment, translators, editing and establishing the final narrative, and distribution are all fundamental to the successful implementation of a documentary film. More research published in this area would be helpful for documentary filmmakers.

CHAPTER 6:

LIMITATIONS

Whilst the film was executed successfully, it was not without limitations. These relate to the subject (respondent fatigue) and the final product (aesthetics).

Risks of filming people with mental illness

There are several ethical risks involved in filming people with mental illness and these were evident during the filming. One subject out of four subjects (the person with schizophrenia) appeared to find the interview stressful after about 30 minutes of talking. This was in relation to describing her difficulties obtaining medication at the clinic, and she was determined to share these experiences as she believed that she could bring about a change by participating in the film. This was established from the introductory interactions whilst going through the information sheet and consent process.

Aesthetic limitations

The time that can be reasonably spent with people affected by mental illness is a limitation to the amount of observational footage (supporting visual images or cutaways) that one can attain. This has a limitation in terms of the aesthetic variety of visuals that may be available to support their personal stories. Nevertheless, the ethical considerations of a purely observational approach (discussed in Chapter 4) outweigh the aesthetic appeal.

CHAPTER 7:

CONCLUSION: THE PRACTICE OF INTEGRATING DOCUMENTARY FILM INTO RESEARCH PROCESSES IS SYNERGISTIC

Documentary film has been identified as a suitable medium to address social and political issues. Mental health as a neglected public health priority is both of these. Few films on mental health set in LMIC appear to have been made, none of which are comparative in nature. This was the motivation behind the making of the feature length film.

Whilst Nichols (2001,2010) and Aufderheide et al (2007) offer useful frameworks to consider ethical issues in documentary filmmaking, representing people living with mental illness in a documentary film is challenging, and has very specific ethical considerations. These relate to the risks and benefits that the patient may experience whilst engaging with the media production process.

The documentary modes conceptualised by Nichols (2010) provides a helpful framework for filmmakers to think about approaches, and decide on a theoretical approach. However, no single framework was appropriate for a film on mental health. A hybrid of modes (performative, expository, poetic, participatory and observational) seemed appropriate for the documentary film.

The research ethics processes required by institutional partners contributed to a more ethically sound film production, and further highlighted the benefits and synergy between the research process and media production processes, such as film or photography, calling for a single integrated process amongst those wishing to disseminate and promote the use of their research. Whilst some tension does exist between the research and communication, it is important that the research findings are carefully balanced by the need to communicate a visually, appealing picture. Practitioners of documentary film should caution omitting important research findings in the event of poor quality footage, and rather find creative alternatives for communicating these. Apart from the informed consent procedure applied to all participants, the additional ‘capacity to consent’ form completed by a mental health worker provided a useful means of verifying the service users mental capacity to consent.

In relation to the production process, securing funding and stakeholder support, briefing the crew on the vision and purpose of the documentary, having access to equipment and translators contributed to the successful completion of the film. During the translation and transcription phase, time-coding was found to be particularly useful for the sub-titling of the film. In post-production, a systematic approach to editing was very useful to identify

themes and to ensure that the narrative flows throughout the film, within the context of a typical three-act structure. The comparative approach was useful in demonstrating the commonalities that people living with mental illness experience despite the heterogenous settings, whilst also enabled the differences to be illustrated. Distribution of the film, and developing stakeholder specific strategies for reaching target audiences is also recognised as an important step in ensuring that the goal of disseminating the film to a wide range of audiences is realised. Conferences, symposia, film festivals and broadcasters are amongst the distribution channels identified.

Limitations were identified, which primarily relate to the fatigue associated with people living with severe mental illness. Aesthetic limitations were also identified given the more limited time spent observing and filming patients with mental illness.

A number of opportunities exist for further research, particularly in the area of evaluation. Firstly, assessing and recording the impact of the film on the subject after seeing themselves on screen would add further knowledge regarding the ethics of media participation amongst those with mental illness, and further identify risks and benefits. Secondly, testing the impact of the dominant performative documentary mode for films on mental health can contribute to future research, and affirm whether this can be proposed as an ideal approach for films on the subject. Other areas for future research include evaluating the impact of the film on other key stakeholders, such as health workers and policy makers, and investigating the most feasibable approaches to disseminate the film including an analysis of the effectiveness of various distribution strategies for different target audiences.

Documentary film, and the performative mode complemented by other modes, has been shown to be an advantageous means of representing persons living with mental illness, and their families. The benefits of integrating the media production into a research process may be of use to other researchers who are interested in using this medium to visually communicate their research findings. The construction of a narrative for the feature length story allowed for presenting the research findings in an interesting and visually appealing way, and an opportunity to communicate deep emotions of the main characters.

Limitations relating to patient fatigue, particularly in the case of patients with severe mental illness (such as schizophrenia), and the minimal observational time that can be spent with subjects has implications for the aesthetics of the film. More evaluative research is

required to assess the impact that the film has on the patient subjects after seeing themselves on screen, contributing to the body of knowledge on the ethics of media participation and further identifying risks and benefits. Other potential avenues for future research include testing the value of the performative documentary mode on other targeted stakeholders such as health workers and policy makers, and research into the development of a distribution strategy which maximises the reach and impact of the film.

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Appendix 1: Information Sheet (Service Users)

Additional information form for service user participants in the documentary film

You will be given a copy of this information sheet

Date:

My name is (_____ *interviewer*) from the PRIME (Programme for Improving Mental Health Care) project at TPO Nepal / University of Kwazulu-Natal, South Africa. My office is in Chitwan / Klerksdorp, and I can be contacted on (_____*mobile number*). The director of this project is Amit Makan. He is based at University of Cape Town in South Africa and can be contacted on +27 21 685 9106 or email a.makan@uct.ac.za. The PRIME Nepal/SA project is funded by the Department of International Development (DFID) in the United Kingdom.

You are being invited to participate in this documentary that involves research about persons living with mental illness, and persons working in the health care sector. If you agree to participate in the documentary film, your pictures and selected quotations from your interviews will not remain confidential. You will be filmed and your picture/face will be appear in the documentary. You will have a choice to be anonymous or to use your real name in the film. If you wish to remain anonymous, your name and contact details will be seen by members of the study team only and every effort will be made to keep this information confidential.

Before agreeing to take part in this documentary film, please read the information below so that you understand what the project will involve. Please read this carefully and feel free to ask me if there is anything that is not clear or if you have any questions about your participation.

What is the purpose of this study?

The aim of this documentary project is to educate and demystify misconceptions of persons living with mental illness and to show progress in how mental health is becoming part of primary health care (PHC) in low and middle-income countries.

We are asking for your participation as we are trying to show visually, using film, how having a mental illness affects your life and your relationship with your family, and your experiences of participating in a treatment programme.

Who are we asking to participate?

We are looking for participants who have had an experience of living with a mental illness, and/or receiving treatment or care from the public health system. We are looking for participants in the Chitwan district (Nepal) / the Kanana Township outside of Klerksdorp in the Dr Kenneth Kaunda district of the North West province (South Africa).

What will participation in the study involve?

If you decide to participate in this study and agree to be filmed, the film producer will ask you questions about your experiences, and may request to spend some time in your home with you and film you as you go about your daily routine. This may take several hours. He may film your family (after asking their permission), a visit by your regular health or social worker or when you attend the clinic.

Will my information remain confidential?

If you agree to participate in the documentary film, your pictures and selected quotations from your interviews will not remain confidential. However, you will have a choice to be anonymous or to use your real name in the film. If you wish to remain anonymous, your name and contact details will be seen by members of the study team only and every effort will be made to keep this information confidential.

What are the possible benefits of participating in this study?

Some researchers say that participating in activities to do with mental health can be good for those living with mental illness, as you will be able to make a contribution. You will be asked to spend time with the film maker which may take a few hours, and be compensated a small amount for your time to cover any transport expenses you may have incurred. Other benefits are that this project will help people understand the positive factors and challenges which you experience in your daily life and your experience of the treatment programme. We also hope that the film taken will help policy makers and planners make better mental health services available for people living with mental illness, and encourage people with mental illness to attend treatment programmes. We also hope that the project will help us to improve the programme in your community so that better services can be received by more people.

What are the possible drawbacks or discomforts of participating in this study?

Apart from the time taken to participate in this study, we will be taking film of you conducting your daily work. This will be made public and may be published in various places. These include posters encouraging people with mental illness to ask for treatment at the clinics, the PRIME website, film exhibitions, conferences and national/international television.

If you experience any discomfort or distress during the course of this interview, related to your condition or to the service you received at your clinic, you can contact (name of independent psychologist / counsellor in the area) to speak about your concerns.

Do I have to participate in this study?

It is your choice whether you want to participate in this film or not. If you decide not to participate, you will not be prejudiced in any way. If you decide to take part, you are still free to withdraw from the film at any time and without giving a reason. Should you decide not to take part, or if you withdraw from the film, this will in no way affect the care you or your family member receive at the clinic. Should you agree to participate, we will ask you to sign the attached consent form. Should you decide after the film shoot that you no

longer wish to give consent, you will have 1 month within which to remove your consent, after which time none of your images will be used in the study.

This study has been ethically reviewed and approved by the UCT Health Research Ethics Committee (HREC REF 139/2014) / Nepal Health Research Council / UKZN Research Ethics Committee (Approval numbers XXXXX)

In the event of any problems or concerns/questions you may contact the film producer, Amit Makan on +27 21 685 9106 or the UCT Health Research Ethics Committee / Nepal Health Research Council / Biomedical Research Ethics Committee, contact details as follows:

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Email: ximbap@ukzn.ac.za

Appendix 2: Information Sheet (Health Care Providers)

Additional information form for health care providers in the documentary film

You will be given a copy of this information sheet

Date:

My name is (_____ *interviewer*) from the PRIME (Programme for Improving Mental Health Care) project at TPO Nepal / University of Kwazulu-Natal, South Africa. My office is in Chitwan / Klerksdorp, and I can be contacted on (_____*mobile number*). The director of this project is Amit Makan. He is based at University of Cape Town in South Africa and can be contacted on +27 21 696 1821 or email a.makan@uct.ac.za. The PRIME Nepal/SA project is funded by the Department of International Development (DFID) in the United Kingdom.

You are being invited to participate in this documentary that involves research about persons living with mental illness, and persons working in the health care sector. Before agreeing to take part in this documentary film, please read the information below so that you understand what the project will involve. Please read this carefully and feel free to ask me if there is anything that is not clear or if you have any questions about your participation.

What is the purpose of this study?

The aim of this documentary project is to educate and demystify misconceptions of persons living with mental illness and to show progress in how mental health is becoming part of primary health care (PHC) in low and middle-income countries.

We are asking for your participation as we are trying to show visually, using film, how having a mental illness affects your life and your relationship with your family, and your experiences of participating in a treatment programme.

Who are we asking to participate?

We are looking for participants who are involved in providing health care services in the Chitwan district (Nepal) / the Kanana Township outside of Klerksdorp in the Dr Kenneth Kaunda district of the North West province (South Africa).

What will participation in the study involve?

If you decide to participate in this study and agree to be filmed, the film producer will ask you questions about your experiences, and may request to spend some time in your home with you and film you as you go about your daily routine, if you wish. This may take several hours. He may film your family (after asking their permission), a visit by your regular health or social worker or when you attend the clinic.

We will use this film, together with quotations from interviews with you about your experiences of working in the health sector, and with persons living with mental illness.

Will my information remain confidential?

If you agree to participate in the documentary film, your pictures and selected quotations from your interviews will not remain confidential. However, you will have a choice to be anonymous or to use your real name in the film. If you wish to remain anonymous, your name and contact details will be seen by members of the study team only and every effort will be made to keep this information confidential.

What are the possible benefits of participating in this study?

Some researchers say that participating in activities to do with mental health can be good for those working with persons with mental illness, as you will be able to make a contribution. You will be asked to spend time with the film maker which may take a few hours, and be compensated a small amount for your time to cover any transport expenses you may have incurred. We hope that this project will help people understand the positive factors and challenges which you experience in your daily life, and in providing a health service to your community. We also hope that the film taken will help health planners and policy makers to make better resources available for people working in the health care sector. We also hope that the project will help us to improve the programme in your community so that better services can be received by more people.

What are the possible drawbacks or discomforts of participating in this study?

Apart from the time taken to participate in this study, we will be taking film of you conducting your daily work. This will be made public and may be published in various places. These may include posters encouraging people with mental illness to ask for treatment at the clinics, the PRIME website, film exhibitions, conferences and national/international television.

If you experience any discomfort or distress during the course of this interview, you can let me know or contact your local TPO Nepal colleagues to speak about your concerns.

Do I have to participate in this study?

It is your choice whether you want to participate in this film or not. If you decide not to participate, you will not be prejudiced in any way. If you decide to take part, you are still free to withdraw from the film at any time and without giving a reason. Should you agree to participate, we will ask you to sign the attached consent form.

This study has been ethically reviewed and approved by the UCT Health Research Ethics Committee (HREC REF 139/2014) / Nepal Health Research Council / UKZN Research Ethics Committee (approval numbers XXXXX).

In the event of any problems or concerns/questions you may contact the film producer, Amit Makan on +27 21 685 9106 or the UCT Health Research Ethics Committee / Nepal Health Research Council / Biomedical Research Ethics Committee, contact details as follows:

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Appendix 3: Information Sheet (Experts and Policy Makers)

Additional information form for experts and policy maker participants in the documentary film

You will be given a copy of this information sheet

Date:

My name is (_____ *interviewer*) from the PRIME (Programme for Improving Mental Health Care) project at TPO Nepal / University of Kwazulu-Natal, South Africa. My office is in Chitwan / Klerksdorp, and I can be contacted on (_____*mobile number*). The director of this project is Amit Makan. He is based at University of Cape Town in South Africa and can be contacted on +27 21 696 1821 or email a.makan@uct.ac.za. The PRIME Nepal/SA project is funded by the Department of International Development (DFID) in the United Kingdom.

You are being invited to participate in this documentary that involves research about persons living with mental illness, and persons working in the health care sector. Before agreeing to take part in this documentary film, please read the information below so that you understand what the project will involve. Please read this carefully and feel free to ask me if there is anything that is not clear or if you have any questions about your participation.

What is the purpose of this study?

The aim of this documentary project is to educate and demystify misconceptions of persons living with mental illness and to show progress in how mental health is becoming part of primary health care (PHC) in low and middle-income countries.

We are asking for your participation as we are trying to show visually, using film, the progresses and challenges faced by the mental health care sector.

Who are we asking to participate?

We are looking for participants who are involved in research or making health care policies for people in the country. We are looking for participants in Nepal / South Africa.

What will participation in the study involve?

If you decide to participate in this study and agree to be filmed, the film producer will ask you questions about your experiences, and may request to spend some time with you, and film you as you go about your daily routine. This may take up to 2 hours.

Will my information remain confidential?

If you agree to participate in the documentary film, your pictures and selected quotations from your interviews will not remain confidential. However, you will have a choice to be anonymous or to use your real name in the film. If you wish to remain anonymous, your

name and contact details will be seen by members of the study team only and every effort will be made to keep this information confidential.

What are the possible benefits of participating in this study?

As a researcher or policy maker, your participation in this project can help raise awareness of the issues facing mental health care in your country and globally. You will be asked to spend time with the film maker which may take a couple of hours, and will be compensated a small amount for your time to cover any transport expenses you may have incurred. We hope that this project will help people understand the positive factors and challenges which you experience in the work that you do. We also hope that the film will be informative for other researchers, policy makers and planners to make better mental health services available for more people living with mental illness.

What are the possible drawbacks or discomforts of participating in this study?

Apart from the time taken to participate in this study, this film will be made public and may be published in various places. These include posters encouraging people with mental illness to ask for treatment at the clinics, the PRIME website, film exhibitions, conferences and in national/international television.

If you experience any discomfort or distress during the course of this interview, you can let me know or contact TPO Nepal representatives to speak about your concerns.

Do I have to participate in this study?

It is your choice whether you want to participate in this film or not. If you decide not to participate, you will not be prejudiced in any way. If you decide to take part, you are still free to withdraw from the film at any time and without giving a reason. Should you agree to participate, we will ask you to sign the attached consent form.

This study has been ethically reviewed and approved by the UCT Health Research Ethics Committee (HREC REF 139/2014) / Nepal Health Research Council / UKZN Research Ethics Committee (approval numbers XXXXXXXX).

In the event of any problems or concerns/questions you may contact the film producer, Amit Makan on +27 21 685 9106 or the UCT Health Research Ethics Committee / Nepal Health Research Council / Biomedical Research Ethics Committee, contact details as follows:

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Appendix 4: Consent Form (All Participants)

Additional information form for all participants in the documentary film

Please complete this form after you have been through the information sheet and understand what your participation in this study entails.

Thank you for your interest in taking part in this study. If you have any questions arising from the information sheet, please ask before you decide whether to take part. You will be given a copy of the information sheet and consent form.

I, *(write your name here),* _____ have been informed about the documentary film project conducted by Amit Makan and _____*Coordinator*.

I understand the purpose and procedures of the film.

I have been given an opportunity to ask questions about the film and have had answers to my satisfaction.

I understand that participation in this study will result in video and pictures of me being made public together with sections of interviews which I have given as part of this project.

I declare that my participation in this study is entirely voluntary and that I may withdraw at any time without affecting any treatment or care that I would usually be entitled to.

I have been informed about any available compensation or medical treatment if injury occurs to me as a result of my participation.

If I have any further questions or concerns or queries related to the project, I understand that I may contact the film producer at +27 21 685 9106 or a.makan@uct.ac.za

	Please tick or initial
I understand that if I decide at any time during the study that I no longer want to take part, I can notify the researchers and withdraw without having to give a reason.	☐
I consent to the processing of my personal information for the purposes explained to me.	☐
I agree to film and photographs of me being made public.	☐
I agree to quotations from interviews conducted with me being used in conjunction with the film and photographs.	☐
I agree that the research team may use my data (information) for future research and understand that any such use of identifiable data would be reviewed and approved by a research ethics committee. In such cases, as with this project, data would not be identifiable in any report.	☐

I confirm that I am happy for the film to use my real name: **OR** ☐

I would prefer to have a different name, and not have my real name used in the film: ☐

_____ _____

Signature of Participant **Date**

_____ _____

Signature of Witness **Date**

(Where applicable)

_____ _____

Signature of Translator **Date**

(Where applicable)

Appendix 5: Consent Form (Mental Health Specialist)

SERVICE USER 'CAPACITY-TO-CONSENT' FORM

VIDEO DOCUMENTARY

Documentary on mental health

Mental health service user participant name:

_____

Mental health specialist name:_____

Capacity/Title:_____

I hereby confirm that in my professional opinion, and based on the care and service provided to the participant, that the above participant *does* have the full capacity to consent to participate in this documentary project on mental health for educational purposes.

Location:_____ **Date:**_____

Producer: Amit Makan **Producing Organisation:** University of Cape Town

Mental health specialist name: _____

Signature:_____

Appendix 6: Discussion Guides by Stakeholder Groups

- Thank you for taking part in this interview. We are producing an educational documentary/film about mental health, and would like to hear from you what your experience is of mental health.
- A few things to remember: there are no right or wrong answers in this kind of discussion, just thoughts, feelings, ideas and opinions.

Questions:

Mental Health Service User Participants / Carers / Family Members

- Have you or a close friend or family ever experienced mental illness? Would you be willing to talk about your experience?
- What kind of mental illness have you or your friend/family experienced before?
- How would you describe the experience?
- What do you think is the cause of mental illness? How do people get it?
- Do you think people treat you or friend/family with respect because of their mental illness? Probe if there have been any changes or improvements.
- What treatment do you or friends/family receive (if any) for your mental illness?
- Has the treatment that you or friends/family received been helpful? If so, how? [probe how general PHC health workers vs. specialists have been helpful]
- Do you believe in traditional healers, and the treatment that they offer? Do you think it is effective?
- Do you think there are adequate public services available for those affected by mental illnesses? (If No, probe why)
- Do you have any suggestions for improving mental health care in country (Nepal/SA)?

Mental Health Specialist (Psychiatrist / Psychologist / Psychiatric Nurse)

- For how long have you been working in the mental health sector?
- What has your experience been of treating persons with mental illness?
- What are some of the common mental disorders (probe alcohol use disorders / depression), and the uncommon mental disorders (probe psychosis/schizophrenia)?
- Which is the most common mental disorder that people in country (Nepal/SA) are experiencing?
- What do you think is the cause of mental illness? How do people get it?
- Do you think persons living with mental illness are treated with respect today? Has there been any progress in the way people with mental illness are treated? Probe: whether friends and family experience stigma, or are responsible for the stigma?
- What are some of the challenges facing mental health specialists in treating persons with mental illness?
- Do you think general PHC workers have a role to play in mental health care?
- What about traditional healers?
- Have you or a close friend/family ever experienced mental illness?

General PHC Staff / Health Workers

- Does your work include mental health? If so, for how long have you been working within the mental health sector?
- What has your experience been of treating persons with mental illness?
- How do you balance treating people with mental health vs. other health priorities?
- To what extent do you work with mental health specialists to treat persons with mental illness?
- How do you think PHC staff and mental health specialists can work best together to improve mental health care?

- Have you or a close friend/family ever experienced mental illness?

Policy Makers

- Would you be willing to talk about any personal experiences?
- How important is mental health in the national health priorities of the country?
- What is the current status of the country's mental health policy and plans?
- What is the role of research in mental health policy and services?
- What are some of the challenges faced in terms of improving mental health care?
- How would you like to see mental health improve in country (Nepal/SA)?
- Have you or a close friend/family ever experienced mental illness?

University / Research Stakeholders

- How does research play a role in improving mental health care?
- How would you explain in simple terms what mental illness is?
- What are some of the common mental disorders (probe alcohol use disorders / depression), and the uncommon mental disorders (probe psychosis/schizophrenia)?
- Which is the most common mental disorder that people in country (Nepal/SA) are experiencing?
- What do you think is the cause of mental illness? How did the people get it? (Probe: biological, psychological & environmental e.g. poverty)
- Do you think persons living with mental illness are treated with respect today? Has there been any progress in the way people with mental illness are treated? Probe: whether friends and family experience stigma, or are responsible for the stigma?
- How did the field of global mental health come about?
- What progress has been made in mental health globally, and what are some of the challenges?
- What are some of the strategies being used to respond to the challenges of the increasing burden of disease associated with mental disorders? (Probe: task sharing, funding)
- Why is mental health of particular importance to countries considering the competing health priorities (e.g. HIV/Aids, TB, Malaria)?
- How does mental health feature on the NCD agenda?
- What is the link between mental health and development?
- From a health economics point of view, are there any benefits of countries providing mental health care? Is there data revealing the cost/benefit / do the benefits outweigh the costs?
- Have you or a close friend/family ever experienced mental illness? Would you be willing to talk about any personal experiences?

Local / International NGOs

- What is the role of civil society in providing mental health care?
- What is the role of researchers and policy makers in providing mental health care?
- How does your organisation contribute to improving mental health care?
- Why is mental health of particular importance to countries, considering the competing health priorities? (e.g. HIV/Aids, TB, Malaria)
- Have you or a close friend/family ever experienced mental illness? Would you be willing to talk about any personal experiences?

Traditional Healers

- Have you or a close friend/family ever experienced mental illness? Can you share with us your personal experience?
- How does traditional healing can help people living with mental illness?

- What kind of treatment/healing services do you provide?
- What kind of healing works best for your patients?
- How do you feel about pharmaceutical drugs / medication, do you think that it helps people with mental illness?
- Do you think mental health specialists (psychiatrists/psychologists) can also help persons living with mental illness?
- Would you be willing to talk about any personal experiences?

Media Organisations

- How do media organisations (like yours) contribute help people with mental illness, or contribute to mental health care? (Probe: Stigma / Advocacy)
- To what extent do people use the media to educate and communicate? Do you think the media is an effective means of educating people and de-stigmatising mental illness?
- What are some of the challenges facing the media in terms of communicating issues of mental health?
- Have you or a close friend/family ever experienced mental illness? Would you be willing to share with us your personal experience?

Appendix 7: Script Outline

Character	Country (NP Nepal, SA South Africa, CC Cross Country	Key Messages
		INTRODUCING PATIENT ILLNESSES (ACT I)
Anju	NP	Establishing Nepal (Shardanagar)
Anju, Sani	NP	Introducing Anju, Sani and Ram Prasad
Sani	NP	Sani admits to drinking all day all night
	NP	Establishing Nepal (Shukranagar)
Narayan	NP	Introducing Narayan
Sharda	NP	Introducing Sharda
	SA	Establishing Kanana (South Africa)
MaAgnes	SA	Introducing MaAgnes
	SA	Speaks of losing her children (loss)
	SA	Her illness was to make noise
	SA	MaAgnes - explains how her problem started (loss)
MaPule	SA	Introducing MaPule Lekone
	SA	Crazy, heard voices (stigma)
	SA	MaPule-explains her confusion after her brother died, did not stop talking (loss)
Seth	SA	Introducing Seth Lekone
	SA	He is a Caregiver and unemployed
		Title Shows Voices from the Edge
		EXPLORING PATIENT STIGMA

	NP	Anju shares her worry & embarressment
	NP	Sharda shares her worry that N is teased
Dr Mark Jordans	NP	Expert on Nepal talking about stigma (MJ)
	NP	What is being done about it
Prof Crick Lund	SA	About PRIME, cross country focus, people living in poverty
	NP	Seth - explains his stigma, reveals schizophrenia
	NP	Seth speaking of MaPule stigma
Prof Inge Petersen	SA	Inge-objective of PRIME access, working with DoH
	SA	Dr Gwen Ramokgopa
Sis Tilo	SA	Expert - Introducing SisTilo, describes clients coming to the clinic, reveals stigma
	SA	MaAgnes-no stigma as she did not tell anyone
		FAMILY/CARERS IMPACT
	NP	Anju - Suicide ideation
	NP	Ram Prasad - Sleep deprived, wander off
	NP	Anju - Dropped out of school
	NP	Sharda -Ns symptoms, his trouble learning, wandering off
	NP	Suffering, what happens when she dies, worry
Prof Crick Lund	CC	Expert on mental illness (CL)
		IMPACT ON MENTALLY ILL
	SA	MaPule - unable to perform tasks (like laundry and cooking)
	SA	MaAgnes - life was greatly affected
	SA	Sani had to quit his job, Anju verifies
Prof Crick Lund	CC	PRIME MH Care Plans
		SEEKING HELP (ACT II)
Junga Bhujel (Chanting)	NP	Introducing traditional healer
	NP	Anju - took him to traditional healer, possessed
	NP	Sharda - Narayan possessed
Nir Prakash	NP	Expert in Nepal - importance of trad healer

	NP	Trad healers say they should not treat med conditions
Prof Graham Thornicroft	CC	Expert Psychiatrist (GT)
	SA	MaAgnes - not interested in TH
	SA	Mentions started to get help from counsellors
	SA	MaAgnes - reveals depression
Prof Inge Petersen	SA	Objective of PRIME, and About priority mental disorders in SA
MaPule	SA	MaPule - husband did not allow her to go to TH
Seth	SA	Seth - family encourage but no faith in them
	SA	Makes mention of medication from clinic
MaPule	SA	MaPule - explains how/when her problem started
One Selohilwe	SA	PRIME has a program for patients with schizophrenia
	SA	SisTilo - mostly schizophrenia, speaks of how the patient arrives at the clinic
Dr Oosthuizen	SA	Explains referral pathways between psychiatric hospital and clinic
	NP	Sharda - took N to hospital, prescribed sleeping tablets etc
Sharda	NP	Sharda - started become aggressive, could not be near him
	NP	Sharda - found out about TPO Nepal, took him there. Reveals intellectual disabiity
		FINDING HELP / TREATMENT (ACT III)
Dr Tirtha Burlakoti	NP	Policy Maker Nepal
Nagendra Prasad Luitel	NP	PRIME Nepal
Anju	NP	Anju-friend visited and told them about health post
Ram Prasad	NP	Ram Prasad - treatment started after meeting Bipan
Bipah Shah	NP	Expert Bipan - explained MI, Sani has AUD, treated as part of PRIME
Sani	NP	Sani - took western medicine
		(NON-SPECIALIST MH CARE)
Nagendra Luitel	NP	Nagendra - explains about PRIME, training health workers
Prof Vikram Patel	CC	Vikram TED Talk - task sharing
Ek Narayan, Padma Bhattarai	NP	Health Worker 1 & 2 Nepal describing training
Dr Dan Chisholm	CC	Expert - Dan Chisholm explaining mhGAP

One Selohilwe	SA	Lack of psychologists
MaAgnes	SA	Explains how she met the counsellor
Pauline Onele	SA	Meet the counsellor, Pauline
MaAgnes	SA	Explains no understanding of depression, counsellors explained
Pauline Onele	SA	Pauline - speaks about the story she read
	SA	Pauline - reads Nonthombeko's story
MaPule	SA	Does not think services are sufficient
Sis Tilo	SA	SisTilo - Kanana Community, and relapse??
Seth	SA	Explains that pills are not available when they go to clinic, they should at least have injection
Dr Oosthuizen	SA	Explains how medication reaches clinic
One	SA	Medication challenges
SisTilo	SA	Explains how medication can not reach clinic. Says it's the professional nurses job.
		LIFE AFTER TREATMENT
Anju	NP	Anju-he has changed a lot now compared to before, because quit drinking he has changed
	NP	Sharda-treatment helped a lot
	NP	Explains could not have done it without treatment
	NP	Further describes behaviour, pull wires etc
Anju	NP	After medicines he is a lot better
Dr Tirtha Burlakoti	NP	Limited health centres
Prof Crick Lund	CC	Policy
Dr Gwen Ramokgopa	SA	Deputy Minister - Translational research
Prof Vikram Patel	CC	Importance of communicating message to people affected by mental illness, and policy makers
		ENDING MESSAGES
MaAgnes	SA	MaAgnes-seen positive changes after attending counselling
Pauline	SA	Pauline-shares MaAgnes openness now
MaPule	SA	MaPule - support group taught her to understand herself
Seth	SA	Seth-how he learnt about her illness, developed patience through her sister, he accepted her
Anju	NP	Anju-hopefully about Sani future, he wants to go abroad, earn money and get married

Sharda	NP	Sharda-explains N is better but still needs vocational training and friends
	NP	She has faith in his potential
Narayan	NP	Narayan-I would like to be a Nepali school teacher
MaAgnes	SA	MaAgnes - now able to smile, and she can watch TV and listen to people
	NP	Sani-hard to stop in the beginning, but became easier
	NP	Anju-changed because quit, very happy
Sani	NP	Sani-looking for job in Saudi, labour job
		PORTRAIT SEQUENCE OF MAIN CHARACTERS

Total Sequences: NP (Nepal) 49, SA (South Africa) 46, CC (Cross Country) 7