

Children with HIV: the Consolidation of medicine, science and the social  
into the clinical practice of paediatric HIV

Richard Boulton

Goldsmiths College, University of London

PhD Sociology

## Declaration

I declare that that this thesis is my own work and that it has not been submitted elsewhere for any award. Where other sources of information have been used, they have been acknowledged.

Signature:

Date:

## Abstract of Thesis

This thesis explores how medicine is practiced in a paediatric HIV clinic in outer London. It draws on ethnographic research that took place in the clinic over the course of a year. The significance of the topic is situated in the complexity of the issues presented clinically by children with HIV in London. During practice recurrent associations of confidentiality, stigma, vulnerability, naivety and innocence emerges around the patient cohort that mainly comprises recent African migrants living their lives in complicated urban environments. These associations are contrasted by the uncompromising requirements of antiretroviral medicine which needs almost perfect dosing adherence in order to suppress the virus. The incompatibilities between complex patient lives and medical requirements must be made compatible through clinical practice. Therefore, the thesis emphasises the clinic as the key site where the 'cultural' issues presented by patients are consolidated with drug requirements to form a functional medicine.

The argument is informed by discussions around Science and Technology Studies (STS), and the Sociology of Childhood (SoC). These discussions highlight practice as 'enacted', where objects such as disease, the body or medicine are not 'given' but gain their shape through their recurrent enactions (Mol 2002, Mol and Law 2004). I have used these discussions to argue that medicine and protocol do not pre-exist practice but must be enacted by practitioners and (child) patients in the clinic. Clinical practice is shown in the thesis as consolidating protocol, drug requirements, patients, practitioners and representations of HIV in ongoing clinical enactions to make the antiretroviral medicine amongst the paediatric cohort operational. To do this, the research focuses on a set of procedures enacted in the clinic: disclosure, adherence, HIV as chronic illness and transition. These procedures inform practitioners on how to maintain care and make medical requirements explicit to child patients (and their parents), enforcing behaviour that accords with the goals of antiretroviral medicine. In this way practice and protocol are negotiated and renegotiated to ensure their effectiveness between all of the associations involved in participating with the condition, paediatric HIV and the corresponding medicine.

Compared to existing STS on the subject of medicine and the clinic, paediatric HIV practice emphasises the clinic's role to consolidate seemingly incompatible associations around patients such as stigma, vulnerability and innocence into medical requirements. The result is that STS that advertently or inadvertently implies that medical practice is messy or disjointed are questioned in light of two important features of paediatric HIV. Firstly, that practice must necessarily consolidate disparate patient lives into medical requirements if treatment is to be successful, and secondly, that practitioners must employ a logic to generate a coherent, well-organised clinical practice that is flexible and pliable to diverse eventualities. The significance of this argument demonstrates the clinic's importance in enacting interventions and attuning medicine, displacing a notion of protocol or guidelines as dictating practice without negotiation, or the belief that the ideal course of clinical practice is fully predefined in protocol. Therefore, the implications of this research underline the clinic as a key site in rationalising how medicine is formulated and applied to patients.

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<b>1</b>	<b>Introduction.....</b>	<b>8</b>
	Setting the Scene.....	11
	The Practice of the Clinic .....	20
	Layout of the Thesis.....	22
	Chapter Outline .....	23
<b>2</b>	<b>Literature Review.....</b>	<b>29</b>
	Object Politics.....	30
	Patient Negotiations .....	43
	The Sociology of Childhood.....	54
	Conclusion .....	67
<b>3</b>	<b>Methodology.....</b>	<b>69</b>
	What is ANT (and after)? .....	70
	Latour vs. Law: following the actor / enacting worlds .....	76
	Bruno Latour, <i>Reassembling the Social</i> .....	77
	John Law, <i>After Method</i> .....	79
	Childhood Naivety .....	82
	Implications for the Study.....	84
	Research Methods.....	85
	Summary .....	97
<b>4</b>	<b>Ethics and Paediatric HIV Practice .....</b>	<b>99</b>
	Informal Versus Formal Ethics .....	100
	Complex Ethics.....	106
	Ethical Assemblages of Innocence .....	111
	Conclusion.....	115
<b>5</b>	<b>Disclosure .....</b>	<b>117</b>
	Formulations of disclosure.....	120
	A Time to Begin Disclosure .....	122

Participation, Adherence, and Impartation of Knowledge.....	127
Confidentiality – a unique problem that affects what is possible .....	130
Dangerous Disclosure? .....	137
A Caveat Apart: Age and Applicability of Disclosure .....	140
Conclusion.....	142
<b>6 Adherence.....</b>	<b>146</b>
CHIVA Adherence Guidelines .....	148
PENTA Guidelines for the use of Antiretroviral Therapy .....	156
Common Ground .....	160
Good Care .....	163
Conclusion.....	169
<b>7 Paediatric HIV as Chronic Illness.....</b>	<b>176</b>
Consolation .....	180
Education .....	186
Professional Negotiations.....	191
Large Scale Organisation of Complexity.....	194
General Healthcare.....	197
Conclusion.....	204
<b>8 Transition .....</b>	<b>208</b>
Transition in Action.....	214
Passing on Problems or Straight Forwardness.....	222
Letting Go of Relationships – Versus Formalised Structures? .....	226
Aging Population .....	231
Conclusion.....	234
<b>9 Conclusion.....</b>	<b>237</b>
<b>References.....</b>	<b>251</b>
<b>Appendices .....</b>	<b>276</b>

# 1 Introduction

This thesis discusses the relationship between clinical practice and Paediatric HIV. It focuses on how diverse networks of social/scientific/medical/political entities are consolidated during clinical practice into care practices geared towards making viral suppression and the management of paediatric HIV possible. It describes one clinic, but from this clinic's practice the associations found have a broad scope, providing insights into the workings of a more general logic employed in clinical medicine. It details the ethnographic observation of a clinic in a London hospital which will be referred to as University Outer Urban Hospital (UOUH). The ethnographic data is used to illustrate the discrepancies between the paediatric patient as described in medical literature, guideline, policy and protocol and the child as presented in the clinic. Amongst other conditions paediatric HIV is particularly interesting because of the complexity of patients' lives and medical requirements that must be managed sensitively by the clinic. This thesis addresses these issues by arguing that the clinic is not only a site where medicine is practiced, but is also central to the task of consolidating patient complexities with medical requirements and making medicine operational. For paediatric HIV, psychosocial accounts are the most extensive and often cited explanations of 'the social' (Lewis et al., 1994; Melvin and Sherr, 1995; Battles and Wiener, 2002; Green and Smith, 2004; Naar-King et al., 2006; Steele, 2007; Santamaria et al., 2011). However, these explanations often use predefined notions of what is social, what is medical and what is scientific. In doing so, these accounts isolate phenomena to distinct spheres, ignoring the ways in which what is social or medical are enacted at the same time



in the clinic<sup>1</sup>. Instead, the account presented here discusses how the clinical practice of paediatric HIV is enacted through the negotiations taking place in the clinic between patients and practitioners, medical science, protocol and their multiple material/semiotic associations (drawing heavily on medical practice as described by Mol, 2002 as will be discussed further). In effect, the argument warrants a view of clinical practice as more nuanced where practitioners are not merely applying science to patients, but where scientific recommendations of dosage and treatment, the complex lifestyles and identities of patients, and interpretations of policy and protocol must be negotiated and enacted together through the same clinical processes. The resulting practice that ensues in the clinic is therefore highly specialised and tailored through protocol whilst remaining flexible, dynamic and relevant to the negotiations that must take place between practitioners and diverse groups of child patients. This project diverts an idea of protocol as pre-existing practice, offering instead a view of protocol as part of an emergent process. Accordingly, protocol is framed as enacted, in negotiation, having a wider clinical context and as never fully completed in the documents presented. Therefore, this piece of work will hopefully provide a resource to those who must imagine the administration of care regimes to children, i.e. practitioners, policy makers and sociologists alike. In the clinical practice of paediatric HIV, antiretroviral requirements, protocol and patient knowledge/participation must be negotiated in order to make it possible for clinical interventions to make paediatric HIV medicine functional.

The clinical practice of paediatric HIV offers a unique example for analysis because the condition has connotations not present in the adult HIV clinic or in the clinical practice of other conditions more generally. A unique combination of associations around naivety, innocence, drug requirements, sex education, public health implications, immigration, and an urban context<sup>2</sup>, make paediatric HIV clinical practice a fine balance of sensitive issues (Brown et al., 2000). For example, most UK patients are part of immigrant African communities, also HIV has wider stigmatising connotations around sex or drug abuse and in

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<sup>1</sup> Armstrong (1987) offers a similar criticism of the psychosocial, arguing that the discipline puts social science in its place as “an emasculated, uncritical appendage of an invigorated biomedicine”. (p1217)

<sup>2</sup> Melvin and Sherr (1995) and Hekster and Melvin (2006) specifically discuss issues affecting children with HIV in London.

addition paediatric HIV evokes wider issues around childhood, naivety, innocence and deservedness (Henderson, 2006; Fassin, 2008). These considerations mean that the study of paediatric HIV clinical practice has a unique contribution to the Science Technology Studies (STS) and Sociology of Childhood (SoC) literature referenced in this thesis. Compared to other conditions, paediatric HIV demonstrates that clinical practice and protocol are not just performed in this context, but must be made possible through the adversity presented (or not presented) at the clinic. Therefore, in comparison to questions of objectivity and standardisation in protocol and medicine, (such as is the focus of Cambrosio et al. 2009), this project diverts the question to assess the everyday challenge of maintaining practice alongside associations such as stigma, vulnerability and naivety that are contradictory to requirements and exceed the objectivity of protocol (also see Dodier, 1998; Latimer et al., 2006; Timmermans and Buchbinder, 2010, 2012). Practice must be made to consolidate disparate factors into one regime of care, and as alluded to, consolidation is achieved not through imposition but negotiation. Therefore, rather than the clinic being hierarchically arranged under protocol, policy or laboratorial medicine (or 'biomedicine'), the clinic is a key site in the formalisation of the medical science and the condition. Clinical practice must be accounted for when designing guidelines, protocol or policy. Because of the high-profile cultural implications of paediatric HIV, such as stigma and vulnerability<sup>3</sup> that must be made compatible with drug requirements through clinical interventions, this account offers a perspective that emphasises the clinic's consolidating role more prominently than other conditions already dealt with in STS or SoC (such as atherosclerosis in Mol, 2002; or childhood asthma in Prout, 1996; or the general conditions of childhood illness described in Christensen, 1998). As a result it makes a valuable contribution to the field by demonstrating the flexibility and cultural awareness required in the clinical management of paediatric HIV. The remainder of the introduction will continue by presenting some of the context around paediatric HIV, the clinic and the research, before providing a chapter outline.

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<sup>3</sup> Authors such as Latimer et al. (2006) and Timmermans and Buchbinder (2010, 2012) have already used the process of genetic categorisation to describe the role of the clinic to formulate the medical science but I will use paediatric HIV to demonstrate that the clinic must also make compatible and formulate a broader range of medical tasks like for example the practicalities of protocol, policy and laboratorial medicine alongside the everyday lives of patients.

## Setting the Scene

UOUH is located in the outer zones of London. The hospital primarily serves three London boroughs. All patients of the clinic come from these three London boroughs, but formally the clinic has no clearly defined catchment area. Alternatively, it was set up because of the large numbers of children with HIV in the local population around the hospital. As a result, patients often have a choice of which London clinic they wish to attend. Clinics that treat paediatric HIV are dotted around London but tend to be in the places where there are the highest numbers of patients nearby. Together, the clinics form a network, one of ‘hubs and spokes’. UOUH is not a large centre compared to other London services, being a ‘spoke’ directly linked to a central ‘hub’ hospital (which I will refer to from here on as CHH) and then to the wider network (CHIVA, 2012a; Judd et al., 2007). The most readily observable manifestation of this coordination was that a consultant from the CHH would sit in on the clinic every month.



1 A visualisation of the London-centred ‘hubs and spokes’ network from the CHIVA website

Of the specific cohort of children and adolescents at UOUH at the time of research, there were 22 children enrolled at the clinic, almost all have both parents with ethnic connections to Sub-Saharan Africa. The population of the area is transitory, and is made up of several multi-cultural communities and identities<sup>4</sup>. Even though the area under research is

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<sup>4</sup> Race and Ethnicity in the three boroughs according to the 2001 census have high proportions of ethnicity minorities, Those of non white British decent were recorded as being around 55% for the principal borough,

presented as anonymous, it is not easily placed under pseudonym as it has many unique attributes. The borough which forms the largest part of UOUH's catchment area has a bad reputation for street crime. It was an area of unrest in the 2011 London riots where ensuing nights of unrest took place among the local communities there highlighting many unforeseen urban problems in the area (The Guardian Online, 2012). The borough also has a predominant position amongst London boroughs in terms of children referred to social care services (Department for Education, 2011). UOUH paediatric department sees it necessary to refer a very high number of cases to child protection (according to undisclosed clinical data). At the time of research, the paediatric department was also dealing with some high profile cases that needed expert attention (Mason, 2005). All of these factors are intended to enable the reader to gain a picture of a very specific urban landscape with multiple layers and dynamics.

The first meeting held at UOUH regarding this project took place in the offices of the Old Nurse's Home. This block no longer exists. Between this first meeting, gaining ethical approval and starting research, the paediatric department had been relocated into a new building as part of a 123 million pound investment project in the hospital (built on the tail end optimism of "the New NHS", see SSFH, 2001). What was once dispersed over a collection of dilapidated old buildings has been consolidated into a centralised hospital building, built to meet modern specifications. Layered with a broader overlapping history and context, the site has served as a workhouse, then as a military hospital before gaining its current status in 1920. The new building replacing the Old Nurse's Home established in 1910, was opened in June 2010. The first days of research and contact with patients at the clinic coincided with the opening of the new hospital. As I began attending the clinic I witnessed the dispersion of the old buildings, their cordoning off and their gradual demolition piece by piece. By the last days of research a car park stood on the spot where the buildings used to be.

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40% the second and 30% for the most distant, this puts all of the boroughs over the average of England which is 13% and puts them alongside the London average which is 40% (UK Census data).

It is possible to see a lot of similarities and significances with this process of renovation and those processes involved with instigating clinical practice in paediatric HIV. Within paediatric HIV, there are questions concerning a history and context of sex, morality and deservedness (or non-deservedness) that is not often openly spoken about (Henderson, 2006; Fassin, 2008). The gradual construction, demolition, transfer and consolidation coordinated to raise as little public attention as possible, is evident in how medicine is practiced in the clinic, in the way patients choose to carry out their lives and the ways in which the two meet to manage the condition. In outer London as elsewhere, HIV is referenced with discretion. The practice of care set up for children with HIV does so in strict confidentiality and this discretion is deeply embedded in the medicine (U.K. Select Committee, 2011). However, far from inactive, it is an area of medicine that is in constant flux and development. The epidemic itself does not have a long history but its face and nature have changed rapidly (Goulder et al., 2001). Perinatal infection of HIV (infection from mother to child) has its own rich sub-story in the HIV pandemic and is an area of medicine which poses its own questions of medical significance on HIV. As far as the effects of antiretrovirals on body development are concerned, paediatric HIV is an under-researched area (Doerholt and CHIPS, 2006), yet in a short span, it has become possible to prevent up to 97% of mothers passing HIV on to their children in the UK (Townsend et al., 2009), and the population of those infected perinatally has begun to age with little precedence in clinical practice about how to proceed. The latest models of life expectancy show that HIV treated with antiretroviral therapy results in a close to average life expectancy, commonly placed well into the 70s (May et al., 2011; Nakagawa et al., 2011). This is a significant development for children who have HIV. Now that life expectancy has risen, it has become possible to anticipate that children with well maintained care will grow to an old age. This projected future is contingent for every individual however, and not all children will have the same health prospects. To ensure that the condition can be maintained as far into the future as possible, patients must follow antiretroviral drug regimes with as near 100% adherence as possible. The virus must be monitored at regular intervals and antiretroviral treatments must be tailored to a patients' personal profile. Implementing this regime to children as they grow has many challenges, most of which

requires a process of decision making that is contingent, time specific and context sensitive to each clinical encounter (see recommendations of Cunningham et al., 2006; Drotar, 2000).

This thesis combines methodologies of Science and Technology Studies (STS), specifically Actor Network Theory (ANT)<sup>5</sup>, and the Sociology of Childhood (SoC) to focus on how clinical practice consolidates diverse child/adolescent patient lives with antiretroviral requirements and care regimes geared towards making HIV management possible. The consolidation of clinical practice runs from the inclusion of children into a compatible understanding of their HIV, to the task of maintaining adherence, conceptualising care, managing chronic illness over an entire lifespan and the eventual transition of patients into adult services. In the process, patients tread the line between suppressing the virus and the dangers of the virus becoming resistant to treatment. Therefore, the research is geared towards investigating the ways in which paediatric HIV is organised through clinical practice and made operational between groups of patients, practitioners, protocol and antiretroviral requirements with little room for failure (in this context, resistance or non-suppression). This is confounded by the diversity presented by the patient cohort.

Brock's (2008) examination of Hari Kunzru's novel *Transmission* offers an allegory of HIV as beyond the scope of one nation and prevention method, indistinguishable from its global context. The allegory can be compared to the populations of migrants arriving in the UK who are infected with HIV. Paediatric HIV is a transient condition beyond national boundaries and a simple infection route, meaning that populations are not uniform and have complex identities. During the course of my PhD and especially in the early days before beginning fieldwork at UOUH when I was unfamiliar with the topic, I attended several charities. Positive Parenting and Children (PPC) in South London where I attended the regular youth club organised for children affected by HIV, the Children with AIDS Charity (CWAC) to discuss the activities they take part in and also the Children's HIV Association (CHIVA) where the project was discussed with key members of the organisation. These

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<sup>5</sup> Certain authors that will be discussed throughout the thesis could be described as using the methodology of 'after ANT' such as Anne Marie Mol. For simplicity I will stick to the term of ANT to describe the fields of ANT and after ANT, but discussion on the different implications of ANT and 'after ANT' can be found in the literature review and Methodology chapters.

charities affirm that there are many ways in which paediatric HIV is conceived or brings people to together<sup>6</sup>. The actors that linked these organisations together were followed into the clinic. Research stems from the conviction that no unified version of paediatric HIV exists which can encompass all of the situations and circumstances where paediatric HIV is referenced. ANT emphasises that objects are formed through the enactment of networks of human and non-human actors, and do not have meaning beyond the networks that they are enacted within. Therefore, objects do not have one version to be interpreted by a human agent, but many that depend upon the situation where the object is enacted (Law and Urry, 2004). From this perspective HIV is not one entity but many working over many networks of care and practice (in the sense of HIV as described in Rosengarten, 2009). There seemed to be many relations between childhood and HIV that brought these groups together, charities would often switch focus between children *with* HIV to children *affected by* HIV. PPC youth clubs would be organised with the aim of providing respite or reducing isolation and enriching children's quality of life. CWAC would educate school children about HIV and talk about stigma. The clinic would take on many roles in the care of children into adulthood. All the while, the relationship between HIV and childhood would shift. Ideas of stigma, deservedness, vulnerability, the route of infection or the relationship to HIV implies multiple avenues of potential analysis and the complexity of the condition. Similarly, terminology could be used such as vertically transmitted, or perinatally infected, or paediatric HIV, or children with HIV, all of which have their own context. Therefore, research is geared to be as receptive as possible to the definitions that the field itself would work with, and attempts to ensure that references to HIV in this thesis are context specific (this point will be discussed in relation to Latour, 2005 and methodology in chapter 3 on following actors). One such version of paediatric HIV in UK services comes from the Collaborative HIV Paediatric Study (CHIPS), which offers a collection of data on service provision given by all UK clinics caring for paediatric HIV.

At its most broad, the number of paediatric HIV cases reported to CHIPS is 1699 (by March 2011). This comprises virtually all children who have received care from UK services (CHIPS,

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<sup>6</sup> This way of looking at HIV can be linked to Bowker and Star's (2000) description of the multiple faceted categorisations of tuberculosis, over many national contexts and histories.

2010). The most common route of infection listed for this group is perinatally from mother to child, comprising 97% of those in the cohort<sup>7</sup>. Of all the possibilities available for defining HIV, CHIPS is responsible for giving the numbers for the paediatric cohort. When CHIPS is compared to the Survey of Prevalent HIV Infections Diagnosed (SOPHID) (which comprises CHIPS data alongside data from all UK HIV services) SOPHID doesn't make the distinction between age and infection route in its public dissemination of data, preferring to detail the whole paediatric group by age. In terms of defining HIV in light of ANT which describes objects as multiple, the thesis highlights the limitations of presenting this statistical reasoning as a definitive representation of all possible ways of representing paediatric HIV. The thesis attempts instead to argue how definitions of HIV must be negotiated. However, it does acknowledge the important function SOPHID performs for services that follow these data sets and allocate resources accordingly.

According to the 2011 Health Protection Agency report (which uses SOPHID and CHIPS data HPA, 2011), those under the age of 15 comprised only 1% of the overall HIV population receiving care in the UK in 2010. These statistics render paediatric HIV as a small part of the UK's total whilst requiring a specialised approach to care. Moreover, when presented statistically, populations with HIV seem stable. However, HIV is a global disease and the data reported in the UK does not reflect the movements of people and medicine received outside of the UK (Bancroft, 2001; Goulder et al., 2001). 79% of the cohort at UOUH are reported to be of Black African ethnicity. The presentation of this epidemiological category of HIV in the UK is particularly marked by the demographics of immigration in and out of the UK. It is beyond the scope of this thesis to elaborate on the complex reasons for the movement of individuals between national boundaries. However I do want to acknowledge that there are multiple histories, cultures and ethnicities of those defined as 'African'. HIV

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<sup>7</sup> A different picture emerges when looking at the numbers given to the National Study of HIV in Pregnancy (NSHPC) between 1986 and 2011, which quotes 2384 cases of paediatric HIV infection. 1972 of these infections were reported to be from mother to child, 267 were blood factor treatment, 61 blood tissue transfers and 81 others were undetermined. This reflects a very rapidly changing history (in terms of individual life) of HIV (NSHPC, 2011). Knowledge of paediatric HIV and was of treating it have changed throughout its history. CWAC's inception was formed at time early on when the condition was still emerging. However, the face of the disease has now altered again. In many respects it also shows how differences can be made between reporting system. Since 2000 the most influential data has been collected in CHIPS, which in many respects defines the area, and so we will uptake their definitions.



accompanies populations on these journeys, even if perinatal HIV is now defined as preventable, a unified treatment of these populations, medicines and histories beyond borders is not yet possible. From the point of view of how representative, standardisable and generalisable these populations can be rendered, there are obvious implications upon *what* the condition *is* and how it is *presented* in UK statistics (U.K. Select Committee, 2011). For a condition that requires a near perfect level of adherence to ensure that viral suppression is achieved, the fact that members of the population often have a disparate medical history and cultural background poses problems for the standardised administration of care (Futterman et al., 2000).

Each clinical negotiation regarding care has a high number of possible interpretations between patients and practitioners. This thesis explores how clinical practice is central to the process of formulating an antiretroviral medicine that can suppress the HIV virus over the largest number of the cohort presented to the hospital. Paediatric HIV requires a clinical approach so flexible that it is difficult to pre-empt definitively in guidelines the problems of uptake and development that children may present at the clinic. This renders the clinic at the centre of processes that inform, define and deploy the resulting HIV medicine and paediatric condition. The research chapters in this thesis offer insights into some of the clinic procedures in place to ensure, as much as possible, that medicine is unified, regimes are followed and what can be deemed as a normal life expectancy is made possible.

Representations of paediatric HIV in popular culture offer a range of capricious peculiarities, so much so that I feel uncomfortable offering broad statements. There is such a dispersal between representations that it is difficult to plot a course between stigmatised representations of HIV and 'medical fact' practiced in the clinic. In the UK, families with HIV feel the need to live their lives so discretely that representations of children with HIV rarely reflect the nature of living with the disease and as a result can be factually very muted and homogeneous (Dorrell et al., 2008). For example, when the stories of children with HIV are shown publicly they are nearly always left anonymous and when video is used the participants are blacked out (Body and Soul, 2011a, 2011b). In contrast, it is possible to find examples in the United States of stories about children with HIV who are not blacked out

(Belluck, 2010a). However, a general disparity can be seen between 'victim' children and more general HIV stigmatisation (Wilcox, 1996 is a prime example of a child with HIV being described as a 'victim'). Newspaper articles can also be found that seem to document the existence of an unwarranted, differentiated prejudice (Belluck, 2010b; Day, 2011). What is not often factored in is that in families, HIV is not isolated just to children. Parents who have acquired HIV through sexual transmission may feel responsible for transmission and this may contribute to the expression of the utmost discretion exercised by families and practitioners<sup>8</sup>. These kinds of discussions and problems are present in the clinic through the awareness of practitioners when carrying out practice (Steele 2007; Lewis et al. 1994). Similarly, other cultural representations of HIV have an influence on clinical practice. For example, care must be adapted around confidentiality. When educating children about their condition and how to treat it, practitioners must consider stigmatised ideas of HIV and how to shield children away from them.

As a result of the above considerations, paediatric HIV is a central 'actor' within the thesis. Compared to other terms, it is distinguished from cultural (and possibly stigmatising) references to HIV, or more general connotations of 'children with HIV'. Paediatric HIV is used in this thesis as the label that is presented and used by practitioners in literature, protocols and during practice as the formalised reference to the condition and corresponding medicine. Therefore, in this introduction it is important to present paediatric HIV as it is established through practice. Clinical practice must facilitate patient understandings of their condition and cultural representations, but also render them compatible with HIV care regimes. Paediatric HIV has its own unique and immediate specificities: stigma, confidentiality, immigration, sex/innocence all work together in dynamic ways. Children and adolescents have their own lives and networks to maintain, as do parents and families (Hekster and Melvin, 2006; Campbell et al., 2009 both offer examples of the 'social lives' of children with HIV). By placing ourselves in the 'shoes' of others it is possible to think about how HIV has the potential to alter the lives of all

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<sup>8</sup> Fassin (2008) discusses the idea of deservedness in relation to childhood and HIV, arguing that children are seen as victims and undeserving in comparison to adults who are blamed and seen as culpable for their infection.

members of society, from young to old, individuals to families in many ways. This thesis will ask readers to assess practice for the ways that it consolidates complex and 'messy' associations such as naivety, innocence, ethnicity, immigration, stigma, confidentiality and sex with drug requirements. The central argument of the thesis is that these associations that are often difficult to place alongside the suppression requirements set for antiretroviral drugs must be negotiated in the clinic between patients and professionals and rendered compatible. This process places the clinic not only as the site where complex requirements are organised, but means that clinical practice is centrally implicated in the generation of antiretroviral medicine. Policy, protocol, guidelines and pill regimes must be adapted in clinical interventions to become functional and those designing policy must bear in mind how their policy will be practiced in the clinic.

To demonstrate this argument, the practices of the UOUH clinical cohort have been selected and researched using arguments central to STS stressing the importance of following actors (Latour 2002). The specificities of UOUH's patient cohort are considered in detail, but what will also become highly visible, yet difficult to separate and not possible to isolate, are places where confronting HIV means following interactions with larger networks of HIV, medicines, dispersed localities, protocols and routines. I would like to invite a way of thinking about HIV medicine without scales, levels or hierarchies that become greater or more specific, but as a network that, when put into operation, references other networks (Latour, 2005). Methodologically it has been deemed important to allow actors 'infinite freedom and pliability' to inform what is important in the field (Latour's 2002). Scales or hierarchies around an object or entity do not exist in an already formed prior state, some form of agency must put them in motion and reference a change in scale. In the space of the clinic, procedures such as disclosure, adherence and transition emerge, they are referenced and maintained in negotiations between patients and practitioners. Alongside STS fits considerations of childhood taken from the Sociology of Childhood (SoC) and this literature has been used to 'unpack' childhood as a 'charged' object, especially in this context of sex, vulnerability and culpability (with the use of literature such as Kehily and Montgomery, 2008). However, as in Oswell (2012), analysis has taken care to highlight the antagonisms but not to 'police' the inaccuracies in imaginations of childhood.

## The Practice of the Clinic

The clinic that takes place in UOUH is part of the standard paediatric ward, it was held regularly once a week, but also attends to other patients than children infected with HIV. The clinic also screens new-born babies to mothers with HIV, to ensure that HIV is tested for and prevented antenatally. The clinic was also responsible for carrying out HIV tests on children or adolescents where HIV may be suspected for a certain reason such as a newly discovered HIV diagnosis in a family or dynamics around HIV and uncertainty caused by immigration. The clinic was run by a paediatric consultant, whom I will call Dr Peters, who was responsible for managing the clinic and individual case records. However, roles were also shared and distributed between one Clinical Nurse Specialist (CNS) for the clinic.

Children would usually come in once every three months. Their first task was to go to the front desk and check in, then the CNS would usually greet them and take their urine if needed and ask the appropriate questions about themselves since their last appointment. She would then make sure the file was given to Dr Peters in the consultation room, the patient would then be ready to be seen by the Doctor. If the patient was beginning adolescence, Dr Peters would see them in the consultation room on their own first to talk about their health and how they had been without their parents. Then the parents would come in and discuss previous blood test results and plans of action. The child/adolescent would then go for a new blood test with either Dr Peters or the CNS, before Dr Peters would fill in the *pro forma* and make some notes, the blood taken and urine would get a label and be sent off to the lab. Between all these steps, there is and was a lot of room for variation. Some of these steps could often occur at different times, they could overlap, discussions could take place whilst another step is being carried out, e.g. with parents whilst children were having a blood test. Nevertheless, this was the general structure that they aimed towards, as will be demonstrated later on. The consultation is designed to be technology heavy, with obvious technologies like blood test results, antiretroviral medicine explications, as well as underpinning procedures like adherence, disclosure and transition (Blume, 1992). These technologies are made to function together in clinical procedure, like in the designated information given before and after disclosure to support adherence, or enable independence and to pave the way for transition. Many tactics are employed and tested to

ensure effectiveness and re-negotiate care if needed (Dodier, 1998; White et al., 2012). The clinics would be held every week on the same day in the morning from 9 am to 12 pm with a less regular evening clinic from 4 pm to 6 pm. Over the year I attended the clinic, there was a general shift from most cases being seen in the morning clinic to the evening one. As a result, the evening clinic went from being once a month to twice a month and most of the children/adolescents booked into evening slots, and my observations followed the patients.

At less regular intervals, the clinic was coordinated in other ways. There would be a staff meeting where all the CNSs, the Pharmacologist, T1 (adult services) consultant (who will be called Dr Chambers), the CHH consultant (Dr Phelps) and Dr Peters would go through each case at the hospital. Dr Phelps would also sit in on clinics to regulate the service. These regular meetings were an essential part of how the clinic was organised<sup>9</sup>. Another essential practice, if more general, was the access given for SHO's and trainees to attend the clinic. On many occasions, I would sit next to individuals attending the clinic for the purpose of training or gaining experience. Those sitting in were from a variety of stages and professions within medicine, from medical students and trainee nurses, to SHO's and visiting practitioners. At a busy university hospital such as UOUH, education and training is never far from the practice of medicine (training even features highly in the classic clinical ethnographies of Becker, 1961; Atkinson, 1997). One interesting visitor who will be encountered later in the text under the pseudonym Dr Wellington, was the former head of the clinic now based back in her native New Zealand. She observed quite a few clinics towards the beginning of my fieldwork and took a lot of time to explain to me how paediatric HIV works (second only to Dr Peters's countless and detailed explanations to my questions). From all the professionals I observed at the clinic, I do not think that any of them ever stopped learning and developing in the field throughout their working lives (Peck, 2000 describes the obligation on practitioners to continually develop). This characteristic is complementary to the argument of the thesis that professional development is essential to making up a responsive and adaptable clinical practice. It ensures that services remain

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<sup>9</sup> Davies (2003), Allen and Pilnick (2005) and Currie et al. (2012) argue that there is a lack of studies in organisational studies that discuss the importance of how the clinic is organised. Clinical organisation is a consideration that is recurrent throughout this thesis.

relevant and informative to the patients they care for and that the clinic remains effective in reformulating medicine to the conditions presented in the consultation room.

## Layout of the Thesis

The following chapters of this thesis seek to show some of the procedures that have been used to make paediatric HIV operational through clinical practice. Contrary to the socio-psychological research around paediatric HIV, this project is not geared to assess what does and does not 'work' in practice. The question will not be framed in this way. Rather, the aim is to show how medicine, the condition, routines of care and viral suppression are made possible through practices occurring in the clinic. Therefore, instead of highlighting an isolated overview of cause in paediatric HIV, much of the research documented will be directed towards revealing how a range of effects and consequences are ordered into being and made operational (Latour, 2002). Over the process of a year, the clinical logic guiding care that became prominent to me comprised: firstly disclosure which brings children into knowledge about their HIV (blood-tests, attending the clinic, taking antiretrovirals etc. Michaud et al., 2009); secondly, adherence which is the attempt to make sure children follow antiretroviral regimes as close to 100% as possible (Gibb et al., 2003); thirdly chronic illness which is used when planning care now and into the future (Bernard, 2008); and fourthly, transition which concerns the management of care between paediatric and adult services (Viner, 1999). I assert that disclosure, adherence, chronic illness and transition are all used in the clinic as procedures designed to consolidate patient complexity with antiretroviral requirements and clinical regimes. I have ordered these procedures into four empirical chapters, corresponding as much as possible to the ways that these procedures are presented and discussed in the clinic and corresponding protocol and literature.

The four procedures are already four major areas of discussion in paediatric HIV and seen as responsible for the organisation of HIV care. Disclosure, adherence and transition all have their own guidelines in CHIVA and each have extensive and specific literature reviews (CHIVA, 2011a). As such they make their way in and out of clinical practice, they can be seen to be followed, ignored, or flagged up in order to make the medicine functional (White et al., 2012). The exception is chronic illness, as compared to the other procedures, it is not

the subject of a specific clinical guideline. However, practice and literature discussions are never far away from describing HIV as being managed as a chronic disease through the use of antiretrovirals, and as will be argued, usages of chronic illness are crucial to maintaining practice.

In retrospect, the resulting chapter list could have been different. Other foreseeable chapters could have been child protection, sexual health and public health. Indeed, the list could go on as could the ways that other onlookers could have organised the same incidences observed differently. However, it is hoped that those who are familiar with the condition or the medicine, as well as those new to this area, will be able to see some frequent and interesting themes develop from a reading of this thesis, as it demonstrates a clinical logic at work in the medicine that must necessarily be negotiated between both practitioners and patients.

## Chapter Outline

### 1 Literature Review

This chapter frames the project in three discussions found across the literature of STS and SoC. The first is on the 'turn to enaction' within Actor Network Theory (ANT), which is concerned with how objects are constituted and altered over their different enactions. This results in a position that questions the singularity of practice and clinical procedures in favour of viewing practice and procedures as multiple (Law, 2004a). Clinical practice and suppression are subsequently framed as not only 'enacted' and 'multiple', but also as made possible through consolidating the multiplicities found in the clinic into the task of making patients adhere. The second discussion highlights the ways in which public and scientific knowledge are consolidated together through the procedures taking place in the clinic. It argues that practice is necessarily negotiated between child patients, practitioners and protocol (Callon and Rabeharisoa, 2003; 2004). I assert that it is a necessary task of the clinic to maintain the science behind viral suppression by facilitating the uptake of antiretroviral medicine in to the lives of patients (see Pontali, 2005 on facilitating adherence). The third section discusses imaginations of childhood, naivety and agency in relation to clinical practice. Discussions in SoC literature alternate between describing

children in clinical situations as naive, innocent and acted upon on the one hand, and on the other that children necessarily contribute/participate to clinical negotiations concerning them and cannot be reduced from the clinical situation. Therefore, the section attempts to resolve some of these contradictions in order to consider how childhood, naivety and innocence are consolidated in clinical practice. Compared to the general trend of literature on paediatric HIV that centres upon a psychosocial approach (e.g. Battles and Wiener, 2002; Naar-King et al., 2006), this thesis strays from this trend by concurring with alternative literature that diverts the search for psychosocial 'causes' and focuses instead upon the emergence of practice through enaction disbanding a hierarchical model of protocol dictating practice (Mol 2002). Therefore, the chapter brings unique strands of theory and practice together to contribute to the STS and SoC discussions mentioned as well as more general literature around clinical practice and paediatric HIV.

## 2 Methodology

This chapter has been split into two main sections: the first describes the methodological approach of the thesis, the second comprises a section of specific methods around how the research was carried out. The first section on methodology builds up an approach to the study of paediatric HIV in regards to STS to discuss three principles relevant to this study. The principles discussed pertain to discussions of irreducibility, semiotics/materiality and the enaction of the social, before the section moves on to discuss how to follow actors through society, or in this case through the clinic (Latour, 2005). This is important to enable research to identify the ways in which diverse patient lives are consolidated with medical requirement, and protocols are adapted flexibly in clinical negotiations. The second section on research methods seeks to provide a guide to the practicalities of conducting research and 'following actors' in the clinic and the main decisions made in the process of collecting data to its analysis and dissemination.

## 3 Ethics

After the methodology and before the empirical chapters lies a supplement on ethics. It has been rendered as an intermediate chapter for two reasons: firstly, the field of paediatric HIV is heavily charged or imbued with ideas of ethics, morals, innocence and deservedness.



Hence it seemed important to discuss how this project would consider these positions. Secondly, the formal ethical procedure for carrying out research in the NHS was so extensive that it also became relevant to the thesis of this project. The ethics supplement considers the relationship between the formal ethics and the ethical stance of the research methodology to evaluate what is ethics and how to act ethically in this context.

## Empirical Chapters

### 4 Disclosure

The term 'disclosure' refers to a practice whereby child patients are given knowledge about their HIV. It usually takes place when children are deemed ready to be informed about their HIV. In the UK and consequently UOUH, the aim is to make children aware of their HIV diagnosis around the age of eleven or twelve (informed by policy of Committee on Pediatric AIDS, 1999a). There is not one sole reason for this but many unique to paediatric HIV: one is that at this age they can understand. Another is that at this age they can ask challenging questions that need well informed-answers. Another is that at this age, it is less likely that the child will tell anyone else about their status. A series of other issues can also be seen around the deliberation involved in *when* and *why* to tell children of their diagnosis as practitioners want children to understand the significance of the disease whilst protecting them from negative connotations around HIV (Mellins et al., 2002). Leading up to the act of disclosing HIV to children, contradictions, inconsistencies, biases and over/under emphasises may all alter the dynamics influencing how practitioners will proceed with disclosure. I argue that in the face the real danger posed through the mismanagement, disclosure is formalised as a procedure in the clinic in order to consolidate children into knowledge about HIV to patients and ensure that patients and practitioners have a shared knowledge about HIV. According to this perspective disclosure is emphasised as not just one act or a series of acts but a long and complex process of educating, re-educating, discussing, asking questions and making explanations that can be compared to the STS notion of translation (Callon 1986; Akrich et al. 2006). The patient, the family and the doctor all have their own role in this process of disclosing. It also has important implications about how HIV is constituted and care initiated. The analysis of this process found in UOUH and over higher scales of institutions and literature, focuses on these ways in which

disclosure is referenced and why it is used, providing an account of this very important step that attempts to incorporate children into medical reasoning.

## 5 Adherence

Adherence is a term that is used a lot in the clinic (see for example Gibb et al., 2003). It has come to take on a meaning that indicates the regular uptake of medicine, but the chapter will ask the question if there is more at work than this. Antiretrovirals need to be taken as close to 100% as possible to ensure that the virus is suppressed and that resistance to the medicine does not ensue. The question of adherence is more immediate in paediatric HIV because of the broad range of issues patients present in the clinic combined with the absolute requirement for to take drugs as advised. This means that it is crucial for practitioners to consider *how to make patients adhere*. I argue that adherence must be achieved through uniting patients, professionals and biomedicine together under the common goal of viral suppression that allows each party to have a better understanding of what is required of them in order to achieve viral suppression. It is important for patients because it involves ways in which they must moderate their behaviour in order to make it possible to take drugs regularly over long periods of time, it is important for biomedicine as it would not be possible to make the medicine functional without patients adhering to their medicine and it is useful to practitioners of HIV medicine as it allows them to make a link between antiretroviral medicine and their patients in order to deliver 'good care' (Mol, 2008). This means that the procedure of adherence takes on a number of capacities. It could be thought of as a form of surveillance, as a guide or as an enabling technology. This chapter focuses on the places where adherence is presented and attempts to highlight some of the tasks and possibilities that adherence is used to appropriate.

## 6 Paediatric HIV as chronic illness

The development of a range of antiretroviral drugs has made it possible for users to suppress HIV for an undefined length of time into the future. This means that in effect, HIV medicine must now plan to maintain HIV in a chronic state over a patients' entire life-span. For children born with HIV, the implications of this are massive and require a sense of attentiveness in clinical management (Bernard, 2008). Children must foreseeably live their

entire life-span according to the requirements of maintaining their HIV adequately. Even though it may be useful for practitioners, there is no way to provide an exhaustive list as to how this can be dealt with, contained or managed as each situation has HIV bearing upon it in a unique way. When abiding by chronic illness, patients and practitioners manage care with an eye on making sure it is possible to continue to suppress the virus into the future. I argue that chronic illness is used in the same way as a procedure to unify medicine, clinical practice and extraneous patient factors together allowing practitioners and patients to achieve a consolidated view of the medicine as a whole. Chronic illness allows patients to bear the everyday maintenance of their HIV and allow practitioners to imagine possible futures of the medicine and adapt reflexive policy (becoming an organising process of medicine White et al., 2012). This chapter explores encounters from the clinic and parts of CHIVA and medical literature where chronic HIV is being discussed, or where a future of dealing with HIV is being imagined. These incidences include thoughts of life with the disease, death, normal life and education on life with HIV and other general health conditions that blur the lines and at the same time become essential and unique aspects of managing HIV.

## 7 Transition

Transition in paediatric HIV occurs around the time when patients go from paediatric services to adult services. This usually takes place between the ages of sixteen to eighteen. Rather than the act being contained in this hand-over period, it goes much further into the care that patients receive (Wiener, Battles, et al., 2007). Paediatric HIV is particularly interesting because the clinic see it as imperative that patient complexities are tamed before patients are transitioned. From an early age, children are educated into a specific knowledge of their HIV, then encouraged to become increasingly independent and responsible for their own health, leading up to transition. Patients are then followed-up into adult services and eventually receive less and less attention from the paediatric department (Fair et al., 2011). I argue that transition is used to coordinate paediatric medicine and more general adult services. In doing so, it formally negates notions inherent to paediatric services of child vulnerability and lack of competence by asking patients to take on independence and responsibility for their own care. There are a range of guidelines

and literature to support these processes, all pointing to a notion of transition that is highly functional and crucial in paediatric HIV care, yet also ephemeral and not so easy to define. This chapter looks at how transition takes place in the clinic and ways in which literature and procedure are put into practice and the issues that it causes.

## Conclusions

The thesis concludes with a discussion of two themes that become increasingly evident through the course of my research. Firstly, in the face of patient complexity, these procedures begin to converge together to form a clinical logic that is employed to serve the purpose of formulating, consolidating and perpetuating paediatric HIV medicine. From this analysis of the very specific procedures found in the literature and clinic, none of them can be found to exist in isolation. They are highly implicated: it is not possible (or doesn't make sense) to engage with disclosure extensively as a precursory stage without adherence, considerations of chronic illness or the processes leading up to transition. Rather than being linked in one distinct relation or even a range of relation, practices are related together over many dynamics to unify practice. However, these links are not static. They are multiple, dynamic and constantly linked and re-linked together in the practice of maintaining paediatric HIV. Secondly, through the clinical attentiveness required in paediatric HIV care, the clinic can be seen as the site where patient complexities such as naivety, vulnerability and stigma are organised alongside medical requirements. This is done through the employment of the clinical procedures identified. However, the way in which they operate is to allow the practitioner to negotiate them flexibly with patients to ensure their effectiveness and their ability to remain applicable to the cohort. Consequently, it is asserted that the clinic plays a key role in consolidating complexity and making antiretroviral medicine functional through negotiation, displacing the notion that protocol dictates practice.

## 2 Literature Review

This chapter discusses Actor Network Theory as applied to Science and Technology Studies (STS), the Sociology of Childhood (SoC), Paediatric HIV and clinical practice. The chapter aims to frame paediatric HIV amongst relevant discussions within the field of STS, and to render valuable insights from clinical practice and the condition of paediatric HIV to debates around STS. Compared to existing studies of STS and SoC, paediatric HIV is particularly interesting because of the sensitivity required by the clinic to manage complex associations such as naivety, vulnerability and stigma into medical requirements. STS has been adapted to demonstrate how practice/guidelines are negotiated between practitioners and patients in ongoing clinical enactions, displacing a model of practice that maintains that protocol dictates clinical practice hierarchically. The resulting argument asserts that the clinic is a key site where patient complexity is consolidated with medical requirements. This thesis argues that a clinical logic is employed when carrying out practice and maintaining protocol that aims to make medicine compatible with patients' lives. The emphasis on a 'clinical logic' ensures the need for STS and SoC as the topic is relevant to the status of medical science and childhood amongst wider social relations. Therefore, the STS offered in this chapter discusses medicine, illness and clinical practice. The first section discusses the ANT approaches of 'ontology politics' or 'the turn to enaction'. The approach is concerned with how objects are constituted and altered in the course of their different enactions. The discussion of 'ontology politics' results in a position that questions how different versions of an object can be discussed and compared, and what it implies for practice. Clinical practice, HIV medicine and virus suppression are subsequently framed not only as 'enacted' but also as 'made possible' through enactions taking place in the clinic. This work is of major importance to the way in which paediatric HIV is approached in the research sections of this

thesis. The ANT concepts of enaction and multiplicity put forward in Mol (2002) and Mol and Law (2004) provide a basis throughout the thesis for thinking about medicine, HIV and childhood as emerging from enactions taking place in clinical practice. Therefore, they are outlined in detail in the first section of this literature review. The chapter then moves on to discuss STS in reference to the production of knowledge, patient participation in knowledge production and the concept of translation. In particular, the collaborative articles of Callon and Rabeharisoa (2002; 2003; 2004) investigate the formation of patient identities and highlight the consolidation of patient outlooks and attitudes into medical reasoning. Here Callon and Rabeharisoa's work is used to consider how practice necessarily contains a translation between the medical science and the requests of the culturally diverse families that attend the clinic. Subsequently, guidelines and protocol must be designed through clinical practice and re-appropriated within the clinic and so implicating the clinic as a key site in the formation of medical knowledge. The second section on SoC emphasises how children's agency can be discussed in relation to clinical practice. On the one hand children can be perceived in the clinic as naive, innocent and lacking agency, but on the other children's irreducible contribution to the negotiations in the clinic that they are a part of cannot be disregarded. Therefore, this section attempts to resolve some of these contradictions from the SoC literature as well as demonstrate how childhood considerations are formulated into HIV medical doctrines through practice in the paediatric clinic. This chapter will use debates in ANT around enaction, discussions of expert/lay knowledge, and debates in SoC around childhood agency to portray the clinic as a key site in consolidating and making functional disparate patient lives and antiretroviral medicine. In contrast to the literature discussed, paediatric HIV emphasises the cultural awareness required in the clinic to ensure that medicine remains applicable to the issues faced by the patient cohort. In so doing, the chapter also demonstrates how this project contributes to these wider fields of literature.

## Object Politics

A good example of 'ontology politics'<sup>10</sup> or the 'turn to enaction' can be seen through an article by Law (2004a) which reflects upon the development of STS and suggests three essential steps of the discipline. Law's first two steps are concepts that would now be considered conventional in STS. First of all he puts forward that science and scientific knowledge is demystified into being viewed as cultural. This means that science can be highlighted as culturally shaped rather than wholly objective. Law (2004a) asserts that this may seem banal today but was revelatory in the 70s when such science studies as Kuhn's (1970) *Scientific Revolutions* were being carried out. The second step put forward in the article is the need to analyse science as a process. According to this step, scientific knowledge is created and validated or superseded procedurally, which leads to speculation that the production of knowledge is contextual. For the third turn, Law (2004b) exemplifies a more contemporary topic in STS, 'the turn to enaction' and subsequently ontology and objects. This strand of STS argues that ontology and objects are enacted and re-enacted into being, replacing the notion that objects exist independently from our interactions with them, focusing instead on how objects are performed into being through one of many possible processes (Latour, 1987). These processes do not create objects that are fully defined, instead an object must be re-enacted according to the context of each successive reference to the object, and each successive enactment of the object alters it from previous enactments according to the associations it is related to. Therefore, according to Law (2004a), an individual object or ontology<sup>11</sup> multiplies through these processes and each successive enaction brings new possibilities for objects to adapt to ongoing situations. As a result, ontologies and objects are rendered multiple and not singular. The ANT stance of multiplicity and enaction forms a major methodological consideration in the thesis. The research chapters draw heavily upon literature, predominantly by Anne Marie Mol and John Law (around 1999 to 2004), detailing issues of multiplicity, enaction and health and so these

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<sup>10</sup> The term 'object politics' describes a particular ANT approach to objects that emphasises a view of objects, process and enactments multiple. It is an adaptation of the term ontological politics by Mol (1999). The term retrospectively positions Mol and Law in the history of after-ANT as the ontology politics literature comes from what could be defined as a middling period in the contemporary state of STS, after the book 'After ANT' by Law, which attempted to argue that an epistemological break with earlier versions of ANT had occurred, and consequently promoted a turn to enactment, not just towards science and technology but towards other more mundane objects (Law 2004b, p.8).

<sup>11</sup> STS also has its own version of ontology that imagines that each specific set of associations formed around an object forms its own distinct ontology that is altered between its different enactments (Law, 2004a). Therefore different ontologies also become multiple and potentially contradictory.

discussion are presented in the first section of this literature review. This section will evaluate the applicability of the 'turn to enaction' by relating some of the key studies of Mol and Law to a discussion of how medicine, guidelines and viral suppression must all be enacted in the paediatric HIV clinic.

Following Foucault's (2003) *Birth of the Clinic* which places the clinic as a key site for the production of medical knowledge, the 'turn to enaction' has significant implications for clinical practice and paediatric HIV (Latimer et al., 2006). The principle that there is not one absolute version of paediatric HIV but many that each depend on the time and place where they are enacted, implies that the condition enacted in the consultation room and in guidelines is done so alongside a larger network of intervening objects. For paediatric HIV this is significant because many objects have the potential to alter how the condition is viewed and, correspondingly, must be acted upon in the clinic. For example child naivety, immigration and confidentiality all have implications about how the disease and treatment must be discussed and how drugs must be administered (Green and Smith, 2004; NAM, 2010a). For Law (2004b), it is through these enactments that objects and ontologies gain their shape whilst constantly being adapted to successive enactments.

Through engaging in 'object politics', the study of clinical practice in paediatric HIV medicine becomes the task of tracing the enactments of objects or ontologies that occur in the clinic and enact the condition. The view of objects as multiple and dependent upon enaction is drawn upon heavily throughout the research chapters of this thesis to describe paediatric HIV to emphasise the many complex mediating tasks that must be carried out in practice to ensure that antiretroviral therapy is successful. This stance is in contrast to the discussion most often found in existing literature around paediatric HIV and clinical practice that delineates aspects of practice as de-contextualised from their enactment, documenting instead distinct spheres of knowledge and action such as the 'social', the 'condition', the 'science' and the 'medicine' (Lewis et al., 1994; Melvin and Sherr, 1995; Battles and Wiener, 2002; Gibb, 2003; e.g. Green and Smith, 2004; Steele, 2007; Mahajan et al., 2008). Ontology politics implies that aspects of clinical practice such as HIV, medical science and social issues are necessarily enacted at the same time in the clinic and not isolatable from each other.



This point is also resonant compared to other predominant sociological positions of 'biomedical power' applied to clinical practice. It displaces the notion of power or biomedical power as unidirectional or singular, and exemplifies the work of Foucault as informing analysis (and ANT) of the clinic as a key site of knowledge production but modifying the relations implied around power/knowledge (see Foucault, 2003, 1988 for a notion of all pervasive clinical power; or Rose, 2006). According to the 'turn to enaction' power is dispersed and enacted multiply and contradictorily over and between different enactions, and power can be enacted multi-directionally between patients and professionals (Munro, 2009). This rejects a model of medicine as hierarchical where protocol dictates practice.

A seminal study that uses the basis of the turn to enactment and ontology politics to analyse medical practice<sup>12</sup> is Mol's (2002) book *The Body Multiple*. Mol's study and its evocations of multiplicity and enaction in a clinical environment are crucial to the presentation of the clinic, childhood and HIV found in the research sections of the thesis. Her work describes how atherosclerosis is performed (or enacted) over different sites of one single hospital. Mol (2002) demonstrates that in different wings of the hospital, such as haematology and surgery, there are different ways of enacting the same object: for example the blood of the patient is enacted differently across different departments. Haematology looks at the blood as a medical sample, using a microscope plate or a routine test. In contrast, surgery sees blood as something that must be kept in the body and must continue to flow throughout an operation. The ways in which the blood is enacted across these departments presents differences, yet the two sites are linked and combined into the larger term of atherosclerosis. Mol (2002) gives an example of the enactment of blood and demonstrates how it is not the same over different sites of the hospital. Each enaction of the object creates a difference, rendering the object multiple. Over different sites and in different situations, objects that would appear to be the same, such as blood and atherosclerosis, in strict comparison actually contain differences. Therefore, according to this line of reasoning each enaction of an object necessarily re-enacts parts of a previous enaction whilst aligning

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<sup>12</sup> The focus of practice is different to the one referred to in this thesis as it offers a more general notion of 'medical practice' rather than 'clinical practice'. This point is discussed further below.

the object with an alternative set of associations presented in ongoing encounters in the hospital.

Mol's (2002) focus on a general notion of 'medical practice' as opposed to 'clinical practice' as described, highlights that practices that take place across HIV medicine are never contained in the space of the clinic but are connected during each enactment to networks over different hospital departments. For example, the blood of children is also something that during clinical practice is enacted over more than one hospital department. Blood tests that take place in the clinic are sent away and tested in the laboratory and the results are enacted again to the parents and child. This requires a complex chain of enactions which range from the clinic, to the laboratory and back to the clinic<sup>13</sup>. The concept of enaction is crucial to the descriptions of paediatric HIV found in later research chapters. However, this thesis adopts the concept of enactment in clinical practice more loosely than Mol (2002) to argue that protocol, guidelines (CHIVA, 2011a), policy such as hospital safeguards or child protection and the influences of other institutions such as CHIVA must all be enacted in the clinic (also see dynamics of protocol and decision making as described in Berg, 1997a, 1997b; Timmermans and Berg, 1997, 2003). This means that the medicine is reliant upon how it is practiced in clinic, warranting a description of clinical practice as specifically important to the formulation of the medicine above the generalised notion of medical practice found in Mol (2002).

In comparison to the arthrosclerosis described in Mol (2002), paediatric HIV emphasises this point around the importance of clinical practice further. For example, important associations of Paediatric HIV not present in arthrosclerosis are the vulnerability of children, ethnic diversity and the high public profile of HIV (Melvin and Sherr, 1995; Hekster and Melvin, 2006). During the clinical practice of paediatric HIV these associations are present in the consultation room, which means that the practice of medicine must be highly contingent on them. Policy and practice must ensure that the practice of HIV medicine does not have negative ramifications for patients. For example if handled by the clinic in the

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<sup>13</sup> The procedure for taking blood has its own set of guidelines see Nutbeam and Daniels (2010) demonstrating how different forms of childhood are also enacted between the clinic and the laboratory.

wrong way, if medicine is administered out of tune with patient lifestyles, if confidentiality is breached, or if the school asks questions about the child's health (Maile, 2005; Melvin et al., 2007; Cummings, 2008; Korbin and Zahorik, 1985).

As a result, it becomes important to document paediatric HIV practice to account not only for recurring enactments over different sites of the hospital, but also the implications of a policy, practice and private life that have a highly complex and dynamic range of consequences which overlap to have profound implications for patients and professionals if enacted without sensitivity and caution (Misztal, 2011). Paediatric HIV practice has to maintain a view of how patients will be able to minimise the effects of stigma as they develop and also much policy holds the clinic accountable for doing so (Munro, 2006; Beckett, 2007). Together these aspects separate paediatric HIV from other diseases such as atherosclerosis and demonstrate how the paediatric HIV clinic must make sensitive, contextual discussions impossible to pre-empt in guidelines. For example disclosure plans to bring patients into knowledge of their condition and how to care for it in a way that is compatible with their eventual transition out of paediatrics. As an enactment this happens both momentarily in the clinic and also over 4 years of adolescent development. In this time, guidelines must be interpreted repetitively whilst children and adolescents present many outside challenges to clinical practice (Atkins et al., 2010). Guidelines in this instance must be made compatible in the face of diverse situations. This is done through the maintenance of a constant dialogue between the clinic and the patient, and the clinic and the guideline, implicating the clinic as a key formulator of the procedures (such as disclosure, adherence and transition) that make their way into guidelines. Guidelines must be designed with flexibility in order for them to be applicable to the clinic and if guidelines do not fit practice they must be changed.

A related set of articles discuss how objects can be fluid and adapted to diverse settings. Law and Mol (2001) and correspondingly Law and Singleton (2005) have carried out further demonstrations of how objects are enacted and re-enacted in different locations that modify the types of conceptualisations found in Mol's (2002) project. An article by Law and Mol (2001) discusses developments of STS alongside Mol's (de Laet and Mol, 2000) previous

work and classifies her approach in terms of exemplifying objects as 'fluid'. Describing objects as fluid allows analysis to conceptualise them as highly dynamic as they move over different sites and are re-enacted each time they move in order to become operational. Conceptualising objects as 'fluid' implies remnants of the object can be found over its different enactions. Therefore, the concept of 'fluid objects' offers distinct possibilities for the analysis of certain aspects of the practice associated with paediatric HIV. If procedures used in Paediatric HIV clinical practice such as disclosure, adherence and transition move as 'fluid objects', the gap between the clinic and the behaviours and lifestyles of patients can be described as flowing amid individual patients and practitioners in the practice of the clinic (distinct from the psychosocial approaches detailed above). This provides the advantage of incorporating aspects outside of the clinic into practice in the clinic over extended periods of time. However, as will be seen in this chapter, it does not account for ways in which care may not translate itself outside of the clinic.

In accordance with outside challenges to enactions in the clinic, Law and Mol (2001) add to the idea of fluid objects. They argue that objects are not only defined by the entities that they are enacted with, but are also defined by what they are not, or what they must avoid happening. These are referred to by Law and Mol (2001) as 'fire objects'. They give the example of Cold War jets which were designed to perform in the possibility of nuclear war and so could take off from short runways in the event of it being destroyed, as well as being able to go fast enough to avoid Soviet anti-aircraft missiles. The example demonstrates how an object (the plane) moves through space and keeps its shape (i.e. not being destroyed) through a relation between presence and absence. I.e. the concept that an object is designed not through what will be present in normal usage but the absent influences that form the potential for things to go wrong (i.e. against what could destroy the aircraft). In relation to the practice of paediatric HIV it could be posed that adherence, transition and disclosure are objects designed by the clinic to remain active against the outside threats to the continued enaction of viral suppression brought into the clinic. For example, with adherence, one of the fire aspects that could be highlighted are the concerns caused by the stigma of taking antiretrovirals in front of strangers, or the difficulty for the average child to swallow certain pills leading to the design of the drug to be easier for children to take and

adhere to (Haberer and Mellins, 2009; CHIVA, 2011b). It places the incentive on clinical practice to maintain a logic which ensures that children are willing to take the medicine and are recorded and encouraged to do so in the clinic. However, this still brings in to question how the object of adherence travels outside of the clinic, or if children ever interpret their own behaviour in terms of adherence<sup>14</sup>.

The conception of 'fire' objects is interesting to highlight because it demonstrates just how far this 'object/ontological politics' goes and further warrants the naming and delineating of 'object politics' as a particular and historical part of ANT. It illustrates that the logical conclusion to 'object/ontology politics' is irresolvable multiplicity. This raises the concern that the further an object is analysed the more it will endlessly continue to reference other actors. Irresolvable multiplicity is an interesting point to highlight here as it demonstrates a trope that the analysis contained in this project does not want to fall into. For example, if the clinic is viewed in this way, it becomes swamped in an endlessly multiple web of associations. Instead, I wish to argue that the clinic makes emergent regimes of care and versions of paediatric HIV that consolidate complexity and make HIV medicine and viral suppression possible amongst the patient cohort. This emphasises the significance of the clinic in formulating medicine especially when considering how entangled HIV medicine is with wider 'social' issues (Melvin and Sherr, 1995; Hekster and Melvin, 2006). More generally, in ANT the conceptualisation of 'fire' objects has not been taken forwards by Mol or Law. Law (2004b) has discussed similar ideas by dropping the term of 'fire objects' in favour of a concept of absence and enactment that is less burdened with specific terminology. Accordingly, further reference to these ideas in this chapter or the thesis will favour the conception of 'absence' in enactment.

Mol and Law have used their focus on ontological politics more broadly to talk about health and illness. Two articles written and revised over the same time period (Law and Singleton, 2003; Mol and Law, 2004) are committed to employing ways to explore the movement of

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<sup>14</sup> Froerer (2011) discusses how childhood understandings of illness can alter between cultures. Using ethnographic research from an Indian rural village, Froerer demonstrates 'non-western' childhoods often left obscured in childhood studies. Considerations of non-western culture, illness and childhood are relevant to paediatric HIV, as the majority of patients are from Sub-Saharan Africa.

objects and the constitution of specific diseases (however, they do not specifically reference conceptions of fluids or fire, which suggests a lack of commitment to the conception of fluid and fire objects in favour of other descriptive methods to be discussed in more detail in the following section). These articles offer further reflections on how to imagine the enaction of disease which is also drawn upon heavily in the description of paediatric HIV found in research chapters. Mol and Law's (2004) study on hypoglycaemia, is concerned with tracing how the condition is not constituted as a solid object within the body but how it is enacted through the places and situations where the body is performed. They detail the ways in which the body not only carries the disease on the inside but also enacts it on the outside. Firstly, hypoglycaemia is enacted through a patient's knowledge of it. Secondly, bodies enact the disease through constantly counteracting the disease. Thirdly, bodies are not in isolation: in everyday life the diseased body acts on, and is acted on by other objects. What is inside the body becomes visible and active outside of the body in these processes. Fourthly, the body is never fully coherent with each of its enactments and must constantly re-enact itself through these different strands or it will perish (also see Prout, 1996; Prout et al., 1999 in relation to childhood asthma and ANT). The study by Mol and Law (2004) explores hypoglycaemia through highlighting commonly overlooked processes around maintaining the disease to demonstrate how it is part of a complex dynamic beyond one simplified version of the disease.

“Medicine should come to recognize that what it has to offer is not a knowledge of isolated bodies, but a range of diagnostic and therapeutic interventions into lived bodies, and thus into people's daily lives. Even the pathological gaze is not merely a gaze, but involves manipulation. Medicine's activities always concern both what is beneath and what is beyond the skin. But if all medical operations, even if they simply seem to address bodies, are interventions in lives, then they should be appreciated accordingly.” (Mol and Law, 2004, p58)

These notions of disease as being beyond the skin hold a major implication for the description of paediatric HIV. Paediatric HIV is a condition where the stigma and vulnerability felt by patients is beyond the clinic and must be dealt with in the space of the

clinic, and so this is a point that will be revisited throughout research chapters. However, as with atherosclerosis demonstrated earlier, the concept of enaction occurring on the inside, outside and beyond the body has limited compatibility to paediatric HIV. Rather it would be more accurate to imagine that enactions taking place both inside and outside of the clinic are designed to conceal the condition. Issues of discretion make their way into the clinic and are clinically ordained, whilst pill taking procedures performed in the house of patients is done so in the utmost discretion (Campbell et al., 2009, 2010). The contribution that paediatric HIV offers this literature over examples such as hypoglycaemia is that compared to these descriptions of illness that offers a serene ordering of objects and enactions, locating paediatric HIV, even when presented in clinical practices, is not as easy to define, classify and separate. This means that the necessity for the clinic to formulate medicine around patients and interpret guidelines and drug requirements flexibly is a more obvious issue than in hypoglycaemia.

This is also the case with another study by Law and Singleton (2003)<sup>15</sup> which explores a different illness, alcoholic liver disease (ALD). The article attempts to render the object ALD to analysis through following disease 'trajectories' through an out-patient clinic. Law and Singleton (2003) describe how the process of making a map strips detail from the object that is being represented by attempting to render reality comprehensive and stable. They go on to argue that it is impossible that an object can ever be understood as fully representative. They also demonstrate the multitude of trajectories and differences of interpretation in each representation of an object and the inferences that can come to bear on an object. In the last section of the article, Mol and Singleton (2003) argue how the site of the out-clinic is an allegory for alcoholic patients and the kinds of objects that move through there by analysing how the out-clinic creates trajectories and boundaries. This relates to clinical practice. In this instance the clinic is perceived as a place where trajectories of patients and medicine could be seen to move through practice. This article emphasises how trajectories link to complexities. The notion of complexity or multiplicity and the requirement for the clinic to create clear trajectories is an important basis for the description of paediatric HIV found in research chapters. Objects such as childhood and HIV

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<sup>15</sup> And to a lesser extent a relating supplementary study: (Law and Singleton, 2000).

are chaotic from the point of view of practitioners of health care services, and a major theme of the thesis is how these incompatibilities must be successfully ordered into practice. The research chapters of this thesis attempt to describe how complexities around paediatric HIV are organised through the enaction of procedures such as disclosure, adherence and transition. What becomes more pressing when analysing paediatric HIV however, is not the passing of objects through the clinic, but the cultural awareness required at the site of the clinic to consolidate patient complexities and requirements into a coherent, functional medical regime (see discussion of Gibb et al., 2003 in chapter 6). It is a limitation not overlooked by the authors when demonstrating their notes:

“[They are telling us that] our metaphor of mapping is too simple. I feel we should have seen this. We will need multiple maps, with multiple points of entry. Then we will have the job of seeing how these multiple maps partially connect with one another. Perhaps the metaphor of a map is a bad one?”

(Law and Singleton, 2003 p236)

Clinical objects such as adherence, disclosure and transition emerge from practice and are made necessary according to the negotiation between the issues that patients present to the clinic and drug requirements. This has the potential to contradict the advice of HIV care regimes, which means that patient movements are not linear but contingent. Good examples of this are the role of disclosure in the face of child naivety to identify cultural representations of HIV as unhelpful to care, or transition planning to anticipate the allure of sexuality and peer pressure before patients are handed over to adult services. All of these aspects must be negotiated and made compatible during clinic practice in order for it to succeed.

Where the study on hypoglycaemia (Mol and Law, 2004) adds complexity to the condition, the other study on ALD seeks to trace linear trajectories through the complexities of the out-clinic (Law and Singleton, 2003). Both approaches highlight different aspects of the interpretation of analysing heterogeneous objects and the conceptualisation of illness. The considerations of disease being inside and outside of the body and the idea of patient



trajectories running through the clinic form the basis of several lines of enquiry found throughout the dissemination of research in this thesis. For example they are used to imagine HIV stigma, childhood vulnerability, its existence beyond the clinic and how complexities can be followed through clinical practice. However, by focussing so heavily on objects and ontologies the negotiation that takes place making these ontologies and objects possible is often overlooked. These articles have their roots in debates around disease and its relation to the body rather than practice (good accounts of the relation between the body and illness can be found in Turner, 1992; Lupton, 2003). Therefore, what is offered in this account in relation to these studies is a more acute focus on the role of the clinic to consolidate complexity and medical requirement rather than following associations through their multiple enactions beyond the clinic.

In contrast to the psycho-social study of paediatric HIV (Battles and Wiener, 2002; Gibb et al., 2003 Green and Smith, 2004), Mol and Law (2004), Law and Singleton (2003) offer a mode of analysis that goes beyond a 'matter of fact' view of the body containing the virus or clinical intervention being either psychological, sociology, clinical or scientific. These STS authors provide an analysis that describes the child, the condition, and interventions as simultaneously enacted together, which has greatly contributed to the approach to paediatric HIV in this thesis. However, while Mol, Law and Singleton emphasise complexity and contradictions between categories, their own accounts are contrarily precise, ordered and lacking in patient/practitioner/protocol negotiation when compared to the complexity generated in accounts of paediatric HIV. Spheres of knowledge, practice, lifestyle, ethnicity, representation and stigma within paediatric HIV are often not possible to differentiate in practice. What is emphasised in this thesis is the clinic's key role to consolidate patient complexity and drug requirements into functional medicine. In paediatric HIV cases, the operation of clinical practice relies precisely on the fact that medical requirements are made flexible enough to span and make compatible many spheres of knowledge, practice, lifestyle, representations, stigma etc.

As stated before, the focus of this thesis is on the role of clinical practice in the formulation of HIV medicine and treatment. The work of Mol and Law plus others who identify with ANT

is important for demonstrating how objects are presented and practiced in the clinic over many enactions of HIV, childhood, blood tests and antiretroviral medicines. By discussing 'the turn to enaction', a number of advances in epistemology become apparent. For example that practice must constantly re-enact aspects of care and the condition that occur repetitively. For example different versions of childhood, or clinical and laboratorial medicine and drug recommendations must all be re-enacted. Each aspect of clinical practice does not occur prior to the situation that it is enacted within, and therefore must be re-enacted each time it is used (White et al., 2012). As noted above, this has many implications for practice and power over explanations of the 'social' in clinical practice found in literature such as the psychosocial (Battles and Wiener, 2002; Green and Smith, 2004; Steele, 2007), or sociological literature tracing biomedical power (Rose, 2006; Foucault, 2010). Therefore, as argued, a model of care as hierarchical where protocol dictates practice becomes untenable as protocol must be constantly enacted, and adapted, in the clinic. These articles are referenced heavily in the research chapters as they open up lines of enquiry around the condition that highlights paediatric HIV practice as an endeavour to organise the multiplicity presented during recurrent clinical enactions. However, many questions and considerations still remain around the ways in which this literature can be applied to paediatric HIV and clinical practice. Compared to the discussion of practice and disease offered by the texts discussed above, paediatric HIV requires a clinical practice that requires sensitivity and flexibility in order to span the divides presented by patients and medical requirements. Therefore, beyond the endless multiplicity generated through engaging in 'object/ontology politics' the thesis wishes to assert how the clinic must be arranged to consolidate medical requirements with complex patient dispositions. It follows that the discussion of the empirical chapters on disclosure, transition and adherence will contribute to this literature by offering a discussion of how enactions taking place in the clinic that consolidate disparate situations into a coherent medicine and make suppression possible.

## Patient Negotiations

The next section turns to scientific knowledge, patient participation and the discussion of three articles by Callon and Rabeharisoa (2002; 2003, 2004) that were written around the same time as the articles in the previous section<sup>16</sup>. The main articles chosen for this section have direct relevance to clinical practice as they demonstrate how care is administered in protocol and practice through the negotiations that take place between patients and practitioners in the clinic. The study will examine clinical practice as a series of processes engaged in enacting and re-enacting, but also as processes of translation where patients as well as practitioners negotiate care. These negotiations decide what is relevant in the medicine and how to apply protocol, guidelines, treatments and resources. Whereas in the articles by Mol and Law (e.g. Mol, 2002; Mol and Law, 2004) the discussion led to focusing on the enactment of specific objects and ontologies in clinical practice, Callon and Rabeharisoa on the other hand can be used to trace how clinical practice and the medicine that is practiced is participatory between patients and practitioners and wider networks of policy, protocol and patient cultures. The focus of Callon and Rabeharisoa is diverted from enactment of distinct ontologies towards emphasising negotiation and translation between actors.

Within STS the relation between scientific knowledge and public participation forms a central debate of the discipline. I will briefly contextualise these debates before moving onto the work of Callon and co-authors. One important preoccupation is that a misconception prevails between the practice of science and the general public. Firstly, that there exists two distinct spheres between medical knowledge and patient/ lay knowledge; and secondly that it is possible to separate objects and tasks definitively between the two spheres (Williams and Popay, 1994; Alderson and Montgomery, 1996)<sup>17</sup>. The stance of ANT would contrast against this style of reasoning by emphasising that the position of participants in scientific knowledge is dependent upon the assemblage of actors enacted

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<sup>16</sup> Michael Callon is a cofounder of ANT, but I argue that there are large differences between the type of ANT that he advocates and the one that can be found in the work already presented in this chapter, these differences have implications for how clinical practice can be conceptualised as enacted and by whom.

<sup>17</sup> Williams and Popay (1994) offer a prime example of reasoning from the position of using differing spheres to account for public and scientific knowledge. This could be confused further by considering a sphere separately for the knowledge of childhood as suggested in Alderson and Montgomery (1996).

around a scientific debate. This means that ANT abandons the centrality of the scientific sphere in favour of a more contextualised notion of scientific knowledge as individual assemblages (Latour, 1987). This is significant for clinical practice as the debate informs how child patients and practitioners negotiate the necessary scientific knowledge required for suppression of HIV with antiretroviral medicine. A large amount of literature already exists on this subject which will only be briefly discussed here. This discussion includes how scientific knowledge is entangled within many other forms of knowledge, and how knowledge that is generated outside of scientific method becomes included within scientific enquiries (Irwin and Wynne, 1996).

Wynne's (1996) study of risk and the environment is one notable study that developed the argument for an understanding of scientific knowledge as having a cultural/hermeneutic character. The study examines the way in which discourses concerning the environment and the risks associated with it almost exclusively verify each claim through linking it to something seemingly scientific or the opinion of an 'expert' (see also Wynne, 1988; Irwin and Wynne, 1996). Like other projects written during or before this period, Wynne wanted to alter the ways in which science is used and conceptualised in order to emphasise its construction through cultural processes (see Law, 2004a). Later literature extends this cultural consideration towards a model of knowledge that emphasises the procedural aspect of the generation of scientific knowledge, rather than there being a pre-existing category of scientific knowledge. Irwin and Michael (2003) produce a model of scientific knowledge that conceptualises scientific issues as 'ethno-epistemic assemblages'. Their model sees the social world as made up of artefacts that move freely across different spectrums of knowledge, from public knowledge to scientific and medical knowledge. Rather than any one form of knowledge sending out intermediaries to take over another form of knowledge, they have boundary areas that allow artefacts to be exchanged between the two without any loss of identity. Irwin and Michael (2003) look at places where the boundaries between public knowledge and science overlap. They emphasise that pure scientific knowledge is impossible to achieve because it must always be in reference to something else, and so advocate tracing how knowledge must be presented as a 'scientific' issue rather than searching for places where public knowledge and science meet.

Although the main focus of the studies discussed above is scientific knowledge, it has large implications for clinical practice. Aside from patient groups, the model of Irwin and Michael (2003) would imply that when patients are in clinical consultations, they are engaging with a form of medical scientific knowledge and that the treatment of HIV is made possible through a patients' engagement in the medical knowledge ordained by practitioners. Rather than clinical practice imposing protocol or biomedical knowledge upon patients (as set in motion by Canguilhem, 1991 and; Foucault, 2010), patients engage in boundary areas and have the potential to participate in the enaction of medical knowledge and the application of protocol (also see Dodier, 1998; Latimer et al., 2006; Timmermans S and Buchbinder M, 2010, 2012). This has a double implication when considering child patients because there exists an additional debate around their capability to make clinical decisions, or their naivety when talking about death or sex (Bluebond-Langner and Nordquest Schwallie, 2008; Kehily and Montgomery, 2008; Bluebond-Langner et al., 2010). However, by applying the same logic it is asserted that children and adolescents presented at the clinic must also be negotiated when engaging in clinical practice (Christensen, 2004; and Prout, 2005).

This thesis will not present power in the same way as discussed in studies such as Foucault (2010) or Canguilhem (1991). The thesis does not describe the interactions going on in the clinic between child patients and practitioners principally as an issue of power. Descriptions of power as central to clinical relations are circumvented in this thesis and power is alternately framed as being multiple and diffused contradictorily through-out the clinic. Agency is recognised as being able to be mutually exerted in both directions from practitioners to child patients and from child patients to practitioners. Therefore, the notion of power is avoided in favour of a conceptualisation of clinical relations as enacted through the continuous negotiation of agency rather than a one-directional imposition of power. The focus on enaction also avoids a conception of power as existent beyond the specific enactions taking place in the clinic, in each successive enaction patients and practitioners must renegotiate how medicine will be practiced. In research chapters,

references to power are minimised due to the commitment of conceptualising practice as enacted.

Callon's own contribution to debates around the distribution of scientific authority could be linked to the concept of translation (Callon, 1986). In its original presentation, when applied to the example of the *Fishermen of St Brieuc Bay*, Callon poses that each time scientific knowledge is practiced it is not simply applied but must be translated between relevant actors, simply put, that knowledge must be rendered comprehensible and compatible over the groups of actors that will use the knowledge. According to Callon, translation develops through four stages: *problematization*, where a problem is identified and made distinct, *interessement*, the process of interest and accepting of the problem between actors, *enrolment*, where the group delegates roles, and the *mobilization of allies*, the process of mass adoption or rejection. The power of the concept of translation is that knowledge is highly contingent upon the negotiation of actors present in the translation. The adaptability of the concept of translation means that it can be used to describe public participation with science as well as the wider transfer of public knowledge. Indeed in French academia the term 'sociology of translation' is more commonly used than ANT (Akrich et al., 2006). Therefore, using the concept of translation could describe clinical procedures such as adherence or transition as translations of protocol between patients and practitioners required by the scientific knowledge of antiretroviral medicine to ensure the ongoing possibility of viral suppression. However, this is not to say that the application of the concept of translation will always be so clearly formulated with one particular mode of employment. Protocols of adherence, disclosure and transition would not simply be translating medical knowledge but also contain a much more complicated dispersion of connotations about ethnicity, childhood, secrecy and stigma (Futterman et al., 2000).

Callon and Rabeharisoa (2003; 2004; 2002) demonstrate a more subtle use of the concept of translation to argue that patient groups<sup>18</sup> form a platform where patients can exert pressure

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<sup>18</sup> In the original articles by Callon and Rabeharisoa (2002, 2003, 2004) they use the term 'patient associations', this term has been substituted here to 'patient groups'. This is to avoid confusion as throughout the thesis I refer to the term 'association' mainly inspired by its defined in STS analysis such as Latour (2005). The term 'association' is used in STS to describe the relationship between actors.

onto medical knowledge. They argue that clinical practice must refer to the considerations of patient groups when being 'translated', and that the agendas of patient groups have a direct influence upon scientific agendas and the clinical practice of medicine. For HIV, many patient groups exist with varying functions and levels of influence, like for example UKCAB, iBase, Microbicides Working Group, Terrence Higgins Trust or AIDS MAP<sup>19</sup>. A smaller amount exists solely for children, a few London-based examples are Body and Soul, Positive Parenting and Children (PPC)<sup>20</sup> and CHIVA, whilst some larger HIV organisations are also involved with issues around children and families like NAM. The group that will be taken forward as an example for the remainder of this section is CHIVA. As a group, CHIVA is not strictly a patient group but started out as a professional group designed to set policy and practice guidelines and protocol. However, the role of the organisation has broadened to include contributions from a young person's advisory board and make recommendations to families and children (CHIVA, 2012b). Therefore, CHIVA operates over many levels of public and scientific channels. I have chosen to focus upon its functioning in this section and the ensuing thesis because it also plays an indistinguishable role in laying down clinical guidelines for practice.

Rabeharisoa and Callon (2002) support the idea that patient groups have a participatory relationship in the scientific knowledge of their condition. Their article (2002) draws on research conducted on French patients' organisations and suggests that patient groups make up major contributions to the study of medical science. The article highlights that patient groups in France provided substantial funds to the research of many conditions such as Creutzfeldt-Jakob disease, ataxia, haemochromatosis, Alzheimer's, cystic fibrosis, lysosomal disease, cancer, autism and AIDS. Rabeharisoa and Callon (2002) argue that through paying for research, patient groups shape the medical science around the disease by setting the research agenda and paying for the research they want to be done and which they surmise is worthwhile. These arguments highlight that patient groups are responsible for informing the research agenda and what is known in medical science on a particular disease (Epstein, 1998). This corresponds to the role that CHIVA and other patient groups

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<sup>19</sup> UK based charities that offer support to those infected with HIV/AIDS.

<sup>20</sup> Body and Soul and PPC are London based charities that are organised around children with HIV.

have in shaping paediatric HIV. However, the process that CHIVA plays in informing medical science is embroiled in the way that the condition is encountered in the clinic. For example, in the face of high levels of African immigration, HIV being a high-profile issue and heavily stigmatised, one implication is that clinical practice and corresponding CHIVA policy tends to focus heavily on the issues of confidentiality and the privacy of families rather than arguments common in other groups around visibility and engagement (Boulton, *forthcoming*; Parker and Aggleton, 2003). Within CHIVA, guidelines are negotiated in practice to ensure that children are protected from the negative stigma of HIV. For example, CHIVA guidelines on disclosure are geared towards educating children on HIV, the inaccuracies common in the public sphere and the importance that they should not tell anyone else about their HIV (Committee on Pediatric AIDS, 1999b; Wiener, Mellins, et al., 2007; CHIVA, 2011c). The effect of patient/practitioner negotiations has made its way into the guidelines and the administration of care through the concern of patients and their families in the clinic, forcing practitioners to engage in the task of repetitively scrutinising the relationship between patients, protocol and their practice in order to facilitate patients. Practice must be aware of the issues presented and demanded from patients, and this is reflected in the CHIVA guidelines that emphasises an approach (or to relate the point to Raebaharisoa and Callon 2002 a type of scientific knowledge and public engagement) that is discreet, educative and flexible to clinical encounters where confidentiality, stigma and ethnicity may have multiple implications.

The emphasis on flexibility in guidelines for clinical practice can be compared to how patient groups influence the local deployment of medicine according to Callon and Rabeharisoa (2003), who focus specifically on the *Association Française contre les Myopathies* (AFM). Their argument emphasises how the group works to facilitate cooperation between patients and professionals. Callon and Rabeharisoa (2003) conclude by arguing that the emphasis on communication stressed by the AFM results in the standardisation of the medicine through the group collating many patients' voices and accounts into one resource. This enables the group to make comparisons on the deployment of the medicine over the entire country with an eye on improving care, resulting in the creation of a set of standards patients can expect from the medicine (Timmermans and Berg, 2003). CHIVA guidelines



also have the role of consolidating patient and practitioner consultations into standardised procedure (CHIVA, 2011d). Although strictly speaking these guidelines are not organised and exercised by patients (as guidelines are written by practitioners), this process of informing and re-informing practicing must be reflected in the assembly of guidelines. According to Latimer et al (2006) medical guidelines, more generally, are designed to be flexible to patients' situations and are revised on a regular basis to insure that they are still relevant to their local deployment. In HIV medicine, as I will show, clinical encounters, protocol and clinical practice is further standardised and shaped through patient/practitioner interactions (Inversely, the patient group also places expectations on patients around how to understand and engage with the medicine – more on this consideration later). Callon and Rabeharisoa (2003) put forward that a major error in the analysis of these contributions from patient organisations would be to assume that they are contrary to science or, the inverse, to claim the superiority of lay knowledge due to increased realism. In their words:

*“On the one hand, it is claimed that objective and universal scientific knowledge is necessarily produced in laboratories within the community of specialists; on the other, it is asserted that truth and effectiveness are local and contextual.”* (Callon and Rabeharisoa, 2003).

Callon and Rabeharisoa (2003) argue that the types of knowledge applied by these groups mutually constitute each other. This implies that in order to deploy medical science in an area, local knowledge and local groups must be taken into account. Correspondingly the organisation of local groups must take into account established scientific view points (see also Landsman, 2006). This can be interpreted in relation to CHIVA clinical guidelines that aim to be flexible towards the personal circumstances of patients. The contrast between what is scientific and what is cultural is emphasised when considering the practice of paediatric HIV. The biomedically defined requirement for suppression, although conceptualised as absolute, is rendered redundant if it is not interpreted by patients and

adhered to by them<sup>21</sup>. For this reason, rather than protocol dictating what practitioners must make patients do, protocol must instead detail to practitioners how to look for contingency in application, negotiation, persuasiveness and flexibility in interpretation of requirements whilst prioritising the overall task of adherence (Drotar, 2000). Therefore, when guidelines are followed in the clinic, Callon and Rabeharisoa (2003) would describe this process as one of local deployment. The process whereby the guidelines/protocols are locally deployed further constitutes the formation of the medicine as it establishes what standards it will adhere to, and what components are essential parts of the medicine and its identity. For paediatric HIV, the deployment of local services has a further innate implication because in the UK the condition is not evenly distributed geographically. The majority of families with HIV are clustered around urban centres and the vast majority around London (CHIPS, 2010). Therefore, the deployment of services between these locations and other areas of the UK must also reflect this in guidelines.

This raises a subsequent consideration around how patients' identities are also being constituted through interactions with patient groups and the application of protocol. Clinical practice has an influence upon how patients' identities are formed (also see narrative analysis as applied to chronic illness Williams, 1984; Sontag 1988; Bury, 2001; Frank, 2010). Patient associations are formed to give patients an opening for communicating with practitioners. The group also organises patients into acceptable ways of interacting with the requirements of, in this case, antiretroviral medicine. It verses patients collectively on how to interact with the medical requirements and through exerting its aims, gives patients an idea on what they should be expecting from adhering to the medicine. For Paediatric HIV, CHIVA has interpreted this as giving children and families the opportunity to follow developments in the medicine. For example they provide sections on the website designed to inform about care and common issues, and allow children to address the collective of practitioners through a formalised child advisory board (CHIVA,

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<sup>21</sup> This is complimented by Stengers (2003) who argues that because the scientific object of medical science is the human body which has the possibility to give an unreliable testimony, there will always be a central question in medical science about the possibility of the practitioner becoming a charlatan. Also linking to a range of discussions in the sociology of health and illness around the limits of creating an evidence based practice through protocol and practice see Berg (1997b); Mykhalovskiy and Weir (2004); Harrison and Checkland (2009); Broom et al. (2009)

2012c). Consequently, in order to be effective, patients who use or participate in the resource must take on the outlook and concerns of the group. However, the ways that patients live with the condition may not always be as simple as patients taking on board the outlook of the patient group. As already stated, for children with HIV, the difficult associations between patients and practice including childhood, ethnicity and inner-urban cultures, often render patients' attitudes incompatible with CHIVA recommendations of practice<sup>22</sup>. When brought together, the practice of medicine (or adherence to antiretroviral medicine) and the lifestyles of sufferers form a complex set of considerations, and it may be the case that child patients do not act in ways compatible with the standpoint a certain patients' association wishes to project, (Gosling et al., 2004; Hekster and Melvin, 2006; Dorrell et al., 2008; Campbell et al., 2010).

Callon and Rabeharisoa (2004) conducted a case study of a patient whose outlook was contrary to that of the Reunion Isles *Muscular Dystrophy Association* (ARM). The article describes an interview with Gino the brother of the vice chairman of ARM. In the interview Gino only contributed to three dialogues. In these dialogues, Gino seems to refuse the ARM and its view of medicine. In the first dialogue he details that he has not searched out a specialist doctor because he knew from other members of the family what he has and that it is non-curable. In the second dialogue he states that he does not participate in ARM meetings. In the third dialogue he says that he has not tested the children for the condition and would rather not know whether the children have it or not. In the first instance, Gino's refusals could be taken as being reckless and amoral. They argue that medical, as well as the social sciences construct public arenas that propagate certain morals and the acceptability of such values. These morals seek to define what is proper and what is human. The authors assert that by Gino remaining silent and refusing to answer some questions fully, it is not a demonstration of Gino's amorality but instead the enactment of different forms of humanity. For Callon and Rabeharisoa (2004) this is a rally for a type of sociology which is reflexive enough to gain symmetrical views of the social world, but can also be

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<sup>22</sup> This could be considered in relation to the "child voice" as described in Komulainen, (2007); Lewis, (2010) where gaining opinions from children is deemed as important, but children may not have formulated an opinion compatible for research, or in this case practice.

taken as a commentary between a public arena, the ARM, and the implications, variances and reactions that this assemblage creates towards members and associates.

Within paediatric HIV, a patients' integration into CHIVA, Body and Soul, PPC, clinical practice or any other organisation is therefore subjected to the personal circumstances and disposition of the individual (Persson and Newman, 2006). Within the empirical chapters of this thesis many examples of staunch participant opinions are seemingly contrasted against the requirements of antiretroviral medicine. However, it is in this process where negotiation in clinical practice and the adoption of protocol and drug requirements as flexible become paramount (Persson et al., 2003). Over time, a patients' requirements change, children get older and develop, the issues they face and convictions they hold also change and must be facilitated into the practice of the clinic and administration of the medicine (Fielden et al., 2006; Bernard, 2008). What can be highlighted from this approach of focusing on negotiation is the process where patients inform and are informed by practice in the clinic which is an essential part of achieving adherence (Castañeda, 2002 talks about this process in relation to the reverberations of imaginations of childhood). Thus, rather than scientific knowledge being something separate to these clinical negotiations with children, negotiations inform how the medicine will be interpreted, understood, valued, researched and subsequently practiced (see Rosengarten, 2009 for discussion of complex interplays between biological materials and knowledges around HIV).

Overall, the discussion of patient groups being involved in the medical science and mediating patient interactions with medicine highlights some interesting nuances in the relationship between scientific and public knowledge. There is not just one way to relate to the medicine but many, and there are also many ways in which the condition and notions of humanity exist (Lee and Brown, 1994). The key implication (and therefore contribution to the literature detailed in this section) for this thesis is that it is in the clinic where disparate patient complexities, humanities, medical requirements and protocol are negotiated. The cohort of children at UOUH live in an urban environment and have diverse backgrounds. The potentiality for difference amongst this group is large, thus it requires flexible and thorough clinical practice (Conway, 2006; Foster et al., 2007). Scientific discourse, clinical

practice and the professional organisation (CHIVA) have linked sets of codes, guidelines and protocol. These guidelines seek to order the complexity of paediatric HIV and render it treatable. However, the ways in which guidelines must necessarily be interpreted and practiced in the clinic allow for a large amount of dynamism, overlap and contradiction. Stengers (2003) further highlights this antagonism and argues that the figure of the charlatan is inherent to the medicine and that 'scientific' medicine strives to distance itself away from it but at the same time cannot eradicate it as the object under research, the 'suffering body', is not capable of giving a 'reliable' testimony of facts. Consequently, in this project the aim is not to emphasise these antagonisms or highlight 'unscientific' aspects of paediatric HIV medicine, but to demonstrate ways in which the practice works in spite of them and is made coherent in accordance to them (also see discussions on evidence based medicine Harrison and Checkland, 2009).

This section is not exhaustive in defining what constitutes patient/practitioner negotiations and medical science, just one particular branch of it. Building on the previous section, this section has focused upon processes of negotiation between patients, practitioners and protocol necessarily central to practice in order to make viral suppression possible. Through the process of ongoing facilitation of the outside concerns of patients into adherence guidelines in the clinic, the consolidation of disparate patient dispositions into knowledge of the virus and responsibility for maintaining it is made possible (Pontali, 2005). The differences between this version of ANT and the one found in the first section can be seen to have alternative implications for how to approach Paediatric HIV. Unlike the discussed Law and Mol (Law, 2004a) articles on 'object politics', Callon and Rebharrissoa (2003) advocate a more keen focus on negotiation between patients, families, medicine, practitioners, protocol and patient groups etc., rather than tracing a minute view of specific objects. This offers more freedom and avoids being overly caught up in considerations of the differences between objects. Through focussing on CHIVA and other organisations and the way they inform/are informed by practice, analysis is provided with a resource that holds many important considerations around the mediation between the practice of medical science in paediatric HIV and the assemblages of the patients as children who are naive, ethnically diverse or culturally different. Within the condition of paediatric HIV, a

wide array of medical/professional and patient groups play a part in the translation of the condition into practice, informing versions of the medicine and informing the identities of patients, resulting in a mutually negotiated definition of paediatric HIV and antiretroviral treatment (Preda, 2005; Fassin, 2008). Through viewing organisations such as CHIVA and the specific clinic, the study of the clinical practice of paediatric HIV is made even more versatile and dynamic as it offers an insight into the ways the application of knowledge and patient/practitioner concern is performed/made possible in accordance to protocol. What is asserted in contrast to a hierarchical model of medicine that dictates practice follows protocol is that the clinic is a key site in the formulation and consolidation of the medicine.

## The Sociology of Childhood

This section is concerned with two issues about childhood: firstly how childhood can be imagined in the clinical practice of paediatric HIV and secondly, the extent to which clinical needs to alter practice according to child naivety, innocence and vulnerability. These are important concerns as they question how clinical practice is made possible around childhood innocence and also how this innocence can be viewed in relation to the clinic and the task of viral suppression. The section will frame the Sociology of Childhood (SoC) in relation to clinical practice through a discussion on social constructionism and ANT<sup>23</sup>. I will use the literature to argue that clinical enactments in paediatric HIV must negotiate issues of childhood when administering medicine. The literature will also be used to highlight processes in the clinic where medicine is operationalised along with ideas of childhood through the application of guidelines to child patients during practice. In the paediatric clinic, what SoC would term 'the imagination of childhood' has many implications for practice. It defines the boundaries between paediatrics and general services (Armstrong, 1979), the role of children in decision making and participation (Alderson and Montgomery, 1996; Bluebond-Langner et al., 2010) as well as the administration of medicines and procedures (Christensen, 1998; Cohen et al., 1999). The key debates to be discussed

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<sup>23</sup> A wider array of studies also exist under the name of childhood studies, which broadly follows the new sociology of childhood shown here but also has developed theory aside from SoC. One particular approach we could assess as to whether it can be used to explore HIV comes from Corsaro (2003, 2005), who has forwarded his own approach to the sociology of childhood. This work runs parallel to the social constructionist accounts detailed above but does not take on the same approach to viewing childhood, following the work of Pierre Bourdieu instead of STS.

around SoC are in relation to childhood power, imaginations of childhood (e.g. as vulnerable or naive) and viral suppression being made possible by facilitating children into clinical practice and guidelines.

James and Prout (1997) credit the new sociology of childhood<sup>24</sup> as emerging from a general paradigm based on a range of problems identified with common held views of childhood, and the study of childhood within the social sciences. They see this as the point in which the study of childhood became of interest more broadly in the social sciences and distinguished itself away from developmental psychology, which up until then was the only discipline interested in childhood issues of this type<sup>25</sup>. The new paradigm expressed a number of core concerns for the study of childhood. Specifically, it placed emphasis on childhood being socially constructed; stopped idyllic ideas of childhood that obscure other social variants such as class and race; put forward childhood as an object for study in its own right; and stressed the idea that children are active participants in their social landscapes and not just passive subjects (James and Prout 1997). The purpose of this paradigm was to establish new and more satisfactory ways of viewing childhood. Since then, the study of childhood across the social sciences has grown and now contains a diverse array of studies (see Moran-Ellis, 2010 for a historical overview of the discipline). Applying SoC to paediatric clinical practice offers insights that highlight some underlying assumptions about childhood, especially around vulnerability, naivety, innocence or incompetence etc. These assumptions often result in diminishing the agency of children in clinical participations and decision making (Mason, 2005). The aim of this section will be to review some of these approaches to the study of childhood and ‘imaginations’ of childhood. When highlighting these considerations on childhood the emphasis is not ‘to police the line of difference’ (in line with the general approach of Oswell, 2012), but to trace how practice is made possible in accordance to them, ensuring that this thesis has a reflexive deliberation on common held conceptions of childhood.

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<sup>24</sup> When James and Prout’s (1997) first edition was published in 1992, they used the term ‘new sociology of childhood’ to distinguish it from work that had previously been carried out. For use here the sociology of childhood will not be referred to as new other than to reflect upon the period when the social constructionism was used to study childhood. Other than as use for distinguishing subsequent studies should always be new.

<sup>25</sup> Also see: <http://www.brunel.ac.uk/research/profiles/sssl/jenks>

The early literature of SoC, developed in the UK during the 90's and predominately used social constructionism to approach issues of childhood (Moran-Ellis, 2010)<sup>26</sup>. This approach sees childhood as an entity that is constructed wholly through social interactions (Burr, 2003). It detaches childhood from the view that it is a stage of mental, intellectual or bodily development from childhood into adulthood, but instead that childhood is a process constructed by society and projected onto children, separate from the biological process of the growth of the body. In this view, childhood becomes a construct wholly created through social and cultural processes that informs the nature of childhood and how children should be interacted with, independently from the 'actual' biological immaturity of the individual. This culture/nature discrepancy leads to an idea of childhood as culturally constructed irrespective of the biological 'actuality' of the child. This highlights commonly-held cultural ideas of childhood as being based on falsehoods and idealisms, like the idea of child naivety or childhood being free of worries and cares, or of the child as pure innocence. The approach argues that these views of childhood result in conceptions of childhood as stripped of any agency, seen as abstracted and incapable of being part of the social worlds that surround them (James et al., 1998; Matthews, 2007; Jenks, 2008). In relation to social constructionism, clinical practice would be considered a key site where childhood is socially construed as naive resulting in practitioners stripping child patients of their agency. According to this model, clinical practice culturally constructs the child patient as naive towards regimes of care and treatments they will follow, excluding them from participation in the clinic and the decision making process according to the justification that children cannot capably rationalise their complex health needs in the long-term before they are an adult ( Christensen, 1998; or Mason, 2005).

In the book *Constructing Childhood*, James and James (2004), put forwards ways in which child healthcare is socially constructed. The book uses policy in the form of Acts of

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<sup>26</sup> Authors such as James, Prout and Jenks (see James et al., 1998 for a collaborative example) worked collaboratively to explore childhood with social constructionism. In more recent literature, Prout has moved away from social constructionism (as in James and Prout, 1997) towards ANT, Deleuze and STS (Prout, 1996, 2005; Prout et al., 1999) whilst James (2004) has continued to champion it, providing a variety of approaches in SoC as a discipline.



Parliament and institutional health policies to exemplify 'social practices' where childhood is seen as a time of naivety and diminished rationality. They go on to argue that these policies hold ideas of childhood that are misconceived and result in policy makers seeing children as a 'becoming' and not an 'actuality' which leads to bad health policy and practice. Subsequently, James and James argue that health policy makers see children as a potentiality (this can also be linked to an idea of 'becoming'<sup>27</sup>) and not an entity able to reason in the present. This means that through policy and in the clinic, children are viewed from their potential as healthy adults rather than being dealt with as an 'actuality' of the present. James and James (2004) use the example of obese children and argue that policy is formed not around the child, but around preventing adult obesity and seeing childhood as the place to tackle adult obesity. One of the strengths of social constructionism is that it can be used to challenge many commonsensical ideas of childhood found in clinical practice or protocol that are based on false or exaggerated conceptualisations that would not normally be contested. For example, the idea that through naivety, children are not able to take on the decisions for themselves that will later decide what kind of life they will lead (also see Woodhead, 1999). Applying this type of social constructionism to paediatric HIV can explain the political nature of some accounts of HIV and children, especially in media reports of children (e.g. media report of Day, 2011) that denote them as being innocent victims caught up in a disease ill-matched with childhood (Meintjes and Giese, 2006; Fassin, 2008). The sensationalised public account of children with HIV as 'innocent victims' is often present in the reasoning of clinical practice and protocol. For example this can be seen when looking at the procedure of disclosure. Policy and practice argue that disclosing HIV to a child should take place at around the age of 11 or 12 when they are able to keep a secret, but before they have taken on public stigma of the disease (Committee on Pediatric AIDS, 1999b; CHIVA, 2011c). Disclosure effectively educates children about a clinical and 'un-stigmatised' version of HIV at the earliest opportunity, which demonstrates how politically aware of childhood innocence those who administer care and policy must be. Variations of the social construction of childhood innocence and sexuality have been used to discuss

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<sup>27</sup> The idea of a child as becoming is theme that can be seen in much literature of the sociology of childhood, but the idea of becoming is different over these accounts. The idea of becoming is one that has differences in meaning over the different stances In SoC (see Prout, 2005).

childhood, HIV and sexuality. These debates argue that the sexual rights of children should be considered not from the perspective of children being protected from outside sexual influences but rather as the owners of their own sexuality and capable of making decisions regarding their own sexuality (Mitchell and Smith, 2001; Mitchell et al., 2004; Bhana, 2007; Kehily and Montgomery, 2008).

However, the approach of this thesis seeks to highlight how antagonisms in clinical practice are made compatible and, therefore, naivety and diminished agency are not described as being 'policed' but highlighted as 'facilitated' in the clinic and protocol. Imagining childhood as a 'potentiality' implies a power structures that is uni-directionally applied by adults on to children which negates all the other possible ways childhood interacts in a given situation, and the wider networks of associations (such as stigma or confidentiality) that are active in clinical practice<sup>28</sup>. The focus on potentialities ignores many other complex impetuses to make clinical interventions (Gallagher, 2008). One counter example that can be sited here is the fact that the antiretroviral medicine that must be taken to allow children to grow into adults will adversely affect their health in the long term (Nachman and Pediatric AIDS Clinical Trials Group 377 Study Team, 2005; Kim, 2010). Consequently, these ideas of enforcement through potentiality and childhood becoming are incompatible to the central argument of this thesis that guidelines are mutual negotiated between patients and practitioners, and that children do exert an influence in the formulation of paediatric HIV medicine. Even in the example given in the previous paragraph on disclosure, a line of power is not so easy to draw when taking into account the wider context that practice operates within (there are serious ethical implications at stake beyond what is "social constructed" for both the family and the clinic if there is a breach in confidentiality, see Santamaria et al., 2011; and Koenig et al., 2011).

The question of power in the sociology of childhood has been discussed at length in terms of 'child voice'. For example, in reaction to childhood studies that have expressed a need to focus specifically on the 'suppressed' child voice in research (Alderson 1996; A. James and Prout 1997), Komulainen (2007) has argued that the focus on 'voice' is misguided and

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<sup>28</sup> Qvortrup (1994) offers a defence and complexification of power dynamics in SoC and social constructionism.

invites researchers to search for issues that may not be present. Komulainen, as well as others in the field have subsequently argued for research to focus on dialogue actually expressed rather than to search for a 'child voice' in order to provide a sounder basis for representing the expressed agency of childhood in areas such as clinical practice (Graham and Fitzgerald, 2010; see Lewis, 2010). This question around the 'child voice' can also be interpreted as a more general question of how power is enacted in relation to childhood. Here, power is expressed in the style of the social construction of childhood and emphasises a view of power that is uni-directional, from practitioner to child patient, thus obscuring the ways in which power can be viewed in practice as going from child patient to practitioner (Christensen 2004). For example, it does not account for the complex arrangements of power found in antiretroviral administration around measurements of body size, antiretroviral dosage, confidentiality, public health, community/ethnicity and the attitudes/commitments of child patients and their families. This complex interplay between medical literature, guidelines and negotiations in the clinic does not fit well with notions of practice as enforced through a child's potential to 'become an adult'. A general problem identified by other authors is that 'the social construction of childhood' resorts to reductionism as it relies on a separation between biological and cultural ideas of the child. In effect it ignores the ways in which the biological is present in cultural ideas of childhood and vice versa (also see Hacking, 1999 for a general criticism; Prout, 2005; Lee and Motzkau, 2011).

Other debates exist within the Sociology of Childhood that are distinguished from social constructionism. For example, debates around childhood, ANT and STS are more compatible with ideas of clinical practice that place childhood alongside other aspects found in the clinic. One such study focusing on the imaginations of childhood in areas such as practice is Castaneda's (2002) book 'Figurations'<sup>29</sup>. The perspective of this study aligns SoC approaches more generally to feminist theory that seeks to highlight inequalities in the representation of gender, science and technology (Haraway, 1991 offers a parallel

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<sup>29</sup> Although the degree to what kind of STS it constitutes is open to discussion as its influence could be seen as most heavily informed by the work of Donna Haraway. Haraway (1991) offers an introduction on feminism, science and technology.

discussion of feminist theory, science and technology). Castaneda's (2002) work shares similar aims to James and James (2004), as it is concerned with the ideas and conceptions of childhood in both health policy and practice. However, by adopting STS, Castaneda develops a distinct approach away from a view of practice as deploying a version of childhood as culturally constructed around child patients. Castaneda (2002) argues towards an idea of childhood that avoids emphasising a rift between how childhood is socially constructed and independent from its material reality by tracing how childhood is embodied, and its imaginative appeal across diverse scientific settings such as nineteenth-century science, cognitive neuroscience, international adoption and accounts of child organ stealing. Through these studies she asserts that the study of associations should not make a differentiation between material and semiotic processes. *Figurations* therefore rejects a disjointed view of childhood as between culturally constructed elements on the one hand and the biological, 'natural' state of the child on the other.

One key relevance of Castaneda's study is the demonstration of the ways in which 'figurations' of childhood are pervaded through the formulation of guidelines, policy and practice and how ideas of what childhood *is* are also made up through these processes. Her study conceptualises these representations of the child through the concept of 'figurations', or more specifically, as each representation of a certain type of childhood as being a 'figure'. She puts forward that a figure of childhood is simultaneously made through semiotic and material practices and implicated over multiple locals and situations. Castaneda argues that childhood is not socially constructed and detached from the biological immaturity of the child, but instead is assembled through material practices such as the body of the child interacting with semiotic practices of designating and defining aspects of childhood. The discussion operates from the idea that semiotic and material practices are embroiled together in the enaction of childhood, each interacting with the other. The child figure alters and changes over the settings it appears within, in turn altering and changing the places and situations where it appears, whilst always being corresponded back to a material child body. Over the historical and geographical presentation of the child, a powerful figure of the idea of childhood can be traced between diverse locations and histories. Castaneda (2002) uses the examples of nineteenth-century science, transnational adoptees and child-

organ theft, but to this list the example of clinical practice and paediatric HIV could also pose an interesting comparison, especially where patients come from across international borders and often depart back over them (Goulder et al., 2001; see concerns of CHIPS, 2011). *Figurations* concludes that the figure of childhood is constantly enacted over the places studied as a potentiality (which can be linked to the idea of becoming) and not a being or actuality. This is certainly similar to the ways presented in the social constructionist approach. The key difference however, is that the idea of becoming is specific to the moment and context where it is found and is malleable back to the material child itself.

The usefulness of this approach for children with HIV lies in the fact that it brings to light the many situations where the child figure is posed between policy, protocol, procedure and clinical practice. The advantage of taking on an approach that is inclusive of both materialities and the semiotics of childhood is that it does not force analysis to isolate the requirements of physical child body from the child in the clinic as presented or imagined with HIV. This is especially advantageous when considering something like the consequences of clinical decision making, which is relevant when considering that HIV is a high profile disease, and that the child cohort is distributed over various ages and stages of development (Bogart et al., 2000; Alderson, 2007a; and Bluebond-Langner et al., 2010). The decisions made in the clinic have serious implications if practiced incorrectly. For example, if the doctor discloses to a child too soon, he risks a breach in confidentiality. If an adolescent with HIV is unaware of the implications of their HIV and become sexually active they risk a violation of public health (Christianson et al., 2008). Therefore, it is important to recognise conceptualisations of childhood that recognise the material aspects of the condition. In paediatric HIV clinical practice it is a defining factor that practitioners are faced with difficult decisions in the clinic between cultural aspects of HIV and childhood and a child's present material health needs.

Questions can be posed around how materialities of childhood, imaginations of childhood and childhood naivety are adopted in the dynamics of clinical practice when shaping protocol (and consequently being shaped by protocol). Imaginations of childhood pervade the protocol and guidelines provided by CHIVA (CHIVA, 2011d). If imagined as a figuration,

childhood can be depicted as being affirmed by the dynamic between practice and protocol where protocol must be adapted to clinical settings to insure its relevance and taken up by child patients (Callon, 1986). This is important for practice which must regularly deal with associations of HIV, childhood, immigration, the child body and antiretroviral medicines that must be rendered 'compatible' in order to achieve viral suppression with antiretroviral therapy. This adds to the question of how policy and practices are consolidated around child patients.

However, if the idea of child agency as 'becoming' or the 'potentiality' of being an adult is again challenged, some reservations still exist when applied to paediatric clinical practice. Even though figurations deals with childhood in a looser, less absolute way than that expressed in the literature on social constructionism, the description of childhood as a 'potentiality' rather than existing in the present is still difficult to apply to HIV practice. This is because, as already mentioned, the problem remains unresolved that the implied underlying power dynamics are contradictory to observed clinical practice. For example, children with HIV generally need medicine to become adult and this medicine can be detrimental to their health. Moreover, the paediatric HIV clinic is also responsible for the very pressing concern of the sexual health of their patients and the public health of the community (see the epidemiological concerns of Wilson et al., 2010 and Campsmith et al., 2009). Many policy articles written by practitioners must foreground the idea of childhood imagined as in 'becoming' to deal with the immediate issues (such as sex and confidentiality) presented in the clinic (Vigano et al., 2004; Watson and Counts, 2004; Nachman and Pediatric AIDS Clinical Trials Group 377 Study Team, 2005; Kim, 2010).

Caution needs to be raised towards the idea of power implied in child figurations. Although it is presented as more dispersed between different geographical and historical contexts, it is unclear who is re-imagining the figure of a child and for what reason. If the child is being constantly re-enacted as naive and as a potentiality, it implies that there is a constant enaction of power being cast towards children over these contexts. It would be poignant to question in relation to the figures of child naivety that are being re-imagined if there is also a corresponding enaction of power. In the analysis of clinical practice provided in this thesis

I would not like to suggest that there is no enaction of practitioner power or reverberation of child naivety. However, I would like to emphasise the ways in which child patients are also necessarily in negotiation with practitioners in clinical practice. In this context, power can be described as more dispersed and contradictory (as discussed in the section above, *Patient Negotiations*). In clinical practice child patients exert power on to practitioners through negotiations at the clinic (Christensen, 2004). This is made even more important as the patient cohort have a diverse range of cultural differences, like ethnic origin (as stated all patients in UOUH were of African origin), viral load, school, financial problems or circumstance, all these factors and many more have a bearing on the identity of the patient and how clinical practice will take place (Green and Smith, 2004; Dorrell et al., 2008). In effect the discussion reverts back to the question of power and oppression (Christensen, 2004; Komulainen, 2007; Graham and Fitzgerald, 2010; see Lewis, 2010). The focus on the figure of the child linked through constant suppression by naivety, obscures other contextual interactions between child patients and practitioners. *Figurations* aims to explore the idea of how childhood permeates through different areas of society and knowledge. As a result it inhibits the other associations that also inhabit the same spaces as these child figures, for example the ways childhood, stigma or ethnicity influence practice. Therefore, the application of child figures in relation to HIV is partial to issues surrounding the portrayal of practice in paediatric HIV. The caution identified towards the idea of becoming and the representations of power in studies of childhood will be important as the thesis moves on to explore more literature.

Moving more specifically on to link ANT with studies of childhood and its application to clinical practice, Alan Prout (1999; 2005) is an author who has championed methodologies developed in STS (as well as ANT see Prout, 1996) in the sociology of childhood. Over recent years, possibly through Prout's influence, debates in the sociology of childhood have taken on an approach that increasingly develops STS and reacts against the social constructionist view of childhood (also see Lee, 2001). One of Prout's more recent theoretical studies has been the *Future of Childhood* where he argues towards a reassessment of the New Sociology of Childhood. One basis for this reassessment is upon the theory of hybridisation as applied to childhood and how these hybridisations create new

objects and new possibilities (can be linked to a reading of Deleuze, 1998). For example, through the intervention of the clinic, childhood could be imagined as hybridised between the child, HIV and antiretrovirals to create a new object combining the three. Prout (2005) asserts that a child should not be seen as something that is in the process of achieving completeness or social and biological completeness, but instead that it is something that is never complete and always being hybridised through social and biological processes (see Latour, 1993; also see the description of the body in Prout, 2000). According to Prout (2005), childhood is dynamic and contains no essential entities, as it is constantly enacted with wider associations. Prout's (1996, 2000, 2005) studies in ANT/STS urge the reader to view childhood not as something that is independent from the places where it is performed, but something that is always reliant on the other factors that are involved in the situations that use imaginations of childhood. The versions of childhood that can be found in situations analysed in this way are non-reducible from the other associations that they are also enacted alongside (see *irreductions* Latour, 1988). Relating STS ideas of childhood back to clinical practice highlights the ways in which procedures taking place in the clinic such as disclosure, adherence, chronic illness or transition do not simply act upon child patients, but consolidate childhood between policy, procedure and practice alongside regimes of practice and healthcare with wider societal/political/biological processes such as stigma, identity and ethnicity. Childhood is not isolated from these practices but formed together with them, and in turn alters the way these practices are performed (Ryan, 2011). This implies that practice must be negotiated with the child cohort to ensure that antiretroviral requirements are made compatible alongside the many child specific associations of patients such as vulnerability, and innocence.

This approach to childhood further alters the social constructionist view of childhood already given and its implication for clinical practice. The challenge is framed by Prout (2005) by a call to reject a view of childhood as separated between mutually exclusive dualisms between nature and cultural, or being and becoming (stemming from Latour, 1993; also see Lee and Motzkau, 2011 for a discussion on dualisms and childhood). The argument demonstrates how childhood is not entirely reducible to either material or semiotic, cultural or biological, being or becoming representations. Rather, representations



of childhood are never fully finished versions of either side of the dualism and constantly hybridised between the two. This approach has the advantage of modifying the discussion of becoming and potentiality away from connotations of child agency (or voice) as suppressed in the present over their potential as adults. It remodels child agency and imaginations of childhood as particular versions of childhood with their own specific context. The approach does not reject notions of childhood as being naive, innocent, vulnerable or incompetent, but rather modifies each enaction as having its own particular context, and multi-faceted network. The acknowledgement of childhood as contextual allows the analysis of clinical practice to more accurately assess how childhood is being accommodated and made possible around child patients. The presentation of children and adolescents in the clinic offered here is heavily burdened with contradictory recommendations for the treatment of patients in practice. The involvement of many conflicting cultural and societal aspects such as immigration, stigma and community makes the idea that agency is simply deferred into the future problematic. Therefore, the relation of power and enaction of knowledge in consultations between patients and practitioners is better represented as multidirectional, which is more freely accommodated in STS versions of SoC (Prout 2005; or Lee, 2008). Associations of naivety and innocence are found within paediatric HIV practice, procedure and guidelines and influence the way that the clinic approaches the child and care is administered. Through the use of STS these representations do not have one version, but many, and can be found to be enacted contradictorily with many facets of power being implied in one enaction. This way of approaching childhood allows the influence of child actors to emerge from the research data rather than being imposed upon it according to a pre-requisite adult-child power structure. Therefore, what is emphasised in research is the role of the clinic to consolidate and make compatible associations of childhood with medical requirements.

The way that SoC is perceived in relation to this project is not an attempt to render the authentic childhood within paediatric HIV or 'police' the line between the agency and imagination of childhood in paediatric HIV practice. Rather it is an attempt to render analysis aware of divisions and describe why the clinic deems it valuable to uphold observed notions of childhood, or in the case of practice how it is organised in spite of medical

adversity and contradictions to make suppression possible. This is in line with the approach of Oswell (2012) in his discussion of child agency. Oswell (2012) meticulously develops an account of child agency as presented over many contexts and histories of health and medicine relating to childhood. The aim is not to pass 'moral judgement' but rather 'sociological reflection', which according to the analysis is framed by contrasting accounts, and posing questions around child agency. The analysis of childhood in the clinic documented in this thesis was conceived under this pretence. When considering retrospectively the encounters observed at the clinic, it is impossible not to appreciate the impetus, implication and urgency of decision making that is carried out in the clinic in regards to considerations around childhood. The implications of growing up adhering to antiretrovirals, and sexual health pre-requisites, or the interruption of child protection services when care is deemed as inadequate (Mason, 2005; Guldborg, 2009), mean that childhood cannot be viewed by practitioners or policy makers as neutral (Lee, 1999). Paediatric HIV is highly ethical due to the interlaced connotations of childhood, HIV and immigration. One of the key considerations for clinical practice is how to treat a condition and child patient with such complex requirements. Therefore, the following empirical accounts of childhood, clinical agency and 'imaginings' of childhood highlight how clinical care accommodates and is made compatible with complex associations of childhood (such as vulnerability or naivety) and HIV, which as a result, constitutes the contribution of this thesis to SoC.

This section has looked at child agency and imagination of childhood in the new sociology of childhood and its relation to clinical practice. In relation to paediatric HIV, it has evaluated the insights gained from the social constructionist approach to childhood, and explored the contribution of ANT/STS to SoC, through approaches such as the idea of figurations by Castenada (2002) and ideas of hybridity and childhood from Prout (2005). Some major themes have emerged such as ideas around children seen through their potential of becoming an adult, an idea that is demonstrated in this chapter as containing inadvertent power structures, and a discussion of agency and imaginings of childhood as dispersed over material and semiotic interrelations. Considerations around how childhood is represented have a resonance for this thesis. In the negotiation of protocol and practice

formulated in the clinic, considerations and 'imaginings' of childhood must be included. It follows that there is a mutual negotiation between guidelines and the child patients practiced upon. This means that child patients are highly implicated in the process of consolidating requirements into a coherent medicine that successfully suppresses HIV over the paediatric cohort. The principal distinction maintained in this section has focused upon the enaction of clinical power to child patients. In the study of practice and protocol that follows, the notion of 'power' is seen as dispersed over a broad array of actors, and capable of being enacted in many compliant or contradictory ways in the clinic and the negotiation of guidelines. Therefore any notion of childhood, innocence and naivety, or enforcement of clinical recommendations will be analysed not as dictated on to child patients but as under negotiation in the clinic.

## Conclusion

This chapter has asserted several perspectives between STS and SoC. The aim has been to frame the discussion of clinical practice and paediatric HIV which will be found in this thesis. Compared to other chronic conditions discussed in STS and SoC, paediatric HIV presents an exceptional amount of complexity to the clinic. All three sections have assessed how objects, associations and knowledges are negotiated in the clinic in complex enactions and translations of care. The chapter has focused upon how paediatric HIV practice is not only defined through these processes, but how practice is mobilised in order to consolidate medicine with children and adolescents to make antiretroviral requirements compatible with complex patient associations, such as stigma, vulnerability and naivety. This locates the clinic as a key site in the formulation of medicine over a model of medicine that dictates that practice follows protocol. The discussions offered have focused upon the 'turn to enaction' in ANT, the collation of patient, practitioner and scientific knowledge and the imagination of childhood in clinical practice. These debates assert that practice is enacted and re-enacted in the clinic according to the associations present, that patients exert pressure and can formulate medical science through practice, and that child patients are highly implicated in the consolidation and formulation of HIV medicine. In the process, notions of power are displaced that do not account for enactions of power and hierarchy that are complexified, contingent and often contradictory. Overall, the preoccupation has

been to conceptualise how incompatible, contradictory associations emerge in enactments of protocol and health care at the clinic, and how these seemingly incompatible associations of e.g. childhood, immigration, stigma, guidelines, protocol and medical requirement are under negotiation together at the clinic and made compatible under the same common goal of suppression. Consequently, all clinical associations from the formal (e.g. protocol, policy, guidelines) to the impromptu (patient concerns, attitudes, aspirations) have been framed as in negotiation during practice. The chapter has also framed the contribution of this thesis to the discussed literature by demonstrating that the specificities of paediatric HIV highlight the clinic as a key site of organising a multiple and incompatible range of associations into a coherent medicine. The range of incompatible associations around HIV and the absolute requirements of antiretroviral medicine make paediatric HIV and the necessity for clinical flexibility a distinctive topic when applied to STS, ANT and SoC. The next chapter on methodology will develop some of the key methodological principles of researching practice as 'enacted', whilst concentrating more readily on how to apply these concerns to researching paediatric HIV and the clinic at UOUH.

### 3 Methodology

In this chapter I discuss the methodological approach employed to study paediatric HIV and more specifically the clinic at UOUH. The chapter will detail the methodological implications of disregarding the search for pre-existing hierarchies of practice in favour of focusing upon how medicine, guidelines and the condition are emergent through practice in the clinic. STS/ANT has been employed as a central tenet of the methodology in an attempt to answer the question of how actors can be followed through negotiations of clinical practice and protocol, through complex patient associations, such as stigma, vulnerability and naivety to be consolidated into functional HIV medicine. 'Following actors' is made especially relevant through the consolidation of seemingly incompatible, politically and culturally 'charged' entities such as childhood, innocence, stigma, HIV, ethnicity, and the requirements of HIV medicine. Designing and conducting research has been as much an exercise in conceiving methods as it has been in making possible the study of a highly contingent and controversial condition<sup>30</sup>. Added to this are the managements of time and practicalities found in every piece of research. STS/ANT has assisted primarily as a method to follow what may seem like contradictory actors through the clinic into a coherent account.

The chapter has been split into two sections between methodology and methods. The first is a description of the methodology considered in this project, and introduces us to three relevant principles of ANT methodology – irreducibility, the focus on semiotics and materiality and the 'enaction of the social' – and how they will be applied. The focus will

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<sup>30</sup> Gad and Brun-Jensen (2010) go as far as putting forwards that ANT is neither a theory or a methodology, stating that notions such as "postplural attitude" or "nonhumanist disposition" (Gad and Bruun Jensen, 2010) as being more useful.

predominately refer back to the question of how to follow actors through clinical practice in the face of complexity and multiple enactions. The second section on research methods comprises a documentation of how the research was carried out. The section seeks to provide a guide to the practicalities of conducting research in the paediatric HIV clinic and the main decisions made in the process of collecting data.

### What is ANT (and after)?

According to Latour (1988), a principal factor in the development of thought that led to ANT is that no entity is reducible to any other. In wider process philosophy this has been referred to as the principle of irreducibility<sup>31</sup>. It implies that no entities should be isolated in a description of the social world at the expense of reducing or dismissing another (see Whitehead, 1979; Stengers, 1997; Deleuze and Guattari, 2004). One prime example of the use of this principle can be interpreted as the intention to eliminate dualisms from sociological thought. Dualisms can be described as the reduction of complex issues to simple binaries such as between nature and culture (or biology and culture as in Prout 2005). Dualisms are challenged by ANT as they ignore the many other possible ways in which the same issues and questions can be posed (Latour, 1993). In reference to the clinic this means that practice should not be viewed as divided between biological/cultural aspects e.g. the disease and its effect on the body on one hand and the formulation/consolidation of guidelines on the other. Similarly children should not be seen as between nature/culture, e.g. between the natural state of innocence and development, and the cultural interventions of adulthood (Prout, 2005; Oswell, 2012). Instead it is through practice that these assemblages of childhood, HIV, medicine etc. emerge within the clinic and should be analysed as such<sup>32</sup>.

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<sup>31</sup> The predominant method of analysis used before ANT to approach cultural aspects of science was social constructionism. Before *Irreductions*, Latour (Latour and Woolgar, 1979) was using a form of constructionism, but ANT soon developed big differences, its own terminology and a unique methodological stance.

<sup>32</sup> Latour credits thought on the irreducibility of objects as giving rise to the methodology (Latour, 1988). In a personal Communication to Graham Harman Latour writes 'Any argument about my "philosophy" has to start with *Irreductions*, which is a totally orphan book.' (Harman, 2009) Although it would be contradictory to state that ANT has one source rather than a process encompassing many sources, and different versions of the early origins. Consequently, right from its inception, an ambiguity exists and as a result, whatever the origins are, they are looser than being able to be defined within one version of early thoughts.

In relation to existing studies of clinical practice and paediatric HIV, the principle of irreducibility immediately brings the proposed research into conflict when compared with the predominant description of 'the social' in relation to the topic. A substantial body of literature on practice already exists in the form of psychosocial studies of paediatric HIV (Lewis et al., 1994; Melvin and Sherr, 1995; Battles and Wiener, 2002; Gibb, 2003; see Green and Smith, 2004; Steele, 2007; Mahajan et al., 2008). What is significant about these studies from the perspective of *Irreductions* is that they work from a model of medicine that dictates that practice follows protocol. These studies are tasked with suggesting ways to improve the efficiency of the medicine by making 'overlooked', 'psychosocial issues' accountable in guidelines (Green and Smith, 2004). As a result the psycho-social reduces the phenomena it describes into, on the one hand the medical intervention and on the other the 'social' aspect of patients that 'disrupt' the administration of the medicine. This emphasis constitutes a breach to the principle of irreducibility as it prompts the reduction of clinical encounters between conceptualisations of clinical regimes, psychosocial issues and the 'ulterior', 'social' world of patients. In effect the psychosocial approach is unmindful of the ways in which so defined 'psychosocial issues' and clinical regimes (e.g. protocol, guidelines and practice) are emergent and intertwined through the same processes taking place in the clinic. Therefore, a basis for this project is to treat the incidences under research and guidelines as contextualised and emergent through the negotiations observed at the clinic and avoid taking reductions or dualisms as explanations. This has implications for research from data collection to analysis. Accordingly, if related to ethnography, it implies that the collection of data is altered from long-standing ethnographic traditions that focus predominantly on behaviours and interactions. Rapidly, all clinical objects, processes, procedures, practices, protocols, policies, and influences introduced by child patients and their families become relevant, and the ways that they can be put together becomes multiple<sup>33</sup>. These issues have been referred to in other terms as the problem of complexity, multiplicity or 'messiness' (Urry, 2005; Law, 2007). The solution posed by Law (2004b) and

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<sup>33</sup> also complexified by literature on the 'child voice' and its pertained agency (Alderson and Montgomery, 1996; Komulainen, 2007; Lewis, 2010), such as how intently we should listen to the 'voice' of child research participants.

Latour (2005), as will be discussed in more detail below, lies in the way that actors are conceptualised and followed.

A second relevant principle of ANT's methodological focus is upon process: for ANT, ontology is achieved through human and non-human actors emerging from material and semiotic processes. Ontology is not simply a question of human agency but rather made up of interactions between the agency of human and non-human actants into a network. As a result, ANT makes a concerted effort to accommodate explorations of materiality into sociological enquiry, and can uphold the assertion that no lines of enquiry are reducible to another (Latour 1996). ANT rejects the idea of a break between the human/culture and nature which maintains that there is a distinction between how reality and the 'natural' world are conceptualised. Latour argues that methodologically, ANT practice can be linked to the insights gained from the turn to semiotics, most commonly defined in post-structuralism of the 60s and 70s, in the way that it shares:

“a semiotic definition of entity building [...] [This approach maintains] that actors are not conceived as fixed entities but as flows, as circulating objects, undergoing trials, and their stability, continuity [...] has to be obtained by other actions and other trials” (Latour 1996, p.275).

The crucial difference of ANT however, is the introduction of a method distinguished from post-structuralism that reconsolidates semiotics with materiality. As Latour explains:

“a method to describe the deployment of associations like semiotics is a method to describe the generative path of any narration. It does not say anything about the shape of entities and actions, but only what the recording device should be that would allow entities to be described in all their details. A[N]T places the burden of theory on the recording not on the specific shape that is recorded. When it says that actors may be human or unhuman, that they are infinitely pliable, heterogeneous, that they are free associationists, know no differences of scale, that there is no inertia, no order, that they build their own temporality, this does not qualify any real observed actor,



but is the necessary condition for the observation and the recording of actors to be possible. Instead of constantly predicting how an actor should behave, and which association are allowed a priori, A[N]T makes no assumption at all, and in order to remain uncommitted needs to set its instrument by insisting on infinite pliability and absolute freedom.” (Latour 1996, p.376)

Therefore, the quote suggests that the starting point of research on paediatric HIV should not be an issue defined ‘a priori’. Instead, the research should hold back judgement in the field about how actors are related. For example, when researching the ‘voice’ of the child (Komulainen, 2007) ANT would not begin by looking for places where it could be demonstrated, but rather focus on the ‘free’ (emphasis of Latour 1996) recording and collection of data and how (or if) the voice of the child emerges from the data collected (revising accounts such as Alderson, 1996). Similarly, definitions of medicine should not rely upon conceptualisations of power and its result in practice. For example, that practitioners decree what is practice or what is pathological and normal<sup>34</sup>. ANT suggests that the research of practice must follow the voice of each actor as presented, the child patient and practitioner involved as well as the specific material interventions involved in the encounter. The problem of messiness and complexity therefore, is approached through the method of allowing actors freedom and flexibility when recording practice. Consequently, the researcher should avoid prioritising points of reference around the condition, such as that of childhood, or HIV, immigration, or medicine, or science, protocol, representation, or politics etc, instead what becomes important is the way that practices will be recorded in the clinic. The interactions taking place at the clinic will inform how a representation of paediatric practice emerges, and is accompanied by a stance that allows actors ‘infinite pliability and absolute freedom’ to demonstrate how they emerge and what influence they have (Latour, 1996, p376). This modifies much ethnographic or qualitative social scientific methodology. The focus is still linked to the ‘behaviours, languages, definitions and attitudes’ of those

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<sup>34</sup> ANTs conceptualisation of power marks the departure point with the semiotics of Canguilhem, 1991; and Foucault, 2010. Both authors have a conception of medical power that is imposes what is ‘normal’ or ‘pathological’ onto patients.

studied as in other forms of ethnography (see Denzin 1988, p.7), but ANT's emphasis is upon following actors and the emergence of associations and materialities.

As a result, ANT method gives up the search for psychosocial causes as is more usual within social studies of paediatric HIV and evident in works such as Mellins, (2004) when looking at adherence; or Santamaria et al., (2011) with disclosure, and instead looks for the circulation of effects (Munro, 2009). Therefore, this thesis on clinical practice looks for effects. When focussing on parent, patient and practitioner interactions it attempts to detail how clinical practice is made possible through the consolidation of medical and cultural associations, such as stigma, vulnerability, naivety and drug requirements into practice and procedure. It does not form an explanation of how clinical practices cause problems for the daily lives or cultures of children with HIV or vice versa, instead the emphasis is upon how entities are presented in the clinic, the emergent assemblages of the clinic and their interrelated effects. In the case of paediatric HIV this may prove to be difficult to justify as those committed to the psychosocial approach may cite the heightened significance of the disease and its treatment and what the consequences of the mismanagement of practice mean for both patients and practitioners<sup>35</sup>. In this context, it is questionable if abstract and 'a priori' definitions of the outcomes of clinical practice are avoidable. This thesis does not wish to refute these claims, and acknowledges the necessity and application of logics such as these to guide and recommend practice, but wishes to differentiate what is deemed as 'social' in this clinical context (Hacking, 1992).

The third relevant ANT principle to be discussed in this chapter is that this account is not designed to supersede other accounts but recognises that it is one version among many. This principle can be interpreted contradictorily as advantageous in disbanding notions of privilege and bias from our account or as antagonistic over the role of analysis. The primary antagonism stems from the fact that the name and operation of the theory are at odds with the main thrust of the approach. As ANT has evolved, it has become more and more aware of itself becoming like a school of thought or discipline (see essays collected in Law, 1999). This highlights an incompatibility within ANT, because ANT emphasises the procedural and

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<sup>35</sup> Treichler, 1999 argues that HIV has a heightened rhetoric in comparison to other diseases.

multiple nature of ontology as enacted in specific locations and therefore ANT theorists reject the idea that ANT can make universal metaphysical claims. Rather than being a generalisable theory of ontology, ANT itself must be enacted in specific locations and vary between its enactments (i.e. the social itself must be 'enacted' Law 2003). Throughout the development of ANT, authors have necessarily distanced themselves from a formalised set of metaphysics, preferring to emphasise the range of non-exclusive stances it is possible to pose towards a given problem (Law, 1999). However, it seems that in recent years the pressure to offer an unequivocal metaphysics (and therefore a resulting singular methodology) has become more pressing<sup>36</sup>. Much contention exists about what its role, or place is. ANT carries a distrust of grand theories with it. Modern ANT does not want to consider itself as constant and universal like scientific method. The creation of a model of social scientific rationale that supersedes knowledge outside of its scope is exactly what protagonists of ANT would like to efface (Stengers, 2000 see "superscience").

The antagonism highlighted has an impact upon how researcher accounts must position themselves amongst other research methodologies. Therefore, the account will be cautious about disregarding other explanations of paediatric HIV, as it is important to maintain a stance that acknowledges the necessity and importance of all encountered methods (see for example Bogart et al., 2000 on factors influencing the administration of antiretrovirals). Consequently, methodologically, analysis is presented with a problem and a solution, the account that will be made around HIV will not attempt to displace or negate other accounts and their uses. Any disseminated piece of research on clinical practice, is limited in its scope. There are possibilities of referencing the networks of HIV at work, but not to definitively set them out once and for all. It should be accepted as being a prerequisite of the research process, rather than a flaw in the research (as is made clear in the small methods section of Mol, 2008). Perhaps the ANT principle of plurality can even be interpreted as being a strength because it offers the possibility of allowing research to acknowledge the utility of what could otherwise be deemed as contradictory

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<sup>36</sup> For example Latour is pressed on the question of metaphysics in a recording made of a discussion at LSE: <http://www.lse.ac.uk/collections/informationSystems/newsAndEvents/2008events/HarmanLatour.htm> [accessed 14 May 2012 16:28:27]

methodologically. It accommodates the requirement of the psychosocial search for causes, and also means that childhood can be allowed to emerge as innocent or naive and evaluated in the context that deems it necessary, rather than searching for a constructed imposition of naivety onto children (more on this point in the childhood section below). It does not necessarily mean that research is futile, lacking validity or inaccurate, the research will add to the richness of the social world and offer new perspectives, and possibilities entrenched in the accounts of actors themselves. This is an important point when considering ANT as a perspective that emphasises new and convincing paradigms beyond those already conceived in the psychosocial approach.

Therefore, the methodology of this thesis aims to facilitate a multi-directional model of power, participation, negotiation, protocol, the induction of knowledge, childhood ethical prerequisites and the consolidation of practice/participation with antiretroviral goals into the research account using the three principles of ANT/STS discussed above. These principles will be adapted to address how incompatible associations of paediatric HIV such as stigma and naivety are consolidated in the clinic into a coherent medicine, and how the clinic becomes a key site of formulating complexity into functional medicine (as presented in the previous chapter).

### Latour vs. Law: following the actor / enacting worlds

Now that these three methodological principles of irreducibility, the dual emergence of materiality and semiotics and the enaction of the social have been introduced, it is possible to turn to the question of how to follow actors? Two of the most extensive methodological literatures on using ANT in social research are Bruno Latour's *Reassembling the Social* and John Law's *After Method*. This section aims to clarify on how to follow actors through their associations and how the research methods are not only descriptive but productive of the realities they describe. In accordance to the context of the clinic, the consideration of how to follow such charged and contingent entities as childhood, HIV and immigration as they are presented and adapted to clinical settings is of foremost importance. Therefore, it is prudent to consider the extent to which theory can be applied to following associations such as these that are necessarily left ambiguous in contrast to biomedical research, and consider

what account is being produced when describing these associations and practices using ANT or STS. Methodologically, Latour (2005) and Law (2003) build upon the three principles detailed in the previous section whilst highlighting antagonisms arising from applying them in the field.

### **Bruno Latour, *Reassembling the Social***

In Latour's *Reassembling the social*, two relevant arguments are, firstly, caution should be shown when using the term the 'social' and secondly, that the 'controversies' presented by participants should be more closely followed than those inclined by the predispositions of the researcher. The first argument asserts that common concepts of the social give the impression of an entity, 'the social' that exists beyond any one individual and beyond any one situation, it has become an entity unto itself that is impossible to situate (Latour, 2005 p159-164). The book argues that society is the product of ongoing assemblages between human and non-human actors, and as such any description of an assemblage can be made up of many intermediary entities unable to be distinguished as solely political, cultural, scientific or social. Therefore, when using the word 'social', Latour asserts that it needs to be conceptualised not as a domain in and of itself but as a description of assemblages that references many others. For example, in clinical practice a trope often used in the literature is that clinical practice must be contrasted against the 'social' issues that children bring into the clinic that must be resolved or negated (especially how Gibb et al., 2003 uses the word "social" when discussing adherence, see chapter 6). The use of the word 'social' to refer to an ulterior domain obscures how other actions taking place within the clinic could also be described as social, and aspects of the lives of patients outside of the clinic could also be seen as clinical rather than purely social.

The second argument is that social research should concentrate less on its own theoretical presumptions or overarching ideas of society, and instead allow itself to be prompted by the 'ontological weight' of participants' accounts and the associations they describe. Social researchers must not sort participants into their own preconceptions, or dismiss, or undermine participant viewpoints. The researcher should allow the participants to inform what associations are existent and the value and structure of the social worlds they are

involved within (Latour, 2005 p165-172). He goes further to suggest that researchers should avoid going out *a priori* to define a social issue and instead feed off controversies as much as possible (Latour, 2005). This theoretical turn that emphasises following the participant, brings ANT and STS in to a cursory alignment with ethnomethodology. The key principle of ethnomethodology emphasises the pursuit of the perspectives of researched individuals above that of theory or the researcher. According to ethnomethodology, researchers are advised not to be guided by theory but instead to let theory come from “within [the] actual settings as an ongoing accomplishment of those settings” (Garfinkel, 1984 p8). The benefits of adopting ethnomethodology are already well stated as blurring the line of micro/macro sociology and the individual and society. This link with ethnomethodology is little stated or discussed in ANT methodology, however in two footnotes in a similar essay to *Reassembling the Social* on the conceptualisation of the ‘social’, Latour (2002) compares his approach to that of ethnomethodology. Latour (2002) acknowledges the similarity, stating that ethnomethodologists have daringly attempted to follow actors with no predefined structure in a similar manner to ANT. However, Latour also distinguishes that against its best efforts, ethnomethodology is constantly brought back to the ‘micro’ order of society. Latour’s (2002, 2005) version of ANT is one that can conceptualise associations between actors not as degrees that get bigger or smaller, or micro to macro dimensions that fit into one another like Russian dolls. Instead, Latour imagines following accounts as ‘flattened out’. This means that when following the accounts of actors referring to structures or scales, researchers should treat each ‘speech act’ as equal, never reconfiguring a structure but tracing the emergence of associations between entities.

On the basis of the above discussion, following paediatric HIV is not an exercise in configuring the structure of clinical practice. An attempt to describe social worlds must avoid recreating the social structures of the HIV clinic, with layers leading from practitioners to child patients. The example of ‘child rights’ evokes the notion of a hierarchical structure to paediatric HIV. Analysis of this structure could go from the clinic to the hospital, to the paediatric HIV hospital network of ‘hub and spokes’, to the CHIVA network of professions and then government policy and international organisations such as the UN (e.g. the “rights of the child” found in UN. Commission on Human Rights, 1999) *ad infinitum* (see Alderson,

2002). Or similarly protocol could stem from the WHO (WHO Technical Consultation, 2011) down through CHIVA guidelines and into the clinic. However, this overlooks the mutual constitution of these categories and the clinical negotiation taking place in their administration. Imposing structures such as these obscures the many possibilities made available to actors when negotiating these entities and the many more intermediaries found between each entity. This point will be poignant in research chapters as analysis relies upon highlighting clinical observations along with the guidelines of CHIVA, and many other protocols such as the American Pediatric Association (APA) and the results of drug trials. These different organisations could be seen as dominating or being dictated by clinical practice and I would not like to suggest that both processes are not occurring. However their interrelations with practice is multiple and contradictory and necessarily in negotiation with patients. The usages of guidelines, policies and scientific requirements have many capacities for practice, according to their emergence during each clinical encounter. Therefore, during clinical encounters which document is active is not so clear cut to isolate. Consequently, it is worth qualifying that when conducting the analysis of observations and the textual analysis of protocol, I attempted to follow actor's references that corresponded with protocol, made protocol relevant and so introduced aspects of protocol as an actor.

The next text on ANT methodology, Law's 'After Method', will be used to compare and contrast Latour's reflection on following the 'social'.

### **John Law, After Method**

John Law's *After Method* also discusses ANT methodology, but the recommendations that he reaches about following actors are not fully harmonious with Latour (2005). One of the main aims of Law's book is to explore how social methods itself is a particular assemblage. Building upon the idea that research methodologies have more than one possible version that can claim validity, Law puts forwards that method is not only a set of procedures for reporting on a given reality, instead arguing that research methods go onto produce distinct realities (Law, 2004b). This means that data collection is embroiled in the enactions of participants, and research results can contribute to the further enactions of the participants

(also see Law and Urry, 2004). Law (2004a) suggests that the act of creating an argument or account around a topic, gains its voice through necessarily silencing something else.

“Not everything can be known: it depends on what is not there. The argument is against what these philosophers call a ‘metaphysics of presence’: the idea that everything could be brought together and created or joined or known in a single location. What is being made present always depends on what is also being made absent.” (Law, 2004a, p83)

In the context of paediatric HIV some implications become clear and must be considered carefully, depending upon whom the account is read by (assuming that the account is read at all). Some immediate questions come to mind: Children and HIV is stigmatised and played out in confidentiality, therefore, how will our account modify the representation of the disease? E.g. is it possible that the public consciousness of HIV positive adolescents could be antagonised if adolescents are represented as refusing to take their medicine and posing a sexual public health risk to their community (Hekster and Melvin, 2006)? Moreover, if the agency of childhood is highlighted as having a productive role in clinical practice, can this adversely affect the imagination of innocence and naivety that may make possible other regimes of care (Cohen et al., 1999)? Also, in each consideration what am I making absent? The social construction of childhood? The psychosocial search for causes? Considerations such as these seem to imply that following the associations provided by actors should never be done naively. Firstly research should acknowledge the use and utility of other contradictory accounts, ensuring that it doesn't obscure the validity of other research, and secondly the researcher still needs to be acutely aware of the implications and applications of their planned research<sup>37</sup>, as is the case here. This poses a modification to Latour (2005) and suggests that a balance is needed between the absolute freedom given to actors and the hindsight required by the researcher when putting accounts together.

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<sup>37</sup> A similar consideration well formulated in research could be discussed in terms of research ethics, especially relevant to research with children (Alderson, 2007b). However, the sense as presented in Law (2004a) is not limited to ethics but broader implications in networks of representation, politics, culture etc



Both Latour's (2005) and Law's (2004) books talk of methodology in relation to ANT, and they are both written around the same time in the vein of 'after ANT' (see Law, 1999). However, there are some sticking points between the underlining principles of each book. The position this project develops on how to conduct research and the validity of the resulting research will vary depending upon which methodology is taken up. Two considerations come to mind, one of the ability of the participants to define their own worlds and the other of the extent that ANT can allow the researcher to imagine how planned research enacts versions of the social worlds it describes (this can be related to the discussion of an earlier antagonism between Latour, 2004a; and Law and Urry, 2004; by Fraser, 2006). If the study were to subscribe to Law's (2004a) considerations on the impact of its own methodology, it would consequently put in jeopardy the possibility of concentrating on the self definition of participants as the question becomes *who do we follow and for what reason?* Latour (2005) advocates a more intent focus upon the participant's 'absolute freedom and pliability' to guide research, rather than focusing on the social world the methodology is creating. Therefore, according to Latour (2005), it constitutes an endangerment of allowing participants to define the clinic and how they make it operational. On the other hand, Law's (2004) perspective suggests that the representation of the clinic must be made to fit into a thesis argument and must ensure that the research will have a positive impact. The methodological stance of this research does not attempt to resolve this antagonism in position.

Consequently, both texts have extensive implications for the description of clinical practice, Latour's approach attempts to ensure that clinical actors reference the ways the clinic consolidates care, whilst Law emphasises the need to ensure that the research deliberates over providing a coherent argument and positive contribution. Therefore, the method employed must offer a balance between the freedom given to clinical agents to self-define the dynamics of practice and the researcher's reflexivity on the effect of describing research findings in wider public arenas (which limits the extent that actor's can self-define).

## Childhood Naivety

One unavoidable preconception of paediatric HIV is that patients are seen in practice and research as naive, innocent and vulnerable (Allen and Marshall, 2008). Therefore, childhood and HIV in this context is not so straight forward to follow in the clinic or protocol and requires a methodological deliberation (beyond the balance proposed in the last section) as to how naivety and innocence should be approached in research. Without disregarding the description of following actors outlined above, the project's methodological approach to childhood will coincide with allowing the emergence of childhood as it is presented through the 'recording device' in the clinic, whilst still maintaining some ethical reservations around researching childhood and HIV (Latour, 1996). Childhood naivety and innocence forms one of the most extensive predispositions in the literature of SoC, including studies conducted around medicine<sup>38</sup>. For this project and paediatric HIV in particular, naivety and innocence have an extra significance because HIV has numerous cultural associations that are incompatible with childhood, such as sex and drug abuse, and subsequently brings about discourses of innocence and deservedness (Fassin, 2008). For example, when contrasting a child cohort whose HIV infection is perinatal against a wider public representation of the HIV disease as most commonly sexually transmitted, connotations of childhood innocence become significant (Henderson, 2006). As stated, connotations of deservedness, victimisation and orphanhood form impetuses for specific charity action to be taken and public interest into how the problems associated with this population are met (Boulton, *forthcoming*). In studies of HIV and childhood, innocence and naivety feature heavily in the descriptions of all aspects of the disease from representation and education to prevention and treatment (Mitchell and Smith, 2001; Mitchell C. and Smith A., 2003; Mitchell et al., 2004; Bhana, 2007; Bhana and Epstein, 2007). Therefore, this focus on innocence and consequent vulnerability is something already affecting our imagination of the condition before researching or reading accounts of HIV, or following actors. Innocence and vulnerability have a heavy bearing on researching clinical practice and the analysis of data.

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<sup>38</sup> Dixon-Woods et al (2005), Davis et al (2008), Christensen (1998, 2000) and Cohen et al (1999) offer useful examples of children being seen as innocent or incompetent in illness or disability.

Accordingly, discussions in SoC have charted the resulting relationship dynamics as they are presented in the clinic. Christensen states:

“In everyday child illness, interactions at home and school between children and adults draw on the traditional hierarchies and values of biomedicine in various ways: Parents and teachers are delegated responsibility, competence and intervention rights “rational” methods are employed in preference to children’s subjective experiences; children’s ability in giving and receiving affection is both valued as part of the reciprocity of human relationships but remains subordinate to other competencies; and children’s actual contribution to practical care is rendered invisible to adults.”  
(Christensen, 1998)

Examples from the clinic are times when the doctor negates a child by talking to the parents, or when parents control the administration of medicine to their child (Clark, 2003). Christensen (1998), along with SoC more generally, argues that commonly held perspectives in medicine and policy rarely see the child as participating in the ‘doctor’s’ clinic or in the administration of taking medicine. However, a contrasting literature also exists that argues against imagining ‘child actors’ as repressed, as it possesses a danger for researchers to misconstrue the extent of domination or the existence of dissent when out in the field (Robinson and Delahooke, 2001; Komulainen, 2007). Successive accounts within SoC have demonstrated the ways in which power between children and adults is not limited to one direction, i.e. from practitioner to patient, and have instead chosen to emphasise the many influences that children can pose in childhood assemblages, both complimentary or contradictory to the practice of medicine, confusing the question of how to follow child actors (Christensen, 2004).

The idea of power as enacted in one direction from practitioners to patients negates the many other ways in which patients could be seen to influence the interactions that take place in the clinic. For example, ANT could be employed to assert that in the clinical relationship between the practitioner and child, the dynamics of how the child, mother and doctor are brought into being and enforced is also an irreducible aspect of the condition. As

such it is not possible to reduce a child's agency from the clinical encounter, and therefore has no unspoken hidden agency ignored by 'adult' practitioners and parents (Prout, 2005; Lee, 2008). From this point of view the questions around dominance, competence and responsibility become doubly serrated and would suggest that the most important methodological procedure for the research will be an awareness and attentiveness of all the possible positions of research participants. However, the question of innocence and naivety remains. As already stated in the many assemblages demonstrated in the clinic around HIV and childhood, innocence still figures highly. According to the practice of following participants detailed throughout this chapter, allowing actors the freedom to demonstrate the emergence of innocence and naivety will offer a good guide on how to proceed. One issue that keeps coming up in research chapters however, is that with an object such as children with HIV, there always seems to be a 'residue' of innocence, naivety or ethics alluded to outside of any assemblage (or beyond the clinic) that is impossible to follow. It is not possible to fully follow all of the guises of this innocence, as it contains associations such as sex and stigma open to becoming sensationalised that have the potential to alter the interpretation of our recording device, the acute focus on clinical consolidation and the dissemination of any research findings, reverting us back to the discussion of Law (2004a). This confuses the recommendation of method, but has been highlighted here as it forms an important key unresolved reservation of the thesis in reference to ANT. It raises the question of whether it is correct to 'flatten out' and follow charged associations of childhood in the way Latour (2005, 2002) recommends in relation more generally to other objects? Consequently, considerations of childhood innocence will be followed up in the next chapter on ethics.

### **Implications for the Study**

The main point of departure for the first part of this chapter has been to consider how associations of ethnic diversity, urbanity, childhood, HIV and medicine can be followed from its 'emergence' through successive processes of formation and reformation in clinical practice. The discussion on methodology in this chapter leaves the recommendations on how to proceed far from clear-cut and makes the term ANT ambiguous and cautions researchers towards fully subscribing to it. Tracing the main discussions gives insights on

the principles of irreductions, semiotic and material processes and the assimilation of broader research accounts into our own account. Accordingly, in the context of paediatric HIV, following the actor through the clinic allowing them pliability has been interpreted as being best served by conducting ethnographic observations at the clinic, whilst following actors over the corresponding protocol referenced in the clinic. My participant observations have been designed to allow the role of practitioners, patients, childhood and protocol to emerge from practice in the research setting. My disposition when following actors has emphasised allowing actors' own references to other sources to define what is relevant<sup>39</sup>. This doesn't mean the attempt to gain a natural or pure form of the interactions taking place, as discussed, childhood vulnerability contradicts such a stance. Ultimately, the methodological stance of this thesis is that this account is also responsible for enacting the social worlds it describes and consequently a balance had to be struck between following actors with 'infinite freedom' and upholding the concerns of vulnerability in the conduct and dissemination of research (Law 2004a). Therefore, following actors in the context of the clinic has been designed to maintain an intent and continuous art of listening, prompting and probing of actors to uncover what is making them act and how they are being consolidated into practice. Research has attempted to follow the actors that accord with the formulation of medical doctrine and render viral suppression compatible with patient dispositions.

## Research Methods

For the remainder of the chapter I will explore how the considerations above translated into specific research decisions employed in the clinic and during analysis. The research site for this project was a small clinic for children with HIV at University Outer Urban Hospital (UOUH). Research began at UOUH with a loosely formed methodology borrowed from STS with the aim of applying it to children with HIV. Throughout fieldwork, the research conducted was also aware of the large body of traditional ethnomethodological pieces of fieldwork and drew inspiration from them, but infused them with STS and SoC, to focus on the processes that obtain reality rather than the centrality of subjects (I have in mind here "naturalistic interactionist" classics such as Goffman's *Asylums*, 1991; Atkinson's *Clinical*

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<sup>39</sup> Much as that of ethnomethodology but with the emphasis on following both material and semiotic actors

*Experience*, 1997, and *Becker's, Outsiders*, 1997)<sup>40</sup>. Therefore, I sought to be immersed in the clinic to uncover the materialities and associations emerging around HIV<sup>41</sup>, and modify the traditional ethnographic focus of behaviours, languages, definitions and attitudes of those studied (Denzin, 1988), towards the development of a stance that followed the objects, agency and potential associations present as informed by STS and ANT (Latour 2005). The following discussion will proceed by describing the field as it presented itself and the objects under study, before moving on to discuss how research was conducted in the clinic, finishing by detailing how the data was analysed and disseminated.

UOUH is a medium sized London hospital located between the boundaries of zone 3-4, affiliated to a University. I would go there on the train once a week and attend the HIV clinic held in the paediatric ward. Most weeks there was a clinic at 900 to 1200hrs, but twice every month there was also a second session in the afternoon from 1600 till 1800hrs. During the days when there was a second clinic I would attend both, leave at 1200 and come back at 1600. Research was conducted at the clinic for just over a year from August 2010 to October 2011, in which time I saw almost every consultation that took place with children who had HIV.

In comparison to other London clinics, the clinic at UOUH is relatively low scale with approximately only twenty children with HIV registered. This number however, is difficult to give definitively, the number of patients I saw during research was twenty two. But during this time, some patients registered were in the process of transferring to adult services which occurs around 16. One patient was not attending regularly for her own reasons, and others would drift in and out of the service due to immigration or moving between areas. There was a core of patients that had seen Dr Peters from a very young age right through to transition, but the population of the clinic on the whole was aging. Three new patients enrolled during research. One, Rob, coming from Zimbabwe, one new diagnosis (not

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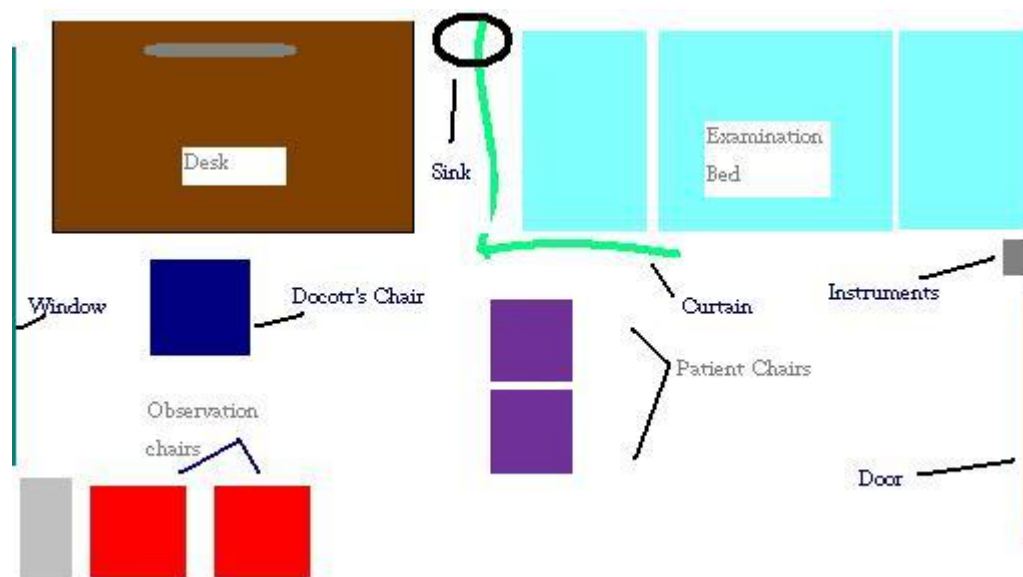
<sup>40</sup> I would not describe this account as a naturalist interactionist account, but I do not wish to ignore the wealth and tradition of relevant sociological work that has taken place engaging with the same problematic.

<sup>41</sup> My emphasis here to use the concept of emergence often used in STS as it focuses on process and not necessarily that of Denzin 1998, see section above on *Reassembling the Social*.

included in research) and one transfer Erica from Manchester. These were the first new cases at the clinic in 2 years and the first paediatric diagnosis at the hospital.

The clinic was run by one Paediatric Consultant, Dr Peters with the help of a specialist nurse who will be called “the CNS”. I was lucky enough to forge a good working relationship with Dr Peters who supported my study and helped me to organise research in the clinic. He came to fulfil the role of the gatekeeper, according to classical ethnography, defined as taking on the job of granting access to the researcher, introducing the researcher to the field and having a personal stake in the research (Whyte, 1988). With great patience, Dr Peters instructed me through the formal NHS ethics approval, guided me through the workings of the clinic and HIV medicine and would answer my questions, and discuss relevant issues in extensive detail. However, from the initial meeting with Dr Peters, he had made it clear that he would help me to understand the medicine, but he could not advise on sociology, so was leaving that part up to me to apply once I had become more familiar with the clinic.

In the usual clinic, I was sat down against the wall facing the doctor’s desk often alongside other observing professionals who were training or affiliated to other departments. The patient chairs were closest to the door and the clinic was arranged for patients to feel comfortable, and feel that they can come and go from the consultation room freely. All patients came into the clinic with their guardians, most were the child’s parents but in Bianca’s case she was living with her aunty as her mother had died and the father whereabouts were unknown.



2 A diagram of the layout of the consultation room, giving the reader an idea of movements in the clinic (not to scale).

Most patients at the clinic came from Sub-Saharan Africa. The exceptions being Abbey, whose mother was from Zambia and father was White-British, and Celina whose father was Afro-Caribbean. A selection of the stated countries of origin for the population studied were Ghana (with the majority), Zimbabwe, Congo, Ethiopia and Angola. All the children could speak English, most of the parents could also communicate in English. However, there were three parents that had difficulty in English and on one occasion a translator was called in. Some adolescents had to explain words to their parents on occasion, especially the mothers of Tabitha and Virgil (who are all discussed further in the empirical chapters). The majority of the population that the research investigated was children who had had HIV perinatally transmitted to them (Foster et al., 2009). Most cases were traced back to transmission from mother to baby, but the team were uncertain in some cases, like Erica's, who was diagnosed at the hospital aged 15, so research settled upon the looser terms of, paediatric HIV for denoting the medicine practiced on individuals under the age of sixteen<sup>42</sup>, children with HIV to refer more generally to populations of adolescents and perinatally acquired HIV to describe the infection route.

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<sup>42</sup> This consideration leads to questions of assessing the differences in defining the condition between other possible ways of transmitting whilst young, what is the significance between alternate transmissions? Principally through sexual abuse, as this was suspected in Erica's case, and how care and medicine must adapt differently to this situation (e.g. adolescent testing Emmanuel and Martinez, 2011; Mullins et al., 2012).



Therefore, led by the STS methodology described above one of the early delineations was identifying which actors to follow in the consultation room. The terms of 'perinatally transmitted', 'children with HIV' or even 'paediatric HIV' that were originally used to set up and conceptualise the project instituted a broad scope during the first days of fieldwork. Children were followed through the state of the HIV infection; between different clinics; over different communities and over different individuals<sup>43</sup>. In practice, this meant investigating the interactions of children with HIV and medical staff, but also tracing the coalescence of medical protocols with the lives of children/adolescents, the role of the doctor who must administer care and channels of medicine, as well as tracing other associations referred to in the clinic. The encounters that were deemed as principally important were situations where the concerns of patients and medical practitioners intersected. Through this process of allowing participants to inform research, the procedures of disclosure, adherence, chronic illness and transition, became prominent. All of these procedures figure heavily in both discussions at the clinic and in the literature and made themselves prominent in paediatric HIV health care and were also followed in research.

Before starting research I had to gain ethical approval from an NHS ethics board, through the Integrated Research Application System (IRAS). This process took me six months in total. During this time I wrote an initial formal ethics application, and had it reviewed in front of a board of around seven people, the first application was rejected with recommendations about how to amend it in order for it to be ethical. After I had made the amendments and attended a second review meeting, it was approved. The process made me think extensively about my research and its ethical stance and is dealt with in more detail in the following chapter on ethics. One of the main outcomes of the meetings was the problem of informed consent. Initially I had made one information sheet for all participants, but the board wanted me to focus more specifically on gaining informed consent with individual sheets for children and adults in a different and more accessible English. When in the clinic, on my first meeting with parents and children, Dr Peters would

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<sup>43</sup> Research methods of children and medical settings forms its own field of study (Woodhead, 1999; Alderson, 2001, 2002, 2007b).

give patients and their parents an information sheet and consent form and inform them about the study. This was done in the consultation room, as it would have caused confidentiality problems if done in the waiting room. Dr Peters then gave participants the option of asking me to leave the room. Overall, the parents and patients of the clinic's cohort were keen to allow me to observe, often parents would comment when I gave details of my study that they thought it was a good thing to generate more information about the condition. The most major concern for all parents was that their personal information remained confidential, which I informed them that I would stringently do by anonymising them in anything that was written including notes. Another concern was observing patients that had not been disclosed to. For these children, Dr Peters would ask parents for their consent on behalf of the child when children were in another room from their parents getting a blood test. In these cases I didn't approach children personally or observe practices such as disclosure sessions outside of the consultation room in case my intervention would lead to an unwarranted disclosure.

The first point of data collection for the project was observing consultations. Observations were undertaken as the primary stage of field work to fit the pre-requisite of maintaining an insight on the 'associations emerging' at the clinic whilst applying as little of my own preconceptions as possible in accordance with the work of Latour (2005) outlined above. Rather than turning up for every clinic (the clinic also saw cases of prenatal HIV prevention and the HIV testing of 'at risk' children), I only attended clinics that had children with HIV booked. During these clinics, I would sit in the consultation room for the duration of the session (in the style of the advice given in Hammersley and Atkinson, 1983).

I often felt like I occupied a strange place in the clinic compared to other professionals and I would sometimes be mistaken for a junior doctor (SHO). To patients in consultations Dr Peters would announce me as a sociologist, inform them that I was conducting research and ask if it was ok for me to sit in. Even after the initial consent form had been given to patients, Dr Peter's would still announce me at each consultation and it would often seem like patients would forget who I was and my purpose. From a patients' viewpoint, my observations seemed to make me indiscriminate from the other regular visitors who would

be sitting in on the clinic and would also have to be announced. Patients at the clinic were used to being observed. Even though I did the utmost to inform participants of my research intentions, the space of the clinic is a place where patients take for granted the fidelity of practitioners. I took on board the trust of patients and responsibility of access to consultations to make my presence as unobtrusive as possible and use the data collected in a responsible and useful way. Most practitioners would also get on as if I was not there, or at least I could not detect a difference. Perhaps there were incidences where I would make someone uncomfortable or modify the behaviour of professionals attempting to be seen in a positive light, but as there is no way to confirm this, I sought to document as best I could the context of each clinical encounter. I questioned my role as observer in relation to classical ethnographic texts<sup>44</sup>, like for example Junker's (2004) *the Field Work Situation*, which provides a matrix between observational styles. On one side, he places observational roles pertaining to heavy involvement with groups under research, citing two roles: 'participant as observer' and 'complete participant', and on the other side roles of comparative detachment to the research site: 'observer as participant' and 'complete observer'. Amongst these roles, I'm not sure which role I attained, at different times in the clinic I would switch from being detached to attached, all the while questioning which actors I was following and the 'social' that I was responsible for enacting (Law and Urry, 2004; Latour, 2005). I would often talk to practitioners and patients. However, I rarely intervened during consultations and so I did manage to have some detachment from participants.

When the doctor began his consultation with the patient or family, I would take notes in a spiral bound A5 jotter. As most consultations contained complex discussions of medicines and regimes, I would often fall behind, and had to develop a shorthand in order to keep up. Faced with the classical dilemma, of *what is it important to document*, Lofland et al. (2004) pose a list of things to look out for: acts, activities, meanings, participation, relationships and settings<sup>45</sup>. However, due to STS methodologies already predisposing the relationship

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<sup>44</sup> Also following on from accounts such as Corsaro (2003), I came to question separately the capacity with which I could observe the children under study. Especially the nature of the adult/child relationship that was present between those being observed and me.

<sup>45</sup> The question of what to put into a research account and how to take field notes is beautifully rendered in Taussig (2011), when reflecting upon drawing he has made in his fieldwork notebooks.

the researcher must have towards objects and networks, these categories were not approached as already defined, needing instead to emerge from the data. Each one is achieved with the participation of all actors found at the research setting. Instead, I tried to allow participants to define units of analysis by following what they chose to emphasise and how they would put them together. This may have resulted in some entities becoming more prominent and others hidden, like associations of childhood<sup>46</sup>. I deemed it necessary however, to investigate what participant emphasised, and why these associations are taken up. In effect engaging with questions of what makes the medicine functional (as well as grounding how I choose to conduct research whilst still adhering to Latour's 2005 conception of Sociology).

Before beginning research at the clinic I had toyed with the idea of tape recording consultations (even putting this forwards to the ethics committee), but after discussing it with the HIV reading group of other PhD student based around Goldsmiths I decided to take notes instead. In retrospect, I still welcome this omission as what would have been gained in precision, would have been lost through the awkwardness of the device being present. Taking recordings of consultations would have also provoked a series of ethical dilemmas as in most cases parents are concerned about the disclosure of their HIV and the recorder would have had big implications as to how consultations were conducted (Lee, 2004; Back, 2010). Taking notes allowed me to fit in more as an 'insider' of the clinic for both patients and doctor alike, my presence was more negotiable. In effect however, the examples that have been detailed in this project are approximations based on the notes taken in clinic and my memory when I came to write my notes up. Reminiscent of some of the central themes of the essays found in Clifford (1992) who notes:

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<sup>46</sup> I was acutely aware of discussions that exist in the Sociology of Childhood around the voice of the child and how to think about documenting it in the account. As it would alter the way that notes are taken in relation to things that children do not say. In the end I decided that this would constitute an over emphasis on the child, and so I have tried to keep the documentation of children's actions relative to those of adults (James et al., 1998; Komulainen, 2007).

“Ethnographic writing is allegorical at the level both of its content (what it says about cultures and their histories) and of its form (what is implied by its mode of textualization).” (Clifford, 1992, p98)

On most occasions during the consultation I didn't say anything other than smile and say hello, but there were situations where I was included in incidences that would unfold in the clinic, like when a parent misplaced their bag, the doctor would lose his pen, or parents would lead a discussion about sociology. Over time, parents and children got used to seeing me in the clinic and so I began talking to many of them on the occasions when the doctor would have to leave the room or when the doctor and child would go for blood tests. As stated, my role as observer therefore, changed in relation to what was taking place in the clinic. On the occasions where my note taking was deemed inappropriate or against the wishes of the parents, Dr Peters would usher me out of the room. This happened on three occasions, twice when he wished to have a private conversation in the process of disclosure, where the child was shy to talk in front of more than one person and once when discussing a personal grievance between a parent and the hospital.

Between these consultations, Dr Peters would often inform me and other professionals present about some of the case histories. This was a major point of functioning for the clinic, he would discuss narratives and developments with the CNS, with Dr Phelps from CHH who would come in once a month to advice and to coordinate, with Dr Chambers from the adult ward T1, with the pharmacologist and at once a month meetings for all members of staff at the ward. These types of narratives were for a myriad of different reasons but became a great source of data for the project. In time, once I became more familiar with the cohort of patients I also became part of some of these stories and narratives (White, 2002). I wrote notes during these moments or just after them, if I was required to verify the story. Stories, narratives and discussions relevant to care or the running of the clinic also proved challenging for note keeping for additional reasons as statements useful to the research would often start and stop very quickly and come out of nowhere (see Atkinson, 1995 on “medical talk”). As time went on and I understood more about the functioning of the clinic, tracing these discussions and passages became easier.

As part of the ethnographic approach of the research, during my time at the clinic I had many direct dialogues with professional participants. These took the form of ethnographic style interviews (i.e. asking impromptu questions, or formulating questions and discussion points between days attending to bring up at opportune moments) with parents and professionals to more formal recorded interviews with adolescents (Spradley, 1979 defines the ethnographic interview style). To organise interviews with adolescents, initially Dr Peters assessed which patients were suitable for me to interview and those that were not. This was dependent upon how much the child understood about their HIV, or the family situation. After I had sat in on at least two consultations with participants Dr Peters asked if the child would also be willing to take part in an interview<sup>47</sup>.

Not all of the children who were observed in consultations were eligible to be interviewed. Children who were unsure or getting used to their diagnosis were not included. The clinic puts many resources towards disclosing HIV in a way that will introduce children to the diseases and its implications in a gradual and gentle manner. It was deemed that any questions that I would have asked children at this stage or even the act of conducting an interview itself would be damaging to this process. There were also some children that were not asked because Dr Peters deemed that it was not suitable for them to be involved in interviews, for example for families who had a lot to deal with already like transition, busy schedules or who had other appointments to attend to (see Bluebond-Langner, 2005 on children's participation being dependant on contextual clinical factors). In traditional naturalism, this would have obvious implications for ideas of representation, but it is a consideration that had to come second to the possibility of causing harm or distress to participants (e.g. Hammersley and Atkinson, 1983; Denzin, 1988, 2003). All is not lost however, according to the principal of STS that stipulates participants should define relative size and scale, the selection of 'who it is acceptable to interview' can be seen as a finding in itself of the process of a number of medical procedures that ensures good practice (like disclosure to be discussed later). In total, I conducted six interviews with adolescents from

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<sup>47</sup> Research involving children must satisfy specific ethical prerequisites in order to get ethical approval, see collection of Greene and Hogan (2005) and preceding chapter on ethics.

the ages of 12-16, these were done in a spare consultation room after the patient had completed their appointment and were recorded onto a dictaphone. I have been hesitant to place a lot of prominence on these interviews in the analysis, but they have been important in offering a different perspective on occurrences at the clinic and procedures such as adherence and disclosure.

Research had to fit around the busy activities of the clinic and of the ward in general. Any observations, conversations or interviews that were carried out had to fit in around the schedule of the clinic, consultations and blood tests. Other constraints on schedule came from the parents or children who had to go back to school, or had places to be, or did not want to spend their time to talk to me for whatever reason. It is important to consider how these constraints of representation, the trust of the doctor, the confidence of parents and adolescents shaped the research. Before consenting their children to the study, most parents were worried about confidentiality and it became important to go through the information sheet and fully explain to participants the processes in place to ensure confidentiality (Alderson, 2002). Adolescents in the clinic had the chance to refuse to take part but most were keen to answer my questions. A further problem in gaining consent was caused by the fact that the information sheets said HIV on them. Parents and adolescents did not want to take away anything that said HIV on it in fear that somebody may find it. These factors may seem trivial, but they do have a bearing upon how the field presents itself.

I was fortunate enough to form a positive relationship with all the staff and am especially grateful to Dr Peters who acted as my 'gatekeeper' giving me access to the clinic and being patient enough to answer my questions and introduce me to much of the medicine. Therefore, the analysis and dissemination that follows research is not a task in criticism or to highlight the failings of the medicine and has been written to avoid these connotations, instead it attempts to describe the specific occurrences that took place in the clinic, what constitutes the medicine, the condition, and how these entities relate in the treatment of Paediatric HIV.

Research chapters are set out to retain the associations present as accurately as possible. And analysis runs directly from incidences at the hospital. Data that is used as an example attempts to retain what was actually said and who said it. However, as note taking or the process of adapting a situation to text can never claim to capture an unaltered piece of reality, there will be discrepancies between the 'reality', that is written and the ways in which readers will interpret the text. For example, even the difference between child agency and attributing 'weight' to the research accounts of children can never be neutral. Whether trying to over/under compensate for the 'voice' of the child, it will always be altered through the readers stance towards childhood (a debate running from Alderson, 1996; to Komulainen, 2007; and Lewis, 2010). Therefore, it is more realistic to say that the analysis of the data collected has taken place over stages, where data has been ordered and made relevant in order to make a final research chapter and then a doctoral thesis. Notes and interview recordings that were taken at the clinic were entered into a word processor, attempting as much as possible to transcribe notes whilst the incidences were still fresh in memory. These documents were then analysed using Nvivo. When actors reference structures beyond the clinic, such as policy and protocol the reference was followed through these documents into a textual analysis (Fairclough, 2003). The references between practice and protocol are not often explicit and so require a certain amount of abstraction to ascertain which jurisdiction actions occurring at the clinic were under. For example, when an entity like disclosure or adherence is referred to, there is often no specific reference to the guidelines such as those found on CHIVA.org.uk, but there is nevertheless a correlation between the two and the impetus for clinical actions can be followed into the protocol. Therefore, the relevant documents pertaining to procedure were analysed alongside the data placed in Nvivo from the clinic, where the focus was on following the impetus for 'actors to act' (see Mützel, 2009 for corresponding discussion of ANT). In Nvivo, case notes were viewed alongside each other with the policy and guideline documentation pertained to in clinic, allowing relevant sections to be 'coded' together (borrowed from the grounded theory approach with reservations Glaser and Strauss 1999, STS emphasises that the associations that are followed are the ones provided by participants, the creation of codes therefore was as much as possible factors that participants would provide themselves). The use of Nvivo to render data collected in the clinic forms a particular



adaptation of what could be construed as 'research data' and allows certain versions of 'sociological conceptualisations' to come into being (Law 2004a). For this reason, I deemed it important once the data was coded to go back over the coding and consider its context carefully. In relation to these considerations Latour (2005) advocates using three notebooks, one as a log, the second to record data and the third to write in as research is going along. Although this research did not formally adopt three notebooks, I have noted and endorsed the task of distinguishing between processes of producing data which are not so easily defined and placed between one part of the research and another. This suggestion helps to ensure that data is reflective and relevant to the process that made the researcher document it in the first place, beyond that of grounded theory.

As a result, although abandoning the idea that my analysis could create a wholly accountable and verifiable version of events, the resulting thesis contains a salient analysis of the relationships that occur in clinical practice and the logic employed to organise the context of paediatric HIV to regimes of care. As a result the ensuing thesis offers many accounts of contingent negotiations between child patients, families, professionals and protocol.

## Summary

The discussions that have been presented in this chapter serve to provide an insight into the logic used in setting up the research. The first section of the chapter discussed the methodological stance with which I have approached the subject under study. It considers how to make it possible to follow actors that are seemingly chaotic, through the consolidation of childhood, HIV and antiretroviral requirements in clinical practice, and the limits of rendering this complexity into one coherent account. The second section on research methods charts the process of how data was collected in the clinic to encompass the existing dynamics between patients, practitioners, protocol, procedure and practice. Overall, this chapter provides a discussion of how actors have been followed through paediatric clinical practice as 'emergent' in order to observe how practice consolidates patients' attitudes, dispositions and associations such as naivety, vulnerability and

innocence into care requirements. This is built upon in the next chapter through a challenge to the ethical position adopted whilst carrying out this thesis.

## 4 Ethics and Paediatric HIV Practice

This chapter has been placed between the methodology and the empirical chapters because at each stage of this project, from compiling literature, to research in the clinic and dissemination of research findings, the ethical deliberations of HIV and childhood have emerged in ever more challenging guises. This section is not wholly methodological or empirical but fits between the two.

The chapter examines the ethical issues resulting from this thesis and its relation to the clinical procedure of paediatric HIV. As the process of gaining ethics was relatively extensive, I decided to produce an extended ethical supplement for the project. What follows is a discussion of the formal ethical procedures applied for, alongside other ethical deliberations encountered during the project. In particular one incident is discussed where the ethical principle of informed consent turned into an unethical scenario that risked a breach to confidentiality in the process of giving an information sheet to an adolescent patient. Rather than approaching ethics as a simple code that can be applied to any situation, or an absolute set of principles that governs the acceptability of research, the project sees ethics as a complex process that emerges from within the networks where it is applied and implicated. The value of an ethical consideration, good or bad comes from all the entities involved in the emergence of a specific enactment. The argument here will link to ideas already developed from STS that place the clinic as a key site in the consolidation of guidelines and medical requirements with associations, such as stigma and naivety, patients present during practice. Amongst these processes of consolidation I would like to introduce ethics as a deliberation that must be negotiated in each clinical encounter, and subsequently in each decision made during research. Fraser (2006) argues that many see

STS, and in particular work by Latour, as lacking a sustained ethical approach. I will discuss this claim using Latour's *Politics of Nature* in reference to Fraser (2006), and to this account I would like to offer a second dimension from Latour (1992) around the ethical design of objects and other ethical themes arising from STS more generally. The application of STS to ethics is made particularly significant in this thesis because of the complexity of ethics in relation to paediatric HIV. In this chapter, the discussion of these texts will be related to what this style of ethics means for the project. The discussion is split into three main sections, the first one examines the formal ethical approval that the project had to gain, and through using STS, what sort of ethics these procedures generated. The second challenges the concept of what ethics meant in the 'field' by offering an example where formal ethics was difficult to adhere to in the clinic. The third brings the discussion together with considerations of childhood and the problems that it causes for an STS version of ethics. The discussion does not aim to draw a clear conclusion about ethics, rather it considers the problem of ethics for the specific situation of researching paediatric clinical practice in HIV and highlights the problems found in relation to using STS and SoC literature.

## Informal Versus Formal Ethics

Before fieldwork could begin in the clinic, the formal ethical procedure of the NHS dictated that the research had to gain approval through IRAS<sup>48</sup> from a Research Ethics Committee (REC), and R&D at UOUH. For this process, applicants fill out a lengthy online questionnaire about their research and research design alongside a set of predefined issues. The completed form is then logged, sent off within four days, and an appointment to have the form evaluated in front of a committee is booked. This procedure is designed to make researchers reflect on what could potentially be ethical issues in their planned research. It could be argued that the completed form creates a comprehensive set of principles for the research to follow (Parker et al., 2005; Taylor HA, 2007; Jong et al., 2012). For illustrative purposes, below are a few details about the REC form followed by how the project fulfilled REC requirements to gain formal ethics approval.

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<sup>48</sup> Integrated Research Application System (IRAS) <https://www.myresearchproject.org.uk/>

Among the first questions on the form are a series of tick boxes to be filled in if research will enrol one of the identified vulnerable groups i.e. children, those unable to communicate, those with a criminal record. The form then goes on to ask applicants to make an assessment between on one side, whether their research is worthwhile and of scientific merit and on the other, the amount of risk or burden it would place upon participants. Once this criterion is met, the rationale of the remaining sections of the form is to provide the committee with enough information to judge whether specific aspects of the design are ethical. For this purpose, the form goes on to ask for a summary of the main points of the project and its scientific rationale. The rest of the form is split into sub-headings that require a research specific response to predefined ethical issues of medical research. In order these sections are: Research participants including the inclusion/exclusion criteria, research procedures, length of study, extent of intervention, risk to participant and myself partaking in research, recruitment and informed consent, confidentiality, incentives and payments, notification of other professionals and publications and dissemination. The final sections ask the researcher to detail again the scientific review undertaken and management of research. Before beginning research in the clinic I made two applications through IRAS, reviewed over two separate meeting by the same board. The whole process took me around six months.



**3 a scan of the completed IRAS form submitted for this project**

Armstrong (2006) traces the development of conceptualisations of ethics in British medicine, such as those contained in IRAS. He argues that the roots of medical ethics do not arise through considerations of patient well being, but through branches of professional conduct and later public health. He puts forward that early ethical doctrines were mainly concerned with professional etiquette, and the description of the duty of the physician to their patients was brief. Armstrong states that one of the main aims of ethics was to protect the discipline from unqualified practitioners while promoting the interests of medicine generally. In the 20th century, ideas of how health was caused by external factors infiltrating the internal body shifted ethics to questions of maintaining the integrity of a respective body. Later in the 20th century, ethics developed into seeing professional or social aspects as being potential sources of threat to a patients' health. Bioethics emerged as a compliment to the medicine. The history of ethics is therefore not continuous but engaged in the development of medicine, ideas of public health and within the understanding of the causes of health problems:

“This idea of continuity pervades the history of ethics but, [...] within the last two centuries alone, medical ethics has shown remarkable shifts in focus and it requires a major effort to link each of the recent strands – from questions of appropriate etiquette to protecting the patient from the doctor – with a long distant past.”  
(Armstrong, 2006, p878)

Ethics goes from being something not associated with the body, to relating to internal pathologies and the transmission of dirt and pollution to internal parts of the body, to considerations of how the processes of treating the body can be potentially harmful.

Rather than taking Armstrong’s condensed history as a complete representation of ethical developments, it is more useful to consider how Armstrong has contrasted historical perspectives of ethics. From these perspectives, the model of ethics that is used to review the IRAS form is decentred<sup>49</sup>. Aspects of the ethical code can be seen as altering according to their context rather than their intrinsic values (also see O’Reilly et al., 2008). One intrinsic logic to REC procedure is that it makes researchers speculate as to the potential harm or discomfort that research could cause to participants or themselves (Department of Health, 2005, 2001). That is to say, it asks researchers to make a context specific evaluation of their research. Therefore, as with any other project, my application included a number of measures that the research sought to incorporate in order to meet with REC policy.

One of the most significant considerations (as it will be visited later on) was that parents and children would be given information sheets at least 24 hours before they gave informed consent. To meet this requirement, I verified that information sheets would be given to participants when they attended the clinic and consent would be taken at their next consultation around 3 months later. Formal ethics under this notion has the role of being a

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<sup>49</sup> The Department of Health (2005) poses an example of a medical ethical model that implies ethics as continuous

safeguard against un-sound research<sup>50, 51</sup>. Discussions such as these have a wider bioethical context and have a hotly debated politics and constitution (Widdows, 2007; Ashcroft, 2010; Petersen, 2010)( also see Armstrong 2006).

I would like to foreground these discussions, and approach the debate by asking if the completed ethical application is all there is to acting ethically? Does the formal REC code offer a sufficient basis from which all subsequent actions taken during research can refer back to? Just how broad can the scope of formal ethics considered to be? And how does it relate more generally to the ethics emerging from clinical practice?

To begin to engage with some of these questions, I would like to use Latour's *Politics of Nature*. According to Fraser (2006), *the Politics of Nature* can be interpreted as offering an approach to ethics that does not engage with a fact and value approach, recommending instead a situation based evaluation of the quality of the specific process involved in making something ethical. As Latour himself states:

“Behind the false distinction between facts and values were hidden an essential question about the quality of the procedure to be followed and the outline of its trajectory, a question now liberated from the confused quarrel that (political) epistemology sustained with ethics.” (Latour, 2004b)

Moreover, in *the Politics of Nature*, Latour argues that his version of STS (applied to environmental politics) involving specific material and semiotic networks cannot exclude but is rather nourished by moral preoccupations. Latour (2004) would see each moment where ethics is denoted as being a unique ethical assemblage. Acting ethically under this notion

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<sup>50</sup> A further set of policies that I incorporated were to only interview children who had sufficient knowledge of their HIV to ensure that I would not disclose anything that they didn't already know about HIV was: to detail that the storage of any data that could identify participants would only be stored on secure university drives, to confirm that Dr Peters would identify potential participants independently, and more generally, to make sure that I recognised the sensitive nature of qualitative medical research in consultations and interviews and confirm that if the research would cause discomfort or was unwarranted at any time I would leave the consultation room or cease the interview and withdraw them from the study.

<sup>51</sup> Also see ESRC Research Framework 2010

[http://www.esrcsocietytoday.ac.uk/ESRCInfoCentre/Images/Framework%20for%20Research%20Ethics%202010\\_tcm6-35811.pdf](http://www.esrcsocietytoday.ac.uk/ESRCInfoCentre/Images/Framework%20for%20Research%20Ethics%202010_tcm6-35811.pdf) [Accessed 17 May 2010]



therefore, is a process where objects are temporarily aligned or misaligned to render actions ethically acceptable or unacceptable.

According to this principle, every project evaluation that is undertaken by the REC must involve an independent set of context specific relationships between the form, the research team, the committee and extraneous entities. Therefore, what is deemed as ethical during these evaluations is not exactly the same between different projects, different members, and different RECs over the passing of time. Furthermore, this highlights the ways that the REC must preside over the ethics of a project from an abstracted position in the interests of a certain form of science, and can never permanently declare that a project is ethical or unethical. Instead, it judges over the conduct implied in the research plan at a distance, to assess if it is ethical towards participants, and if the project has a scientific rationale which makes it worthwhile (Fitzgerald et al., 2006). The ethics themselves are not contained in the final report of the judgement of the REC. What will become of the ethics will also depend upon what happens in the many instances when the research is being carried out. The research plan discussed between the researcher and the REC becomes a set of rules agreed upon and constantly re-applied to the research of clinical practice thereafter.

NHS type ethical frameworks are implicated at many levels and the reasons why it is important to adhere to them forms a wider argument around facts, values and morality (STS seems to imply). However, making this project ethical is a larger task, the ethical considerations that will shape fieldwork will be more complex, broader in scope and implied at all stages of the research. Adhering to an ethical code will be a task that will mediate between every subject under research from inception to clinical practice to dissemination (Dixon-Woods and Angell, 2009). Rather than creating a line between what would traditionally be seen as formal ethics and informal ethics, each ethical consideration can be seen as being part of a larger process of enactments that gives ethical systems their value. Therefore, the ethical considerations of this project must negotiate many diverse stances of what is ethically right or wrong, not one single ethically right or wrong social world or

clinical consultation.<sup>52</sup> (As can be seen through Gino's alternative adoption of ethics found in Callon and Rabeharisoa, 2004 discussed in chapter 2).

## **Complex Ethics**

This pulls into question the concept of creating a predefined ethical code before research begins. Many of the ethical decisions that are made whilst carrying out research would not specifically make it on to an REC form about ethics. In addition, what is deemed as ethical can be different between the process of applying for formal ethics and what occurs at the research sites.

I will use the example here of a discrepancy that opened up in the field concerning the information sheets (IS) for the project. To recap, it was required for my submission to the REC that the application included a pre-made IS, to be evaluated and approved before being used. For this purpose, I designed an information sheet that attempted firstly, to contain easy to follow digestible information that was as comprehensive as possible, and secondly, to act as a resource that participants could take away, reference, and question me about. In my first application to the REC, an integrated information sheet was presented and reviewed in front of the committee. The application was rejected as amongst other reasons, the IS was deemed not to be comprehensive enough for each particular group taking part. The board suggested that I created separate sheets, one for adults and another for children in a more basic language<sup>53</sup>. Following reevaluation, these information sheets were then approved with minor errors to correct. The task of applying for ethical approval is an extensive one and if an application fails, a researcher must wait at least a month before the committee can reconvene and re-review the application (Department of Health, 2001). One of the criteria that the committee judge an information sheet from is how well participants will be able to understand why they are being asked to take part in the research. This was interpreted as a task that must reference HIV in order to explain to

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<sup>52</sup> This is not to suggest that ethics are valueless, instead their values are contained in the networks they are enfolded within, and have a value amongst the actors and objects they are enacted alongside. (Williams-Jones and Graham, 2003)

<sup>53</sup> Faden et al., (1986) have charted the history of informed consent and document much of the legal, moral and philosophical framework of the concept.

participants why I am researching HIV and childhood. In the moments when research was being formulated, complying with this task seemed wholly ethical (Examples of the information sheets and consent forms can be found in the appendix 1.1 -1.4).

I was aware of how stigmatising HIV was relative to other illnesses (I had spent some time at a charity before researching in the clinic who informed me of the difficulty of organising events, or raising awareness as parents and children would be wary to pick up a leaflet with HIV written on it.) At the clinic however, good services rely on giving patients precise and well thought out information. Supplying articles that have HIV written on them, such as antiretrovirals and pamphlets are essential to providing HIV healthcare. Many groups like charities, the clinic and drug companies do attempt to give out paraphernalia with HIV written on them, so it did not constitute an ethical breach per se, and when completing my IRAS application I did not see any reason to change the IS<sup>54</sup>.

In the clinic I gave out information sheets with the Consultant present, he would usually introduce the study and then I would explain it, and give participants an information sheet, asking them to take it away, read it and think about taking part. The last thing that I would explain is that the sheet had the word HIV on it and participants should be aware of where they put it. For me it was a simple matter of them looking after the sheet, but for a few participants the issue became more serious. One distinct example was a patient I will refer to as Jemima, who chose to let the specialist nurse hold on to the sheet because she had sports straight after the consultation and was afraid that somebody might look into her bag as she was changing. In this situation, a formal ethical requirement came into conflict with the situation at hand in the clinic and switched to become unethical<sup>55</sup>. The fact that the document was potentially risking a breach in confidentiality of the child's status arose from the method employed by me to create a document that sought to provide the maximum amount of transparency to participants. Although participants must take and sometimes

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<sup>54</sup> Savage (2000) provides a discussion from a practitioners view-point of identifying issues when conducting ethnography in the clinic, emphasising the need for contingency.

<sup>55</sup> Possible ways that I could have resolved it during planning were to not use the word HIV and instead 'your condition' but this would then allay even more ethical considerations of the possible interrogation if found and participants may not be clear as to why they are taking part.

hide boxes of antiretrovirals from undisclosed family members at home, it was unreasonable in this situation to ask them to conceal yet more incriminating artefacts. The decision to let participants read the sheet in the clinic was not the ideal formal ethical situation imagined before research. One of the functions of the sheet was to be a reference at home for participants to refer to. However, in this situation it became more ethical to let the participant read the sheet in the clinic, and inform them to contact the clinic with any questions, who would then be able to give out my contact details. This demonstrates how ethics worked in practice (see Gallagher, 2009 for other case studies involving childhood).

Following the discussion of Latour earlier, positions the ethical considerations amongst all of the objects and actors found at the scene. In this instance with Jemima, an ethical paradigm was set up between me, the Consultant, the information sheet, her bag, her classmates, her parents, the school, the clinic etc. It could be asserted that ideally, all potential ethical issues should be identified and planned-out before research begins. However, the specificity of the ethical set up found in this situation is too complex to pre-empt on an ethics form, and even if it could be pre-empted, it would be a lengthy and unpractical task to detail it all in one form.

This leads to an idea of ethics as something that must be re-formulated and applied at each successive moment in the research. Every event of the research must be judged as to whether it is acceptable or causes harm to participants or the researcher, it is not the simple application of a code but something emergent alongside all other entities in a specific situation (Latour 2004). In accordance to this view, it could be suggested that ethics is irreducibly bound with the situation that it is enacted within, and is altered between the different places where it is enacted (see *Irreductions* in Latour, 1988). Moreover, rather than ethics being a singular entity, there can be discrepancies between ethical considerations that overlap or contradict each other depending upon the context in which they are applied. There is more than one ethical consideration at play during these encounters at the clinic. One is the desire to provide participants with a resource that explains the purpose and procedure of the research and gives them details of who to contact if they have any problems or questions. Another is the fact that it is the

researcher's responsibility to maintain or avoid situations where there is a risk to breach confidentiality (Benjamin and Sohnen-Moe, 2004). For these situations, the pursuit of the ethical action emerged from the interaction itself and involved the application of considerations developed outside of IRAS. According to Latour's (2004b) version of ANT, ethics would not be something that humans send out in their interpretations of the natural world (as in the Copernican revolution stance). Ethics are not a set of considerations that are wholly deployed by a human actor when navigating the outside world. Instead, ethics are created through the interaction between human and non human-actors together (Shaviro, 2009). Objects such as an Information Sheet and a gym bag are able to cast ethical agency with humans. The IS is designed to act as an intermediary that attempts to pre-empt the main concerns of participants and as a resource they can refer back to. Therefore, it contained information about why I wanted them to participate, how the data will be handled, the safe guards in place that will ensure that no harm will come to participants from taking part, the measures taken to ensure anonymity and the assurance that participation was voluntary. The IS was designed to be read by children and adolescents and was written in a clear and accessible English, and therefore its use by someone other than the child was not foreseen, or part of the IS's planning.

An older text by Latour (1992) can be used to demonstrate other ways to examine ethics as formulated through the process of enacting objects. Along with objects such as seatbelts and sleeping policemen, Latour (1992) uses the example of a doorstop of La Halle aux Cuirs at La Villette in Paris to illustrate how people can act at a distance through objects. In order to keep the heat in the conference hall, the door must be kept closed. The door to La Halle aux Cuirs is not only designed to be a barrier to keep the heat in the building, it is also designed to let people move easily in and out of the museum. However, if the people who use the door leave it open, it causes the problem of letting the cold air in again, and so an extra device, a groom, is designed to make sure that the door closes itself when people forget to close it. The groom then, is designed to perform and re-perform a process between human and non-human actors, it is making sure that those who have opened the door close it again for the wellbeing of those who will continue to use the building and the heating bill of a publicly funded building, maintained for public use. Performing these

actions ensures that the groom acts in accordance to a set of morals each time it is left open, in this case the morals of public money and public space. It is a demonstration that ethics is a complex interplay between human and nonhuman objects. In the same way, this could be applied to the information sheet that was used in the clinic as it had the ability to act unethically if handed out at the wrong time. The IS can be seen to perform a process at a distance to inform participants about the research and answer questions that may arise. However, this becomes exposed when the IS was taken out of its intended clinical context. The interplay between the sheet, the bag and the movement of Jemima after the clinical appointment – what I've referred to above as an ethical assemblage – was something that had to be disciplined into acting ethically. In this instance by explaining that the IS needs to be kept secret and preferably not giving the sheet to Jemima to take away. Instead she might have been advised to contact the clinic with any questions<sup>56</sup>.

The negotiation of ethics can be seen as becoming an assemblage of allies, keeping human and non-human entities as acting compatibly with the research aims to keep the research ethically sound. A criticism made towards this kind of STS argues that it takes on a 'winner-loser' terminology. Radder (1992) finds a problem with the way Latour (1992) uses ideas such as allies and opponents, strategic negotiations, and technical manoeuvres to explain how scientific ideas and ethical norms are maintained. He argues that these types of militaristic ideas do not favour analysis of the 'loser', scientific dissent or the things science tries to suppress. Analysis usually results in a normative stance of science, which creates a tension as the STS of Latour is apprehensive about normativity (also see Keulartz et al., 2004). Fraser (2006) also launches a similar criticism in reference to Latour (2004), commenting that Latour's analysis of the actual relations at work around a specific ethic takes attention away from other possible versions of ethics. As has been demonstrated in the methodology chapter, Latour advocates research methods that allow actors to emerge and inform what to follow when conducting research (Latour 2005). This complicates our ethical stance as following through actors and giving them free reign will mean that the

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<sup>56</sup> Michael (2004) also offers a similar demonstration of human and non-human actors acting contradictorily in the incident of the 'disastrous interview episode'. Where the intervention of a dog sitting on the legs of the researcher, a cat pulling away the tape recorder and unwilling participant make it impossible to conduct a recorded interview.

researcher will pay the most attention to what is made prominent to the research at the expense of less distinct connotations. For example, by following through the ethics contained on the IS, is a versions of ethics being foreshadowed that may have not been formalised into the IS (Law 2004)? Using a Latourian style of STS in ethics, means that ethics must be seen as an association that when enacted, suppresses many aspects deemed as unethical. The functionality of STS relies upon the importance of not being able to reduce entities from the networks that have created them, and focus on identifying, without researcher-bias, the relations that are at work in and around each enactment. So, although it is opposed to going off and following the suppressed strands and their possibilities, a sound account should still attempt to identify what is suppressed in a version of ethics or science and the relations it shares. The question is whether it is a more useful approach to trace ethical relations of a certain network, or to trace all possible ethical considerations neglected or otherwise. A Latourian style of STS would see the search for the possibilities as allowing a purposeful inventiveness of the researcher that would lead to an inaccurate account (see discussion of Latour, 2005 in chapter 3).

### **Ethical Assemblages of Innocence**

A further ethical dimension opens up for the project when considering associations of childhood innocence, as doing research with children brings its own set of ethical considerations (Alderson and Morrow, 2011). This is further complicated in the context of illness and HIV. The idea that ethics is formed in complex patterns of ordering and disordering between human and non-human agents is incompatible with certain notions of childhood, that views childhood agency as always in the process of 'becoming' (Castañeda, 2002)<sup>57</sup>. This means that children are seen as objects that are not finished, or are seen from their potential of becoming adults. From the point of view of an ethics that is formed in a complex process around the interaction of objects, much policy renders them as not being

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<sup>57</sup> The concept of becoming has a subtle range of meanings in Social theory. A broad distinction of becoming can be made on the one side between the philosophy of Deleuze, who had an idea of becoming as a flow that never crystallises into specific entities. And on the other, Latour's modern alteration of the Deleuzian concept that concentrates upon the specific moment where entities become so specific that each further evocation of that object renders it as different, (see Harman, 2009 p6, p30).

capable of engaging with ethics (Alderson, 2007b). Adults must make interventions on their behalf to make them adhere to ethics.

This confuses the idea of an ethical enaction, or a process that makes research ethical, creating a view of children as being ulterior to ethical actions. It renders them to the contradictory status of an object with diminished agency. STS discourse focuses on how the interaction between objects makes them part of assemblages that are ethical or non-ethical, whereas common-held views of childhood as unfinished, depict children as apart from ethical assemblages. A child instead becomes something that is acted upon ethically by an adult. This is not to say that children should necessarily share blame if involved in an ethical issue, but rather that the enaction of ethics and the ethical consideration would be reliant upon the presence of the child. Going back to the example of the clinic, if I did give an information sheet to a child and they take it without complaint, the point is not that I would not be to blame, the point is that in this instance the child is ethically charged<sup>58</sup>, and the process that would subsequently hold me to blame would be a complex assemblage drawing on the ethics around the child and processes occurring in the clinic. Therefore, to state that ethical responsibility is only in the jurisdiction of the adult practitioner or researcher is a simplification of the process of being ethical and disregards the many ways child patients can pose ethical interventions.

A stance taken from the sociology of childhood develops the idea that childhood and adulthood are mutually constituted objects, and that this is hidden in many everyday scenes of childhood illness. Christensen (1998) points to ways in which children's incompetence is constituted in illness. One such example given is in the design of medicine bottles. Many

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<sup>58</sup> It is questionable if it is possible to describe something as ethically charged or ever be able to pose an STS style account and avoid being essentialist about what an ethical charge would constitute. A conflict arises between the ideas of childhood that formal research ethics work from, an STS point of view that stresses finding the value of objects from tracing the actual relations between objects, and a child-centred deliberation that seems to lie unreachably entangled in the formal ethics. One aspect left unclear is what constitutes these supplementary ideas of ethical caution that have gravitated around childhood. The argument put forwards that ethics is a process found in the relation between objects at a given moment, does not begin to explain why ethical considerations are more charged around objects like children, or the difference between ethically charged groups like between childhood and disability. The origin of each ethical dilemma, childhood or disability, come from different objects and set of relations, yet formal ethics can bring the two together seamlessly as requiring the same type of ethical deliberation (Miller, 2003).



bottles of medicine including those designed for children have a top that is designed to be pushed down as it is screwed off making it very difficult for young children to open. Although Christensen does not specifically talk about ethics, the example of the bottle can be seen to have an ethical consideration built into it (similar to the groom). The design renders the child as part of an ethical consideration that they are unable to engage in on their own, they must be supervised or monitored. Since the writing of Christensen's article it has become necessary to distinguish between the considerations of social constructionism<sup>59</sup> that this supplement does not wish to suggest. To modify the argument for use here, it must be distinguished that the competency of children who are ill cannot be constructed outside of ethical considerations, this would be impossible. In each enaction, the competency of the child is an irreducible part, and however the child's body is viewed, it still has a direct impact within the situation. The medicine bottle may seem like it has rendered the child incompetent and not a part of the process of opening the bottle, but in fact the specific incompetency of the child must still be enacted with a child failing to take off the top of the bottle, or with an adult taking the top off of a medicine bottle to give some medicine to the child. In each situation the child has not been reduced from the process of opening the bottle, an idea of childhood dexterity is at work each time the bottle is opened due to its design. This can also be seen alongside the discussion of action at a distance, detailed above. The medicine bottle becomes a non-human actor which acts according to the potential for children to be unaware of the dangers posed by taking the medicine and to cause harm to themselves. In situations where a child is trying to open or tampers with the bottle unsupervised, the bottle fails to open and so becomes part of an ethical process to restrict access to the medicine where it could cause harm (Christensen, 1998, p196-198).

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<sup>59</sup> Ian Hacking (1999) highlights the internal irrationality of Social Constructionism, in his book 'The Social Construction of What'. He points out the difference made by Social Constructionists between local claims and general ones. For example, for Hacking when the Social Construction of Child Abuse makes the claim that it is socially constructed, the argument remains oblivious to the constructions of grownups who were abused but were not aware of it until a later construction of child abuse, leaving questions as to what is constructed (chapter 5, p125-163). It also causes a friction between the locally constructed entity and idea of it being apart from a general nature or reality of things. This makes it unclear as to what is constructed in each instance the concept is used for analysis. Hacking concludes that the most useful task of a social constructionist account is as a device to raise a reader's consciousness.

Relating this back to formal ethics procedures, both the research ethics for Goldsmiths and the IRAS application for the NHS have questions relating to children. In this way, the project must be designed with a certain idea of childhood in mind. The research has to demonstrate how vulnerable groups such as children will not be taken advantage of during the research or subjected to something that they would not want to do if they 'understood the situation better'. The formal ethics procedures want to insure that children understand as much as possible about the research, have the opportunity to say no, and make sure that they are not subjected to any harm during the research process (Alderson, 2001, 2002). Thus, the methodology and research methods are imbued with a reductionist idea of the child and child vulnerability. Once out in the field, the formal ethical approval intends on research having an idea of the vulnerable, non-understanding child in mind when interacting with them. A similarity arises between the way the child is represented in formal ethical approval and the ways in which research will engage with notions of how the child should be interacted with. To relate the two examples of formal ethics and the IS given to Jemima at the clinic, a similar idea of the child is evoked over the two places. The formal ethics application asks specific questions that conjure up a naive and incompetent version of the child, and at the clinic, the relation between the doctor, the IS and the gym bag was also working under a version of the vulnerability of the child. The idea of the child in each instance is different but it is also possible to compare the two. Certain ethical considerations can be seen to permeate through the whole project in similar ways, yet also rely upon the relations and set up of specific moments in the research. Even though STS can be seen through this argument as pioneering a way in which ethics can be explored as emergent, the extent to which it can be applied to children with vulnerable or incompetent agency that seem to exude the situation in unknown ways is uncertain. More generally, the task at hand for formal ethics is to consistently project a version of research, the tools used for research and the objects under research that is accepted by each group involved. Whether reductionist or not, research must seek to be compatible with the concerns of formal ethics and carry out the committee's wishes in the field, whilst working within the bounds of what is acceptable to everyone encountered in the research (Mannion, 2007). However, what is acceptable in a given context is not something straightforward or stable,

as relationships are subject to constant re-negotiation and each consideration must also be compatible with the wider scientific rationale of the research.

## Conclusion

This chapter has focused on the deliberation of ethics carried out in the course of this project. In relation to the thesis argument that places the clinic as a key location where medical doctrine is consolidated with patient complexity, this chapter has demonstrated how ethics must be maintained and interpreted in each clinical encounter and the effect this has on research. Paediatric HIV in particular evokes a complex array of ethics. This implies that clinical deliberations around ethics must be constantly interpreted in practice and protocol, and are highly implicated in the process of formulating of what is acceptable in HIV treatment. This project has had to adapt to these ethical 'assemblages' and successively ensure that the execution of research is acceptable alongside them.

The ethical components that this project has deliberated over have been: that childhood HIV is a heterogeneous assemblage; that a child's agency in ethical considerations is a complex process that defines their competency and potential for the future; and that the task of being ethical is a complex navigation of gaining ethical approval from formal committees, to each person I encounter in research and each object that is used in research along the way. This section has discussed many of the objects that are embroiled with insuring this project acts ethically, from formal ethics such as the REC and CRB check, which made me pledge and consider how I would act ethically at each opportunity, to other objects of the research. For example, the IS in my hand extended towards Jemima, the poster on the wall of the clinic, the highly charged body of the child. Each entity that was present in the phenomenon is irreducibly part of the resulting ethical consideration. The encounters detailed in this chapter are largely simplified from the much larger network of assembled objects that move through the clinic, but still demonstrates how many human and non-human objects are involved in the process of rendering a dilemma ethical or unethical, and more widely, how ethics is a complex and dynamic process that must be continually navigated, rather than a fixed set of rules to be applied. In this chapter I have

been apprehensive about the extent that it can absolutely define a set of ethics, instead trying to illustrate the many levels of ethical considerations that must be used to make a project ethically sound. Rather than just following a list of artificial scenarios or predetermined codes, the task of rendering this project ethical will instead be down to a complex set of processes and considerations that must be evaluated at every stage to deem whether they are ethical or not, from research design to writing the research up. This emphasises the argument of the whole thesis by demonstrating the ethical complexity presented in the clinic by the patient cohort. This chapter has discussed how ethics has been navigated in research, but the same ethical complexities must also be negotiated in the course of clinical practice. One unresolved problem in the chapter has been that by using the STS of Latour, there remains a level of doubt as to the suppression of less dominant ethical possibilities and to the limits of using STS over vulnerable groups such as children, health and illness and the problematic ways that child agency is thought of and enacted (also see Misztal, 2011).

Combined with the methodology section, this chapter has attempted to provide evidence of how a reflexive and thoughtful approach to the ethics of paediatric HIV research and practice has been attempted in this project. The limitations raised in relation to ethics and its applicability are placed highly on the research agenda. This chapter has been designed to highlight the deliberations made towards ethics, and the ethical approach of the thesis before introducing research. The proceeding chapter and the remaining chapters of this thesis will present research data collected from clinical observations and will focus on empirical research findings.

## 5 Disclosure

The purpose of this chapter and the research chapters that follow, is to trace a medical procedure already well defined in paediatric HIV and the clinic. The chapters in this research section will follow the procedures of disclosure, adherence, chronic illness and transition. They will explore how these medical procedures are enacted through the negotiation between patients and practitioners. It is argued that these procedures are used to coordinate patients and practitioners to make compatible complex patient associations, such as stigma, vulnerability and naivety with antiretroviral requirements and instruct each group on how they should conduct themselves in accordance with the medicine. Rather than arguing that there is a hierarchical structure ordaining that protocol dictates these procedures and practice in the clinic, the research of this project emphasises how these procedures must be negotiated in the clinic each time they are enacted. Therefore, the clinic is emphasised as a key site in the formalisation and consolidation of HIV medicine. This chapter will look at disclosure and investigate the ways in which the procedure acts to bring patients into knowledge of paediatric HIV medicine and as a result make care regimes that rely on patient responsibility possible. Disclosure is a good place to start these research chapters as one of the primary formal tasks of the paediatric HIV clinic is to provide patients with knowledge of their HIV.

Individuals perinatally infected with HIV experience a period as they are growing up where they are surrounded by, and therefore necessarily informed about HIV. The stigma that surrounds the condition often excludes what can and cannot be said to a young child in the context of assumed child naivety (Letteney and LaPorte, 2004; Ostrom et al., 2006). In this respect, HIV differentiates itself from other chronic conditions and has big implications upon

how HIV must be disclosed to infected children. The fact that children are coming from a position of not knowing to knowing evokes questions around what extent the news will be distressing for children and when to tell them. A patients' consciousness of their HIV status can have a large impact on a patients' self-projected life course. Disclosure is one set of formalised guidelines and protocols that practitioners will refer to when addressing how to orchestrate in the clinic a child coming into knowledge of their HIV, and is deemed as an important step toward creating a knowledgeable and responsible patient (Santamaria et al., 2011). Consequently, disclosure not only prioritises, but makes possible a medicine founded upon consent and mutual understanding, asking patients to uptake medical knowledge of HIV and act responsibly. Therefore, I will assert that when practiced in the clinic, disclosure consolidates a disparate range of medicines, technologies, practices, professions, childhoods and patient attitudes together. The formalisation of disclosure guidelines are designed to show practitioners how to systematically inform patients on what is deemed as important for them to know about the medicine and HIV. Accordingly, patients are asked to take on that knowledge of the virus in the way it is presented to them and internalise it into their conduct outside of the clinic (CHIVA, 2011c). However, rather than overemphasising one group over the exclusion of the other, it is argued that all relevant groups of child patients and professionals are organised into the medicine and have a role to play to ensure the medicine's effectiveness and the suppression of the virus. HIV imposes its own specificities onto the medicine. The fact that patients may be taking antiretroviral drugs for something they may otherwise see as invisible, or the fact that stigma installs fear in staff at the clinic to ensure that children do not become informed in an 'unwarranted disclosure', or the fact that families and the consultant must be confident that the child is capable of keeping their HIV a secret means that disclosure for paediatric HIV must be highly developed and meticulous in the way it is conceived, carried out, explained and re-explained to children (Gosling et al., 2004). Disclosure is not fully contained in the written guidelines, instead it must be negotiated at each clinical encounter between patients, parents and professionals in accordance with drug requirements and protocol.

Using concepts developed in STS, that of translation, enaction and multiplicity, I argue that disclosure is used to coordinate care regimes between the attitudes and behaviours of children and the aims and tasks decreed by medical science and practice. My aim is to frame disclosure as taking place between negotiations of parents and professionals where each party mutually influences the other. Accordingly, disclosure can be seen as a technique that brings together patients and professionals through the creation of common conceptualisations practiced in the clinic that make it possible for professionals to relate medicine to children and for children to understand and start to question the significance of the medicine. This draws upon the discussion in chapter 2 around lay/expert knowledge Callon (1986; 2004). The exercising of disclosure in practice locates the clinic as a key site in the consolidation and formulation of medicine as coherent and functional. Even though it could be stated that the formalisation of the procedure of disclosure into a guideline or protocol is done exclusively between practitioners and then imposed onto children, this process of the formalisation of disclosure is not isolated from practices in the clinic or the interactions that have been used to identify certain clinical factors as problematic. Therefore, what is irreducible from the formalisation and practice of disclosure in the clinic is a mutual negotiation of medicines and wider societal factors that result in a shared knowledge of HIV being built between child patients and practitioners (see Berg, 1997b; Timmermans and Berg, 1997, 2003). This means that analysis must take into account outlying connotations such as childhood naivety, incompetence and HIV stigma (Christensen, 1998; Cohen et al., 1999; Atkins et al., 2010). Whereas much STS, for example the object politics in literature review of Mol (2002), or Mol and Law (2004) would point to the endless complexity and diffusion of these entities across their different enactions, in the face of the incompatibility of associations around paediatric HIV such as stigma, vulnerability and naivety with medical requirement, the discussion of this chapter and thesis places the paediatric HIV clinic as a key location where complex patient associations and drug requirements must be consolidated if HIV medicine is to be made functional and successfully suppresses the virus.

The discussion below centres on how disclosure is used in the clinic to consolidate child patients into knowledge, through techniques that adapt and readapt to situations with

children to build up a common knowledge of HIV and how to deal with the condition that will form the beginning of a knowledge base designed to develop throughout a patients' life.

## Formulations of disclosure

Enactions of disclosure have a range of subtle differences that inform and guide practices in the clinic. The CHIVA model of disclosure (CHIVA, 2011a) is the model that practitioners in the UK (including UOUH) subscribe to when beginning disclosure. The CHIVA model echoes the stance put forward in a policy statement made by the American Academy of Pediatrics (AAP)(Committee on Pediatric AIDS, 1999a) which recommends that it is ethically right for children to be given their diagnosis, even though each case is acknowledged as particular. Internationally, this is the most influential policy around disclosure of HIV to children, and is far reaching across many national services, although interpretations of how to proceed according to the policy aren't necessarily the same. (Wiener, Mellins, et al., 2007).

The interpretation made by the CHIVA model of disclosure advises practitioners that:

“Children and young people should have ongoing explanations about their health condition appropriate to their age and level of understanding. This knowledge should be built upon in stages over time.” And that “The majority of children should have had an open discussion about having HIV by the time of transfer to secondary school. Exceptions should be documented, along with the plan for ongoing appropriate interventions to advance the child's knowledge” (CHIVA, 2011c).

Although this is in line with the AAP statement that advocates an individualistic approach and stresses the requirement to disclose, it more specifically details recommendations of 'building up' knowledge of HIV and details an ideal age limit where the AAP does not.

Therefore, networks of medicine from large institutions to individual practitioners use disclosure as a terminology that refers to a process that is not a single incident of telling children they have HIV. As is regularly advised to parents, disclosure is not a onetime



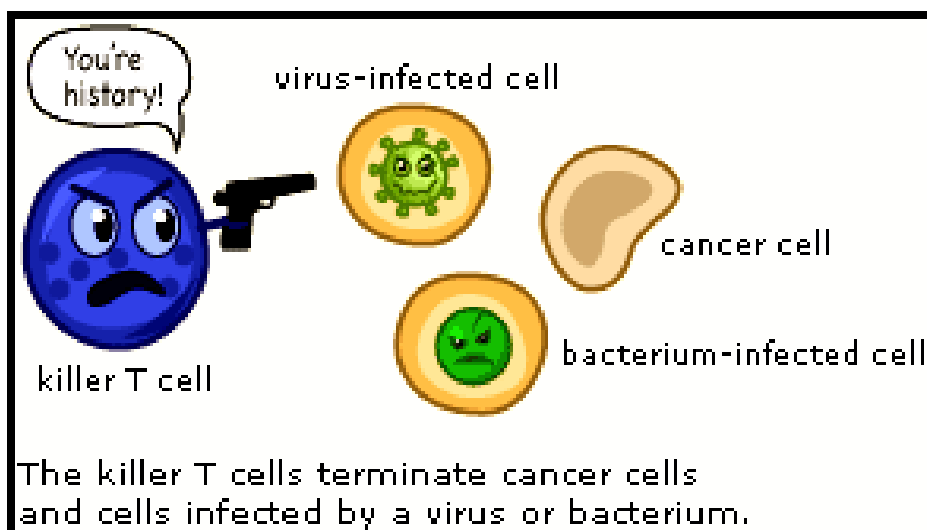
ordeal, but something that is ongoing as a child grows up (NAM 2010a). Moreover, according to the CHIVA model and observed in the clinic, disclosure is a process of gradual education for children about how a virus works and is transmitted, the immune system and medicine. Although this may seem straightforward, some of the complexities of implementing disclosure as a procedure in the clinic will be explored further in this chapter.

If disclosure is analysed as a clinical technique (alongside the other chapter headings of Adherence and Transition), one key question is how it makes certain ways of treating HIV possible. This invites us to view the larger role of disclosure in the ordering of children and parents into compatible interactions with broader tasks of the medicine and the treatment of HIV. I argue that disclosure is used in the clinic to ensure the effectiveness of drugs, define the boundaries of medicine and enable HIV treatments regimes that rely upon patients understanding and taking responsibility for their condition. Therefore, disclosure works to coordinate medicine between the naivety/competency of child patients and the prevailing medical knowledge of HIV treatment. In these processes of coordination codes of ethics and sanctions for procedures are implicated over many levels locally, nationally and internationally (Committee on Pediatric AIDS, 1999a). The recommendations of the CHIVA model make their way into the clinical practice in dynamic ways (CHIVA recognise this themselves in their advice to parents, but made clear the unacceptability of not telling a child over 12 see CHIVA, 2011a; NAM, 2010a). As practitioners including Dr Peters are only too aware, each case has its own particularities that confound interpretations of the ethical code and methods to disclose accordingly (Foster et al., 2007, 2009). On the one hand, disclosure can be seen as a procedure formalised to consolidate a shared knowledge of HIV between patients and practitioners. However, on the other hand, a highly subjective question lies behind the reasons as to why it is necessary to disclose to children. The process of disclosing evokes more than questions about the necessity to include children in knowledge of HIV to make individuals responsible with a stake in their care (as in the Disclosure Processes Model see Chaudoir et al., 2011). The fact that children are coming from a position of not knowing to knowing evokes questions around what extent the news will be distressing for children and when to tell them. Ideas of vulnerability are inseparable from the act of disclosing to children, which is related more generally with associations

around illness and childhood (Bluebond-Langner and Nordquest Schwallie, 2008). In accordance to the already difficult task of conveying the bad news of HIV infection to the patient, doing so with child patients activates an intervening charged association of child vulnerability making the procedure more uncertain. These questions of conveying knowledge of HIV according to a child's disposition must be coordinated in the clinic. The task forms part of a logic that seeks to make children compatible with medical requirements. The question will become more acute when discussing how children are deemed *ready* to be disclosed to.

### A Time to Begin Disclosure

At UOUH the formal process of disclosure begins in sessions between the children and the clinical nurse specialist (CNS). In the majority of cases the decision of when to start is made in a negotiation between case history, the desire of the parents, Dr Peters' judgement and the recommendations of protocol to approach the subject before children are 12 years old. When disclosure is deemed appropriate, children have a session booked to see the CNS where she uses a set of slides to begin to approach the subject of HIV. The process takes place between the clinic and at patients' homes, using slides and a laptop.



4 A slide taken from the disclosure presentation depicting a T cell fighting infection

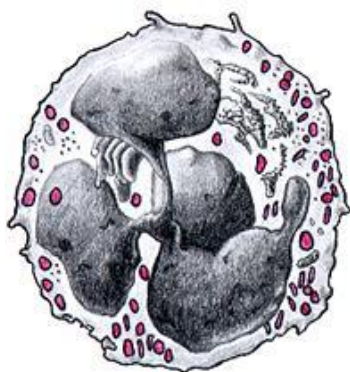


Fig. 8 - Neutrophil

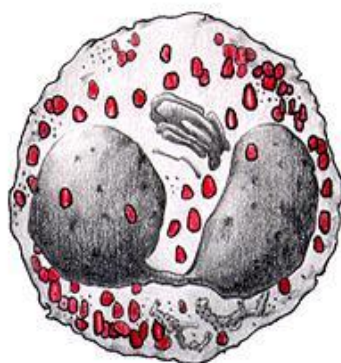


Fig. 9 - Eosinophil

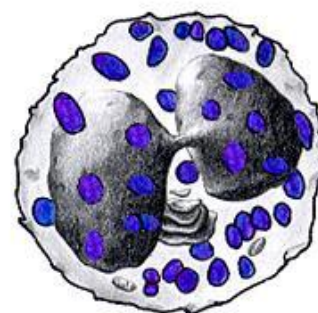


fig. 10 - Basophil

5 A slide used to describe white blood cells

When I asked the CNS how she discloses to patients she responded:

“The first one [presentation] I use is about blood, the second one is on a virus and how it works, and we just go through like that. First session I’ll talk about one then we’ll go over it in another session and then go over it again”

After looking at the slides I asked “it doesn’t say HIV on these slides, how long do you go through like that without using the word HIV?”

“We do about six sessions like that building up the knowledge of how it works and then after about six sessions I’ll introduce that they have a virus, then I’ll ask the parents how they want to proceed, some of them want us to tell them, others want us all to be together, some will want to tell them themselves.”<sup>60</sup>

The slides that the CNS uses seek to define aspects of the immune system without mentioning the word HIV. The logic behind this method is that children will be introduced slowly to relevant knowledge about the biological consequences of having HIV before being told that they have the disease in a pre-emptive attempt to circumnavigate negative stigma, as will be demonstrated later. Within these considerations lies a connotation of distress, child vulnerability and the potential misconception of HIV that seems inherent to paediatric

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<sup>60</sup> Taken from informal interview with the CNS, Nov 2010

HIV<sup>61</sup>. After these sessions take place Dr Peters can begin to talk in consultations openly about HIV. Children then become part of discussions about blood test results and drug regimes that would previously have only been relayed to their parents. Therefore, getting to this stage is important to allow children to get used to actively participating in the ongoing medicine concerned with their treatment and understand how to avoid public health risks and further transmission (Campbell et al., 2009).

These procedures of disclosure consolidate and inform patients upon what the clinic expects them to know and allows practitioners to discuss care regimes (making it possible to achieve tasks like “facilitating adherence” Pontali, 2005). This demonstrates that the logic of disclosure seeks to equip the child with a common biomedical knowledge of what is HIV, what it does, how it works, how it is transmitted and what are the consequences. Therefore, the default position of those who treat children is that they are naive and do not understand the implications of HIV, the medicine used to treat it and the ensuing potential threats to public health, and so formalised disclosure methods are employed to introduce to children why they must visit the clinic and the significance of confidentiality (see discussion of education, innocence and children’s sexual rights in Mitchell et al., 2004; Bhana, 2007).

To aid the disclosure model, support is sought from the psychiatry team at the ward and practitioners refer children when they identify distress (Santamaria et al., 2011; Mellins et al., 2002). For the clinic it becomes important to consider how individuals will react to the procedure of disclosure, and when it is the best time to begin. As each of the issues discussed has the potential to interact differently in each case, the age range and stages of disclosure vary. The CHIVA recommendation is intentionally wide, with the recommended age below 12<sup>62</sup>. At UOUH the age between cases for beginning disclosure work ranged broadly from broaching the topic at 8 or 9 years old to reaching the deadline of 12 years of age. During the first ‘warm-up’ stage the word HIV is absent from the discussion until the

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<sup>61</sup> Melvin, (1999; 1995) is written by a psychiatrist in the UK in particular discusses the importance of gradual steps of disclosure although an international discrepancy exists as can be seen across the articles reviewed in; Wiener, Mellins, et al., (2007)

<sup>62</sup> Cases of children over 12 years not knowing their status are common. At the clinic two new cases, Rob and Erica, were enrolled at the clinic respectively at the age of 12 and 15 not knowing their diagnosis. The plan by health professionals in the clinic was to disclose as soon as possible.

team are sure that the child can keep a secret. Factors which prompted warm-up disclosure sessions were often on the types of questions children were asking at home such as why they were taking medicine and why they had to come to the clinic. Another contributing factor in a few cases, (such as Harry, Celina or Bianca<sup>63</sup>) was that they had family members who had died from HIV, in these cases the potential for asking questions was even more feared by staff. In several cases, for example like Harry's mother, parents may wish to tell their children on their own without the team. The job of Dr Peters then becomes one of putting pressure on the mother to disclose, but he is limited in the ways he can deal with the situation.

In each case therefore, a number of individual factors are evaluated alongside the CHIVA model recommendations, and disclosure becomes a negotiation. This negotiation promotes the general benefits of including patients in knowledge of their care, and the construction a shared knowledge of HIV and how to treat it. However, other questions can also be seen to become embedded in these decisions like that of vulnerability or cultural difference, and the threshold to distress. Disclosure in this case is not the straightforward inclusion of patients into knowledge, but the navigation of medical knowledge and child standpoints to arrive at a mediated, age appropriate, ethically acceptable knowledge of HIV<sup>64</sup>. In this context, the critical question for the clinical logic becomes when is the right time to start to talk about HIV?

The reasons for starting disclosure in the cases I observed in the clinic were case specific. For example, warm-up disclosure sessions began at the age of eight for Celina, firstly because her father was willing, secondly the nature of the questions she was asking (see Blade incident detailed later), thirdly the fact that her mother had died from the disease and fourthly her bad behaviour reported from school made Dr Peters deem it necessary to begin. Similarly, with Bianca who was nine, the team began disclosure when the school

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<sup>63</sup> Three cases existed where a parent had died from AIDS: Harry was living alone with his mother after his father had died, Bianca was living with her aunty as her mother had died and the father's whereabouts were unknown and Celina lived with her father after the death of her mother. All of these parent deaths had taken place when the child was young and the children had limited reminiscence of the parent.

<sup>64</sup> This point is relevant to discussion of 'age appropriate development' in Kelle (2001; 2010); and 'what children know about their disease' in Bluebond-Langner et al. (1990; 1991)

reported her mood as 'angry' and her auntie was struggling to understand the cause. It led the team to speculate as to the reasons for the anger. She knew that her mother had died but not the reason for her death. This coupled with the fact that she must take antiretrovirals and visit the clinic prompted Dr Peters to send her for sessions with the CNS and the ward psychiatrist. Another nine year old, Pierce was also advocated to start early due to his perceived intelligence, the questions he was beginning to ask and his wit in consultation. Dr Peters proposed to the mother to begin disclosing over the next year. His mother agreed he that was ready to start immediately. Both the mother and the doctor remarked that he is a 'bright kid', and expressing the desire to start early to pre-empt awkward questions.

As is recommended in the NAM booklet (NAM, 2010a) and accounted for in most leading literature (see for example Battles and Wiener 2002), the process of informing children about HIV should not be considered as a singular event but something that may take time and discussion between children, parents and professionals to come out. Informing patients about HIV is a process, a process that will improve medicine by allowing individuals to develop a rapport around talking about their condition openly with professionals. As with other model patients of chronic conditions, children will be responsible for building upon this knowledge over the rest of their lives to best understand how to manage their condition. The involvement of children makes the question of disclosure essentially different to the way that disclosure is presented to adults. For example, there are questions of vulnerability and distress that are more easily overruled when disclosing to adults, and also HIV has an added specificity that it has a negative stigma that, on the one hand, practitioners must avoid and on the other must educate on in a manner that circumnavigates negative connotations (see Cummings, 2008 on managing stigma in an Indiana public school). This demonstrates that disclosure in this context is specific and requires a highly flexible set of procedures if it is to fulfil its task of building a shared knowledge whilst accounting for this unquantifiable vulnerability. As will be discussed, in contrast to STS accounts of the clinic detailing the proliferation of complexity through enaction, such as Mol (2002); Mol and Law (2004), paediatric HIV exemplifies the

importance of how procedures of disclosure must be enacted cautiously, but meticulously in the clinic to consolidate the complexities presented by patients into functional medicine.

## Participation, Adherence, and Impartation of Knowledge

The process of disclosure is designed to emphasise the gradual inclusion of diagnosed children into the knowledge of current understandings of HIV, its treatment and how it is transmitted. It is assumed prior to beginning disclosure that children need to be taught the conceptualisations necessary to have an appropriate comprehension of HIV and what that implies. Consequently, children are educated on what HIV is, what is a virus, how the immune system works, different types of cells, the medicine and how they all work together. However, in the early stages of disclosure work, which can last from 8 to 12 years of age, the word HIV and descriptions of the disease are absent from the discourse. This results in an interplay between the CSN and the Consultant, where each one seeks to build a neutral knowledge base before being ready to impart what is deemed as a neutral understanding of HIV to be developed as the child grows older<sup>65</sup>.

This neutral impartation of knowledge can be seen as emergent in a negotiation between Dr Peters and twelve year old Abbey when in the process of being disclosed to. Her mother and father brought her in for a consultation after the CNS had given Abbey some sessions on disclosure.

Dr Peters: *"I know that [CNS] came to see you, what did she talk about?"*

Abbey: *"She talked about blood cells"*

Dr Peters: *"Did she tell you about red and white blood cells?"*

Abbey: *"Forgotten"*

Dr Peters: *"The white ones are important they fight infection... [The CNS] will see you again in the next few weeks to go through a few more things... We looked at your blood cells and*

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<sup>65</sup> Walkerdine (2009, 1993) challenges the way in which the practice of developmental psychology universalises concepts such as masculinity and is Euro-centric. Similarly then I would like to raise a caveat as to how 'neutrally' conceptualisations of HIV can be taught to children, even though the neutral impartation of knowledge remains a key aspiration for professionals.

*that was good 420. We want that number to be high, and we will continue with things the way they are as long as it stays like that."*

Abbey was not yet taking antiretrovirals but had apparently been asking difficult questions throughout the whole process. There was the fear that she was receiving a stigmatised message about HIV from school. As Abbey left the consultation room to get a blood test done with the CNS, without Abbey in the room, her mother began to question Dr Peters.

*Mother: "Sometimes she asks me why she comes here and what it's for, and why she has to have blood tests. And we have to tell her that she comes here so that we can watch over her. Then she comes home from school sometimes and she said she learnt this about HIV and that."*

Disclosure work had already begun with Abbey but she was still asking some questions about the nature of the condition. Dr Peters needed to make a clinical judgement as to how Abbey conceptualised HIV. There are things that he wished to discuss with her and things he wished her to understand. In this incident alone he attempted to go through a blood test with Abbey. The team were seeking to build conceptualisations with Abbey of what blood cells do and how the immune system fights infection. Dr Peters hadn't used the word HIV yet, but was preparing ways to impart the knowledge. The extract demonstrates that the clinic is attempting to consolidate Abbey into understandings of HIV compatible with the goal of virus suppression. During this slow introduction to HIV, Abbey must conceptualise her CD4 count as a number that equates to her health, the logic is she will want a stake in keeping the CD4 number high and approach her HIV in this tact of keeping numbers high and managing medicines.

The culmination of Abbey's disclosure sessions came when she contracted an unknown virus and was hospitalised for a few days. The virus was interpreted as being symptomatic of the HIV becoming more active in Abbey's body. At Abbey's next consultation after hospitalisation, it was decided to put her on to antiretrovirals and to tell her that she has HIV during the proceeding consultation. Whilst Abbey was getting a blood test in another



room, Dr Peters informed the parents that they will start Abbey on antiretrovirals. In consultation with the parents Dr Peters recommended that Abbey is told her diagnosis immediately before going on to ask how they wanted to do it. It was decided that the CNS will tell Abbey with her parents and Dr Peters present. Once Abbey had finished they went into a separate room and disclosed her virus to her. The element that gave disclosure immediacy was the fact that Abbey would have to start treatment. It was important that Dr Peters can talk openly to Abbey about HIV before administering medicine and making her take tablets. The decision to disclose must be balanced between the necessity to disclose as early as possible and competence of the child to bear the news and keep it a secret (Alderson, 2007a). Therefore, disclosure is never fully defined in this situation but can be seen as emergent depending upon the negotiations prevalent in the clinic.

The logic at work guiding disclosure aims to facilitate a common knowledge of HIV asks children to participate much more heavily in the medicine of which they are centrally implicated. This logic demands that good HIV medicine follows from a well maintained patient consciousness of HIV (Fassin, 2008). Children are being asked to take on conceptions of HIV and given the room to develop a further knowledge over time and come back and question the doctor about it. From this point of view, patient knowledge has been seen as important to aid adherence, facilitate a child's adjustment, decrease the prevalence of 'risky' behaviours (i.e. public health Campbell et al., 2009) and promote patient consent and good ethics<sup>66</sup>.

Therefore, the negotiation that can be found in the literature is no longer whether disclosure should take place for children with HIV but how it should be done and the best time to do it. Disclosure can be seen to be designed to be conscientious of the ethical and competence ramifications associated with HIV, but also as a triumphant consolidator of patients and professionals together into a common knowledge of HIV. This balance is

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<sup>66</sup> Alderson (2007a; 2006) details the tricky relation between competence and consent, these implications are also prevalent in literature on disclosure. Wiener, Mellins, et al. (2007) have made a literature review of HIV disclosure to children where consent and adherence are highlighted as a recurrent issue.

necessary as a counter for the absolute confidentiality required around a patients' HIV status.

### Confidentiality – a unique problem that affects what is possible

Unlike other chronic illnesses affecting childhood which must also disclose in terms of educating how the body and their disease works (e.g. see Levi et al., 2012), paediatric HIV is distinctive because of the utmost importance placed upon insuring that children will not tell anyone else once they are given their diagnosis (Dorrell et al., 2008). One of the principal concerns of parents when educating children about HIV is the fear of a breach in confidentiality. This demonstrates the awareness adopted in clinical to attune practice according to the possibility of a breach in confidentiality. As argued in chapters 2 and 10, this sensitivity makes paediatric HIV distinct in comparison to STS models of clinical enactment found in Mol (2002), Mol and Law (2004). Paradoxically, it is the case that practitioners want to talk about HIV in a neutral way from as young age as possible but must be sure that the child can act responsibly with the information before being told. Dr Peters made it explicit to me on several occasions in quiet moments at the clinic that, in his opinion, the biggest issue of proceeding with disclosure is that the “parents are worried about the child telling someone”<sup>67</sup>.

For example, going back to Abbey, before disclosure work began her mother was concerned of a potential breach in confidentiality. Dr Peters explained this situation to me in the clinic.

*Dr Peters: “[Abbey is a] twelve year old girl who doesn't know her diagnosis which is not great. Mum was doing an experiment with her and she was going to tell her a secret and if she can keep it, then we can start to tell her status. It's always the professionals who cock up in my experience. I don't know of any child who has told. It's the big scare with the parents, it's usually the big issue that the child will tell someone. When I was a boy it was*

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<sup>67</sup> This is not an isolated view, Waugh's (2003) study in South London also implied that word getting out was the biggest barrier to disclosure.

*the thing in the playground you would call someone a spastic. Now it's that you say they have AIDS"*

In this respect, HIV differentiates itself from other chronic conditions, and has a big impact upon how it must be disclosed to children. The negative connotations around HIV are at odds with treatment (see Cunningham et al., 2006 on adherence). In all cases observed, a highly sensitive assemblage formulated around the fear that the child may be unaware of how sensitive knowledge about their status can be, the potential situations where the child could make an unwarranted disclosure and the implications this could have for the lives of families in their communities.

The immediacy of confidentiality in the consultation room was salient in the case of Gregory who was 13 years old at the time of research. His family had immigrated to the UK from Ghana when Gregory was young. The news that Gregory had HIV was a shock to the family who were uncertain of the infection's origin. At the end of Gregory's consultation, Gregory's father explained to us in detail some of the problems associated with making a HIV status public.

*Father: "The reason I say is because, if he goes there [Body and Soul] and he makes some friends and he gets some numbers and they start saying where they got the disease from... [Starts to look at me I assume it is because he had just been given an IS] I haven't got it, my wife, I have been with her for a long time she has got it. I have another girl and she hasn't got it. No one in the family has got it. He will start to ask questions where did he get it? Sometimes I sit and think about these things. Sometimes I cry... I cry. Especially after I come here. If people know, they will not want to drink anything, not want to eat anything, they will not want to come to my house. We are Africans and we do not have sympathy for these things. I wonder what people will think."*

As well as demonstrating the considerations of confidentiality the passage also introduces complexities around ethnicity. The sense of community expressed here around the difference between African and European sensibilities towards HIV is not something

explicitly part of the protocol making process or the expansion of a child's knowledge base. However, it translates and must be consolidated into clinic practice in other ways. The differences that can be seen in the sensitivity when disclosing HIV to children compared to other diseases is one of them, another can be seen in public health measures that seek to elucidate the HIV status of members of the patient cohorts family and community. Dr Peters explained to me:

*"It's important to go through to see if any of the family has HIV, because if individuals don't say they have the virus it causes problems."*

Treatments of many other chronic conditions take it as their aim to increase patient knowledge and so improve the general medicine (for example the collection of essays in Budd and Sharma, 1994). However, with these considerations, the aim to educate children with HIV on their condition can be seen to have stigma issues interacting with it. Here, it is in the concern of a breach of confidentiality, propounded mostly by the parents. In other conditions such as asthma, diabetes, sickle-cell anaemia or cancer there are no such parties advocating blanket confidentiality of an individual having the condition (Dyson et al., 2010).

Within these examples exists the stigma associated with HIV. Being stigmatised by HIV is the reason many families fear a breach in confidentiality (Mahajan et al., 2008). I would like to suggest that the CHIVA model of paediatric HIV disclosure is associated with stigma through the mutual negotiation between clinical practice and guidelines. Stigma affects the way that HIV is disclosed. As discussed, the parents seek to make sure that knowledge will remain confidential and demand the clinic to act accordingly (Alonzo and Reynolds, 1995). This activates concerns of children being subjected to stigma. Therefore, the CHIVA model must accommodate the dangers of ostracisation of immigrant communities, whilst giving children a non-stigmatising view of HIV (U.K. Select Committee, 2011). The way that it is recommended that HIV is taught and talked about in the clinic is to emphasise that HIV is a disease like any other in an attempt to actively minimise stigma. The following case of Celina demonstrates how a negative connotation of HIV emerges from a clinical negotiation and is minimised by the staff.

Celina's mother died when she was very young, and so she was living with her father who wasn't infected with HIV. Celina was born in the UK and had been attending the clinic since a young age. During an afternoon clinic, 7 year old Celina attends with her father. The staff in the consultation room comprised Dr Wellington, a visiting consultant who used to be head of the clinic and Dr Peters. Celina's mother died from AIDs several years ago and so she lives alone with her father who takes care of her. During the appointment Celina had to leave the main consultation room to have a blood test. Dr Peters took her into the other room where the CNS did the blood test, leaving myself, Dr Wellington and Celina's Father in the room. As Dr Peters is out of the room Dr Wellington started to talk to the father.

Dr Wellington: *"How is she at home?"*

Father: *"She can be a handful sometimes, she keeps me on my toes"*

Dr Peters came back in the room as Celina is being tested. He sat back down at the desk and turned to the father.

Dr Peters: *"Have you tried to tell Celina about her status?"*

Father: *"Yes I have started to explain small things to her, I tell her that her mummy and sister had weak blood and that she has the same thing."*

Dr Peters: *"She's getting wiser"*

Father: *"Yeah she asks lots of questions"*

Dr Peters: *"What kinds of questions do you try and answer then?"*

Father: *"For example I was watching Blade and she came and sat on my knee, I made sure that I cover her eyes when there are scary parts. I say to her that Blade has bad blood and that her sister and mother had bad blood and that she has the same thing, then she asks me 'is your blood strong', and I say yes and she says 'you'll look after me then'".*

Dr Peters: *"We usually start to tell them when there about 11 or 12 for two reasons, because they can start to understand it and they won't tell others."*

Dr Wellington interrupted: *"The trouble with using Blade is that you can't be sure as to how she's going to understand it. She could start to think that she's like a vampire and she could think that there's something wrong, like that she's the same as a vampire."*

Dr Peters: *"Would you like [the CNS] to start talking to her about HIV"*

Father: *"Yes that would be a good idea"*

Then Dr Peters changed the subject to talk about the future of her treatment. After the blood test Celina and her father left the clinic and Dr Peters came back into the consultation room and started to write up notes on the appointment. As he started to write, Dr Wellington spoke to him: *"I thought I had to speak up when he was talking about Blade, it seems to me that the vampires in that film are depicted as evil. Even though, Blade himself is a good character who fights off the disease and is not turned evil because he gets it from his mother"*

Dr Peters: *"I'm not sure that I know enough about it"*

Dr Wellington then turns to me: *"Have you seen it?"*

Me: *"Yes, the vampires get scary faces when they drink blood."*

Dr Wellington: *"Yes there are all sorts of negative things, she might start to relate to the vampires and it has all sorts of negative stigma"*

Dr Peters: *"Yes sure."*

In this passage a negative connotation of HIV was presented in the clinic, and through negotiation with the parent, an alternate 'acceptable' version of HIV emerges and is relayed to the father. It demonstrates the key role the clinic plays to adapt medical regimes to patient dispositions.

A few weeks later whilst Celina was doing a blood test, I asked the father some questions:

Me: *"What does she know about her... HIV? [Father says her situation at the same time]."*

Father: *Well not much she might ask me some things but I find it hard to answer. She sometimes asks me why she has to take medicine and I say that it's because of her blood and she says 'don't I have enough blood already?' That's why we need help from the professionals. The closest we came was when we were watching the film Blade, you know that film Blade? [I nod], we were watching it together and she asked me the question, blades mummy had something wrong and gave it to blade, but he's a good one and the others are bad ones, am I like blade? And I say you're not a vampire like blade, but you do have a virus, like your mother. That's why we need a bit of help from the professionals who will be able to*

*do it better. I don't want her to go along and then suddenly find out... She reads the newspaper, I don't want her to find out from somewhere else and then for it to become like a blow to her".*

Me: *"She's very intelligent."*

Father: *"Yes she is, she tests me some times, I think she got [her intelligence] from her mum who used to be supervisor in Waitrose, you have to be intelligent to do that, she got that from her mother, from me she got the rebellious side, she tests me sometimes, which she got from me. [After a Pause] But life is beautiful, I'm glad to be alive, I just want her to have a nice life and then I can rest my eyes, I want her to have a chance, the best chance".<sup>68</sup>*

The consensus reached by the staff and father was to minimise the possibility of Celina stigmatising herself by educating her about the virus whilst avoiding negative connotations of HIV. This again demonstrates the awareness required in the clinic to limit the many possible interpretations of HIV to versions of HIV that are compatible with ongoing care and a patients' 'quality of life'. This is in contrast to an STS notion of clinical practice that generates further complexity as in Mol (2002), here complexity interpretations of HIV are being consolidated into functional practice.

Four weeks later in a morning clinic in the same room during a quiet period an SHO asked Dr Peters a question about the difficulty of disclosing a HIV status to young children. He replied:

*"Yes there are difficulties we generally try to tell them when they're 10-11. There was a dad a few weeks ago I think you were here weren't you [referring to me]? When the dad spoke about that vampire thing... Blade, when he started talking about bad blood"*

Me: *"Weak blood"*

Dr Peters: *"Yes weak blood, we want to avoid that."*

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<sup>68</sup> Informal interview with Celina's father Oct 2010.

Through this model a contradiction in clinical practice also emerges. One cause of action sees the risk of stigma as too great to let anyone other than the clinical team become aware of the child's HIV, but another seeks to reassure children that HIV is not the condition they may hear about from the 'outside' world (Sankar and Luborsky, 2003). Confusingly, from whatever the CHIVA model shares with other chronic illness models of disclosure, it is unable to offer the recommendation that the answer to disclosure without any stigma lies in educating those around the child about the disease, for example at school. In contrast to HIV in other international contexts such as those described in Maile (2005) and Cummings (2008) clinical staff in the UK strictly discourage disclosure to the school or anyone else outside of direct family and HIV professionals. Instead, staff at the clinic must concede that any breach of confidentiality could have disastrous consequences, and so educate the child that HIV is not negative on the one hand, and on the other tell them to keep it a secret. From this angle, disclosure also has public health implications as practitioners want to ensure that 'naive' children will become knowledgeable and responsible before becoming sexually active to avoid inadvertently transmitting HIV. It is difficult to present this factor in a way that does not make adolescents imagine a negative self image of themselves when socialising or meeting prospective partners (Michaud et al., 2009). However, this message must also be conveyed to children, and it is imperative that it is done in a way that circumnavigates negative stereotypes. Therefore, the clinic facilitates a dynamic in each clinical encounter that evaluates whether the entities presented are acceptable or non-acceptable to the task of maintaining confidentiality. This ensures that it remains possible for patients to be able to continue to take tablets uninterrupted.

For example, in an incident during a staff meeting the clinical team discuss Harry. Harry's mother had held off giving him his diagnosis but had told him that his father had died of HIV, prompting the pharmacologist to question whether this will make Harry associate HIV with death.

The potential distress involved in disclosure is not merely confined to the stigmatising effect of HIV. Practitioners recognise that a patients' consciousness of their HIV status can have a large impact on their psyche and self-projected life course (Bradford, 2002; Santamaria et



al., 2011). During this period the team seek to protect children from misinformation about HIV. The clinic is in a race to educate children before they gain unwanted knowledge. Some issues identified are that HIV could be connected with mortality, stigmatisation and their contagiousness. During disclosure from the age of about 8 to 12, children are closely monitored by the clinic and any problems are referred to the ward psychiatrist. Two cases that were seen as symptomatic for displaying mental health illnesses were Celina and Bianca. Celina was showing her genitals to boys at school, and Bianca's behaviour was interpreted by her school as being 'very angry'. The use of the psychiatrist is intended to help children come to terms with the condition and ease any anguish HIV may cause. As a supplement to the model of disclosure, psychiatry is the mode of choice to resolve these wider issues of distress such as anxiety and depression caused around the time of disclosure (according to both AAP and CHIVA guidelines). The use of the psychiatrist is further complimentary to the process of creating a shared knowledge base of HIV and promotes ways of thinking and dealing with confidentiality and stigma that are compatible to medical models of adherence (Steele, 2007). The examples demonstrate that complex connotations of HIV that maybe taken up by children must be negated through clinical practice as a matter of priority.

### **Dangerous Disclosure?**

Compared to existing STS approaches to illness such as Mol and Law (2004) and the turn to enaction, paediatric HIV holds a real sense of harm that can be caused through the inadvertent impartation of patients' HIV status, that highlights the necessity of systematic policy when introducing children into knowledge of their HIV treatment. The example of paediatric HIV demonstrates how charged the objects of childhood and HIV are, and the importance of clinic as a key site in the consolidation of complexity into a functional medicine. In the management of complexity, the communication of any medical knowledge to children must be screened to ensure that it won't be taken and used in a detrimental way at a later date.

While research was being conducted, Rob had recently come over from Zimbabwe. He was living alone with his mother who was also infected with HIV, whilst the father was assumed to still be in Zimbabwe. Any clinical negotiation with Rob was further complexified by the fact that he was also infected with hepatitis B<sup>69</sup>. At the time of research he was twelve years old, a bit older than the clinic would normally like to begin disclosure, triggering a scramble to disclose to him effectively. Rob attended the clinic a few times to have some sessions on disclosure. The CNS had attempted to explain what HIV and hepatitis B are, how they work and to disclose to him that he had both viruses.

Before Rob's appointment, Dr Peters explained to us that Rob didn't know his diagnosis, so it was the first time that they could talk openly about his HIV. Towards the beginning of a consultation, Dr Peters began to question Rob about disclosure sessions: *"Did the CNS come to your house to talk to you about your diagnosis?"*

Rob: *"No... But my mum told me."*

Dr Peters: *"Was it a shock?"*

Rob: *"No I knew that I had something."*

Dr Peters: *"Do you know what it is?"*

Rob: *"...No"*

Dr Peters: *"What did she say"*

Rob: *"That it's important to take my medication everyday to stop me from getting sick."*

Dr Peters: *"Did she say what it was called?"*

Mother: *"[nudges him] When we came to see... [the CNS]"*

Rob: *"She said not to talk to people."*

Dr Peters: *"Are you sure you can't remember what it's called?"*

Rob: *"No"*

Dr Peters: *"What you have is HIV. It's a disease that attacks the immune system that you contracted when you were very young. We were worried about you telling anyone as we don't want people to be mean to you. [Goes onto talk about his test results.]"*

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<sup>69</sup> The populations of African immigrants in the UK that have a high prevalence of HIV are also linked to high levels of hepatitis B. At the clinic every child is tested for hepatitis B and treated if necessary alongside HIV, see Futterman et al., (2000)

Later in the consultation Dr Peters goes on to talk about Rob's regime with his mother: *So you're [referring to Rob] on 3 tablets a day. Because he's got hep b we...*

Rob: *"What?"*

Dr Peters: *"Do you know you have hep B?"*

Rob: *"No"*

Dr Peters: *"Didn't [the CNS] go through it when..."*

Rob: *"No [pause]"*

Dr Peters: *"I'm sorry then that's the worst way to find out. Hepatitis B is an infection that attacks the liver, and sometimes people who are infected with HIV are also infected with hep B."*

Rob: *"40,000 people die of Hep C a year, I read it in a book."*

Dr Peters: *"You don't have Hep C, the infection goes up to about E, some are caused by blood to blood contact others through things like uncooked meat. You have hep B which is not as bad and we can treat it at the same time as HIV. I'm really sorry to tell you like that, it's the worst way to find out, but at least now you know."*

After the appointment when the CNS comes in,

Dr Peters: *"He couldn't remember the name HIV"*

CNS: *"Ah bless"*

Dr Peters: *"And he didn't know about his hep B."*

CNS: *"We talked about it"*

Dr Peters: *"I'm sure, I'm sure. He probably blanked it."*

Although Rob's shock here was about hepatitis B, this is due to the complex nature of having to disclose HIV at the same time as hepatitis B, and the enactment of the procedure displays the link between the severity of being diagnosed and mortality.

From this example what is evident is a rushed, and thus altered version of the attempt to disclose to Rob using a neutral standardised knowledge of HIV, negating stigma and misinformation. However, the focus on the process of HIV disclosure is at the expense of taking away emphasis from hepatitis B. What is at stake in terms of disclosure's impact on

Rob is revealed through his reaction to finding out he has hepatitis B. In this case the recommendations put forward by CHIVA begin to define what is not warranted during disclosure, in this case non-understanding, stigma and distress. Underneath the treatment of paediatric HIV there are deep malignancies that must be allayed systematically. However, the full extent of how HIV will impact upon a patient's life is rarely clear, and so the approach to disclosure must be purposefully skilful at pre-empting potential problems. Disclosure is not a simple enaction or translation of knowledge but is a complex engagement of associations and management of incompatibilities around HIV and a child's community. Decisions must be made in the clinic that plan how patients will manage their treatment alongside their everyday lives/school lives ensuring that confidentiality will be maintained in every situation. However, in contrast to the generation of endless multiplicity in medicine described in STS studies such as Mol (2002) and Mol and Law (2004) the complexities highlighted by disclosure must be addressed immediately in clinical practice. An aspect that is unclear is the extent to which disclosure is responsible for posing ethical issues between different cases that are not necessarily the pressing ethical concerns for patients. For example, child vulnerability is felt acutely by medical staff, but what is uncertain is how patients will interpret vulnerability. Different individuals will have different thresholds of distress (see Henderson, 2006 around South African orphan's perception of vulnerability).

### A Caveat Apart: Age and Applicability of Disclosure

After a consultation with 12 year old Gregory I posed a question to Dr Peters about if he has any difficulty to explain HIV in a way that a child can understand? He responded to me:

*"Yes, that's one of the challenges of paediatrics, to explain in ways that both mum and child can understand. He's only known his diagnosis for 6 months. The real challenge is to explain in ways that the parent understands and not to reveal things to the child."*

This statement brings up a recurrent question about age and competence, and how to address children and parents differently often whilst in the same room.

As discussed earlier, the purpose of disclosure is referenced in CHIVA and consequently by Dr Peters as being useful in promoting adherence and making patients able to maintain their HIV in a chronic state. It is a fundamental notion in protocol that children gradually gain the knowledge of their diagnosis before puberty. However, it is worth considering further the internal negotiation around vulnerability and competence that goes on when making decisions about disclosure (Christensen, 1998; Cohen et al., 1999; Alderson et al., 2006).

In cases of paediatric HIV, when the patient diagnosed is older than 12 years, disclosure is undertaken immediately. In a similar case to Rob, Erica had recently come from the Congo. She was 15 years old when she was admitted to UOUH with an AIDS defining illness and diagnosed as HIV positive<sup>70</sup>. Once diagnosed, Dr Peters decided to tell her immediately that she had HIV. The case became more akin (although important differences remained) to how disclosure would be approached in an adult case. The issues considered did not centre upon whether she was ready or able to conceptualise HIV and the importance of keeping it confidential, as would be the case in paediatrics. The only issue that was deemed distressful was finding out her HIV positive status, which is not isolated to, but is antagonised by the fact that the case is in paediatrics (Armstrong, 1979). From Dr Peters's perspective he wanted to tell her immediately in order to start treatment as soon as possible.

This can be branded as an extreme case of disclosure compared to the CHIVA model, what this example highlights is the contingent nature of disclosure and the idea of vulnerability and competence applied to younger age groups. Although the clinic works from a protocol, many factors need to be decided upon independently in each case. Even though the age of 12 is a recommended target and a slow procedure of education is detailed for use in the clinic, the way these ideas must be applied and the objects that further make the model applicable to individual cases are ongoing and progressive. The dangers are also detailed by what the medical model wants to avoid, mostly around misunderstanding. If the age is adjusted then the model must be altered. However far a case may differ from the model,

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<sup>70</sup> The differentiation between HIV and AIDS is that a case is defined as developing into AIDS when the immune system has deteriorated to the extent that opportunistic infections are no longer suppressed.

the necessity for disclosure doesn't cease to be any less relevant. Treatment, empowerment, minimisation of distress/QoL, consent are still sought under the term disclosure (Mellins et al., 2002). However, what is different in Erica's case is the association disclosure has with age and development, as the child in question is in fact adolescent, the connotations of vulnerability and competence are blurred between childhood and adulthood and so disclosure can take place immediately. In this context of a more immediate notion of disclosure, the technique at work becomes less prolonged and extensive. The difference in clinical approach contrasts the measures employed to manage complexity in younger patients. Disclosure is still used to consolidate adolescents into medicine and render them responsible, but it is not the extensive process of building up a carefully managed initial knowledge base around HIV as it is with younger children.

## Conclusion

The way disclosure has been followed through this chapter has been informed by STS (see chapter 3 on following actors) and demonstrates that disclosure is enacted within the clinic to bring patients into medical knowledge and create a shared understanding of HIV between patient and practitioner that informs care, standardises practice and can be built upon throughout a patients' lifetime. The different cases detailed in this chapter highlight disclosure designed to consolidate patient complexity into compatible understanding of HIV and HIV medicine. In this chapter (along with the others that will follow) I have demonstrated the places in the clinic where procedures of disclosure are applied. Disclosure has been referenced alongside discussions taking place in professional bodies responsible for setting policy, protocol and guidelines. Hopefully this has demonstrated the different forums in which disclosure is referred to. Inspired by 'object politics', it can be postulated that protocol and guidelines are enacted and interpreted recurrently in the space of the clinic during the task of disclosure. It is the negotiation in the clinic between the practitioner and the patient that implies the ways that these relations are at work and how the medicine is to be relayed, practiced and responded to. Therefore, protocol is under negotiation whilst remaining an impetus for action in the clinic (Berg, 1997b). However, beyond 'object politics', the enactment of disclosure guidelines as described in this chapter

must also perform the task of consolidating patient complexity into medical knowledges of HIV. Accordingly, the clinic is a key site in the formulation and application of disclosure.

Consequently, disclosure is not uniform, in each case where disclosure is implied there are associations that are unique. Disclosure in paediatric HIV has more than one version when taken as a whole or even when applied to individual cases (Mol, 2002). Factors of stigma, confidentiality, the importance of avoiding resistance, public health considerations and age all interact with differing outcomes and consequences. All of these factors manifest differently across the clinic and highlight the attentiveness required in practice to address them. What has come into question throughout the chapter are the implications generated from adopting a systematic approach to disclosing HIV to children who are receiving treatment (Timmermans and Berg, 2003), and the antagonism between vulnerability and competence in relation to disclosure. In this light, disclosure is responsible for bringing children into medicine by making them aware of their HIV. In contrast to the other STS accounts of clinical enaction discussed in chapter two, that demonstrate practice as generating multiplicity over multiple sites, such as Mol, (2002), or Law and Singleton (2003), disclosure emphasises the importance of ordering complexity in the clinic in the act of imparting knowledge to children. Disclosure contributes to the reciprocation between the medicine and the lives of children with HIV, and makes sure a certain mode of defining and treating HIV become and remain possible. The procedure attempts to ensure that patients possess the knowledge necessary to understand the importance of drug regimes, aiming to maintain that the condition can remain chronic for the largest number of cases (as is the logic of Lepping, 2007). Therefore, disclosure is a facilitator for the long-term maintenance of HIV. It acts as a go-between that will address complexity through making sure that patients reason with their HIV in the ways presented resolutely to them by practitioners.

When the impact of medicine is taken as a whole, it is difficult to assess the full extent that disclosure has upon the operation of the clinic. It can certainly be traced across a broad range of the activities that take place there. It can be seen in incidences of children asking certain questions, to Dr Peters being freer to discuss regimes with the child present in the consultation room. Consequently, disclosure becomes necessary to protect 'vulnerable' and

'naive' children from knowledge of their HIV in an attempt to minimise the risk of distress and a breach in confidentiality (Kelle, 2001). However, the implications as to how these processes of disclosing permeate much further into treatment are also salient. The extent of how disclosure will impact upon a child's development, adjustment and future attitudes towards HIV medicine can be questioned<sup>71</sup>.

The connotations of vulnerability and competence that are to be found formalised in the guidelines to individuals below the age of 12 can also be questioned. When discussing disclosure in the light of STS descriptions of clinical enactments it is these factors that are difficult to place. On the one hand it could be argued that childhood is multiple in protocol and practice and that ideas of vulnerability and competence are constantly re-enacted between the clinic and presenting children. However, this seems to leave us with some loose ends, knowledge of HIV and childhood here seems to have some serious and very dangerous implications. The fact that parents and practitioners need to be extremely worried about what a child may disclose to others, or the very real harm that could be done to children if the version of HIV presented to them is not well screened seems to imply some ulterior connotations to concepts such as multiplicity, transition and irreducibility. When the objects of childhood and HIV are presented in this way the complexity and contradiction generated are seemingly overwhelming. Compared with STS accounts discussed in the literature review that make the elucidation of this complexity as their goal, such as Mol (2002), Law and Singleton (2003) and Law and Mol (2004), this chapter has shown how complexity must be ordered and made compatible as a matter of immediacy in the clinic through the negotiation of disclosure between patients and professionals.

The concluding argument of the chapter is that the formalised introduction of children, into specific knowledge around HIV is part of a larger clinical logic that reasons to make large-scale paediatric HIV suppression possible, as will be elaborated through-out the proceeding chapters. Even though the extent of disclosure's impact may be difficult to quantify definitively, it can be asserted that from this angle, when put into process, disclosure

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<sup>71</sup> Articles such as Steele et al (2007) highlight this issue as having important implications for the administration of treatment.



becomes a unifier of clinical practice whilst remaining dynamic and never fully defined (Mol, 2002). The processes demonstrated document the attempts by the clinical team to bring patients into knowledge through a negotiation between the practitioner, the medicine, issues of community and ethnicity, cultural representations of HIV and broader issues around the lives of children coming into adolescence. Through this negotiation, disclosure and its formalisation in practice and negotiation in the clinic can be seen as a concerted attempt to unify and make compatible disparate associations of childhood and HIV to the clinical treatment of HIV.

The next chapter will be about adherence where I will continue to follow techniques designed to bring patients into knowledge, consolidate practice between patients and professionals, standardise care and make the suppression of HIV with antiretroviral medicine possible. Subsequently, the idea that clinical procedures are unified through formalised procedure will be employed in all of the following research chapters of adherence, chronic illness and transition.

## 6 Adherence

The previous chapter introduced us to the formalised procedure of disclosure which was shown to determine how children are included into knowledge of HIV. Building upon these findings, this chapter will explore how the procedure of adherence can be described as a technique that encourages patients to conform to antiretroviral regimes.

To those infected with HIV, antiretroviral medicine provides the promise of being able to suppress their virus unforeseeably, for an extended time period into the future. For children who acquired HIV at birth before the advent of antiretroviral medicine, the outlook was that they would face an AIDS defining illness and mortality before adulthood. With the advancement of antiretroviral therapy it has become possible to interrupt the progression of HIV and increase the life course of an infected individual (Sharland et al., 2002; Foster and Lyall, 2005). The advancement carries a limitation however. If anti-retroviral drugs are not taken at strict regular intervals and doses, patients risk viral suppression failing and becoming resistant to that drug and all antiretroviral drugs in that category<sup>72</sup>. Therefore, in this context the issue of adherence to antiretroviral treatment has become salient (Chesney et al., 2000; Marhefka, 2004).

As with other chapters, adherence is seen as a procedure that consolidates the medicine, the patient and the practitioner through clinical practice and protocol to make viral suppression possible over the largest number of the patient cohort. As will be discussed

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<sup>72</sup> Antiretrovirals are categorised into groups according to which phase of the retrovirus life-cycle that the drug inhibits. There are several categories, the most common used examples in the clinic are Protease inhibitors and Nucleoside reverse transcriptase inhibitors (WHO, 2011).

however, with adherence there is a fundamental difference. All of the other procedures that are described: disclosure to transition have emphasised their flexibility and adaptability in approaching child patients. Adherence does not. If suppression is to be achieved, the regime must be followed exactly as given, the processes of disclosure and transition can afford to be flexible to ensure that maintenance of paediatric HIV is possible, negotiation around adherence is limited. Any deviation jeopardises the possibility of viral suppression. Therefore, practitioners must persuade patients to follow adherence guidelines exactly (McCoy, 2009). In any negotiations around the uptake of medicine, the factor of adhering must be portrayed as absolute, as once breached, the negotiation no longer becomes around how to adopt medicine but between resistance and salvation, life and death. The implications this has on practice distinguishes paediatric HIV amongst other accounts of STS as it stresses the absolute requisite that practice successfully translates to children the need to stick 100% to their antiretroviral drug regime. For example, the arthrosclerosis and STS described in Mol (2002) lacks the immediate clinical requirement for practice to coordinate medical requirements with complex patient lifestyles and everyday actions. The promise given to HIV patients that they can manage their illness seamlessly into their daily lives over their lifetime is contingent upon patients following drug regimes (Pontali, 2005).

In relation to STS, adherence can be seen as an imperative enaction or translation that often offers patients an unsettling choice (Rosengarten, 2004; Persson and Newman, 2006). Adherence is formalised through a protocol to facilitate a negotiation that aligns drug taking into individual lives, and demonstrates to patients what is required in order to suppress the virus. For patients it offers a regime to follow everyday that promises suppression (Gibb, 2003). It is in this process (as with the previous chapter) that adherence consolidates affected populations, practitioners and medicine together. Aside from the concept of adherence between practitioner and patient however, there is also a translation taking place between the medical science and clinical care (this antagonism is applicable to all chapters but it is in adherence it becomes particularly obvious). The medical science behind antiretroviral therapy has a clear requirement in order to produce itself effectively, i.e. that patients take their medicine when required (Mol, 2002). The problem for the medical science comes when considering how to reproduce suppression alongside patients who can

cause many unforeseen and unaccounted problems outside of the optimum conditions. It is the job of clinical medicine therefore to make patients reliable, organise the application of the science and make suppression possible. In this context, I will consider the ways in which adherence emerges in the clinical negotiation and re-negotiations of drug requirements between children and practitioners over a child's growth into the consequent 'responsible' adult HIV patient.

In relation to childhood, HIV and antiretrovirals, 'adherence' takes on a particular set of contextual meanings and responsibilities. This chapter discusses how, as well as being descriptive of an act, adherence also refers to a set of techniques and tools developed to ensure drug regimes are monitored and followed effectively. However, rather than asserting that adherence is a task laid out and defined by medical science, the aim here is to assess ways in which adherence is a negotiation between drug development, protocol, practitioners and patients through the clinic (Lutfey, 2005). Considerations of adherence are integral to paediatric HIV medicine. Organisations of professionals such as the Paediatric European Network for Treatment of AIDS (PENTA) and CHIVA regularly discuss how to make children adhere to antiretroviral medicine. The presentation of adherence in CHIVA and PENTA relative to the field will be our starting point, before going on to discuss the common ground needed between patients' and professionals to make regimes work, and finally the concept of *good care* that is used to curb scientific priorities and unify the desires of patients with the scientific discussions of professionals.

## CHIVA Adherence Guidelines

On the website for the 'Children's HIV Association' (CHIVA) under the heading *Guidelines: Adherence* (CHIVA, 2011d) there is a selection of resources i.e. protocols and guidelines designed for use in the UK across health services dealing with paediatric HIV. Amongst this section there are four documents on adherence. Two are for practitioners, titled *Protocol to Enhance Adherence* and *Pill Swallowing Techniques* (CHIVA, 2011e), one is for parents or carers called *Taking medication: a fact sheet for parents and carers* (CHIVA, 2011f) and one factsheet has been made for children, *You and your medicine: A factsheet for young people*

(CHIVA, 2011g). The protocol (CHIVA, 2011b), made for practitioners attempts to offer a set of key points. When followed, the protocol ensures that practitioners will think through the potential barriers to adherence in individual cases and how demanding the regimes will be for individuals. It asks practitioners to think of how they can potentially give adherence support to patients, such as pill swallowing techniques, pill boxes or the arrangement of follow ups and the timings of appointments when starting and maintaining a pill regime. When starting a regime the protocol advises that a series of consultations be booked, the first one assesses what time to start, then an appointment is booked within two weeks of starting the treatment, followed up by the CNS on the telephone. After four weeks patients are supposed to attend another appointment to assess how the treatment is going and then appointments go back to the regular once every 3 month consultation. The perceived aim of these documents details the measures practitioners can employ to 'enhance adherence' and gives advice to children on how to maintain an easy routine of medicine taking.

The documents set out what is expected of practitioners and children and introduces a standard to follow. Dr Peters is well integrated in the HIV network. He uses CHIVA guidelines, has contributed to certain documents and regularly advises some of the SHOs to look at them. Consequently, this version of adherence is something that figures highly and is discussed frequently as part of his role of paediatric HIV management. However, from the outset these guidelines of adherence can be seen as particular and applied to a specific problem<sup>73</sup>. Therefore, it will be useful to consider how the problem of adherence is specifically conceptualised and interpreted in clinical practice in relation to the wider field found in journal literature and professional organisations?

The definition of adherence that is fed down to the clinic is perhaps ambiguous. In relation to children with HIV, Simoli *et al* (2007) possess the definition:

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<sup>73</sup> For example it could be considered how blood tests and other necessities of the medicine are also under the gambit of adherence, or how specific it is about children going away taking their antiretrovirals rather than the idea they must adhere with all branches of the medicine. These lines of questioning could be followed, but they threaten to become confusing and ambiguous. The question of how it is constituted in the clinic assumes more clarity whilst engaging with the particular notion of adherence to pill regimes.

*“the extent to which a patients’ behaviour coincides with medical advice mutually negotiated between the health professional and the patient, is a universal challenge with all illnesses and in all age groups.” (p e1372)*

This would suggest that there exists a well developed notion of adherence in medical terminology to denote patient behaviour. However, this chapter would like to elaborate on this definition by firstly suggesting, inspired by Mol 2002, that there are multiple versions of adherence at work in paediatric HIV that are highly attuned not only to the condition of children with HIV but also to each individual case. And secondly that adherence is indistinguishable from the negotiation itself between practitioners and patients that aims to make interventions work, and circumnavigate personal patient barriers, behaviours and attitudes that are incompatible with adherence. (Cunningham et al., 2006; Naar-King et al., 2006).

There are further versions of adherence as presented in journal literature designed for practitioners (additional to the adherence documents on CHIVA), that seek to identify behaviours and factors that could indicate the likelihood of non-adherence. Commonly stated reasons for non-adherence amongst this literature were: knowledge of HIV status, depression and anxiety, medicine side-effects, medicine size or taste, care giver status or relationship, confidentiality, regimen characteristics formulation or changing regime (Simoni et al., 2007; Steele and Grauer, 2003; Haberer and Mellins, 2009). These authors are tasked with rendering the disparate actions and behaviours of their patients into a series of recommendations compatible for use in medical science to improve its effectiveness. It is not possible to state definitively, or to account for every patient action in relation to adherence, but these assessments are necessarily positioned in order to make a procedure such as adherence and therefore the suppression of HIV on a large scale possible. Also the discussion of 'enacting the social' in chapter 3 brings into question what ideas of care and sociality are enacted, (Law and Urry, 2004). In contrast to the ways that STS, such as Mol (2002), or Mol and Law (2004) describes multiplicity as unfettered in medical practice, paediatric HIV adherence purveys the cultural awareness required in the clinic to negotiate patients’ dispositions in accordance to adherence requirements. It is the role of

practitioners in the clinic to consolidate and apply these discussions of adherence and make them compatible in a clinical setting.

In order to make antiretroviral medicine functional, the role of those who administer the medicine in this negotiation, identify and predict incompatible personal barriers, behaviours and attitudes with adherence. Amongst some articles, the way that this is problematised is to suggest that medicine must make itself responsible for making the wider 'social'<sup>74</sup> aspects compatible with the medical laboratory and drug trial recommendations.

*"Conclusion. Good adherence with taking prescribed medication was associated with virologic response. Social factors were important in explaining nonadherence." (Gibb et al., 2003)*

In attempting to instigate this process, actions in the clinic ask for children and parents to participate with larger scales of ordering into medicine, asking children to work towards and take responsibility for viral suppression (see for example McCoy, 2009 and the patient work that goes on to adhere). In effect to embrace antiretroviral adherence alongside their own everyday culture.

Adherence can be conceptualised here as a procedure that is made to work over different forums, from literature discussions and protocol, to individual cases, to larger groups of patients. It translates individual behaviours to make them applicable over larger collective groups of patients (Callon, 1986). Individuals are involved in shaping this process but also perceive the routine of taking the medicine differently.

Rather than describing adherence as simply behavioural, I will argue that adherence pertains to the negotiation of clinical encounters into predictable patterns that inform guidelines, protocol and the situations that are presented in the clinic. The starting point is to consider how clinical interventions involve a specific negotiation of what adherence is

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<sup>74</sup> I have highlighted the word social here, as I think that this way of presenting a problem as social is overly simplistic and reductive to the incidences and relationships going on in each circumstance (Latour, 2005).

and what it will be taken to mean by both patients and practitioners in order to make antiretroviral medicine functional.

Over a few months in the clinic, a case where adherence was negotiated unfolded, arising from a consultation where the adolescent was informed that they would have to recommence antiretroviral therapy. Jemima was born in the UK to African parents. She had been attending the clinic for virtually her entire life. At the time of research Jemima was 16 years old, she had been off of antiretroviral medicine for five years. But after her last blood test, her CD4 count was found to be lower than 100, the recommended level to flag her up as being at risk, and so the team decided it was time to restart her on anti-retroviral therapy. A week previously at the monthly staff meeting, the team of nurses came together with Dr Peters, Dr Phelps from CHH, Dr Chambres from T1 and the pharmacologist to discuss Jemima's case. Using her record they devised a regimen based upon her resistance profile. Although there was some uncertainty, they agreed to put her on a regime that contained some of the drugs that she was previously taking at 11 to prolong their usefulness. Jemima's appointment was brought forwards from her usual date due in 3 months to the clinic taking place in the next week. Consequently, during a morning clinic, Jemima and her mother came into the consultation room. In attendance at the clinic were myself, the CNS and Dr Peters. For about 20 minutes Dr Peters explained to Jemima the need for her to go back on anti-retrovirals and detailed the regime, possible side effects and the importance of taking it regularly when Jemima interrupted him: *'I just want to get my prescription and go, how much longer is this going to take?'* [pause]

Dr Peters: *'Why?'*

Jemima: *'I need to go to school'* [pause]

Dr Peters: *'Do you discuss your HIV much with your mum?'*

Jemima: *'When we leave here it's like it doesn't exist, we never talk about it.'*

Dr Peters: *'Do you think much about your HIV?'*

Jemima: *'No, the only time I think about it is when I come here'*

Dr Peters: *'Will taking your meds remind you of your HIV?'*

Jemima: *'Yep'*

Dr Peters: *'And if they weren't there how would it be?'*



*Adherence*

Jemima: *'Pretty normal'*

Dr Peters: *'would you like to see the counsellor?'*

Jemima: *'Nope'*

Dr Peters: *'Sometimes it helps to get things out in the open'*

Jemima: *'Yeah but they won't be able to change anything, it is the way it is.'*

Dr Peters: *'It can be quite helpful to talk about these things, you think about it and tell me next time.'*

After the clinic Dr Peters came back into the room. The CNS is out of the room doing a blood test, he closes the door and says to me:

*'There isn't a much clearer way of putting it, she was very articulate in saying why she doesn't want to take her medicine; because it reminds her of HIV.'*

This passage demonstrates the attentiveness a practitioner must uphold to fit guidelines to adolescent attitudes in the clinic. Dr Peters was quick to locate Jemima's attitude in relation to adherence and identified it as a common response. Before Dr Peters begins to discuss with Jemima the need to take treatment again, he is well versed on how to portray *acceptable ways to pursue adherence* when starting a new treatment, and interprets the situation in relation to his knowledge of protocol. The clinical intervention is crucial in processes of adapting protocol to patients' lives. One question that arises is how adherence problems are discussed abstractly between wider networks of professionals, identified in the clinic and policy is translated for use? The differing interest in adherence between CHIVA, Dr Peters and the specific patient (and parents) in consultation, points to a negotiation between what is recommended and the case at hand. Dr Peters sees it as his role to manage between the requirements of anti-retroviral medicine and what he sees as an attitude contrary to treatment.

A few weeks later Dr Peters highlighted to me that he was familiar with Jemima's attitude by saying that problems usually start when children get to about 14 or 15. He used the example of Nadine who he had a very good relationship with up until she was 14 years old,

but then apparently (as Nadine did not attend a clinic during the year I did research), started to have problems with her mother and her sister and then with the clinic<sup>75</sup>.

In seeming quick to place Jemima in the incident, a process can be seen to take place where the clinical encounter in the consultation with Jemima is simplified in order to organise it into the context of an overall case alongside a set of adherence issues. Her case can then be collated alongside other cases (White, 2002; Atkinson, 1995). Another place where this can be highlighted is during a staff consultation meeting where Jemima's case came up again alongside Nadine's. Dr Peters was talking to two other consultants [Dr Chambers and Dr Phelps] about what to do with Nadine, an adolescent who had been referred to social services. Dr Peters:

*"She's [Nadine] a girl 16 going on 25, she has her life and she doesn't want HIV to be a part of it. [Refers to me] was here last time when Jemima was in and she said quite clearly that every time she's in here and takes the medicine it reminds her of her HIV."*

Procedures such as adherence influence how Jemima's case is discussed and considered at the clinic. The way her attitude is understood also influences the kind of attention she receives. Immediately, Jemima is understood as lacking in competence and in need of sensitive management<sup>76</sup>.

At the most basic level, ready evidence for this comes from how Dr Peters immediately interprets Jemima's stance as a potential barrier to treatment and makes it a priority to address, monitor and alleviate these perceived issues. The stance that is taken here flags up an adherence issue and relates it both to Jemima and Nadine. Before the confirmation is received about whether Jemima will take the medicine, the potential problem and dangers

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<sup>75</sup> A BBC Radio 4 programme, *Inside the Ethics Committee*, contains a similar practitioner deliberation where practitioners discuss the ethics and decisions made towards an adolescent with HIV who refused to take their medicine and eventual died from AIDS. The practitioners involved in the programme lamented over the lack of institutional control they had to force the adolescent to adhere but conclude that adherence based on coercive practices is counter-productive (see BBC, 2010).

<sup>76</sup> See Miller and Drotar, (2007) for an example of the type of criteria used in clinical reasoning to evaluate competence or Christensen, (1998) for SoC critique.

have been calculated and the team are made aware and are ready for any slip ups (as already discussed, papers such as Gibbs et al 2003 would call this the *social* element). Therefore, in contrast to the proliferation of multiplicity generated at the clinic described in Mol (2002) and Mol and Law (2004) the pre-emption of possible adherence issues here shows an attempt to tame complexity before it arises. At the point that this discussion took place, Dr Peters had not had any further contact with Jemima since the dialogue described in the previous paragraph.

In the event, Dr Peters was proven to be hasty as in the weeks and months to follow Jemima attended the clinic regularly and adhered to her medication even though after a few weeks she was found to be resistant to one of the drugs and so had to come back the clinic intensively to arrange an effective regime. For Jemima, blood tests became more and more difficult, at one point in frustration Dr Peters says to the CNS: *'she has no veins that girl'*.

Within this employed CHIVA logic, there is an uneasy balance between what is required and the anticipated ways that patients may respond to treatment. Cases are monitored in terms of adherence and potential threats to good adherence. Therefore, the clinic is a place where case specific issues are assimilated with the recommendations of anti-retroviral medicine in an ongoing negotiation. This negotiation develops the idea that adolescents may lack the competence to adhere and must be imparted with the skills to adhere (see Anderson et al., 2000). With this ongoing concern for adherence, the amount to which this negotiation affects the management and what is pushed forwards to children about HIV is significant. The actions that are carried out under the guise of adherence are inherent to the management of the clinic. From a sociological perspective (as well as STS) it is useful to trace the ways that adherence is used as a technique and question what is under negotiation? For what reasons? What this negotiation makes visible? What is made possible? And what is assumed (e.g. vulnerability and incompetence)? In order to decipher other important nuances of how adherence functions, attention should be given to other parties responsible for organising data about drug trials.

## PENTA Guidelines for the use of Antiretroviral Therapy

In addition to the guidelines of CHIVA, another body, the *Paediatric European Network for the Treatment of AIDS* (PENTA) uses a version of adherence to build up policy on the paediatric administration of anti-retroviral drugs. However, a necessary discrepancy is opened up between the version of adherence described in CHIVA and observed at the clinic and the one used to communicate between affiliates of PENTA. PENTA is made up of many members who are also implicated in CHIVA and London based departments, Dr Peters and UOUH are also integrated in this network. The self-professed role of the organisation is different to CHIVA who aim to be a first point of call for UK professionals. PENTA is a collaboration between European paediatric HIV centres and mostly carries out large scale antiretroviral trials. The centre piece of PENTA's campaign and subsequent website is an attempt to provide a definitive guideline on paediatric treatment entitled: *'The 2009 PENTA Guidelines for the use of antiretroviral therapy in paediatric HIV infection'* (Welch and PENTA Steering Committee, 2009). This offers a set of stripped down recommendations for those responsible for the administration of antiretrovirals. Primarily, it details how to make the decision of when to start treatment, what drugs to start with and recommendations on resistance testing and drug monitoring. The idea of adherence within these recommendations does not entertain an idea of adherence as judged by 'social' factors (referencing the usage of Gibbs 2003 again) such as in the previous example of CHIVA guidelines. Although it does offer some recommendations useful in cases of bad resistance, the guidelines rely upon adherence being as close to 100% as possible, and so non-negotiable.

Even though this underlines the discourse involved with Jemima in the clinic, the way the subject of adhering to antiretrovirals was approached during the consultation was different. Even if Jemima did everything that was required of her by the medicine, the idea of adherence was approached with an alternative tact. The notion of adherence that Dr Peters was negotiating towards was not only the task of giving tablets and advice on when to take medicine in order to suppress the virus, but also the factors that are likely to come in the way of this, how to fit the regular taking of drugs into children's and parent's lives, and the importance for adherence's sake to organise follow-ups. It is the clinic's role to insure that

the body of the patient is compatible with the version of viral suppression developed in medical science<sup>77</sup> and applied to the protocol. Between the stripped down recommendations of groups such as PENTA and the actual implementation of drugs over prolonged periods, the clinic must deal with a broader range of personal issues and complexities that affect the implementations of administering antiretrovirals to children and adolescents (Dorrell et al., 2008).

To do this, in each situation where Dr Peters must start or alter a course of anti-retrovirals he must use a broader gambit of tools to ensure adherence is as compatible as possible to the way adherence is presented in PENTA guidelines.

Compared to other accounts of STS that emphasise different versions of disease over different sites of medicine, such as Mol (2002) and Mol and Law (2004), the focus of this chapter is not the proliferation of adherence, but the cultural awareness employed in practice to make medical requirements compatible with patient dispositions. This is not to suggest a deficit in the different branches and organisations of the medicine, but to highlight the utility of adherence in clinical practice to coordinate different notions of adherence in the overall task of viral suppression. There are obvious differences between the way that drug data relying on adherence is collated into documents that can be used as a recommendation in the mass suppression of paediatric HIV, and over each circumstance in the clinic where adherence is implied. Therefore, in order for the guidelines to be relevant there is a negotiation that takes place in the clinic between these recommendations, the clinical advice on pill regimens and the act of ingesting a pill at home. A certain amount of

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<sup>77</sup> Stengers' (2003) concept of medical science argues that unlike other branches of science, medicine cannot escape the fact that the object of its practice is always going to be the *suffering body* and as a witness to objective proof it offers a poor testimony. By this she means that in the process of evaluating good medicine from bad medicine, the agency of the patient cannot be cut out of the equation. Unlike the natural sciences that can claim objective facts from the objects they study, medicine must also rely upon the testimony of the suffering patient to say if they are healed or not. In her essay she puts forwards that this is why the figure of the charlatan is never far away from those that practice medicine. Much as it would like to eliminate the human subject from medical procedure it is impossible, as the human subject is always going to define the questions that are demanded of medicine, as medicine is always going to endeavour to seek a cure. Although this argument becomes unclear when compared to branches of medicine such as preventative medicine that do not deal with the body itself. Perhaps medical branches such as preventative medicine are also symptomatic of the need for medicine to organise broader 'social' aspects that the natural sciences do not have to engage with.

unavoidable ineloquence in this negotiation on the part of medicine is that in effect some enactions of adherence ask children to face up to their illness, their mortality or to stigmatise themselves (which can be found in discussions around paediatric HIV and depression see Scharko, 2006).

One striking example Dr Peters informed me of was about Gregory's case before he was diagnosed with HIV. When presented at UOUH, Gregory was critically ill and was immediately put onto life support, his condition was found to be due to an opportunistic infection resulting from AIDS. His parents were told of his diagnosis and advised that the hospital would like to start antiretroviral therapy immediately. Initially the parents refused to consent to treatment because they would not accept the hospital's diagnosis of AIDS. A child protection case was filed against them and it was not until the day before they were summoned to court under child protection policy that they agreed to the treatment (Beckett, 2007). For Gregory's parents, HIV is implicit of a deeper ignominy and so to grant Gregory antiretrovirals was to admit that he had the virus<sup>78</sup>.

In other asymptomatic paediatric HIV cases, the team fear that for children, taking the medicine assumes visibility and is also an admission of illness and HIV. For Jemima, as she stated, the disease is not visible without visiting the clinic or taking antiretrovirals. The worry for the clinic is that the tasks undertaken in the interest of adherence become the most noticeable time when children will think through the consequences of immunodeficiency, and the need to suppress a virus<sup>79</sup>.

Inevitably then, the clinic must negate the equation children may have that taking the medicine and talking about it in the clinic makes HIV, stigma and their own mortality visible. Separately to Luke, Marty and Serge I posed the question: *do you talk about HIV at home?* Each one responded that they do not talk about it at home and they only talk about it in the

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<sup>78</sup>Accounts more extensively focused on the role of patients in making children with HIV adhere to antiretroviral medicine are also present in the literature (see Reddington et al., 2000; Wrubel, 2005)

<sup>79</sup>Persson (2005) argues that when HIV is made visible through lypodystrophy it generates a large cultural anxiety. Creating associations from stigma, differentiation, and discrimination to affinity, empathy, and desire. In the circumstance of negative connotations it is logical that those infected would like to keep their HIV invisible.

clinic<sup>80</sup>. It is impossible to explain something like the danger of drug resistance to children without conjuring up at some point the consequences and inevitability of what resistance will mean (Silverman, 2000). Dr Peters reasons that in negotiating medicine for HIV, these patients should consider that the medicine will keep the virus repressed and hence invisible, which is an acceptable reasoning for adherence. However, the reasoning necessarily involves setting itself against a notion of the consequences of the HIV virus. It becomes the job of those involved in caring for children that they take on board compatible and non-threatening concepts of HIV, antiretroviral medicine, normality, invisibility, and the consequences of immuno-compromisation (Wrubel et al., 2011). As seen in reference to Jemima, the doctor must make sure that she doesn't reason that the virus is invisible and so not take the medicine, and instead reason that the virus is invisible and it will be the job of the medicine to keep it invisible, and that she should trust the doctor's analysis of blood tests and recommended pill regimes.

It is worth noting here that this relationship between antiretroviral medicine and child patients necessarily involves a clinical assumption of what children's priorities and concerns when dealing with HIV treatment are, and the necessity to maintain the patient-practitioner relationship as paternalistic (Baines, 2008). If adherence is to be made compatible between the children taking antiretrovirals in the clinic and the discussions that go on in PENTA, there must be a common ground tread in the clinic. The clinic must find ways of stressing the importance of adherence to children from when they are young and unknowledgeable (or put another way, naive and lacking competence), to the point where it is deemed that they are 'responsible' adults (Fair et al., 2011). This is a unique factor in paediatric HIV adherence and one that is addressed in clinical medicine and CHIVA between the discourses that take place for children and parents and discussions about dosing going on in PENTA. The clinical awareness implied is little discussed in STS descriptions of clinical enactments and offers a contrast to accounts of atherosclerosis or hypoglycaemia discussed in chapter 2, 'object politics' by Mol (2002) or Mol and Law (2004). Adherence is tasked with

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<sup>80</sup> Taken from interviews with Luke, Marty and Serge between May and July 2011.

communicating between all groups and aligning them towards the same goal of viral suppression.

## Common Ground

However, even if PENTA and CHIVA play a role in educating children about the dangers of non-adherence, the medicine (or tellingly the meds as they are referred to in the clinic) must also be personalised and internalised by children as they take them. It perhaps makes more sense if antiretrovirals are conceptualised as not entirely created and given meaning in medical science and imposed upon children (as in the Gibbs' 2003 article only for the wider culture that children introduce to jeopardise it), but instead that the antiretrovirals only become functional when negotiated successfully by the child into their wider cultural networks (Prout, 1996; Scheldeman, 2010). For example, during several consultations children and adolescents spoke about tablets in terms of shapes, sizes and colours, when discussing pill regimes. Routinely in consultations Dr Peters would talk about antiretrovirals with patients, informing them about their regimes, what they were designed for and what they were doing, answering if they were working and any questions that may arise. In the clinic when discussing with Luke (aged 16) the roles of the individual tablets he was taking, Luke asked 'colours please' when Dr Peters would refer to a particular antiretroviral. Similarly during a consultation with Dorothy (aged 16), she became mixed up with her pill regime when asked by Dr Peters to confirm what antiretrovirals she had received from the pharmacy, she explained what she was taking in terms of size<sup>81</sup>. This indicates that children have their own approach to medicine and adherence, and that they organise the medicines into ways compatible for them to remember and adhere to successfully. This could also imply that children's understanding of antiretroviral medicine such as these, are interpreted by practitioners as lacking in competence or displaying naivety<sup>82</sup>. However, In contrast to notions of incompetence as constructed in SoC such as Christensen (1998), the process

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<sup>81</sup> Katko et al (2001) suggest that there is a correlation between non adherence and caregivers not being able to identify pill regimes. However I would argue that there are more complex levels of understanding and internalizing knowledge about antiretrovirals than the approach presented in this article.

<sup>82</sup> The discussion here draws on classic studies of children's understanding of their medicine by Perrin and Gerrity, (1981); Korbin and Zahorik, (1985); Bluebond-Langner et al., (1990)































crating naivety documented here is a process made visible between the complexities presented at the clinic and the attempt of practice to make patients adhere.

The perceived child's interpretation can be seen to make its way into the medicine in certain ways, observed evidence points to places where Dr Peters must navigate discrepancies between what he interprets as the common attitudes of children and adolescents and the specifications of drug requirements. In this context, the clinic is highly geared, pedagogically towards alleviating any potential problems. For this reason, a folder with an A4 sized sheet that has all of the antiretrovirals attached to it, is regularly used in clinic, I observed the sheet being used to explain new drug regimes to children and to settle disputes between children and the doctor about which antiretrovirals they were taking. This sheet has the potential to be used in many other circumstances and is an example of the clinic facilitating or finding common ground between a medical knowledge of the tablets and a child's interpretation (Alderson et al., 2006).



# antiretroviral drug chart

Drugs licensed in the European Union – December 2008

Generic name	Trade name	Formulation	Standard adult dose	Pills/day	Major side-effects	Food restrictions	
<b>Nucleoside reverse transcriptase inhibitors (NRTIs)</b>							
<b>3TC, lamivudine</b>	Epivir		150* and 300mg tablets	150mg twice a day or 300mg once a day	2 1	<b>Common:</b> Nausea, vomiting, diarrhoea, headache, abdominal pain, insomnia, rash, tiredness <b>Rare:</b> Hypersensitivity reaction	Take with or without food
<b>Abacavir</b>	Ziagen		300mg tablet	300mg twice a day or 600mg once a day	2	<b>Common:</b> Rash, nausea, vomiting, diarrhoea, fever, headache, loss of appetite, tiredness <b>Rare:</b> Hypersensitivity reaction	Take with or without food
<b>AZT, zidovudine</b>	Retrovir		100 and 250mg* capsules	250mg twice a day	2	<b>Common:</b> Nausea, vomiting, fatigue, headache, dizziness, weakness, muscle pain <b>Rare:</b> Blood disorders, lipotrophy	Take with or without food
<b>d4T, stavudine</b>	Zerit		15, 20, 30 and 40mg* capsules	People over 60kg: 40mg twice a day People under 60kg: 30mg twice a day	2	<b>Common:</b> Lipotrophy, peripheral neuropathy, nausea, diarrhoea, abdominal pain, dizziness, tiredness, rash <b>Rare:</b> Pancreatitis	Take with or without food
<b>ddI, didanosine</b>	Videx		25, 50, 100, 150 and 200mg* tablets	People over 60kg: 400mg once a day or 200mg twice a day People under 60kg: 250mg once a day or 125mg twice a day	2 or 4 (chewed or dissolved in water)	<b>Common:</b> Peripheral neuropathy, nausea, vomiting, diarrhoea, rash <b>Rare:</b> Pancreatitis	Take at least two hours after and 30 minutes before eating
<b>ddI, didanosine (extended release)</b>	VidexEC		125, 200, 250 and 400mg* capsules	People over 60kg: 400mg once a day or 200mg twice a day People under 60kg: 250mg once a day or 125mg twice a day	1 or 2	<b>Common:</b> Peripheral neuropathy, nausea, vomiting, diarrhoea, rash <b>Rare:</b> Pancreatitis	Take at least two hours after and two hours before eating or drinking anything except water
<b>FTC, emtricitabine</b>	Emtriva		200mg capsule	200mg once a day	1	<b>Common:</b> Nausea, vomiting, diarrhoea, abdominal pain, headache, dizziness, weakness, rash	Take with or without food
<b>Nucleotide reverse transcriptase inhibitors (NRTIs)</b>							
<b>Tenofovir</b>	Viread		300mg tablet	300mg once a day	1	<b>Common:</b> Nausea, vomiting, diarrhoea, dizziness, low blood phosphate levels <b>Rare:</b> Kidney problems	Take with or without food
<b>NRTI / NRTI fixed dose combinations</b>							
<b>3TC / AZT</b>	Combivir		Tablet comprising 150mg 3TC and 300mg AZT	One tablet twice a day	2	See 3TC and AZT	Take with or without food
<b>3TC / abacavir / AZT</b>	Trizivir		Tablet comprising 150mg 3TC, 300mg abacavir and 300mg AZT	One tablet twice a day	2	See 3TC, abacavir and AZT	Take with or without food
<b>3TC / abacavir</b>	Kivexa (EU)		Tablet comprising 300mg 3TC and 600mg abacavir	One tablet once a day	1	See 3TC and abacavir	Take with or without food
<b>FTC / tenofovir</b>	Truvada		Tablet comprising 200mg FTC and 300mg tenofovir	One tablet once a day	1	See FTC and tenofovir	Take with or without food
<b>NRTI / NRTI / NNRTI fixed dose combinations</b>							
<b>FTC / tenofovir / efavirenz</b>	Atripla		Tablet comprising 600mg efavirenz, 200mg FTC and 300mg tenofovir	One tablet once a day	1	See FTC, tenofovir and efavirenz	Take without food
<b>Non-nucleoside reverse transcriptase inhibitors (NNRTIs)</b>							
<b>Efavirenz</b>	Sustiva (EU)		600mg tablet* and 200mg capsule	600mg once a day	1	<b>Common:</b> Rash, dizziness, sleep disturbance, abnormal dreams, impaired concentration, nausea, headache, tiredness <b>Rare:</b> Depression, psychosis	Take with or without food
<b>Etravirine</b>	Intelence		100mg tablet	200mg twice daily	4	<b>Common:</b> Rash, diarrhoea and nausea	Take with food
<b>Nevirapine</b>	Viramune		200mg tablet	200mg once a day for two weeks then 400mg once a day or 200mg twice a day	2	<b>Common:</b> Liver toxicity, allergic reaction, rash, nausea, headache <b>Rare:</b> Stevens Johnson syndrome	Take with or without food
<b>Protease inhibitors</b>							
<b>Atazanavir</b>	Reyataz		100, 150*, 200 and 300mg capsule	300mg with 100mg ritonavir once a day	2 §	<b>Common:</b> Nausea, diarrhoea, rash, abdominal pain, headache, hyperbilirubinaemia	Take with food
<b>Darunavir</b>	Prezista		300mg tablet	600mg with 100mg ritonavir twice a day	6	<b>Common:</b> Diarrhoea, nausea, headache	Take with food
<b>Fosamprenavir</b>	Telzir		700mg tablet	700mg with 100mg ritonavir twice a day	4 §	<b>Common:</b> Lipodystrophy, nausea, vomiting, diarrhoea, rash, abdominal pain, headache, dizziness, tingling around the mouth	Take with or without food
<b>Indinavir</b>	Crixivan		200, 333 and 400mg* capsules	800mg three times a day	6	<b>Common:</b> Kidney stones, abdominal pain, liver abnormalities, lipodystrophy, muscle pain, nausea, vomiting, diarrhoea, rash, headache, dry skin and mouth, tiredness	Take one hour before or two hours after food or take with a light, low-fat snack
<b>Lopinavir / ritonavir</b>	Kaletra / Aluvia (resource-limited settings)		Tablet comprising 200mg lopinavir and 50mg ritonavir	Two tablets twice a day	4	<b>Common:</b> Lipodystrophy, raised liver enzymes, nausea, vomiting, diarrhoea, abdominal pain, rash, tiredness, weakness, headache	Take with or without food
<b>Nelfinavir</b>	Viracept		250mg tablet	1250mg twice a day or 750mg three times a day	10 9	<b>Common:</b> Lipodystrophy, nausea, vomiting, diarrhoea	Take with food
<b>Ritonavir</b>	Norvir		100mg capsule	Full dose: 600mg twice a day To 'boost' other PIs: 100 – 200mg once or twice a day	12 1 – 4	<b>Common:</b> Lipodystrophy, nausea, vomiting, diarrhoea, abdominal pain, muscle pain, headache, weakness, numbness around the mouth	Take with food to avoid nausea
<b>Saquinavir</b>	Invirase		200mg capsule and 500mg tablet*	1000mg with 100mg ritonavir twice a day	6 §	<b>Common:</b> Lipodystrophy, nausea, vomiting, diarrhoea, abdominal pain, muscle pain, headache, rash, fever, tiredness, dizziness	Take within two hours of food
<b>Tipranavir</b>	Aptivus		250mg capsule	500mg with 200mg ritonavir twice a day	8 §	<b>Common:</b> Lipodystrophy, nausea, diarrhoea, abdominal pain	Take with food
<b>Fusion inhibitor</b>							
<b>T-20, enfuvirtide</b>	Fuzeon		Powder reconstituted in water	Injection of 90mg under the skin twice a day		<b>Common:</b> Injection site reaction, respiratory tract infections	No food restrictions
<b>CCR5 inhibitor</b>							
<b>Maraviroc</b>	Celsentri		150*, 300mg tablets	300mg twice a day, 150mg twice a day with all ritonavir-boosted PIs except fosamprenavir and tipranavir or 600mg twice a day with efavirenz	2 – 4	<b>Common:</b> Headache, dizziness, nausea, weakness, flatulence	Take with or without food
<b>Integrase inhibitor</b>							
<b>Raltegravir</b>	Isentress		400mg tablet	400mg twice a day	2	<b>Common:</b> Headache, diarrhoea, nausea	Take with or without food

\*Formulation(s) shown. § Includes ritonavir capsule(s).

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This drug chart is produced by an organisation called NAM. NAM provides people working in the global fight against HIV & AIDS with up to date and impartial information. Please visit us at our website where you can read the latest HIV news and sign up for free email updates.

NAM, Lincoln House, 1 Brixton Road, London, SW9 6DE. Email info@nam.org.uk Web www.aidsmap.com

6 The NAM drug chart widely available to patients, shares an informative logic with the sheet used in the clinic, but doesn't give as much of an illustration of size as the actual pills used in clinic

Another example of finding common ground is the effort put into insuring children take their medicine as quickly as possible to minimise the bad taste, and make children more likely to adhere (also considered in CHIVA, 2011e guidelines).

In a clinic with Francine (aged 14) Dr Peters asked her how quickly she takes her medicine and if she is still having problems swallowing it like she did when she was younger? She responded that she is now much quicker, her mother then added that she uses a piece of apple to take away the taste. Dr Peters then shared that he knows how bad they can taste and he says that he went on a course where he had to taste them, consequently he advised Francine to swallow them as quickly as possible (asking these questions about pill taking is not a unique incidence see CHIVA factsheets).

This extract can also be read as an attempt to facilitate the concerns of children into regimes that aim to maximise adherence. Along with a specific section for practitioners on the CHIVA website to advice on pill swallowing techniques, Dr Peters administers advice to children in an individual negotiation to each patient (Garvie et al., 2007; Diamond and Lavalley, 2010; CHIVA, 2011e). And so in each negotiation the advice is honed in (here on a child insufficiency, that of diminished swallowing capability) and made to fit alongside the input and considerations of the child and their parent. The logic that is employed is one which therefore brings together and manages ideas and requirements of adherence into individual cases, and in so doing, seeks ways to make them compatible, creating a unique and effective mode of adherence to each individual patient. This point can be seen as internal to adherence. Adherence operates as a compelling force that can be applicable over the full cohort of relevant patients and professionals and unites these groups together under the common aim of suppressing the virus and avoiding resistance.

## Good Care

Therefore, when identifying what adherence makes visible, what is not suggested is that adherence is an imposition of medical power upon child patients but rather is an ongoing negotiation between drug requirements and the issues encountered with the uptake of

medicine for children. In the process of administering antiretrovirals at the clinic, each case is evaluated individually between the drug requirements, ways to make children comply and ways to enact medicine moralistically, this process is encompassed in concepts such as *good care* and alters what it means to adhere. I will appropriate Mol (2008) here when she argues that

*“good care grows from the collaborative and continuing attempts to attune knowledge and technologies to diseased bodies and complex lives.”* (back cover)

For Jemima, Dr Peters translates *good care* as the opposite of laying down a regime that must be arbitrarily followed regardlessly. He takes care to fully explain the implications of the medicine to her, and in the process is attentive to reasons why she would not want to take it and gives flex where he can. In Jemima’s consultation mentioned above where treatment was started, Dr Peter’s negotiates with Jemima her pill burden and the start date of her regime to ensure continuity and gain trust, proposing that she starts on the Monday instead of Friday so she can go out with her friends without having to worry. In the clinic there is nonetheless an uneasy tension between the imagined desires of Jemima and the absolute necessity of the regime.

In the week before the consultation at the staff meeting. Dr Phelps a consultant from CHH asked: *‘Will she take the tablets?’*

Dr Peters: *‘I think she will, [the CNS] is going to sit on her.’*

CNS: *‘Yeah I will.’*

Dr Peters: *‘That will be 8 pills a day she’ll balk at that’* (The discussion was in relation to the possibility of putting her on a new regime, which they toyed with before deciding to prescribe her old regime with less of a pill burden.)

In incidences such as this, the process of administering drugs is considered individually for the ways it can fit into what is known about the patients’ disposition and life.

Not only does this display a more abstracted version of adherence than that which the CHIVA or PENTA guidelines work from, but it also highlights the engagement of several different versions of adherence. One (I will call) as a laboratorial requirement of taking the drug 100% on time, and another as a set of considerations to make children as compliant as possible, motivated to take their medicine, there also exists a possible third that encompasses choice and a notion of what is morally right in a specific case i.e. *for the good of the patient*. Overall these enactments of adherence can combine and are translated and used strategically in dynamic ways over departments and organisations to attempt to achieve a comprehensive understanding of the mechanisms of the drugs and to maximise their effectiveness (see discussion of the charlatan in Stengers, 2003).

To this, observed examples can be included of pill regimes being altered in individual cases to insure the multi-faceted (laboratorial, compliance, moralistic) requirements of adherence. For example, Pierce (aged 8) was changed over to a regime of Combivir with a smaller pill burden on the demand of his mother as the old regime was deemed to have too many requirements. In Pierce's case, the laboratorial requirements of viral suppression was moulded around the wishes of the parent who must organise the treatment in everyday life. Dr Peters told me after the consultation that Combivir was not ideal for Pierce as it was usually administered as an adult regime, as the dose is too high. Therefore, what can be seen by prescribing Combivir to Pierce is the clinical work taking place to facilitate an ongoing, multilayered negotiation in the clinic around the appropriate action to take to ensure adherence (Sharland et al. 2000 provides details on paediatric specific regimes). This process of attuning antiretroviral regimes demonstrates the flexibility adopted at the clinic to facilitate complex patient dispositions to medical requirements.

In a similar case that demonstrates multiplicity, Rob aged 12, was reluctantly taken off of Atazanavir as it was making him jaundice and his eyes visibly yellow. Rob came to the UK from Zimbabwe and was referred to the clinic during the year research was conducted. A GP that saw Rob when arriving in the UK made the wrong decision to stop treatment, and so during his first appointments the team were worried about resistance. After consulting Dr Phelps at CHH and the pharmacologist, it was decided that he should be put on a regime

that included Atazanavir. After 3 months on the treatment Rob reported in the next consultation that the regime was causing his eyes to go yellow and that he was being bullied at school because of it. Dr Peters identified that it was the Atazanavir causing it (NAM, 2011) and the regime was changed to another protease inhibitor, Darunavir, to ensure for one reason, that Rob was happy to continue to take the medicine. Again, after the consultation Dr Peters shared his reluctance with me to change him over as the Atazanavir was proving effective, but in the end it came down to a quality of life issue and so was accepted that the regime should be changed (Welch and PENTA Steering Committee, 2009 offer guidelines on inconvenience of changing regimes). In comparison to other STS accounts of multiplicity, such as that of Mol (2002) and Mol and Law (2004) that highlight multiplicity in practice, paediatric HIV demonstrates the importance for practice to manage patient complexity flexibly into drug requirements. Whereas Mol (2002) points to the generative process of objects becoming multiple, the account given here focuses on how multiplicity becomes ordered into a necessary clinical process. The antiretroviral drugs of Atazanavir, Darunavir etc, their positive effects on the body, their many unwanted effects, the desire of the child and the bullying taking place in the school playground point to an idea of multiplicity that must be managed into the task of viral suppression. This emphasis on the consolidation of complexity is especially pressing when applying enactment to the study of paediatric HIV.

The role of the team at UOUH is not only to manage these disparate branches of CHIVA, PENTA and patient wishes, but also to seek ways in which to make contradictions in adherence compatible. One way this is done, as has been demonstrated, is to suggest alternative regimes. However, this negotiation goes much further into ways to monitor, identify and ensure adherence.

One of the most conspicuous ways this negotiation of contradictions becomes visible is from looking at some of the technologies proposed for use in the clinic with the idea of aiding children to adhere (Blume, 1992). At the half way point of fieldwork, Dr Peters became aware of the PointCare NOW machine, which if purchased for the clinic would be able to give CD4 results during a child's appointment. Dr Peters recognised the application of the

machine for improving adherence as it would make it possible for him to check if patients are being truthful in consultation about taking their anti-retrovirals. If patients were to say that they were following their treatment and the machine would suggest an irregularity in the CD4 measurement, Dr Peters would be able to confront them and attempt to resolve any issues or push the importance of taking them reliably.



**Fast**  
The PointCare NOW reports 12 blood parameters in 8 minutes allowing children & adults to leave the clinic with a test result and clinical decision.

**Simple**  
Sample processing & data analysis are fully automated. Barcode reader and barcoded labels automate sample tracking. There is no need for highly-trained technicians.

**Stable**  
Heat stable reagents eliminate cold chain shipping or storage. Reagents and controls are not light sensitive.

The image shows a PointCare NOW machine, a compact, light-colored diagnostic device with a screen and a sample slot. The screen displays the PointCare logo and some text. The machine is designed for use in a clinical setting.

7 A picture of the PointCare Now machine taken from [www.pointcare.net](http://www.pointcare.net)

Kirk, 15, was in the consultation room on his own without his mother, Dr Peters routinely has preliminary consultations with children without their parents, before calling them in later, (this is to make sure that children can talk about things they may not be comfortable talking about with their parents present). Dr Peters asked if Kirk had missed any doses in the past month. Kirk responded tentatively looking at the floor and said that he missed one dose. After the meeting Dr Peters turned to me and said that if he had a machine on his desk he could tell in cases like Kirk's if he was lying and that he would be able to tell for himself how many doses he had missed and then stop issues before they became larger problems. The incompatibility displayed here is balanced between good care on the one hand and requirement on the other, and highlights that the notion of good care is itself reliant upon the testimony of the patient being reliable (combining Mol, 2008; with Stengers, 2003).

These incidences show the logic that Dr Peters employs to straighten out contradictions in negotiations of adherence. This is based upon the attempt to achieve the ideal state of

objectified, reliable medical science and antiretroviral medicine through clinical intervention. The logic employed by Dr Peters wishes to take exact measurements at exact timings and to make visible the times when the medicine is not followed so that it can investigate and hope to quantify and resolve some of the reasons why a child may not want to take their medicine. What it also shows is a logic that could potentially standardise, to some degree, all consultations to insure that children cannot lie about taking their medicine. It shows a desire to circumnavigate 'the social' (as identified in the literature earlier see Gibbs et al. 2003), a desire (going back to Stengers 2003) to make bodies give a reliable testimony. Although no such circumnavigation is ever possible, the agency of the patient can never be reduced from a doctor/patient clinical enaction. In contrast to the description of medical power as uni-directional such as in Foucault (2010), even if Dr Peters had the machine, he would still have to enact and negotiate the patients' blood into the machine and interpret the results from the machine back to the patient as adherence recommendations. The incident implies that the clinic is a key place where complexity is consolidated and that a logic ensues in the clinic which seeks to negotiate complexity between patient and practitioner. This passage uses the concept of enaction and mutual constitution taken from the description of atherosclerosis or hypoglycaemia described in Mol (2002) and Mol and Law (2004) in the literature review. In contrast to these studies however, this extract again emphasises the attentiveness required in Paediatric HIV practice to manage complexity in the clinic (see 'object politics' in literature review). Ultimately however, literature on the management of drug requirements and patient uptake lays down an enaction of adherence as something that must be constantly improved rather than something that is maintained or adapted and essentially different over the different places it is enacted (as can be seen from literature that aims to identify all possible reasons for non adherence, Steele and Grauer, 2003; Haberer and Mellins, 2009; see especially Simoni et al., 2007).

Therefore, even though it can be asserted that all of the actors discussed throughout this chapter are eventually united in the goal of suppressing the virus, the associations maintained by individuals, the means individuals wish to employ to suppress the virus and the ends that individuals warrant all contain important differences between different



groups of patients, practitioners and professionals. In the clinic, incompatibilities between usages of adherence are encountered and negotiated to ensure positive results. During these practices the priorities of medical science are balanced by the notion of 'good care'. 'Good care' ensures that the outcome for parents is not wholly decided by the application of scientific method but requires an assessment of what will ultimately be beneficial to each individual patient. The role of 'good care' is used to unify enactments of adherence in the clinic, between patients and the discussions of PENTA. Therefore, 'good care' in this context places a responsibility on the medical science to maintain a sound rationale for action in each individual situation and makes patients responsible for acting morally in their own interests, inviting them to reflect on what they want from care<sup>83</sup>. As can be seen in the example of both Jemima and the circumnavigation of responsibility from the *Pointcarenow* machine (Mol, 2008).

## Conclusion

This chapter has highlighted a mutual negotiation that takes place in the clinic, one between the recommendations of antiretroviral medicine, the clinic and the child at home who must take the medicine. Adherence in the context of STS becomes a translation between the medical model of viral suppression and the lives of children and parents that must take the pills regularly. Adherence requires doctors to understand common reasons for patient non-adherence, organise cases together to identify common themes, and act authoritatively and patriarchally towards children to make judgments in their best interests (Alderson, 2008). Adherence asks children and parents to take on board the importance of taking medicine at regular intervals and act accordingly in ways compatible to meet requirements. To those collating drug trials, adherence must be quantified as a constant variable which has its own implications on the medicine. Adherence works towards unifying groups of practitioners, patients and biochemists (and CHIVA and PENTA). Adherence has specific meanings and purposes in each of these different contexts and groups. From trials, to guidelines, to

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<sup>83</sup> I am not suggesting here that the desires of children will necessarily result in a direct alteration to the medical science, but rather suggesting that a nuanced dialogue takes place between the way children present their opinions to carers and the way care will consequently be tailored and adjusted accordingly.

practice, to the home there exist scales of adherence that all actors imply (Mol, 2002; Latour, 2005). However, there is a central allure to adherence that encourages each group to unify their efforts and standpoints to achieve the task of viral suppression. It is at this point where adherence can be questioned as to what it *is* and what purpose it ultimately serves. Adherence can be described in a variety of different ways, for example adherence could be described as a technology that is applied to patients and professionals, or the employment of a method. Evoking Foucault (2010), adherence could be described as a form of surveillance used to modify the behaviour of individuals according to knowledge/power structures. It is more persuasive however, to consider the ways in which adherence is employed in negotiation according to the context presented in the clinic. To emphasise any of these roles of adherence over another would obscure the main strength of adherence: its flexibility. The concept of surveillance assumes that power structures act in one direction and for one purpose, whereas the strength of adherence lies in its continued applicability between each relevant party. Patients can be seen to take up the logic of adherence and actively shape how adherence is constituted. For example, Jemima's refusal discussed earlier can be read as Jemima placing her will onto adherence and consequently altering the way adherence must be conceived and applied. If adherence is to be imagined as a method, a technique or even a form of surveillance, the contingent nature of adherence must be stressed, it is neither exclusively applied, employed or enforced, but is a combination of situation-specific dynamics which have been designed to be applicable (but non-breakable) in the most contingent way possible that will still result in viral suppression. It is this clinical immediacy to consolidate complexity 'at all costs' that sets paediatric aside from other clinical studies of STS such as those in chapter 3 on object politics. For example, in comparison to the idea of allegory found in Law and Singleton (2003) that highlights how illnesses in the clinic are always referencing other places, this thesis demonstrates how the paediatric HIV clinic must consolidate outlying references in the clinic into functional antiretroviral medicine.

Consequently, the focus of the discussion has been on the ways that adherence must be negotiated and re-negotiated with the end state of suppression in mind each time it is referred to. The ends that those who enact adherence have in mind go towards defining

the boundaries of the procedure. For example, it can be postulated that practitioners have the end in mind that they will bring together patients with biomedicine to manage patients and suppress HIV, and alternately, patients have the end in mind that they will take the pill everyday under the promise that their HIV will be kept invisible, this evokes different connotations of adherence. The ends that patients and practitioners are striving towards in this postulation are translatable and so can make the medicine *functional* and viral suppression *possible*. When the ends are not aligned or are incompatible the medicine breaks down (in the style of allies described in Latour, 1987), this would happen in the case of children not seeing the point in taking their medicine or the need to adhere (Anderson et al., 2000). This highlights the boundaries of adherence and the emphasis, in cases like Jemima's that a dialogue is maintained and all foreseeable negative connotations are addressed in protocol.

If adherence fails it brings forwards the possibility that viral resistance could ensue and render future attempts to suppress the virus impossible. Therefore, adherence is purposively presented in a undemanding way that circumnavigates irrelevant particularities such as the biochemical differences between regimes and the composition of drug categories (bringing to mind the idea of the black box by Latour, 1987). Adherence is simplified to patients between taking medicine and ensuring suppression on the one hand, to not adhering and risking immunocompromisation and possibly death on the other (Gibb et al., 2003). Therefore, the compromise at work in adherence between practitioners and patients is fragile and must be maintained with the utmost caution that ensures each party knows the risk of failure. It is this real sense of danger encompassed in adherence that marks paediatric HIV as developing a more acute awareness of culture in the clinical consolidation of complexity than other studies of illness and medicine in STS (such as Mol 2002, Mol and Law 2004).

In order for adherence, and consequently the rest of the antiretroviral medicine around HIV to work, all parties must share a compatible idea of the consequences of non-adherence which justifies the maintenance of antiretroviral regimes. It is not acceptable to maintain this negotiation ambiguously due to the stakes and the limited opportunities for rectifying

the situation if medicine is not followed. Antiretroviral medicine must be maintained in ways which makes sure adherence stays functional and persuasive. Tablets are made as invisible as possible by practitioners, are presented to adolescents as reliable and as a means to keep their virus as invisible as possible if taken precisely. Adherence must successively maintain contradictions in care and render them compatible, whilst practitioners must strive to ensure, and to continuously identify and engage with the reasons why children and adolescents may choose not to adhere (e.g. “facilitation” of adherence in Pontali, 2005; or “achieving” adherence in Cunningham et al., 2006).

When carried-out efficiently, adherence makes possible a process of standardisation that the clinic can employ in order to compare cases against one another and maximise the uptake of medicine amongst the entire cohort of patients. Through the formalisation of adherence as a procedure in protocol, cases can be compared and calculated against each other in order to make the medicine and dosing more effective (Iedema, 2007). Consequently, outlying cases can be brought more persuasively into antiretroviral medicine. Therefore, it becomes prudent to consider adherence as an entity that makes possible the observation of unruly bodies to scientific scrutiny via clinical management (Waldby, 1996).

If (informed by Stengers, 2003) the ways in which child and adolescent patients may not always give a ‘reliable testimony’ are considered in terms of how well they have followed their regime (Kirk and the point care machine come to mind), it raises speculation that all of the reasons as to why children do not adhere to medicine may not be possible to explain. In an attempt to make the medical science around antiretroviral therapy as effective as possible, biomedical reasoning often attempts to circumnavigate the considerations of adolescent bodies that are not able to ‘testify’. For medicine to be considered as effective or not, ways in which cases can be measured and made comparable alongside each other become essential, it tells those designing therapies at which point medicine will become successful and if a patient is doing what is required or not. However, the clinical logic of standardising and regulating pill taking behaviour is at odds with the attitudes of children who adhere through the promise of remaining healthy, as for many, taking anti-retrovirals is conceived as the only time their HIV becomes visible. To counter these considerations and

to aid with meeting requirements, the clinic filters its behaviour through notions of 'good care' which moderates the administration of drugs between requirements and the considerations of patients.

In relation to the STS already discussed, it can be argued here that adherence is negotiated between making antiretroviral medicine as effective as possible and making medicine serve the interests of those it is attempting to treat. Through 'good care' a balance is maintained between requirement, quality of life and patient choice (see Mol, 2008). However ideological this may seem, the negotiations that take place between practitioners and patients in the clinic ensures that these considerations have a bearing on the medicine. What is emphasised in addition to this use of STS is the cultural awareness needed in paediatric HIV clinical practice to consolidate patient choice with absolute drug requirements. In the context of the clinic, the application of scientific method can take on many manifestations, as practitioners aside from biochemists must ask to *what are we attempting to apply scientific method to? The behaviours of individuals? the attitudes of individuals? the extraneous elements that take place in their lives?* (and to these questions of child competence and the desire for confidentiality can be added and scrutinised as to how compatible they are to scientific method Christensen 1998). Therefore, practitioners must maintain a balance as each clinical negotiation is multifarious and not exclusively directed from guidelines. Guidelines must be interpreted, negotiated and reapplied in each respective clinical encounter.

Throughout this chapter, the description of adherence in paediatric HIV has assumed a difference to the ways in which adherence is applied to adult populations. Imbued within paediatric adherence are connotations of child incompetence and naivety. However, the discussion has avoided highlighting innocence as a unidirectional imposition of power on to incompetent children, in order to frame ways in which childhood is a negotiation and associations such as innocence and naivety are emergent and accounted for in the clinic (see Prout, 2005; Lee, 2008 on negotiations of childhood). Adherence applied to children must ensure that the task of following medicine is 'facilitated' or 'achieved' in accordance to the lives of children, not imposed upon them (see the pre-occupation of Pontali, 2005;

Cunningham et al., 2006). These considerations have distinct implications for the question of how 'scientific' the notion of adherence can be made to be. As adherence is formalised, it must adapt to the needs and comprehension of its child cohort as presented in the clinic. As can be seen in the chapters of disclosure and the proceeding one on transition, a great deal of resources and attention are spent to the task of bringing children into knowledge and making them responsible. Therefore, these processes of formalising adherence must necessarily be integrated with notions of child incompetence and incomprehension, naivety and vulnerability (It forms part of a separate question to assess the merits of this process).

The procedure of adherence sits integrally alongside the titles and arguments of the other empirical chapters of this thesis: disclosure, chronic illness and transition (forthcoming). The procedure forms part of a clinical logic that seeks to consolidate complexity into a coherent and functional antiretroviral medicine. Adherence is at the core of processes of HIV care that seek to consolidate patients into care, unite groups in a shared knowledge and make viral suppression possible for children with HIV. However, as part of this regime of care, the unique factor of adherence is that success is reliant upon it. Indeed, the other procedures of disclosure, chronic illness and transition all allow themselves to be as flexible as possible on many factors as long as patients understand the absolute need to adhere 100% to antiretroviral medicine. From the point of view of the practitioner, what is demonstrated as under negotiation in this chapter are ways of making this absolute need understood and how to make it persuasive, contributing to the STS discussed in 'object politics' by suggesting the immediacy employed in the clinic to organise complexity. This requirement is of central importance for each group involved, although it has the potential to be understood differently or understated by patients. In comparison to all of the other medical procedures found in these chapters, if suppression is to take place, adherence must be stated, re-stated and corrected if necessary.

The next chapter will look at chronic illness and demonstrate how procedures such as adherence are aligned into longer periods of time between the lives of patients and over the entire cohort. Adherence, in the context of chronic illness becomes a factor that all groups must come to rely on and put their faith in with the promise of suppression and viral

invisibility. Enactions of chronic illness used in the clinic and care guidelines consolidate disclosure, adherence and transition with wider regimes of care over the lifetime of children with HIV to ensure that suppression is made possible in the long term. This line of reasoning will form the core discussion of the next chapter.

## 7 Paediatric HIV as Chronic Illness

Since the discovery and implementation of antiretroviral drugs has made the suppression of HIV possible, services aiming to deal with Paediatric HIV have begun to plan for the long-term care of children and the chronic management of HIV using antiretroviral therapies (Gibb, 2003; Foster et al., 2007). The clinic observed at UOUH is no exception. However, descriptions of HIV as chronic can be seen to be more context specific and variable than the simple long-term application of treatment and suppression. Viral suppression contains many limitations and caveats, Dr Peters was always more cautious when describing HIV as a chronic condition, preferring instead to say things like: *in some ways HIV can now be seen as a chronic condition* (also see Siegel and Lekas, 2002). Therefore, the way that paediatric HIV references associations of chronic illness needs some consideration.

This chapter focuses on ways in which paediatric HIV can be referred to as a chronic illness. However, descriptions of chronic illness as a singular entity, as exclusively describing either large or small time-scales or as a priori to the encounters where it is referred to will be different. Discussion stems from considerations of chronic illness not as innate to HIV management but as enacted according to a purpose and argues that chronic illness is used as a procedure in the clinic and protocol to consolidate patient and practitioner actions into HIV care. Compared to the previous chapters on adherence and disclosure, depictions of chronic illness as a procedure that informs practice are perhaps more concealed, and less readily seen as being formalised into guidelines in the clinic. Nevertheless, I will demonstrate how the usage of enactments of chronic medicine/care are heavily implicated in the organisation and implementation of HIV care, and are used in a similar way to adherence, disclosure and transition to coordinate patients and practitioners together.



Through the utilisation of chronic illness as a procedure, it is possible to conceptualise care as a continuum and gain a foresight of how to allocate care throughout a patients' development through childhood, into adulthood and beyond. Discussions of chronic illness are well documented over a wide range of disciplines. In sociology, chronic illness runs from Parson's classic *sick role* to Mol and Law's demonstration of *embodied action, enacted bodies*. A parallel tradition can be found in psychology literature. two relevant examples would be Bradford (2002) and Eiser (1990) who have both provided theoretical and applied accounts of chronic illness specifically related to childhood. Narrative analysis accounts have also been used between disciplines to describe patient experiences (see Williams, 1984; Bury, 2001; Frank, 2010), but with limited attempts to consolidate patient, practitioner and scientific accounts. In medical literature the numbers of references to chronic illness fracture further amongst disciplines, fields and traditions of medicine. Examples from the HIV literature, discuss concepts such as 'adjusting to' or 'living with' HIV, 'long term care' and the 'legacy of perinatal HIV' (Foster et al., 2007, 2009; Koenig et al., 2011). When citing HIV, this literature refers to chronic illness as if it is innate, doesn't need to be achieved and can be taken for granted.

The examples cited above are indispensable in the ways that they offer conceptualisations of illness as continuous. However, I will be displacing traditional ideas of chronic illness by avoiding considering it as something a priori that exists independently of the situation where it is found. Instead, following Law (1999), the approach employed considers how chronic illness is presented, referred to and made useful in the clinic, and as a result will further the thesis argument that places the clinic as a key location of formulating medical procedures that consolidate complexity into a coherent antiretroviral medicine. Drawing on other STS accounts that describe chronic illness as enacted such as Mol, (2002) or Mol and Law (2004), this account presents the clinical logic of HIV medicine to convey chronic illness as something that must be achieved through HIV care. The logic of chronic illness is employed in the clinic to ensure that practitioners and patients conceptualise effectively the contingency of antiretroviral treatment. I have identified four categorisations where 'chronic illness' or 'chronic care' were referred to in the clinic. Each encounter uses chronic illness in ways similar to a procedure to coordinate care. The first is enacted to console

patients who must foresee their life with HIV. The second is behind educating children into knowledge about HIV for the reason that they will have to take responsibility in the long-term for their care. The third is used in professional negotiations to plan the long-term care and field of HIV medicine. The fourth is enacted when plotting general health care and other regimes of medicine. Through adopting considerations of STS, I argue that what emerges are the ways in which chronic illness serves to consolidate care together. Referring to HIV as a chronic illness functions to bring practitioners together with families and patients to create care regimes that make long term care possible. Specifically, through the use of STS I wish to present the consolidating logic of chronic illness not as one of imposition by one actor or institution on another (as many previous explanations of 'the social' have done), but rather as a process formulated through the combination of all objects and actors present at the places or over the places where chronic illness is enacted (Mol, 2002). Compared to the last chapters on operationalising medical knowledge, the emphasis here is on how care is imagined by practitioners and patients and can remain stable over long periods of time and not just moments of pill taking or bringing patients into knowledge.

It could be asserted that looking at HIV through the lens of chronic illness implies that 'macro' views of the virus, or an overview of paediatric HIV over the long-term must be taken on board<sup>84</sup>. Following STS however, the conventional lines of micro or macro will be blurred, large scale medical planning can be found in everyday practices, and vice versa, everyday practices can be found in medical planning. I have left these kinds of judgements about scale to be defined by the actors under research (Latour, 2002, 2005). Moreover, the illustration of clinical observations of chronic illness and paediatric HIV are a good example of the STS principle of scale not preceding its enaction by a relevant actor (see the discussion of Latour 2002, 2005 in chapter 3 of this thesis). Another STS principle put to work in this chapter, is that rather than positing a unified definition or correspondence between discussions around chronic illness, drawing on Mol (2002), this chapter accepts that references to and usages of chronic illness have large discrepancies even amongst medical practices and ways of treating Paediatric HIV, resulting in many versions of chronic

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<sup>84</sup> This approach to analysis is intended in the vein of debates that form 'macrosociology' or discuss the 'macro-micro' divide in sociology (Latour, 2002).

care/illness. This leads to an interesting contribution to STS as chronic illness is portrayed as a vital clinical logic that must reference a single clinical encounter as well as the lifespan of an individual patient. Therefore, chronic illness is neither confined to a specific moment nor suspended indefinitely over time. Rather it is referenced and made stable through being referred to in the clinic. The interactions of patients/professionals are influenced by a dynamic set of materialities, including the virus of HIV acting in a stable and constant way over time, and the body of the child developing in expected parameters (Kelle, 2001, 2010). This all serves to highlight the point that in the clinic, enactments of HIV as 'chronic' are integral to the way care is visualised and maintained, and acts as a force that compels practice, protocol and care to act together over the long-term, able to react against a range of unforeseeable problems that could affect care (Pickstone, 2000). The most basic example being the long-term mission to keep patients upholding the responsibility to suppress the virus using antiretroviral drugs. Therefore, the overall argument is served by this chapter when considering how the idea of HIV being chronic is utilised<sup>85</sup> in the clinic, what chronic illness' function is and how different groups of patients and practitioners combine in clinical practice to evoke chronic illness with a range of purposes in mind. Therefore the clinic is highlighted as a key site in consolidating complexities into functional medicine.

If ideas of STS that draw on process philosophy<sup>86</sup> are used to examine ideas of HIV as chronic, the notion of antiretroviral medicine and HIV care as the simple restoration of bodily norms to maintain a chronic status can be displaced. Instead, it can be suggested that the suppression of HIV is not isolated to the cause and consequence of taking a pill and suppressing the virus, but suppression is also linked to the act of taking the pill and the process it brings about to alter the patients' immune system, body and their interactions with the virus. This implies that patients must live their lives not to reach an end point or cure, but instead constantly maintain HIV as 'balanced' between compatible ways of taking

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<sup>85</sup> The use of the word 'utility' is intentionally broad, it is used to document the ways in which chronic illness is not only descriptive but also the way that it is used to enact practice, inspired by Law and Urry's idea of 'enacting the social' (2004).

<sup>86</sup> This point refers to the conceptualisations as pioneered by Whitehead and Deleuze but modified in the work of Stengers and Latour amongst others.

medicine, living life, avoiding resistance and other unwanted effects<sup>87</sup>. This is how it will be developed here, not as one concept or even one process, but a dynamic used in the clinic to influence the present and future of care. Chronic illness makes that which is uncertain manageable for both patients and practitioners now and at a future date by consolidating protocol and care into conceptualisations of how care will unfold. In relation to STS two limitations come to mind, one is that the concern felt by the clinic when attempting to maintain care as chronic is not so easily contained in enaction, and the second develops the previously discussed antagonism in STS around the charged child figure (echoing Castañeda, 2002 figurations). When consolidating care in the long-term over the span of a lifetime, childhood is no mere object or agency, but charged with considerations about life, lifespan and human experience. The implications become poignant when considering what it must mean for a child to think through their entire future dealing with HIV, it is the practitioner that must guide them through the process.

What follows are some examples of the ways in which HIV has been described as chronic and how enactions of chronic illness have been used between protocol and the clinic. The accounts that have been selected are nuanced and extremely specific to firstly paediatric HIV and secondly the contexts and incidences where they occurred. What is also highlighted is how enactions of HIV as chronic inform and make possible the maintenance of long term care over a patients' lifespan. Through following this line of thought, references to HIV being chronic can be found reverberated in dynamic and multifarious ways through the interactions of staff over many departments and job titles, as well as between family relations and medical professionals.

## Consolation

The CHIVA guidelines, *Talking to Children with HIV*, details what to respond to a child who asks, 'am I going to die?'. The text advises:

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<sup>87</sup> Persson (2006) talks about how taking a tablet for HIV doesn't simply imply a restoration of bodily norms but instead has a complex effect. Pearson links chronic illness to the effect pills have, here the discussion will go wider to encompass other ideas of chronic illness and care, (also see Rosengarten 2004)

*HIV is still associated with dying and this does need to be addressed with the young person. It can help to explain that although many children and adults do die from HIV in developing countries, this is usually because they do not have access to medicines or good health care. Reassure the young person by saying that with treatment available now, most children and adults can live good quality lives and that we expect them to have a reasonably normal lifespan. Explaining that HIV is a chronic health condition is important, that it won't go away but can be well controlled by medication. It may be helpful to give examples of other chronic health conditions which require ongoing medications (CHIVA, 2011c).*

This question and model answer reverberates through UK institutions dealing with paediatric HIV and advocates using the notion of chronic illness to console patients. 'Learning to live with HIV' is a common theme used to relate to parents and children/adolescents and help them to find ways of coping. In a patient booklet published by NAM, under the heading of living with HIV it gives the advice, '*Children with HIV can have a happy, normal and thanks to HIV treatment, long life*' (NAM, 2010b).

Similar ideas of chronic illness and consolation can be seen to reverberate through practice at the clinic in UOUH. During research, Anna was 14 and lived with both of her parents and her older sister. Her mother was from Zambia and her father was white British but she had been born in the UK. Anna had been attending the clinic from a young age. She contracted HIV from her mother, her father and sister didn't have the disease (at the time of this consultation her sister was not aware that any of the rest of her family had HIV<sup>88</sup>). During a clinic with Dr Peters, Dr Wellington (the former head of the clinic) and me, Anna was asked to come into the consultation room alone (at adolescent age the procedure is to see patients alone first without their parents, see chapter 8 of this thesis), leaving her parents in the waiting room. In the consultation room Anna did not say much and was looking toward the floor in a fixed gaze,

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<sup>88</sup> I am unaware of the details of where the HIV infection originates in this case. A lot of the dynamics of the partnerships discussed in this thesis are not spoken about in the clinic. Michaud et al., (2009) discusses the disclosure issues between families and the complex dynamics that exist between who is granted knowledge and who is not and some of the reasons for disclosing or not between family members.

Dr Peters: *'Is your sister still unaware of your HIV?'*

Anna: *'No, not sure'*

Dr Peters: *'Are you worried about telling her?'*

Anna: *'Not sure'* Shrugs and is looking downwards.

At this point Dr Wellington interrupted: *'You look serious'*

Dr Peters: *'It's always a bit like that with Anna, sometimes more so, do you think a lot about it?'*

Anna: *'It's ok'*

Dr Peters: *'Did you read something about it?'*

Anna: *'I read something'*

Dr Peters: *'There are groups that you can join; maybe we can talk about it with mum.'*

[silence]

Dr Peters: *'...You know, in the past we were very worried about how to treat HIV, but now we think that if you take your medicine there are enough different meds out there to last you for your entire life, and there's no reason that you can't live a normal life.'*

The last line of this dialogue asks Anna to consider the medicine as lasting over her lifetime. Dr Peters is, in effect asking Anna to consider HIV as chronic (and the advice is consistent with the policy highlighted of CHIVA). The advice is meant to console and focus Anna, ensuring that she will uphold the belief that her potential life expectancy is in her own hands if she adheres to the medicine provided. Her disposition has been interpreted as 'serious' and perhaps a little down. Dr Peters pre-empts the effect HIV has on her mood, and equates dealing with the disease with negative connotations. As well as asking her if she would like to join the support group *Body and Soul*, he also refers Anna to the ward's psychiatrist (Murphy, 2009; Melvin, 1999; Forsyth, 2003). In this incident Dr Peters' logic is to consider it helpful for Anna to regard her lifespan as long and only limited by the amount she will adhere to her daily medication. What becomes noticeable in this logic is firstly, the emphasis placed upon the comfort gained from the possibility that she will be able to manage her condition for a reasonable life-span and secondly, the negation of other connotations differentiating her from other girls of her age who do not have to take medicine. As far as presenting the disease as chronic, more emphasis is put on the fact that

she will be able to manage her virus with antiretrovirals for a long span into the future than the consideration of having to take medicine everyday for the rest of her life. What is being demonstrated to Anna in this situation are ways that HIV doesn't necessarily equate to death. The version of chronic illness/care used here is meant to persuade Anna to trust the medicine and engage with it with fewer worries. The example demonstrates the logic of clinical practice to promote HIV as chronic to allay the fears felt by practitioners towards the alternative connotations patients could adopt about HIV. The clinical attentiveness to wider cultural versions of HIV makes paediatric HIV distinctive compared to other chronic illnesses, and the chronic illnesses so far discussed using STS, such as Mol's (2002) atherosclerosis or Mol and Law's (2004) hypoglycaemia. This clinical attentiveness acts to persuade Anna to consolidate her attitudes of living with HIV to a medical ideal of HIV as managed by ongoing and stable care. As a by-product, the idea of chronic illness presented in this circumstance gives the patient a line of medical advice to follow that assures that adhering will surpass the unwanted future effect of HIV infection, i.e. death from AIDs (also assured in articles like Gibb, 2003). Therefore, the advice and execution of policy encourages patients and practitioners to consider the pre-eminence of virus suppression that they must attempt to achieve, acknowledge and accept together. In effect adolescents are encouraged to reason that they have HIV, the consequence of HIV is AIDs and the only proven way to deal with it is through antiretroviral medicine (Wong and Ussher, 2008; Thorpe, 2009). Therefore, one idea of chronic care brings patients and practitioners together in the attempt to allay fears of the future.

In another scene, Abbey, (aged 12 whose parents were from Ghana) goes to get her blood test with the CNS, leaving her mother and father alone with Dr Peters to discuss Abbey's case.

*Mother: 'Sometimes she asks me why she comes here and what it's for, and why she has to have blood tests [at the time of research Abbey had not been disclosed to], and we have to tell her that she comes here so that we can watch over her. Then she comes home from school sometimes and she said she learnt this and that about HIV.'*

Dr Peters: *'HIV now is like asthma or diabetes it's chronic, we can't cure it yet, but that's how we think about it. She can live a long normal life on the medicine.'*

Mother: *'When she grows up I worry about where she can work, what she can do.'*

Dr Peters: *'There's nothing that she can't do, possibly be a surgeon or a dentist, and when she's older the tough thing for the parents to hear is that it's almost sure that if she chooses to have children she will be able to prevent her children from getting it.'*

Mother: *'She says that she doesn't want children she must know something.'*

Dr Peters: *'That's quite normal, she probably finds sex quite disgusting at the moment, she's still very young.'*

Mother: *'How will she find a man, who will understand her and take the time to make a relationship with her?'*

Dr Peters: *'The CNS will go through relationships with her, not now but when she's a bit older, one of the things we work on is how to maintain and make good relationships.'*

After Abbey has finished her blood test and the family have left the clinic, the CNS comes back into the consultation room and Dr Peters says to her: *'the mum had a lot of questions about Abbey growing up getting a job and finding a husband. I tried to answer them the best I could but I'm not sure if I did.'*

CNS: *'She has asked those questions before, how did the husband seem?'*

Dr Peters: *'Supportive.'*

In this conversation, Dr Peters is asked questions about the future of Abbey's life. Again Dr Peters uses a certain version of HIV as being chronic, but to his own admission he feels that his console could not broach the gap. The clinical logic strived towards aims to consolidate speculations of a patients' future with the ongoing maintenance of care. Abbey's mother asked a series of personal questions about the problems she fears that Abbey will face when growing up. Dr Peters answers each one from a medical management perspective of trying to minimise the perceived effect of HIV in each circumstance<sup>89</sup>. As with Anna, Dr Peters' attempts to persuade patients, or in this case the parents, into putting their trust into the

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<sup>89</sup> Forsyth (2003) and Murphy (2009) offer papers which advice practitioners how to approach the topic of HIV with children.



medicine. Promising firstly, to treat Abbey in a manageable way that does not exclude her from any chosen career and secondly that it will support Abbey through future relationships. To Dr Peters' mind this may not have offered much reassurance, but it is one he can offer confidently through the logic of evidence-based medicine<sup>90</sup>.

Here, as with Anna in the first example, chronic illness is implied twice: once through the response of antiretroviral medicine's effect on the body and HIV, and again in the reassurance given to children by the doctor about being able to manage the disease into the future. In both examples the use of chronic illness as consolation brings together patient and practitioner. The consultant offers a promise to patients that they can put their trust into the medicine, it gives practitioners a clear example of what to aim for and what is at stake<sup>91</sup>. In this process, the consultant comes into contact with children who must bear HIV over their whole lives. Therefore, it becomes the responsibility of the consultant to explain the medicine and allay fears, in doing so the consultant necessarily influences how medicine in this context will be administered and applied to include the fears of children/adolescents (as well as highlighting the consideration present of the vulnerability of childhood in relation to taking on potentially traumatic news). For the child patient and the family this consolidation serves to galvanise them to place their conviction into the medicine and alter their behaviour in accordance to suppressing their HIV with antiretroviral medicine. This is problematical when considering that the condition remains relatively invisible to many patients apart from the tablets they must take, and also the amount of personal fears and uncertainty that must result from imagining a whole life taking medicine (Ostrow, 1999). Therefore, the contingency of care makes practitioners consider carefully how chronic illness is referenced in the clinic. A cultural awareness in care is emphasised here that makes paediatric HIV practice a particular condition, this notion of clinical cultural awareness distinguishes paediatric HIV from existing STS descriptions of chronic illness such as Mol (2002), Mol and Law (2004). The cultural attentiveness in clinical practice used to

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<sup>90</sup> For Mol (2008), this is what is echoed in the logic of care. She sees a distinction between care made for the collective and what would constitute the best individual care.

<sup>91</sup> Since the 90s the promise given to patients was suppression of the virus if taken as recommended (see De Cock, 1997), interestingly in more recent years the 'promise' of antiretrovirals has broadened to include things like once a week therapy and HIV prevention (Mayer, 2011; see the use of the word promise in Tenorio, 2011)

console patients by describing HIV as a chronic illness through treatment orientates both patients and practitioners towards a consolidated vision of medicine.

## Education

To modify the identified use of chronic illness as consolidation, if we go back to the extract from CHIVA, it can be seen as the role of the clinic to inform children about HIV. I will argue that this role of educating serves as a way to not only console patients (as can be seen from the descriptions of Anna and Abbey above), but also to formulate ways of successfully living with HIV and maintaining the disease as chronic<sup>92</sup>. The clinical intervention is designed to make patients project into the future the question of how their lifestyle is compatible with their care. In effect, this ongoing action consolidates the future complexity of all possible patient lifestyles to the medical regimes needed to suppress the virus. For example, the following extract describes the explanation of an anti-retroviral regime to an inexperienced patient – Rob, where a logic pertaining to chronic illness can be seen reverberating through the consultation.

Rob (aged 12) needed to be informed about the need for him to take a drug regime to suppress both his HIV and hepatitis B. Rob had recently arrived from Zimbabwe to the UK. He had been diagnosed and treated in Zimbabwe but his treatment had stopped when he arrived in the UK and consequently his CD4 count was beginning to drop, so it was important to re-start treatment as soon as possible. This was the first time that a doctor had explained an anti-retroviral regime to Rob as although he had been diagnosed with HIV since very young, he had only recently had his HIV disclosed to him. During the clinic Dr Peters took extra time to explain to Rob his new drug regime as he also had to talk about the considerations of hepatitis B:

*'So you're taking Truvada which has two applications. One is to suppress your HIV and the other works on your hep B. The second drug is Atazanavir, which is what's called a protease*

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<sup>92</sup> This logic can also be seen through literature on paediatric HIV and *coping strategies* (see Martin, 2004; Murphy, 2009)

*inhibitor, which works in a different way to stop the virus replicating. This drug needs to be boosted with Ritonavir, the third drug. But they're all working, that's the bit that matters.'*

Whilst the doctor is talking to him he looks down towards the wall not interrupting or asking any questions when prompted. Why then go into such detail to explain it to him? The logic that is behind this description is to make Rob familiar and comfortable with the regime, to answer any questions he may have and make him as aware as possible of what he is taking and why (see Steele et al., 2001 on the role of the caregiver). Whether or not he wants to know or understands fully is subordinate to the fact that if Rob is to successfully suppress his HIV he must take anti-retrovirals for a long time to come, and therefore he must be put in good habits and be knowledgeable enough to know why it is important. It is this view of the chronic uptake of the regime 'off into the future', which makes it important for children to be indoctrinated in the prevailing knowledge of anti-retroviral therapy. This practice is essential to the administration of medicine and is only possible through clinical practice. It is not only in this isolated example that Dr Peters takes the time to explain regimes and how they work. A lot of time in clinic is spent by Dr Peters explaining regimes, drugs and bodily mechanisms. This demonstrates the emphasis employed in the clinic to consolidate patient dispositions into the requirements of care management.

The following example comes from the case of Erica, aged 15. Erica was living in the UK with her uncle, she had initially been living in Manchester but the family had now moved to London<sup>93</sup>. In the couple of weeks prior to the incident, Erica had come into the hospital with what was later to be discovered as an AIDs defining illness. An extremely rare event for the hospital (and complicates further the uniformity of the clinic population see introduction). Dr Peters deemed that it would be best if they disclosed her diagnoses to her quickly and begin treatment as soon as possible. Two weeks later she attended a consultation to start anti-retroviral therapy:

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<sup>93</sup> Erica was originally from the Congo but was seeking asylum the UK, leaving her mother and father behind in Congo after her father was placed in prison for war crimes. The route of Erica's HIV infection was unknown.

Dr Peters: *'I've got your results from last week, resistance profile went missing so we're going to do that again today, and I would like to start you on medicine. It will be three different antiretrovirals in the form of 2 tablets a day, which I would eventually like to take down to 1 tablet a day. But we will start with 2 to make sure [resistance]? Side effects – we're not expecting any side effects but you might get diarrhoea but it should pass quickly. The other thing is that you might feel a bit nauseous so it's best to take them just before you go to bed to lessen the effects of it. The important thing to remember is to take the medicine to make sure your CD4 count is high and viral load is low, if not you can become resistant. Have you heard of that before? When you don't take the medicine the virus replicates itself very quickly and when it does it makes a mistake each time, if it replicates whilst you have the antiretroviral in your body it will work out how to replicate only the virus that is resistant to the drug. So the point is to take them because if you become resistant you become resistant to all those [drugs] in the same group. The bottom line is that once you start you have to continue. I don't want to make it seem scary. You have [the CNS's] number in case you want to talk about anything. There is a very rare side effect that could occur of blistering, if that happens check in to the A+E. Do you have any questions?... Nothing?'*

As well as demonstrating the desire to educate on antiretrovirals, the extract shows the concern that Dr Peters has that children understand how the treatment works and how important it is that the patient takes on responsibility for taking the medicine. During every consultation I observed, Dr Peters asked the question: *'did you miss any doses?'*. If participants responded that they did he would then go into an explanation of the importance of resistance. The logic of chronic illness used in this circumstance is an attempt to ensure that patients understand that their chronic status is wholly reliant upon them taking their medicine on time and maintaining a chronic state of care. It again reinstates the point that this logic of chronic illness is essential to the administration of medicine and locates the clinic as a key site where complex patient lives are organised compatible with antiretroviral regimes. Compared to the chronic illness discussed in STS such as atherosclerosis in Mol (2002) and hypoglycaemia in Mol and Law (2004) that also reference complexity, this consideration of educating children on the contingency of treatment in

paediatric HIV highlights a notion of immediacy in the approach of the clinic to consolidate complexity and the dangers of clinical mismanagement. The logic of chronic illness is also corroborated by the extra support groups set up for children and adolescents. Prompted by regimes of clinical management, one of the mantras on the home page of body and soul is the sentence, *'nobody can go back and start a new beginning, but anyone can start today and make a new ending'* (Body and Soul, 2011c). This sentence upholds the aim to motivate children and adolescents to consider ways in which they must take responsibility for their care.



8 An image from the Body and Soul website, each of the words, 'hope', 'courage' and 'trust' can be clicked upon for a motivational message, under the caption highlighted is the word 'life'.

Hidden in the way that care is maintained is a simplification of issues and an accommodation for the perceived child's frame of mind. The education of children with knowledge of their condition and disease is gradually built over the years according to a patients' understanding<sup>94</sup>.

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<sup>94</sup> We could raise a point here in relation to the classic Piaget (2001a, 2001b) and literature that challenges this linear regimented model of child development, as seen in the sociology of childhood (Walkerdine, 1993, see 2009).

During a routine consultation with Gregory (one month away from being 13), Dr Peters explained to Gregory the results of his blood test. After the test Dr Peters asked if there are any questions,

Gregory answered directly: *'Can you cure the virus?'*

Dr Peters responded: *'At the moment it's not possible to cure it, the cells that HIV gets into are white cells and it gets into the longer term cells that can't be cured without killing the cells, so I think it's a long time from a cure, but the disease has changed, we can't get rid of it but it has become chronic. Do you know anyone with asthma or diabetes? It's like that. So basically were not smart enough yet.'*

The logic here is that it is important for Dr Peters to convey the nuanced and conditional nature of maintaining HIV as a chronic condition whilst making it possible for Gregory to understand and make sure that his worries about the condition are allayed.

Emphasis has been placed upon children understanding their diagnosis to maximise the possibility of adherence and therefore insuring the disease can be rendered as chronic. Not only does it make it possible for medicine to maintain a continual balance, but it is an ethical issue that children over 12 know as much as possible about what they have and what they take (see the discussion around the AAP Committee on Pediatric AIDS, 1999b in chapter 6 of this thesis). It is a consideration which informs the roles that each party must uphold. For children like Gregory, understanding HIV is an ongoing process of realisations and discoveries. Those who are in charge of administering care must ensure that each stage can be deemed to be worthwhile and that they act responsibly (Budd and Sharma, 1994). Making an ethical judgement on child 'well-being' requires the case-specific enaction in the clinic of a reliable scientific medicine that can provide knowledge on how to proceed at the present and in the future. In this case, Dr Peters acts to inform Gregory of the workings of the medicine in order to ensure that Gregory can conceptualise the contingency of being able to be treated with anti-retrovirals as long into the future as possible (without causing distress).

Therefore, additional to chronic illness being used to console patients, this example of care management and education emphasises chronic illnesses' use to educate patients, to make sure they will take responsibility for maintaining their HIV, which in turn ensures it can be maintained chronically by practitioners. Practitioners and children must develop a common knowledge of medicine and common ways of conveying medicine and HIV to maximise the amount of patients that can maintain chronic care for their HIV (emphasis can be placed on the word "facilitating" as in Pontali, 2005). This is done through a process of education in the clinic that emphasises enactments of chronic illness to describe the maintenance that will be necessary in the present and into the future. In turn the virus can then be entrusted to respond and remain dormant. It highlights how clinical practice incorporates patient complexities into medical reasoning and viral suppression is made possible.

## Professional Negotiations

Contrary to these examples however, another line of enquiry regarding HIV as chronic takes place between professionals at the clinic in order to coordinate care, such as the reservations about maintaining a balance for patients who must live most of their lives on anti-retrovirals. Some of these negotiations go on behind closed doors (or at least the ones I observed did) (Downey et al., 1998; Long et al., 2007 discuss how conversations are organised around the hospital).

The dangers of non-adherence and resistance make HIV distinctive amongst other conditions mentioned in the clinic such as asthma and diabetes, or the chronic illness already discussed in STS such as Mol and Law's (2004) and Mol's (2002) discussions of hypoglycaemia or arthrosclerosis (for one, making adherence for HIV amongst the highest rates of adherence compared to other diseases DiMatteo, 2004). Therefore, the reference to HIV being chronic has a particular meaning and although it pertains to the process of managing the disease, the balance that must be maintained, the changeability of the patient body and the virus itself when taking antiretrovirals can evoke ideas of repression and mortality rather than maintenance (Persson et al. 2003; Persson and Newman 2006; Rosengarten 2004). For this reason, the way HIV is presented above as a chronic illness to

reassure patients, is in contrast to the ways that medical professionals must talk about and organise care amongst them-selves. Practitioners must be highly aware of their activities in accordance with the idea of HIV projected to patients, giving an idea of the attentiveness required in the clinical approach of paediatric HIV (in comparison to other accounts of STS such as Mol 2002; Mol and Law 2004). If these negotiations took place in front of patients they would have the opposite effect of consolidating patients and practitioners together (reminiscent of Goffman's, 1990 "backstage" or Latour's 1987 breakdown of networks). However, it is still necessary in the functioning of the medicine for these discussions to take place between clinical practice to coordinate practitioners and organise cases and medicine together.

The following extract from the clinic is a corresponding but different perspective of chronic illness than the one used to reassure patients. As part of professional development, Dr Peters often invites SHOs into the clinic for training. During one of these training sessions, between patient consultations, Dr Peters informed an SHO about the limitations of maintaining paediatric HIV in a chronic state:

*"These children we're handing over are very complicated. A lot of them had treatment when there was only one anti-retroviral drug available then they took that for a few weeks and they became resistant. So they took the next one and so on. When you become resistant to one [drug] you become resistant to all the drugs that are like that, so [for some of them] their options are now quite limited."*

The way that HIV care is being described here is very different to the ways used to comfort or educate children and parents in the previous examples. It gives a glimpse of a different idea of chronic illness, of a sense of the unknown and individual nature of each case, where the medical team are attempting to order individual resistance profiles that may have become chaotic and not treatable according to general recommendations<sup>95</sup>. Under this notion, chronic illness must be achieved. Each case must be individually tailored and the

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<sup>95</sup> Other ways we could site this would be from literature on *psycho-social functioning of children with HIV* (Ostrow, 1999; Mellins, 2004; Naar-King et al., 2006; Steele, 2007)



exact outcome of antiretroviral combinations is unknown (Cunningham et al., 2006). The discussion about how to ensure the continuum of care as well as the idea of HIV they are describing are not as simplified as those offered to patients. From the same virus has come a new possibility, a strain of HIV that may fail to respond. This switches the once responsive and treatable HIV in to an unruly virus, just as it frames the possibility of antiretrovirals as having a limited and contrary effect. Both the pill and the virus have become potentially non-compliant to the task of viral suppression. In this eventuality, the practitioner must struggle to keep the virus chronic whilst the virus would no-longer respond stably. Part of this struggle must be done behind closed doors, and then translated (in the sense of Callon, 1986) and presented differently when being relayed back to patients in the process of educating, consoling or making them adhere in the long-term, or else it would prove counterproductive and result in a break down in the medicine. It highlights the maintenance that must be undertaken at the clinic to ensure that the clinical logic employed continues to consolidate contradictory and complex patient associations such as stigma, vulnerability and naivety to achieve viral suppression. In comparison to other accounts of chronic illness in STS or SoC (e.g. Mol 2002; Mol and Law 2004; Christensen 1998) the cultural awareness and attentiveness employed by practitioners when screening clinical conversations marks paediatric HIV as distinct.

A second set of reservations discussed between professionals is the damage done by antiretroviral drugs themselves. In another discussion with an SHO between patients, Dr Peters was asked how long HIV can be suppressed for? Dr Peters closed the door and responded:

*“From a viral point of view it’s possible to suppress the virus indefinitely, but it seems that there are likely to be cardiovascular complications. Theoretically there are enough drugs to last a patients’ entire life providing that they don't mess around with them. But it seems that there can be complications with their cardiovascular walls from the strain of living with the virus for so long, which is particularly difficult in children [with HIV] because we don't know exactly what is going to happen. Some of them will live for a long time on meds. We measure all our kids for cholesterol here; if we see it shooting up we do something about it.”*

The door was closed during Dr Peters' answer to insure that any patient in the waiting room would not over-hear the conversation. What is flagged up here is the unknown outcome of prolonged exposure to antiretroviral drugs. For those administering care, it is prudent that they are aware of any potential dangers and the importance of monitoring more closely the possible health outcomes of these patients such as their hearts and cholesterol (Sani et al., 2005). This evokes another consideration of the management struggle towards chronic illness and the unruly antiretrovirals that begin to become counterproductive. However, as can be illustrated through the act of closing the door, the doctor considers that any patient that would overhear the discussion may find it potentially distressing. Therefore, the idea of chronic illness relayed between children in the clinic is not the same as the one discussed in training doctors and organising the clinic (see Kelle 2010 on age-appropriateness and 'normal' development being used to inform clinical practice). There are multiple versions of chronic illness. The logic behind this extract, aims to ensure that practitioners organise adversity during practice by administering medicine consistently with an eye to the future, the case as a whole and an idea of the dangers in mind. This is incompatible with the idea of chronic illness presented to children of a younger age as it may create unwanted negative connotations<sup>96</sup>.

## Large Scale Organisation of Complexity

This logic of organisation is also at work over larger 'macro' scales of resource allocation in clinical medicine. In certain discourses that take place in reference to paediatric HIV medicine, individual patients are hardly phased in at all. As can be seen through the conclusion of a paper co-authored by many senior UK based HIV paediatricians,

*"The success of HAART has seen perinatally acquired HIV become a chronic disease of childhood. Increasing numbers of young people living with HIV will transfer to adult services in the United Kingdom or Ireland during the next decade. The varied and*

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<sup>96</sup> This line of reasoning is reminiscent of that of Priestley, (2000) when he demonstrates a logic at work in education that aims to maintain "moral" and "spiritual" growth in childhood.

*complex needs of these young people must be met by the development of multidisciplinary transitional care services between pediatric and adult health care providers. The legacy of their pediatric care will continue to impact in adult life and careful long-term follow-up of this unique cohort is required to improve outcomes for young people with HIV in the future.” (Foster et al., 2009)*

In this passage, factors affecting individual patients are not present, and so it becomes the responsibility of the paediatrics as a whole to ensure that HIVs chronic status is maintained. During a quiet morning at UOUH whilst there were no patients waiting to be seen, Dr Phelps (attending as part of the regular consultations from CHH) starts to discuss with Dr Peters the diminishing patient cohorts witnessed in both clinics. They both reach a consensus that small centres like the one in UOUH would cease to be necessary in the future. The larger centres would continue but there would also be increasing numbers of isolated cases around the UK, (a new isolated case in Stockton on Tees was highlighted). Dr Peters then gave the example that in the last three years only one patient had been referred to the service. [In the six months after this discussion took place both consultants went on to concede that what was said wasn't entirely accurate as three more patients registered to UOUH and two to CHH, all three from Sub Saharan Africa, but still not enough to halt the general decline.]

In this discussion, HIV care is put into a larger scale to highlight the way that practitioners must think about resources into the future according to considerations of paediatric HIV being a chronic illness (see discussion of Latour, 2002, 2005 and “scale” in chapter 3). The concern is upon numbers and the centres/services that will be needed to serve them. The discussion is not so much on how they will continue to care for children with HIV, or the continuing lives of children who grow to be adults with HIV, instead they discuss what paediatric HIV will look like epidemiologically in the future<sup>97</sup> (Judd et al., 2007; also found in

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<sup>97</sup> This may seem like a very specific example, but it runs alongside other ways of organising medicine and between patients and practitioners. It is used when giving blood test results to parents with HIV to new-born's without the condition. Quite often before they get the results of the baby's routine third test Dr Peters would say: 'You'll receive a letter, it will say the child doesn't have HIV. No new babies have been diagnosed here in seven years'.

articles such as Waning et al., 2010). This way of thinking works from an idea of HIV as existent between a collection of patients and not specifically in a patients' body (see Mol and Law 2004 and the example of hypoglycaemia). The chronic illness it subsequently evokes is one of a diminishing presence and extent. It is a very useful conceptualisation as it allows practitioners to measure extent, decline, exposure and most importantly, where resources should be placed<sup>98</sup>. The way this logic is presented is different to the way that HIV as chronic illness is relayed to children in the consultation room. It is alternate to a way of presenting chronic disease that is relevant to consoling or educating children dealing with HIV, instead being a way to talk about chronic disease to make it relevant to organising paediatric HIV on a large scale. HIV becomes a large scale entity with its own ebbs and flows, and the potential to be confronted beyond individual cases. However, it still demonstrates the logic of the clinic as a site to organise the complex implications that arise in the long-term management of paediatric HIV.

So far a range of enactments of HIV as chronic have been demonstrated. Rather than there being one that can be used between different groups, I would like to suggest that each use of chronic illness in the clinic is itself a particular version aimed at different groups for different purposes whilst also making it possible to consolidate groups together under the task of viral suppression. Two versions of chronic illness have been seen distinctly, one to console and educate patients, and another to ensure practitioners apply medicine with an eye on its long term implications. Between these two versions it remains possible to translate each enactment of chronic illness into an overview that ensures that medicine is followed and adapted into the future<sup>99</sup>. This discrepancy must be accounted for in protocol to acknowledge acceptable versions of chronic care, to discuss regimes with patients and coordinate care into the future. However, the examples already demonstrated suggest that rather than there being two or three distinct versions at work here, there are many different nuanced situated enactments of chronic illness and corresponding long term care employed in the clinic. This becomes significant when describing chronic illness as discussed between

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<sup>98</sup> Perhaps this would be interesting to develop using literature from the *Sociology of Expectations*, see Borup et al. 2006

<sup>99</sup> Lawton (2002) argues that a patients' life-course often coincides with clinical decision making.

the clinic and over guidelines as it is integral to enactions of chronic illness that it can be applied to individual circumstances but also defined as a dynamic that stretches out over the future that must be sensitively navigated by practitioners. If STS is used to analyse the sites where HIV is 'enacted', it would suggest that enactions of HIV are simultaneously placed in the present to consolidate and maintain care, but also over the future in the promise of suppression if the medicine is followed<sup>100</sup>. However, in contrast to the proliferation of more and more multiplicity demonstrated in relation to Mol (2002) in the 'object politics' section of chapter 2 of this thesis, the consideration stresses the need for the clinic to be a site that must succeed to consolidate possible future actions and complexities with courses of action decided in the present. The differences between versions of chronic illness presented in the clinic and relayed in protocol suggest that paediatric HIV care is a fine balance of context specific evocations of illness that are simultaneously in the present and into the future. The functioning of HIV medicine is reliant upon the consolidation and management of disparate versions of chronic illness into a coherent clinical practice and corresponding protocol.

## General Healthcare

The boundaries of chronic HIV and long term care become wider and more difficult to define still when considering the role of the clinic to serve more conditions than those directly applicable to HIV. Practitioners also assume the management of broader health and welfare care, blurring the lines of what is Paediatric HIV medicine and more broadly, primary health care (conflated by the fact that the GP and HIV patients have an ambiguous relationship due to confidentiality see Casserly et al., 2009). This process consolidates yet more medicine together in the task of suppressing HIV. General care is organised for paediatric HIV patients according to an idea of chronic illness and chronic care. The way that this chronic care and chronic illness is envisaged is influenced by and influences understandings of HIV.

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<sup>100</sup> This highlights an antagonism in the object of HIV that is not specifically confined to the chronic illness described in ANT accounts such as that of hypoglycaemia of Mol and Law (2004), where the illness is described as contained between its temporal and spatial enactions. Interestingly, this line of thought seems to question how we conceive of the logic of temporal ordering within STS.

In addition to anti-retroviral medicine and medicine relating directly to HIV, the general care children receive must also fit into the maintenance of their chronic status.

Many patients in the clinic have other requirements linked to but also aside from HIV. One example is hepatitis B as in Rob's case. Another is Spastic Diplegia (Laverda et al., 1994).

Luke (aged 15), developed Spastic Diplegia through catching meningitis when he was about eight years old. Luke was born in the UK but his parents were African. He lived with his mother and father and was amongst the longest attending patients at the clinic. During the time of research, he had to make some decisions in relation to the ongoing care of his condition. On one occasion, Luke came in alone to an afternoon surgery with only me and Dr Peters in attendance. Luke had to use a frame to walk with. As he manoeuvred the entrance, Dr Peters held the door open for him, gave him the time to sit down and then passed by him to take the place at the desk.

Dr Peters: *"How are you doing with your walking?"*

Luke: *"Yeah fine"*

Dr Peters: *"I know that we spoke to your dad about surgery, he wants to wait until after the A levels. You know it's pretty serious and it's going to take a year of physio, I can see why your dad wants you to get your school work done. I've got the opinion of the doctor here and he says that it might be best to wait. What do you think about that?"*

Luke: *"Yeah might be best"*

With that Dr Peters changed the subject and asked Luke questions about his exams.

Towards the end of the clinic when Luke's mother was present in the room, Dr Peters brings up the idea of surgery again. Dr Peters put the letter in front of him and went over it again with Luke and his mother.

Dr Peters: *"To go back to the question of surgery. Reading between the lines, the Consultant implies that Luke doesn't seem keen to have it done. It's a really big operation and I think that he [the Consultant] wants to be sure that it's what you want. Really at the end of the day it's up to you."*

At the end of the clinic when I was alone with Dr Peters, I asked him again about Luke's condition.

Me: *"What kind of surgery does Luke need to have?"*

Dr Peters: *"Luke has Spastic Diplegia from having meningitis when he was young, it was through this illness that they discovered that he had HIV, and then diagnosed the mother. The surgery is a difficult decision for Luke and his family because the operation that he would have to have is extensive and would take several surgeries - about four, they would have to break and reset some of his bones and reattach tendons. I can see why he has reservations because there is a risk that at the end of surgery he might not even be able to walk as well as he can now. So it might be best to wait until his walking has become worse to go through with the operation."*

Luke's example (and that of Rob with hepatitis B) demonstrates that it becomes the role of Dr Peters and the clinic to manage and coordinate other branches of medicine into the care that patients receive at the clinic. HIV becomes sidelined and the task of chronic management becomes a task of coordination. The focus of this task is not just about consolidating different groups and medicines, but rather consolidating different medical branches and a notion of a patients' general healthiness alongside the chronic management of HIV (Vargas and Cunningham, 2006). Viral suppression is not a lone aspiration of the medicine but must act alongside and become compatible with other attempts to manage well-being. It consolidates ideas of life course and quality of life with HIV care. We ask *what is best for Luke?* Luke and his parents must also be managed to ensure that they are happy with decisions made about care. Patients, parents and practitioners are consolidated through considerations of chronic illness that question if they are happy with their choices for care now and into the future. They make a choice and take a stake in their care (or career for the consultant). Chronic illness is also enacted through the process of making sure that it remains possible, desirable and not contradictory to follow HIV medicine, for both patients and practitioners. If this was not the case patients could simply be referred to the GP and would not have to inform the consultant. The conditions of hypoglycaemia or atherosclerosis documented in Mol (2002) and Mol and Law (2004) must also be managed alongside other conditions, but what is interesting in this case is the cultural awareness

required in the clinic to make sure that the treatment of other conditions are made compatible with paediatric HIV treatment and the dangers that can come about through mismanagement.

It is not just through different ailments where this occurs however. For instance there are the ongoing issue of dental care and eye care (Ramos-Gomez, 2002). The ward refers to a specialist dentist that is familiar with dealing with HIV, in the case of Erica during her second consultation Dr Peters gave her details of a dentist. Dr Peters routinely examines patients' eyes during their consultation every 3 months and if necessary refers them to an optician (detailed in the handbook of Portegies, 2007). When Harry burnt himself by squeezing a hot water bottle, Dr Peters made sure that his referral was all in order. Other examples are ringworm, chest x-rays for asthma, inoculations. Patients would see the GP as well, but it would all be coordinated through the consultant. In these moments, HIV orders itself alongside these other conditions and the practitioner must proceed in ways that will address, as well as comply with all possible symptoms.

It is convenient for patients to ask for Dr Peters' advice on wider health issues during consultations. However, it is also the practice of those who administer medicine to coordinate services and collect data into medical files that aim to be as 'complete' as possible (White, 2002). This goes beyond the jurisdiction that attempts to present medicine as 'scientific' and becomes a process in coordinating services and provisions (Pickstone, 2000, p34). The question for practitioners becomes what can be considered as a 'normal' lifespan and quality of life? How to organise wider aspects of medicine into paediatric HIV care? What aspects of care are necessary to maintain the chronic status of the disease? And what possibilities arise from the clinic taking on these responsibilities? One such example is sex education, to Dr Peters own admission: 'it's not part of general paediatrics training, but very important for this clinic' (Campbell et al., 2009; HYPNET, 2011). Another is that even school can become a routine part of the consultation, each consultation would contain the question 'how's school' (Melvin et al., 2007)? And when there's a problem at school Dr Peters often seeks to resolve it as can be seen here:



*Mother: Is there any reason why he would be sleepy at school?*

*Dr Peters: Why would you say he is?*

*Mother: At the school they ask me if he's on medication.*

[The psychotherapist had apparently informed the school that the child was on medication but emphasised the need for confidentiality, prompting the mother to originally say that the child was on antibiotics. The school had said that they could put somebody with the child as he works. Dr Peters was concerned that once it had been said that the child is taking medicine that must be kept confidential, it sparks the curiosity of staff members at the school.]

*Dr Peters: Are literacy and numeracy going ok?*

*Mother: yes he does really well, I think that he has anger problems*

*Dr Peters: I think he's doing really well, but it sounds like he just needs a little help with things.*

*Mother: instead of putting it on his record, I could share it with someone at the school who could know and manage the situation*

*Dr Peters: I think that if there was someone who could keep it confidential, possibly. But there isn't any way of knowing in this environment so I'd just keep on to it.*

General conditions of health and treatment that are dealt with in the clinic blur the lines of HIV care and ensure that HIV's chronic status remains an act in process, as demonstrated in Mol and Law (2004). HIV care and treatment is never uniform but must be made to fit. From the example above, care and the condition must fit between the requirements of school in order to maintain confidentiality and consistency. Parents and patients must remain comfortable in their communities if care is to be upheld into the future (U.K. Select Committee, 2011). Considerations around community form concerns for well-being, quality of life, social life and lifespan that are not so easily dismissed and must be assimilated into the medicine. They contribute to sense of cultural awareness found in paediatric HIV clinical practice. Another consideration found in other cases is that HIV care must be maintained alongside, hepatitis b, spastic diplegia, ringworm, accidents and emergencies. When required, it is an essential feature of long term care that HIV care must be made compatible in the clinic, or if put into STS terminology, 'translatable' into all of these circumstances.

From management in the clinic to discussions between professionals over protocol, paediatric HIV care relies upon operationalising modes of chronic illness/care to consolidate the medicine and make viral suppression possible in the long-term.

Rather than there being one distinct condition of paediatric HIV, there are many different time specific and contingent conditions. Strategies of care, as have been discussed, are not uniform, the allocation of drug regimes is a negotiation between many relevant and hard to foresee factors over many groups, populations and time-scales (Pontali, 2005). The successful administration of antiretrovirals can be dependent upon many further health issues or wider everyday issues. What is required of the medicine is liable to change over time. Regimes of care must alter in line with scientific enquiry and ways of persuading and relating to patients must be kept up to date. The references to chronic illness in the clinic can be conceived as a dynamic of chronic management that ensures that care regimes remain relevant to practitioners and patients as a coherent whole, that is practicable into the future. At the most practical level this is illustrated by the adjustments that must be made to antiretroviral regimes according to growth (Nachman and Pediatric AIDS Clinical Trials Group 377 Study Team, 2005).

Many of the cohort observed at UOUH had to change their regime as they grew older. At the age of eight Pierce needed to up the dosage of his tablets, as did Bianca when aged eight, Dr Peters charts another general change in patients at fourteen<sup>101</sup>. The chronic management of HIV must follow patients as they grow. Decisions made in the past and must be made compatible with present and future care.

Additionally, over time medicine does not only need to be altered for children growing to become adults, the medicine itself alters as their effects are more fully discovered and their guidelines change. These factors imply that both protocol and antiretroviral drugs are enacted as described in Mol and Law (2004). When Dr Peters first started at the clinic many children were taking Stavudine, which was withdrawn due to Stavudine causing lipodystrophy (among other toxic effects). More recently children taking Didanosine (DDI)

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<sup>101</sup> Attested to by the need for protocols such as Cole et al. (1998)

have been phased off of the drug, when possible, because of the relation between the drug and liver problems (Giaquinto C et al., 2008). A change currently taking place in the clinic is related to Atazanavir as it is known to cause jaundice (Molina et al., 2010). During appointments with children on Atazanavir, Dr Peters would advise them about jaundice. Rob even asked to be taken off of the drug because he reported that children at school were bullying him because his eyes were yellow. When faced with complex projections of drug requirements and drug changes in the future it highlights the need to coordinate care and potential issues through regular three month consultations. It exemplifies the attentiveness of practitioners to consolidate complexity into clinical versions of chronic care. In these examples, chronic illness is organised according to the aim of consolidating and coordinating clinical tasks to be compatible with the long term task of viral suppression (see the ongoing trial details of the WHO Technical Consultation, 2011). Bodily elements and functions are ordered alongside compatibilities in medicine, growth is planned for, the attitude of the child is taken into account and kept positive and the diligence of the practitioner to balance connotations of chronic illness is used as an assurance of good care (Mol, 2008). If these entities change they must do so with a coherent and compatible idea of chronic management in mind. Therefore, it is important for practitioners to think in terms of what is compatible with the drug and care regimes they receive now, and possible consequences and outcomes of managing care in the future (see for example the deliberation detailed in Wrubel et al., 2011). If patients grow, or want to take different drug regimes, or if a drug becomes incompatible with other care needs, it becomes a judgement of priorities of what to change and when to change it to ensure the virus is still suppressed and doesn't become resistant to the antiretroviral. All the while, the presentation of chronic illness must also be done in accordance with projecting a positive version of future care to child patients. In this process therefore, considerations of what it means to manage a chronic illness consolidates medicine around HIV. Considerations of the child body/mind, patient/parent desires, 'normal' lifespan and patient quality of life are consolidated into a coherent and ongoing paediatric service. What is interesting in paediatric HIV clinical practice compared to other STS accounts of chronic illness that emphasis enaction, such as Mol, 2002 or Mol and Law 2004, is that paediatric HIV evokes a more sensitive range of complexities (e.g. many

entities in the clinic are social, cultural, political as well as medical) and the attentiveness of practitioners to consolidate these complexities in the clinic.

## Conclusion

This chapter has looked at how enactments of chronic illness serve a function in paediatric HIV to consolidate care over different groups and diverse clinical scenarios. Chronic illness has been distinguished in this chapter as a procedure consolidating patient complexity into medical requirement. A series of instances from the clinic at UOUH are used to argue that chronic illness achieves consolidation through an intricate relationship between medical technologies, professionals, children, families and the virus. Rather than chronic care being exerted by one group onto another (e.g. from the medicine onto patients), it functions as a dynamic whose formation relies upon a relationship where all parties compromise towards an accepted version of chronic illness. Therefore, instead of there being one unified version of chronic illness at use and applied to paediatric HIV, chronic illness has many versions that are context specific to the clinic as it is presented during practice and over protocol. However, compared to other STS accounts that also detail how multiple versions of chronic illness are made to cohere, like atherosclerosis in Mol (2002), or hypoglycaemia in Mol and Law (2004), the account offered here demonstrates the cultural awareness needed in the clinic to consolidate complexity, such as the fears of patients, patient development or the individual circumstances of patients into the medical requirements of HIV. Some of the ways in which chronic illness is referenced in the clinic have been categorised above, but the chapter doesn't wish to limit it solely to the four categories offered. Each category has its own specific reference to chronic illness but can also be seen to correspond together in a clinical logic to ensure compatibilities between versions of chronic illness.

The first categorisation emphasised was the use of chronic illness when consoling patients. During these moments in the clinic, through protocol, the consultant asks the patient to imagine a future where HIV is contained through careful management of the disease with medication. This idea of care encourages patients and practitioners to galvanise behind the promise of maintaining care into the future. According to the practitioner this promise is to

ensure that they will keep up to date and practice the prevailing biomedical knowledge to the best of their ability now and into the future. For the child, they must put their faith behind the medicine and continue to follow it throughout their lifetime (Lawton, 2002). The doctrine fuses patients together by assuring them that the virus will remain invisible long into the future if they continue to follow medical advice. When the process of enacting chronic illness takes place in practice or guidelines, it makes each party (patients and professionals) aware of the needs of the other and adapts the medicine accordingly. Similarly when children are educated about the virus, a version of chronic illness is acted out that emphasises to children the importance and significance of having HIV. HIV, antiretrovirals and the body are presented to children as interrelated whereby the importance of intervention with antiretroviral medicine is stressed. The logic of chronic illness acts as a cohesive that brings together representations of the virus and immune system into a logic that becomes persuasive for children to follow, and explains to practitioners what is needed to ensure viral suppression.

The chronic illness enacted when consoling or educating patients (described in the first and second sections of this chapter) is contrasted when looking at how professionals discuss cases and the maintenance of viral suppression out of the view of patients. The worry of maintaining HIV as a chronic condition, potential dangers/limitations of service and cases where suppression could be in jeopardy are all discussed covertly, before being relayed to patients. The worry for practitioners is the message that children may take away if the implications of future HIV care are talked about openly in consultations (Kelle, 2001, 2010). It is necessary for practitioners to discuss concerns and dangers in order to coordinate care and develop action plans, guidelines and protocol. Consequently, practitioners must be aware of the message about the illness that they are projecting, and to which party, to ensure that they maximise compliance/coordination and minimise distress. Therefore, enactments of chronic illness referred to over these circumstances are not wholly compatible with each other, but refer to a logic of care from now into the future that is vital in the task of planning medical resources. The final section of this chapter demonstrated the consolidation of HIV alongside wider regimes of care. When consolidating services and medicine together into *general healthcare*, the idea of maintaining chronic HIV into the

future can be described as organising the provision of services and the coordination of care. In the process of making sure that other medicines are compatible with the HIV medicine, all medical tasks must be purposefully ordered from that moment with a forwards compatibility to possible care scenarios in the future. It unifies all medical practitioners towards the same task and makes care accessible and available to patients, ensuring they know where to go and what to do to manage the virus (see Law and Urry, 2004 on enacting the social).

All of the versions discussed have distinct interpretations of chronic illness, but they also correspond towards a unified definition of chronic illness concerted in the clinic. Therefore, to use specific STS terminology chronic illness could be said to be either 'translated' or 'enacted' between its usages to adapt to differing purposes in the clinic, and is also translatable back to other overarching versions of chronic illness. In this way it is possible to trace the consolidation of care back to Callon's (1986) original reference to translation and the four stages of *problematization*, *interessement*, *enrolment* and *mobilisation* of allies or Law and Urry's (2004) enacting the social. However, some aspects of chronic illness as 'enaction' or 'translation' must be modified to consider the clinical logic encountered in the examples of this chapter. The demonstrations of chronic illness found in this chapter require a promise to be made between practitioners and patients. A promise that the disease will remain invisible and antiretrovirals will be upheld. The chronic illness that is to be treated is both in the present and over the future. Therefore, the term cannot be wholly understood as a mobilisation of actions or a condition managed and stretched into the future, as it is between the two. And so when using the procedure of translation, it must be clarified that precisely the allure for practitioners to use chronic illness as a procedure is its contingent sequencing into the future and the formulation of a resulting plan of action in the meantime. Therefore, it involves a consolidation and coordination of factors that must be done in accordance to a desired outcome in the future, relevant to a course of action in the present that will ensure that the virus is suppressed and other intervening factors in the case remain possible to manage. This alters the attention of Callon's (1986) classic example of translation and Law and Urry's (2004) of enaction by considering the cultural attentiveness required by the clinic to consolidate complex actors and associations around

childhood and HIV such as stigma, vulnerability and naivety into momentary interventions as well as avenues for future practice, whilst seemingly being indispensable to achieving viral suppression in both temporalities.

In this section I have built upon the themes of the previous sections by presenting chronic illness as akin to a clinical procedure adopted to fulfil a range of purposes similar to disclosure and adherence. Chronic illness has been presented as a consolidator of complexity mobilised in practice to bring medical requirements, patients' lives and professional actions together to elucidate a course of action from a specific moment in the clinic, off into decisions about the future of care. The next chapter will be the last procedure of paediatric HIV care that will be presented, and will give some sort of closure to clinical practice by dealing with transition, the process that moves patients out of paediatric services into adult ones.

## 8 Transition

As children with HIV grow older through adolescence and into adulthood, questions arise around the transfer of care from paediatric into adult services. The procedure of transition has been denoted and formalised to address this hand-over. Depending upon its context, when practitioners refer to the idea of 'transition', at times it can seem to be so clear but at others such as considering when the exact moment transition occurs, it seems almost entirely contingent. If it is the simple act of handing adolescents over to adult services, what should be included in this description? Behaviour? Circumstance? Relationships? Background? Moreover, at what time does it begin and when does it end? At the age of fifteen? At the first transition meeting? Once they are exclusively using adult services (RCN, 2008)? The preceding chapter discussed HIV as a chronic illness and how uses of chronic illness unite patients and practitioners in the aims of viral suppression. If transition is focused upon in the same way, it can also be seen as a way of ordering patients and practitioners and coordinating services. However, what is different here is that transition is done so under the proviso of child/adult services. When viewed from this angle, transition has the role of bringing together two branches of medicine formed around a distinction of what it implies to be a child and an adult (see Bundock et al., 2011 on "crossing the divide"). Within the distinction of paediatric/adult services many corollaries can be found around the perceived special needs of childhood. This chapter has not been designed to verify or falsify the rationale behind the foundations of a distinctive paediatric medicine, although many interesting questions will be raised. Rather the aim of this chapter is to highlight the ways in which transition is used to make and to consolidate these differences across the medicine. Through the maintenance of transition as a procedure, the functioning of the medicine, the distinction of two branches of medicine and the chronic status of HIV are made possible.



However, it also becomes important, as will be seen, for practitioners to shape transition into a progressive logic that smoothes the way for children to become responsible adults able to manage their own HIV effectively (Taylor and Bury, 2007).

As the positive results of antiretroviral treatment in suppressing HIV and preventing mother to child transition have become apparent, a successively growing problem over the last decade for those perinatally infected with HIV (as well as those caring for them) has been the transition from paediatrics to adult services (Bernard, 2008). Paediatric services are encountering unprecedented numbers of adolescents reaching the age where they need to leave paediatric care. Due to the fact that HIV suppression with antiretroviral therapy relies on almost 100% adherence to insure against resistance, practitioners make a large effort to ensure that patients continue to get the support transitioning adolescents require (Campbell et al., 2010; Wiener et al., 2011). The cultural sensitivity of the complex associations found in paediatric HIV such as naivety, stigma and vulnerability requires clinical practice to be flexible and meticulous in the way it manages this complexity. This cultural awareness differentiates paediatric HIV from other descriptions of complexity in medicine in STS such as Mol (2002) and Mol and Law (2004). During research at UOUH the term transition seemed to loom in and around every case that had reached a certain age. Usually at around fifteen, questions started to be raised about transition in managerial discussions by consultants or the CNS, then the question would usually begin to come up in patient consultations. Further on in this section I will share some of these encounters, alongside discussions around the ways in which transition is operationalised and made effective. I will argue that transition is used and maintained in practice in order to bring together and address distinctions between adult and child services in HIV medicine and make whatever differences presented between the two possible to manage. This process takes place in many ways in the clinic and there are many tasks associated with transition. For example, negotiations with patients ask them to take on responsibility for their condition as they reach adulthood, another would be the tasks done by practitioners in

meetings, emails and file swapping when coordinating cases and services together<sup>102</sup>. It is for this reason I am cautious in fully placing or positioning definitively what transition is.

In the literature, transition has an extensive selection of definitions, in terms of both HIV and other chronic conditions<sup>103</sup>. The general guidelines set by CHIVA offer their own definition:

*[Transition is defined as] “a purposeful, planned process that addresses the medical, psychosocial and educational/vocational needs of adolescents and young adults with chronic physical and medical conditions as they move from child-centred to adult-orientated health care systems.” The UK National Service Framework (NSF) sets clear recommendations for transitional care supported by a wealth of Department of Health (DOH) guidance and resources. In contrast, transfer is the physical event of the young person moving from paediatric to adult services and if unsupported by the process of transition has been associated with increased morbidity and mortality in other chronic diseases of childhood” (CHIVA 2011, p.5).*

Even from this broad starting point the boundaries of transition can already be imagined as broad and transient, this explanation offers no definitive statement pertaining to transitions beginning or end. The passage makes reference to an act, frameworks, guidance and the need for support. What is more, it introduces us to the notion of transition as a process.

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<sup>102</sup> Amongst the literature broader notions of transition are also emphasised as in Viner, (1999) who emphasises that transition is more than just an administrative hand-over

<sup>103</sup> A common distinction frequently posed is that HIV transition is distinct from transitions in other childhood illnesses. One distinction encountered in the literature is that the level of stigma and confidentiality involved with HIV transition make it markedly different from other illnesses (NCB, 2011). This must without doubt make HIV distinct, and for the purposes of the report, fulfils a certain requisite in coordination. However, transition will also be considered as distinct from the point of view of multiple ontologies (well demonstrated in Mol, 2002), this will mean that forms of transition are not only distinct from each other but also the contexts and places where it is demonstrated and referenced are also distinct, whilst also coming together to form coherent wholes. And so I will avoid making that initial distinction too heavily as from this perspective it would be seen as one *enaction* amongst many. Care will be made however, to attempt to focus as specifically as possible, places which can be inferred to refer to the explicit act of transition of patients in HIV services.

To those familiar with STS the last statement will seem noteworthy, as central tenets of STS are imbued with 'process philosophy' (as originating from Whitehead 1972). In the quoted definition of transition, CHIVA acknowledge the difficulty to offer even a provisional set of boundaries and the quote implies that practitioners and parents should imagine transition as a process. This suggestion is highly significant to discussions of STS (or this kind of process philosophy), where all entities are seen as in the process of becoming. Transition, according to this notion would be a series of hybridised references around the medicine, the child's care needs, differences between services, countless other possibilities around the case and other outside influences<sup>104</sup>. The importance of this process and the reasons why it is deemed as necessary by practitioners to formalise guidelines of transition, lies in what defining transition as an open process makes possible. In this case, comprising factors of adolescence into transition makes it possible to consolidate care regimes together, between paediatrics built around the perceived needs of childhood and general HIV medicine. My ruminations of transition may not be exactly from the stand point that CHIVA policy is coming from. For the purposes of creating guidelines for CHIVA, transition is referred to as a process with the belief that to best manage the situation practitioners, patients and families should not think of an end point or ideal situation but rather highlight and ensure that patients are prepared for and will be supported through what could be a long process (Fair et al., 2010). Therefore, practitioners may not hold a distinct notion along the lines of enquiry found in Deleuze (2004) on becoming, but there is a relation, as transition's aim is to organise the act of switching care whilst emphasising the need for flexibility and the patient themselves assuming responsibility for their care, in the process practitioners are made aware of the many broad implications possible between the different services of paediatric and general medicines without offering a fixed end point for how this should look like other than changing the hospital ward. My argument is that knowingly or unknowingly there is a convergence. The reference above of transition being a 'purposeful, planned, process' implies that organising care will have to be sensitive to individual contexts and situations and not able to hold one definition that fits all circumstances without interpretation. Again in this chapter, the clinic is highlighted as a key site where pressing

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<sup>104</sup> This point is reminiscent of Place (2000) who offers a monograph which demonstrates how a child body in intensive care is hybridised between the technologies keeping the child alive.

and seemingly contradictory complexities in patients' lives, in this case issues around adolescents growing older, are organised in accordance with medical requirement to ensure the continuation of care.

In the CHIVA protocol, models of transition are added, diversifying the attempt to organise the possibilities of how handing over care services can be carried-out. Transition according to these perspectives is extensive and on-going well into the hand-over to the new service. It ensures that practitioners must always be aware of transition when practicing the medicine and ensures that actions that take place in the consultation are made compatible with the notion of transition and work towards a *successful* transition as their goal<sup>105</sup>. However, caution must be displayed when isolating these practices as each reference to transition necessarily invokes an irresponsible child and the ideal state of a fully grown responsible adult patient. In this sense, the transitioning patient is dealt with as if in the state of becoming a responsible and independent adult until being transferred. After transition irrespective of if patients are responsible or not, references to transition slowly disappear as patients are no longer regarded as children (Persson and Newman, 2012).

Discussions from the Sociology of Childhood (SoC) therefore, also bring transition into question by pointing out that it feeds into a misconception of childhood as a process of *becoming* that obscures recognition of childhood in the present (Christensen, 2004; Prout, 2005). This chapter will follow this question alongside the general enquiry of the thesis around maintenance and consolidation, to highlight how transition maintains distinctions in the clinic between the adult, adolescent and child in order to ensure that ongoing viral suppression remains possible. The procedure of transition is needed as a way to think through end-points, outcomes and the different patient requirements between adult and paediatric services. In this sense, transition is already a method to address and rectify situations where over fixation on ideas around childhood is a problem and to facilitate childhood into HIV medicine. Linked to questions around childhood lies a question about the foundations of paediatrics as a specialism aside from general medicine. When considering what exactly is implied in a specialised medicine for childhood, there becomes a

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<sup>105</sup> Fair et al., (2011) provides an overview indicators of transition success

need to define what is specific about the child to warrant a specific branch of medicine (Armstrong, 1979). There are many propositions that could be discussed in relation to why paediatrics is upheld, like for example, the rise of child centric moralities and ethics in relation to child mortality rates (Armstrong, 1986), development (Kelle, 1993, 2009, 2010), the vulnerability and competence of children in medicine (Christensen, 1998, 2000), or the specialist configuration of child rights and clinical decision making (Bluebond-Langner, 2005; Alderson et al., 2006). As with other chapters, these questions will be modified through focusing upon transition as a clinical procedure designed to adjudicate childhood and adolescence within paediatrics, and make children compatible with adult services. The discussion will set a tone that attempts to describe the existing dynamics of medicine that require the formalisation of transition into clinical care rather than questioning the necessity of the paediatric/general medicine distinction (as with Oswell, 2012 the point is not to police the line between adolescence and adulthood but to describe its manifestations). To this end it becomes an active question of this chapter to ask the extent to which the facilitation of adolescence is taken up into medical practice? At times in the clinic, transitioning patients are not in the position of either adults or children. This consideration is important to bear in mind as the accounts below are read further.

A poignant if basic question to ask at this stage will be why it is deemed as vital to transition patients? Transition makes certain modes of care and medical regimes possible. Accordingly, making patients transition when they reach a certain age sustains the opportunity for paediatric HIV medicine to specialise its care to children. This is an important idea in relation to the medicine and allows the reasoning as found in previous chapters; that patients and care must inevitably change and adapt to different clinical eventualities. Splitting the services into different categories allows practitioners to focus more specifically and prepare protocols that deal minutely with all possible barriers to care<sup>106</sup>. In the process, these categories also become prescriptive, patients are ordered into categories of specialities and over time must conform to care regimes. Consequently, this process of adapting services must necessarily be mutually constituted around patients and

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<sup>106</sup> Both White et al. (2012) and Bowker and Star (2000) describe clinical classification as a process that is continually maintained.

practitioners to ensure that it is relevant and persuasive to patients, making it an elaborate assemblage over many time-scales and contexts that are difficult to reduce to binaries such as becoming and actuality, usefulness and uselessness. In what follows I will discuss clinical examples of transition at work and discuss some of the key concerns voiced in the clinic, firstly, around passing on problems to new services, secondly, that practitioners must let relationships with patients go and thirdly, that the population of children with HIV in the UK is ageing, which has a number of considerations. These considerations will serve to display how transition is used to 'bridge the gap' between services and coordinate medical practices through harbouring a reflexive and dynamic relationship between patients and practitioners (Viner, 1999). During transition, the clinic seeks to replicate its effectiveness as a key site in managing complexity by moving adolescent patients out into a more suitably attuned clinic, ensuring that the paediatric HIV clinic remains specialised and relevant to the complex issues and associations presented by child patients such as stigma, sex and alcohol.

## Transition in Action

Each case of transition is necessarily caught between the requirement to move patients out to adult services, whilst minimising disruption and maintaining the same level of care. The first step taken in this process is to begin to see children without their parents. In general, with the parents out of the room, the doctor takes the opportunity to ask if adolescents have had any problems with their care and make children think independently about issues affecting their care (Fair et al., 2012). This practice was upheld with all adolescents at UOUH, most usually after the age of about 14. Dr Peters would see children on their own for a few minutes before asking parents to come and join them. During this time Dr Peters would ask questions about medicine, school work, and then as they got older towards fifteen, about sex, alcohol and cigarettes. At the time of research most of the patients at the clinic would see the Dr alone for a percentage of their consultation. The discussions, especially about sex and alcohol are seen as part of Dr Peter's job, and should be discussed long in advance to transition.

*'Sexual health promotion including hepatitis B and HPV vaccination and sexual health education for adolescents needs to start in paediatric services prior to coitarche, continue through transition and into adult service.'* (CHIVA, 2011h)

Interestingly, it is seen as part of the role of the clinic to educate children with HIV about sex, alcohol and cigarettes. Dr Peters admitted an apprehension in taking up this role and on occasion questioned whether he was qualified and if paediatrics gives the adequate training to provide sex education. To trainee doctors sitting in on the clinic he would advise them that *'paediatrics doesn't normally involve sex education so you need to be prepared'*. Sex in this instance is something that is excluded from paediatrics and must be introduced in the interests of transition and bridging the gap between the two services. Members of CHIVA are referred to HYPNET for guidelines on what it is important for adolescents with HIV to know about sex<sup>107</sup>. This set of guidelines is in turn compliant with guidelines set more generally about transition from the Department of Health (Department of Health, 2006, 2008). The resulting guidelines by CHIVA contain a list of issues that practitioners must negotiate with adolescents. This includes epidemiology and public health implications, HIV transmission and the risk of transmitting, the importance of consent, confidentiality and child protection with potential partners, the law around transmission and disclosure of HIV status to others and partners (HYPNET 2011). This concern with a potentially broad and highly significant list of issues demonstrates that transition is not the neatly contained act of passing over cases to adult services. A sense of immediacy is placed upon consolidating the complex associations around adolescence and sex with public health concerns to halt further transmission (one unique to paediatric HIV in comparison to STS and SoC descriptions of medicine). Practitioners are well aware of and geared towards resolving the potential issues that can become problematic to managing the health care of patients into

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<sup>107</sup> It is an issue which has a broader set of discussions in the literature. Ferrand et al. (2007) in a study of London youths with HIV identified the potential and increasing problem of children with HIV becoming 'sexually active', a point shared by Bernard (2008) who states that most of the issues now being faced by an ageing population were unforeseen. Brown et al (1994), put forwards that adolescents with HIV are more likely to partake in risky behaviour, although the idea of a heightened risk beyond average is unlikely given the fact that children with HIV must talk about sex more extensively than their peers. Recurrently in the literature, as well as observational data, there is a big concern about 'sexual activity'. There are numerous reasons for this but it is interesting as a side note to think of ways that the sexuality of these children is conceptualised during these policy interventions, in literature or when advising adolescents (Fernet et al., 2011; Elkington et al., 2012).

the future. The process of transition is entrusted with ensuring that patients meet the requirements of adult medicine that are absent from paediatric care. Issues around sex have been identified as important for adolescents to understand in order to ensure a *smooth hand-over*, make children aware of the significance of HIV, and protect public health (Hekster and Melvin, 2006). In regards to transition, practitioners and governing bodies identify incompatibilities between paediatric regimes of medicine and the responsibilities counted upon for adults using HIV services and use the period of transition to formally address what is missing. The inherent morals within paediatrics of child vulnerability and diminished competence are often contrary or irrelevant to the notion of child patients being *sexually aware*, whereas adult HIV services rely upon and aspire to the notion of a sexually responsible and aware patient. One of the roles of transition therefore, is to prompt a clinical negotiation with patients in an attempt to order their attitudes in accordance with what is expected of them once in adult services. In doing so, transition can be seen as cohering together paediatrics with more general HIV medicine and public health, making these branches compatible and sustained viral suppression possible.

The set up in the clinic is that Dr Peters would talk to the boys about sex and the CNS would talk to the girls. The general message of these talks was that teenagers should not begin to smoke, be careful not to binge drink and become aware of how to have safe sex and when it is necessary to tell potential partners about their HIV. During these talks, questions ranged from boys like Marty asking for condoms to try on, to Virgil asking whether it will be possible for him to have children. Like Luke, most adolescents had dismissive undertones and found the conversation awkward:

*Dr Peters: Do you drink?*

*Luke: Everyone drinks.*

*Dr Peters: I drink, good, I should say bad if it were my son I'd say bad – [Dr Peters continues to talk about binge drinking and then starts to talk about sex and how he needs to take care that he has safe sex, advising him that if anything goes wrong that it is Luke's responsibility to get PEP<sup>108</sup> from the hospital for his partner.]*

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<sup>108</sup> Post-exposure prophylaxis is a method of HIV prevention to give those exposed to HIV a HIV-attacking medication to stop the virus replicating and avoid them contracting HIV (Christenson et al. 2008).



*Luke: I know all that.*

*Dr Peters: Good I'd rather that you heard it a 100 times than say to me that you didn't know.*

Pedagogic overtones can be seen in the above passage operating through policy that highlights the importance of discussing with adolescents specific issues around sex. A connotation prevails that adolescents need to be prepared for the time when they will be considered an adult from the point of view of the medicine<sup>109</sup>. Although the types of issues to be discussed have been alluded to in policy, the way that these discussions are framed around the responses, concerns and outcomes of each case are acknowledged to be broad and unpredictable. In order for practitioners to be able to address the complexity presented they must adopt flexibility with patients. What is made expressly clear in guidelines, is that practitioners go through the process of negotiating with adolescents, 'adult' topics around health, HIV and responsibility to assert them into configurations of transition and beyond (Campbell et al. 2009; Campbell et al. 2010 have conducted research on the anticipation of transitioning).

In the consultations I observed, none of the parents had a problem with the idea that the doctor wanted to see their child alone. Dr Peters would often send parents up to get medicine before rejoining their child in the consultation room. In the context of the clinic, there were no challenges from parents on Dr Peters' judgment of when to start seeing the adolescent independently. In this sense the parent's role would also have to be made compatible with protocol. Within paediatrics parents are required to attend each consultation whereas after transition, adolescents must get used to taking over the role their parents would have once played (Battles and Wiener, 2002). When these independent sessions begin to take place, they do not specifically reference transition. It is later on,

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<sup>109</sup> We could consider Foucault's (1998) notion of confession here as presented in reference to science sexualis, i.e. that adolescents are being formulated to be disciplined sexual individuals. Christianson et al (2008) for example argues that teaching adolescents the law around HIV transmission (and we can extend this to all public health warnings) made adolescents feel as if they must 'switch off lust' or 'balance lust'. We could ask how much interventions are designed for individuals to learn how to discipline themselves. However, there are some omissions to this, because to stray from Foucault I would like to disband with the idea of power conceived as travelling in one direction, i.e. from medical discourse on to the subject/patient.

when patients were nearing the age of sixteen that Dr Peters would start to approach the subject of transition.

In theory, adolescents have a choice of where they would like to go. CHIVA guidelines emphasise choice when approaching the subject:

*“Different models of transition exist and the model chosen is determined by the patient group, available resources and geographical setting. It is thought that there is no superior transition mode and that the key to a successful transition is a flexible approach paced to the individual needs of the adolescent.” (CHIVA, 2011h)*

Again the emphasis of this guidance is on process and flexibility, individual need and circumstance. Guidelines argue that this approach is the ‘key to a successful transition’<sup>110</sup>. Therefore, complexity is addressed in clinical practice through flexibility. However, in all observed cases patients chose to stay at UOUH and go upstairs to T1 (the name given to the adult HIV clinic at UOUH). At the time of research a new clinic which specialised in adolescents and young adults had opened up in central London, but none of the adolescents in UOUH wanted to go there.

*Dr Peters: “There’s a really nice clinic that’s just opened in the centre of town, but none of our children want to go there which makes it easier for us because Dr Chambers comes down from T1. The children from CHH have all signed up but we haven’t managed to sell a single one yet. It was set up because the cohorts from CHH and here are both aging so they set up this service, really nice service just for 16 – 24 year olds and we haven’t managed to sell it to a single one.”*

Dr Peters would present the different models to adolescents but they would invariably elect to stay at the clinic. What can’t be under-estimated is that choice and flexibility in the framework of the clinic have been proven to result in improved adherence and compliance

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<sup>110</sup> What makes up a ‘successful’ transition is highly contingent and will be dealt with here as such (Fair et al., 2011)

with the advice of practitioners and subsequently aid the causes of individual and public health (Fair et al., 2011). Choice and flexibility in transitioning is an acknowledgement of adolescence as a time for experimentation and development. Accordingly, transition is built to address a specific resonance around facilitating adolescence into HIV care (Persson and Newman, 2012). The attentiveness required to deal with adolescence and HIV in the clinic emphasises the need for flexibility in guidelines. This contributes to STS accounts of medical multiplicity such as Mol (2002) and Mol and Law (2004) by highlighting the clinical awareness of diversity and the effort put in to consolidating multiplicity into care regimes. If the question is raised: what is being included in this category of adolescence and where it sits between childhood and adulthood? Consequently, transition can be considered as a regime of medicine in itself not quite paediatrics and not yet adult services?

When a patient would confirm that they wanted to stay on at T1, Dr Peters would consult them as to which doctor their parents saw and make sure that they saw a different consultant through fears about confidentiality. In most cases this wasn't an issue, with the exception of Luke, who after a chat with Dr Peters, was undecided where to go to, but was sure that he didn't want to go to the same Doctor as his mother and confronted her with it when she later came into the consultation room.

*Dr Peters: 'we were having a little chat before you came in about transition [of care]. I wonder if it's good to refer him to the same doctor as you. We were thinking of Dr Schunk, I also have a good relationship with him.'*

*Mother: 'mmm but...'*

*Luke: '...I might want a different doctor'*

*Dr Peters: 'Dr Chambers may have to keep confidential which he's very good at, but it might not be good as a young man growing up to have to confide in the same person as your mother.'*

This process is designed to make adolescents take a stake in their care. In the example, a potential compromise had been identified and avoided by Dr Peters. It serves the aim of encouraging Luke to develop questions about his independence and promotes Luke's trust

and confidence in the medicine. This concern with Luke as a patient aside from his mother also demonstrates the desire that each branch of HIV medicine is allowed to specialise itself with the specific populations and issues that are important to them (Bowker and Star, 2000; White et al., 2012). Services like the adolescent clinic in central London attempt to specialise in order to address issues relative to this age group. Within transition there is a consolidatory logic in operation. The relevant logic here would be that a smaller group means that the ranges of possible issues can be addressed more specifically, and that adolescents and their specific needs can be accommodated and compiled together into a specialist group that can become dedicated to define and address adolescence and its facilitation into HIV medicine. This again highlights transition as a regime between paediatrics and adult services designed to 'bridge the gap', but also introduces the notion that transition not only works out incompatibilities between two regimes of medicine but actually has its own specificities.

Once these issues are worked out, the process of transition continues by inviting the transitioning consultant from T1 to the clinic to have a consultation together with Dr Peters and the adolescent patient. For patients staying at UOUH this would usually be Dr Chambers. These sessions are designed so that the new consultant can get to know the case and specific issues regarding the patients' treatment. It further demonstrates the attention put into ensuring a 'smooth' hand over.

In one of these planned sessions in the consultation room, Dr Peters and Virgil were talking whilst waiting for Dr Chambers to come down. Virgil was 17 and at the age to transition. He was born in Angola and had spent time in other European countries but had been attending the clinic for several years. At the time of research Virgil was living with his mother. When Dr Chambers arrived he came in and shook hands with Virgil.

*Dr Peters: When they're taller than me I transition them, do you want to say a bit about yourself... Well you were born in Portugal but you've lived in many other places like Switzerland, Portugal, Germany and you were diagnosed in Germany weren't you? I don't know about that. We knew there was a problem with resistance from a phenotype test they*

*Transition*

*sent to us, but his CD4 was high so we didn't restart him on treatment, viral load is not high either...*

*Dr Chambers: Though there are plenty of possibilities.*

*Dr Peters: Yes but at the moment it's all fine... and he has a retinochoroiditis.*

*Dr Chambers: Do you have any brothers sisters?*

*Virgil: Yes both younger.*

*Dr Peters: They've not been tested, the mother has said that they were tested [not at the hospital] and are negative.*

*Dr Chambers: You live locally?*

*Virgil: Yes.*

*Dr Chambers: Does your mum come here?*

*Virgil: Yes.*

*Dr Chambers: Do your siblings know?*

*Virgil: No not sure.*

*Dr Chambers: What are you doing at the moment?*

*Virgil: I'm at college.*

*Dr Chambers: So what would be the best time to come in?*

*Virgil: Morning*

*Dr Chambers: Well it's up to you when you come in there's no absolute time to transition*

*Dr Peters: When they're taller than me...*

*Dr Chambers: We have three sessions a week; we need to speak to your mum to make sure that you're ok with everything. I don't know if [Dr Peters] keeps you waiting?*

*Dr Peters: Yes like today.*

*Dr Chambers: We try not to keep people waiting but sometimes like most hospital wards we can get delayed. It's the same set up as down here with a specialist nurse.*

After the consultant from T1 has sat in on a session or two, the patient then transfers to adult services.

The passage demonstrates the lengths taken to ensure that the continuation of care is as smooth as possible, as well as the attempt to consolidate complex patient cases from one

clinic to another. From the point of view of practitioners that must organise HIV care, many voice concerns that the cases that are being handed over are highly complicated with much diversity, age considerations, resistance to medicine, and movement of patients between national territories (Fair et al., 2010, 2011). It is engrained in the policy of the clinic that this complexity is addressed during transition and deemed as necessary for policy to remain relevant. Dr Chambers then continues to make compatible the paediatric branch of medicine into adult services, the task of adhering to antiretrovirals remains principal, but the way that patients are expected to relate to this medicine and the ways in which the medicine is administered are not identical. The process of transition that is referred to in CHIVA guidelines purposefully allows for an open interpretation by practitioners to insure that models of care and adherence to antiretrovirals are compatible with adolescent's lives (CHIVA, 2011h). Guidelines have at their base the necessity to hand over cases and re-manage them into recurrent clinical encounters with the idea that flexible services will be more able to cater for patients' continuing needs. Therefore, according to this process, transition is a multi-faceted/dimensional technology used to organise large and small scale patient care. Transition is charged with the consolidation of paediatric regimes of medicine and the consequent morals of vulnerability, naivety and incompetence to adult ideals of patients being responsible for their own care and sexual awareness. Complementary to existing accounts of complexity in medicine like Mol (2002) and Mol and Law (2004), a sense of cultural awareness is implied through-out clinical practice and guidelines to consolidate this complexity to ensure a smooth hand over. What becomes unclear in this process however is the extent to which this period of transition constitutes its own medical regime, geared around the specificities of adolescence.

### **Passing on Problems or Straight Forwardness**

In the example of Virgil, staff at the clinic in UOUH considered this case to be straight forwards. The case itself fitted nicely with the outcomes that CHIVA and clinical guidelines are trying to attain. Dr Peters would mention in departmental staff meetings or to interested trainees that Virgil was his most straight-forwards case of transition. But what about the application of policy to more troublesome cases, where adolescents are in violation of the broad aims of the guidelines to maintain adherence?

Practitioners aim to hand over cases as neatly, with as few problems as possible. In the case of Virgil, the team were enthusiastic to pass him over, however there were cases at UOUH that were more problematic. The process of having to transition children to adult services creates questions about benchmarks for practitioners to maintain. One is that when passing over adolescents, Dr Peters professes that he tries to hand them over in the 'best shape possible', which involves the adolescent being knowledgeable of their condition, the associated dangers and adhering to medicine (Bundock et al., 2011).

In the case of Wendy, it was mentioned on a few occasions that it may not be a good idea to transition Wendy without the case being in 'good order'. This was discussed mainly during staff meetings with Dr Phelps (attending as part of the regular consultations from CHH) and Dr Chambers from T1. At the age of 16 Wendy was not adhering to her medicine and not coming to appointments. During this time, Dr Peters became divided between the idea that Wendy may wish to associate herself with the adult ward and be more likely to attend the adult clinic, and on the other hand that Wendy may give up completely if she loses the familiarity and guidance of the paediatric HIV clinic that she visited throughout her childhood.

The following example was noted down in a meeting of clinical staff, initially Dr Peters was asking advice from Dr Phelps with the nursing team and pharmacologist listening on, awaiting the arrival of Dr Chambers.

*Dr Peters: One option is that I could refer her [Wendy].*

*Dr Phelps: How old is she?*

*Dr Peters: 16, T1 [the adult clinic] is more flexible, but I feel as if I can do better, it may be arrogant but you feel like you messed up if you refer them and they're not sorted out.*

*[At this point, Dr Chambers from T1 walks in.]*

*Dr Peters: Come in we were just talking about how to make your life more difficult. We're talking about what to do with a 16 year old of mine who's not attending the clinic. Half of me wants to sort it out before I hand her over, half of me wonders if she's sick of the paediatric services.*

*Dr Chambers: well it's good to have things tied up before you hand her over.*

*Dr Peters: the difficulty is that I might not see her again, she hasn't been attending.*

*Dr Chambers: Well I'm happy to do whatever.*

As can be seen, there is an absolute and pressing need running through this passage to ensure that the case, or the complexity of the case as could be referred to by STS, is in 'order', emphasising again the desire to consolidate complexity. The task of transition involves sharing stories and experiences of dealing with the particular patient in question. This is done in an attempt to organise complex patient negotiations into neat case files. Towards the end of fieldwork a new technique of building narratives was being introduced at the UK's largest paediatric HIV clinic and consequently being practiced by Dr Peters. It involved the consultant handing over, to provide a *case history* of the adolescent being transitioned. This case history would entail the doctor going over case notes and, documenting the key moments in the case history, starting with 'presenting'. Dr Peters was beginning to implement this at UOUH at the end of fieldwork, whilst I was still observing cases at the clinic, he had done one such case history which was five pages long<sup>111</sup>. Dr Peters said to me that the purpose of producing the document is to make children conscious of some things that they may have not been aware of, to provide a resource to practitioners and to consolidate care. When these documents are produced, cases are formulated into one narrative or one logical structure, and consolidated into one document. The case notes are essential to the creation of this document as well as the memories and experiences of the consultant handing over. An official story is finalised and cases are translated (Callon, 1986) and made comprehensible to other services. In these case histories, narratives flatten complexity and attempt to turn the unruly into that which is straight-forward. Therefore, this stands as an obvious example of transition as a force to compel services to unify and render visible aspects that may have been difficult to deal with previously during care.

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<sup>111</sup> This is reminiscent of several papers which highlight that practitioner deliberations on how to classify cases are crucial to organising clinical medicine. For example White, (2002); or Atkinson (1995) on case management; or White et al. (2012) and; Bowker and Star(2000).



Case histories are designed to further coordinate as many aspects of case management as possible. However, for Dr Peters the problem is further expounded by the fact that the process of transition involves balancing very extensive and sometimes limited drug histories:

*These children are very complicated who we're handing over. A lot of them had treatment when there was only one antiretroviral drug available, then they took that for a few weeks and they became resistant. So they took the next one and when you become resistant to one you become resistant to all of the drugs like that, so some of their options are now quite limited<sup>112</sup>.*

This is why the guidelines are designed to ensure, as much as possible, that practitioners can interpret transition as an open-ended process with many possibilities. It is not practical for practitioners to employ one technique or a range of techniques in the hope they will work in each circumstance, the freedom to attempt a range of creative solutions must be available to practitioners. As alluded to in the passage above, compared to other conditions (such as those already described in STS of Mol 2002 and Mol and Law 2004) there is a cultural sensitivity to the complexity presented to the clinic by adolescence and HIV (such as sex, alcohol, 'social life'). Amongst CHIVA recommendations and patient case histories, there are impositions from the antiretroviral medicine that must be engaged with effectively to ensure viral suppression. The refusal of Wendy to negotiate with viral suppression renders her incompatible with the process of transition, whilst reaching the age she will be considered an adult and so need to transition to adult services. The guideline considerations exemplified here are concerned with the continuity of medicine and the management of a case from its history into the future. It is important that transition is done efficiently to make it possible to maintain the case. Adolescents are required to become more compliant with maintaining their condition and practitioners must continue to specialise in their field of medicine (Bowker and Star, 2000; White et al., 2012). Practitioners are encouraged to acknowledge the peculiarities of each case whilst administering care over the whole demographic of the patient cohort. Wendy's refusal to

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<sup>112</sup> Taken from informal interview with Dr Peter's Oct/2010

attend causes incompatibilities with care and it becomes uncertain how the protocol of transition should be applied to the situation. The formalised transition guidelines therefore, must be designed and interpreted by Dr Peters in ways that attempt to engage with adolescent specific factors, such as the facilitation of Wendy's refusal.

This offers a contrast to cases like Virgil's where he attends, adheres and follows with little protest. His case is seen as the most 'straight forward' as the application of transition takes place with less need for intervention. However, it is the desire of those who design transition to make guidelines as applicable as possible. The procedure of transition is designed to address care regimes in paediatrics and make notions of child vulnerability, naivety and incompetence compatible with adult services and 'patient responsibility'. In the process it creates a third transitional regime that attempts to understand adolescence and cater for its needs, and consequently aligns case histories into one coherent discourse of viral suppression. The enactment of transition in the clinic makes it possible to manage medical regimes and adolescence into one lifelong task of viral suppression (Department of Health, 2006; Fair et al., 2010). However, some cases prove to fit neatly whilst others need more work to become compliant.

### Letting Go of Relationships – Versus Formalised Structures?

The passing on of problems is not the only consideration made when children reach the recommended age of transition. Another consideration made by both practitioners and some children is that there is often some anxiety and sorrow at the prospect of ending of a long relationship (see for example Fair et al., 2012 "It's like losing part of my family"). It is also something that is expressed in the medical literature. In a report aimed at improving transition for adolescents with HIV commissioned by the NCB there is a discussion about the result on adolescents of the change in relationships and the adjustment to greater autonomy occurring during transition (NCB 2011). This leads us to consider the possible alternatives to transition and why it is deemed necessary to transfer patients. Children with HIV have to fit the pre-existing restrictions of paediatric medicine, which means that after a certain age patients are required to leave the service.

In consultations with Dorothy, Jemima and Luke, Dr Peters repeated a similar quip to each patient. That when they reach the age of sixteen and a half, people begin to shout at him to transition them over to adult services, then adding that if they're not transferred by the age of 18 people start to scream at him and so on.

Although it is not made explicit who are the people that will 'scream' at Dr Peters in the event of non referral, the idea being conveyed to adolescents is the inevitability of their transition and that it is part of an unchangeable scheme. The reference to transition being made here is that it is a necessary process that is beyond the individual. The traditions of medicine that distinguish paediatrics as necessary are not so easy for individuals to challenge, even if notions of vulnerability, naivety and incompetence can be identified within them. Some practitioners get a sense of adolescents becoming lost in the process transition. The Royal College of Nurses released a guideline more generally on transition, titled *Lost in Transition*, demonstrating the sense of loss imagined through a pun on the film title *Lost in Translation* (RCN 2008). Those who deal with HIV (including Dr Peters) would say that HIV causes more issues in transition than other chronic diseases due to confidentiality and stigma, and so adding to the feeling of being lost. This can be linked to the argument running through this thesis that paediatric HIV needs an extra cultural awareness in contrast to other conditions discussed in STS accounts of medicine, such as atherosclerosis in Mol (2002) or hypoglaecaema in Mol and Law (2004).

The majority of the children at the clinic have grown up in the care of Dr Peters. He would often talk to me or to staff and trainees about how he does not like to pass patients over and how he is becoming less and less aware of the passage of time. For example, in an instance between appointments Dr Peters said to me and an SHO: *'I've been here for 6 years and Dorothy is one of those that I still see as a kid'*

At the time of research Dr Peters had been head of the clinic for 6 years and so for many of the adolescents who were fifteen or sixteen, appointments to the clinic are amongst their early memories. In the clinic some children even expressed how unhappy they were to leave, like this example from Jemima:

*Transition*

*Dr Peters: Have we talked about transition?*

*Jemima: I don't want to go.*

*Dr Peters: You want to see me until you're twenty nine?*

*Jemima: No I'm used to it here.*

*Dr Peters: Well I would go to Dr Chamber's clinic.*

*Jemima: Don't want to go.*

*Dr Peters: Let me explain. I would come up and we would do it gradually, [the CNS] would still be here to make sure that it went through smoothly.*

*Jemima: Can she come up too?*

*Dr Peters: One day you'll be sick of all the kids around here,*

*Jemima: No I won't I've been coming here for 17 years.*

*Dr Peters: Yes I know you're very used to it.*

This poignant example highlights that transition is not inevitable in the minds of every adolescent. The clinic is attentive to what adolescent patients expect and attempts negotiate their attitudes to comply with transition. Dr Peters highlights the reasons why it is important for her to leave and evokes an idea of maturity that he expects Jemima to feel in retrospect sometime in the future. To ensure a smooth transition of care it is important for practitioners to attune patients to the reasons why transition is necessary. This clinical action once again highlights the attentiveness employed by the clinic to consolidate complex patient attitudes to necessary medical regimes. What are consolidated here are the attitudes of adolescents with the clinical reasoning that the adult clinic will be able to meet their needs more readily. Most other children didn't express the same sentiments, but for the clinic this is a time when they would observe patients carefully for signs of psychological strain. The following practitioner conference paper demonstrates that there are some difficult discrepancies to assimilate when transitioning adolescents:

*"The issues were raised in a series of studies from St. Mary's Hospital, the London hospital which for many years has had the largest paediatric HIV clinic in the country and has more recently developed the 900 Clinic, a transitional services to help young*

*people manage the shift from child-friendly services into an adult clinic. In addition, a national survey shed light on adherence issues for young people with HIV.*

*Tania Wan presented data on the health outcomes of 58 perinatally infected young people who were seen between 2006 and 2011 at the 900 Clinic. The young people transferred from the paediatric clinic between the ages of 16 and 18 and their current median age is 20, with the youngest 16 and the oldest 26. Three quarters are black African; there are more women than men.*

*At their last follow-up, two-thirds of the young people were taking antiretroviral treatment, and 95% of this sub-group had an undetectable viral load.*

*However there were a considerable number of complications. A fifth of patients had a CD4 cell count below 200 cells/mm. A few of those with undetectable viral load had failed to fully restore their immune function.*

*At the time of last follow-up, a quarter had chosen to discontinue antiretroviral treatment, despite considerable support and intervention from clinic staff. Just under half of this group had a CD4 cell count below 200 cells/mm" (Pebody 2011; also see Wan 2011).*

The causes as to why transitioned children may choose to stop taking their treatment is under contest (Miles et al., 2004; Wiener, Battles, et al., 2007; see Vijayan et al., 2009). However, an attempt to formally organise transition can be seen in the ways that those practising the medicine are attempting to address it rationally. Interestingly here, and echoed in the decision to emphasise the central London adolescent clinic at UOUH and CHH, is the idea that children need a certain amount of specific and focused support. A body of literature is geared towards identifying reasons why transition may be undesirable to adolescents (for example Vijayan et al., 2009 takes on this task). Whilst not all practitioners uphold a simplistic line of causation that reasons that adolescents who are unsupported will stray (Miles et al., 2004 offers some long-term adjustments as to why adolescents may prefer to transition). What seems more certain is the need that some sort of specialised clinic evolves (in the UK at least) to assess some of the problems in the age group (as is the aim of setting up the adolescent specific 400 club at St Marys). In this instance, transition is being formalised to offer methods designed to negotiate adolescence and case histories and

make them compatible with adult services. What is also thrown into doubt is the idea of exclusivity in HIV medicine between paediatrics, general medicine and a regime of adolescence set up around transition. HIV and adolescence blurs the lines between childhood and adulthood, development and child/adult rights. Each case is unique and requires patients to follow antiretroviral regimes closely. Therefore, cases need specific, sometimes intensive and individual support, the support required is difficult to define solely by age. CHIVA transition guidelines escape questions of age by setting a broad and flexible method that attempts to consolidate gaps in care with a set of procedures that are open to the many possible circumstances presented by adolescents at the clinic. Therefore, a contrasting consideration would be to question if transition also causes some patients to adapt abruptly to being managed? As with Jemima. Following Latour (1987), if transition is described as a 'battle between allies' to define scientific fact in antiretroviral medicine, the sorrow felt over the loss of the paediatrician/patient relationship has little credence in the rationalisation and organisation of care in relation to medical science. Although, it is open to speculation that issues around the benefits of a close paediatrician/patient relationship can be found in the rationale behind the set up of the 400 clinic or the central London adolescent clinic.

Considered from this angle, the question can be raised as to the amount the medicine asks patients and practitioners to comply, adapt, cohere and take responsibility. As with other chapters I would like to assert that the channels in which actions and decisions are made are diverse, and that transition is not the result of one rationale or even a set of rationales, but is enacted and made operational through a range of nuanced assemblages (that are not directly comparable or translatable see Callon, 1986). However, what is emphasised complementarily to this nuanced STS view of medicine and the condition as an assemblage is the immediacy expressed in practice to consolidate the complexities of adolescence between services. From these processes, transition acts in the clinic to consolidate the non-responsible child patients of paediatrics to approaches of care characteristic of 'responsible' adult patients. This consolidation means that both practitioners and patients are attuned to the rationale that the clinic's effectiveness relies upon its ability to specialise to a specific cohort.

## Aging Population

UOUH and other Paediatric HIV clinics in the UK are responsible for formulating and sending off data about their service for use in the Collaborative HIV Paediatric Survey<sup>113</sup> (CHIPS). It was the responsibility of the CNS to compile and send off the necessary data for CHIPS. The survey collates data from virtually all UK clinics dealing with paediatric HIV. One of the outcomes of the data has been that the population of children with HIV has been revealed to be ageing:

*“Similarly the age distribution of the cohort has changed considerably over the years. In 1996 the median age was 5.1 years (inter-quartile range, IQR 2.9-7.6) and this increased year on year to 12.4 years (IQR 9.1-15.2) in 2010. Furthermore, the proportion of the cohort aged ≥10 years increased from 11% in 1996 to 70% in 2010.”*  
(CHIPS 2010, p.1)

If the number of patients registered at these clinics continues to decline it shows a decline in perinatally infected children. Tellingly, it is not discussed in the report whether the number of adolescents infected in other ways has grown. However, it can be asserted that transition from child to adult services is likely to become more emphasised as the numbers peak. The CHIPS 2010 annual report states as one of its aims that it will concentrate on looking at transition related issues:

*‘[our future plans are to] begin an analysis of the whole of the CHIPS cohort, concentrating on adolescence, secondline, mortality, and transition to adult care’*  
(CHIPS 2010, p.2).

For practitioners therefore, the significance of transition for children infected with HIV at birth is rising as the population is aging. At UOUH as prenatal screening of HIV has become more successful the general trend is that children are getting older not to be replaced by

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<sup>113</sup> [http://www.chipscohort.ac.uk/summary\\_data.asp](http://www.chipscohort.ac.uk/summary_data.asp)

younger patients. The birth of a child in UOUH with HIV had become highly improbable at the time of research. In a telling discussion in the clinic, Dr Peters was talking to Dr Phelps about what an aging population means. Dr Peters expressed that he thinks that as populations continue to age that it will become necessary to close clinics like the one at UOUH and Dr Phelps concurred with this. Although this was to be contradicted by the fact that numbers at UOUH remained stable – in the low 20s – due to an influx of African immigration into the area, the general trend still holds and therefore has a bearing on the way that adolescence and transition are conceptualised in HIV medicine.

Another aim of CHIPS is to:

*‘gain ethics approval to enable young people leaving paediatric care to be followed-up in adult care through the UK Register of HIV Seroconverters’ (CHIPS 2010, p.2).*

Following through this report gives us an interesting impression as to how the boundaries of the paediatric HIV population become visible. The concern of the report demonstrates a perceived lack of overview of the future of this population. It highlights that medicine needs to interpret and reinterpret data to make sure that it is possible to coordinate services around populations (Fair et al. 2011 highlights the difficulty even in how to measure a successful transition). If transition is to retain the purpose of coordinating medicine, the task at hand for those organising paediatric HIV care has been to create clinical services that specialise and respond specifically to the needs of children with HIV in the UK. As is exemplified in paediatric HIV, in comparison to STS descriptions of atherosclerosis by Mol (2002) or hypoglycaemia by Mol and Law (2004), there is a significant sense of cultural sensitivity in the logic of paediatric HIV clinical practice that attempts to consolidate the complex and contradictory associations of patients, such as stigma and vulnerability with drug requirements. In Mol (2002) or Mol and Law (2004) issues akin to vulnerability and stigma are diverted in favour of tracing the multiplicity of found over different sites and different objects of the hospital or on the body of the patient, what the study of paediatric HIV makes salient is the attentiveness needed in the clinic to manage complexity, or in this case to organise adolescence specific services. The impetus of vulnerability in the clinic



makes it important to follow patients and see what becomes of them. However, as the group of transitional patients grows and the extent of paediatric HIV increases and decreases accordingly, there becomes an issue of traceability and follow-up of long-term patients who have grown from one service to another. These channels of visibility and traceability of patients who have transferred must be organised and maintained in order to achieve a visible follow up (Allen and Pilnick, 2005; Currie et al., 2012). And so the boundaries of paediatrics and transition is not neat and finalised, once adolescents are transitioned to adult services, there is a line of enquiry that is present between the two, and deemed as important to maintain by practitioners for improving adult services.

Those administering care must ensure that problems of all scales and sizes fit with regimes of individual care, the broad allocation of resources and demography. It is not possible for the agency of one individual person or institution to oversee the whole coordination of resources, but if care (or the suppression of HIV with antiretroviral drugs) is to be replicated in the long term over as much of the population as possible, practitioners must act in ways that are compatible with the rest of HIV medicine. In the process of care, children and parents must also be asked to take on board these conceptualisations. As with Virgil and Wendy, Virgil would follow and fit protocol whilst Wendy was more unruly and so transition was delayed. Far from being fully laid out in protocol, much is asked of families and practitioners. In the clinic, during transition practitioners must consider what is available, what is for the best and what is possible, and adolescents must be prepared to form new relationships and take on new roles. As the organisation and demography of HIV is shifting with policy and politics practitioners, patients and practice must adapt. Teenagers and practitioners alike must specialise, adapt and take on responsibility for care. They must forge ways of negotiating with broad structures of biomedicine, whilst finding solutions for the unique problems that arise in maintaining HIV. Therefore, the clinic is a key site of formulation for how HIV medicine will be consolidated into the dispositions of transitioning adolescents. As argued, the scope of the complexity of adolescence and HIV engaged with by the clinic, marks paediatric HIV clinical practice as distinct for the way that a sense of cultural attentiveness must be employed in comparison to other STS studies, such as Mol (2002) or Mol and Law (2004). In this context, transition as practiced in the clinic, is part of

the process of organising complex (often contradictory) adolescent associations such as stigma, vulnerability, sex and social-life with the task of attuning medicine to patient requirements. Transition assumes its place alongside established and formalised channels of medicine, but is also never fully formulated so as to become counterproductive. Transition works fluidly, as demonstrated in Mol and Law (2004), between adult and child services to promote responsibility, dispel vulnerability, naivety and incompetence whilst adapting adolescent specific issues to adult care.

## Conclusion

This chapter has attempted to highlight transition as a vital procedure of paediatric HIV medicine. Although it is not clear where transition begins and ends, it has been argued that transition plays the fundamental role of bridging two regimes of care, from paediatrics to adult HIV services. Transition is enacted in the clinic to consolidate complex case histories between two services to ensure a 'smooth' handover and ensure services remain attuned to paediatric cohorts. Paediatric medicine is influenced by associations that emphasise childhood as a time when patients are deemed vulnerable and naive and therefore incapable of taking on the requirements of medicine, such as regularly taking antiretrovirals, arriving for appointments at the anointed time or comprehending and enacting effectively the advice of doctors. In contrast, HIV patients in adult services are required to be responsible for their care and must be sexually aware. Once patients become 'sexually active' they are at risk of causing an offence if their actions can be seen as 'reckless endangerment' in the eyes of the law (Christianson et al., 2008). This complexity is felt acutely by clinical services. In comparison to other STS accounts that emphasise complexity in medicine, for example Mol (2002), or Mol and Law (2004), the account offered here demonstrates the attentiveness of practitioners to consolidate adolescent complexity to medical services. In these STS accounts, emotive, moral or vulnerable objects are not specifically represented. Within paediatric HIV it is impossible to overlook the ways in which practitioners must purposefully be attentive to moralistic adolescent complexities of vulnerability, and stigma, actively consolidating them into medicine. Transition is enacted to offer a bridge between the two temporal stages of adolescence and adulthood in the

medicine. In doing so however, the transitional period forms a part of the medicine that takes on board adolescent-specific considerations. It opens itself to questions that adolescents may have about relationships, sex, drugs, alcohol, friendships and socialising. Whether it does so convincingly is open to debate, but the medicine formally invites consultants to become aware and ask questions about adolescents' attitudes relating to their condition. Rather than being wholly defined by these questions however, transition remains tailored towards ensuring the continuation of viral suppression with regimes of antiretroviral medicine. If transition was set up as dedicated to predefined adolescent problems it would not be as effective. It is precisely the adaptability and openness of the procedure of transition in clinical practice and the negotiation of protocol to balance adolescent attitudes with drug requirements that ensures the medicine's effectiveness. This point of view lends itself to an STS discussion around becoming. Transition functions through its ability to assemble medicine between paediatrics and ideas of responsibility that come from adult medicine, as well as making it possible to address age related specificities. This renders transition not as a clinical procedure built solely around a stage of development, but a period of absolving the healthcare of the past in preparation for the responsibility of future care. Imagining transition in this way highlights how the upkeep of a specialised paediatric HIV service and the consolidation of children into adult HIV medicine is made possible. However, to this sense of managing the future (in contrast to STS accounts of complexity in medicine such as Mol 2002; Mol and Law 2004) paediatric HIV also brings with it an immediate set of dangers that could occur in the case of clinical mismanagement.

This example of the need to make multiplicity compatible can be seen through the examples given of passing on problems, letting go of relationships and aging populations. 'Passing on problems' demonstrated that transition must be formulated to remain flexible enough to be applicable to both straight-forwards and more complex cases. It was shown to be important that transition should be designed to facilitate the possibility of collating cases even if this collation often breaks down. The section on letting go of relationships highlighted that there exists formal traditions within the medicine that inform the negotiation practitioners and patients must have when changing care. Therefore, it clarifies that the procedure of

transition is not solely set up in relation to age and adolescence, but is better seen as a force that colludes together several already highly developed regimes of care in order to allay the real danger of adolescents failing to uphold adherence. Finally, the consideration that the paediatric HIV population is aging emphasises that transition needs to be systematically formalised around the needs of the patient cohort. Throughout this chapter therefore, I have argued that transition is being systematically designed and executed to address the needs of patients and ensure that patients continue to stick to requirements, but it is done so by promoting flexibility in care. In this sense it remains balanced between paediatrics, adult responsibilities and adolescent specificities. Therefore, transition can't be placed in either paediatric or adult services but is made necessary between the need to specialise care to each service to ensure that both paediatric and adult services can continue to attune their services to complex needs of their cohorts. As a result, this account of transition contributes to STS views of multiplicity, such as Mol (2002) and Mol and Law (2004), by demonstrating the importance employed by services to consolidate complexity.

Compared to the previous chapters, transition fits alongside the thesis by elaborating on aspects of practice and protocol that consolidate care and ensure that practice is attuned to the paediatric cohort. As a procedure, transition can be seen to manage different services within medicine and inform practitioners and patients on their roles and responsibilities. The clinic is highlighted as a key site where complexity (often contradictory and presenting a real danger in the case of mismanagement) is consolidated into functional medicine. Transition forms the final empirical examination detailed in this project and aptly, is the impetus that sees individuals leaving paediatrics. The final chapter will conclude and summarise together the combination of procedures described throughout these chapters.

## 9 Conclusion: medical procedures in practice, the consolidation of medicine, science and 'society' into the clinical practice of paediatric HIV.

The research chapters of this thesis have attempted to highlight that within the clinical management of paediatric HIV medicine there lies a clinical logic<sup>114</sup> produced and followed by patients, practitioners and protocol, configured around the procedures of disclosure, adherence, chronic illness and transition<sup>115</sup>. Or to be more precise, each of these procedures is one procedure amongst many designed and performed to work within many possible care scenarios, (albeit that from situation to situation they will differ in importance, maintenance and conceptual weight). The administration of medicine and the consequent suppression of HIV through antiretroviral medicine have been shown as enacted and made possible through the negotiations of patients, practitioners and protocol in the clinic (Callon and Rabeharisoa, 2004, 2003). Therefore, what is significant in the model of practice demonstrated is that firstly, the equation that protocol dictates practice is displaced, and secondly that the clinic is a key site in consolidating complexity through the enaction of

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<sup>114</sup> The use of the word 'logic' wishes to imply that there is a recurrent deliberation in the clinic about how these procedures are designed, exercised and can be employed to work together towards a common goal of managing HIV care and virus suppression with antiretroviral drugs (these issues are relevant to STS as applied to organizational studies Czarniawska and Hernes, 2005; Jones and Munro, 2005; Whittle and Spicer, 2008; Woolgar et al., 2009).

<sup>115</sup> If I refer to a 'procedure' or 'these procedures' further into this text, it is in reference to the chapter headings of disclosure, adherence, chronic illness and transition. It is not to say that these are the only medical procedures at work in paediatric HIV, or that we can so easily define the boundaries of these concepts as procedures, but I am using the word procedure here to imply that these concepts are stabilised and formalised to achieve a certain purpose in the medicine.

## *Conclusion*

these procedures to make functional antiretroviral medicine possible. The contribution of this account is that alongside STS and SoC such as Mol (2002) or Mol and Law (2004), the requirement to consolidate cultural complexity is highly pressing and managed with a high level of clinical attentiveness in comparison to other conditions, such as atherosclerosis or hypoglycaemia. This management takes place through the procedures described.

As paediatric HIV requires an acute culture awareness, throughout the thesis I have presented the notion of consolidation as a supplement to the ideas of multiplicity and enaction in Mol (2002) or Mol and Law (2004). Consolidation describes the aim of practitioners to take on the complex or diverse situations presented by patients in the clinic and incorporate them into a general medical framework. In the case of clinical enactions around paediatric HIV, the clinic must work to make possible the suppression of HIV using anti-retroviral therapy. This means that practitioners must consolidate outlying cultural or incompatible medical elements into the overall task of viral suppression. I have used the concept of consolidation to describe the purposeful actions of practitioners to bring together incompatible medical and cultural objects. The existing literature on enaction overlooks notions of vulnerability and stigma, consolidation attempts to account for how practitioners incorporate much larger, much more hidden associations of stigma and vulnerability into a functioning clinic or strict antiretroviral regime. Consolidation therefore, is used as a way to conceptualise the cultural and ethical implications encountered in the clinic that an idea of enaction cannot attain with a strict focus on objects and actors.

I am not suggesting that the procedures or the vulnerabilities described pre-emanate the situations they are found in, or are essentially unchanged from one clinical scenario to another. Rather, that through the formalisation of these procedures into guidelines and protocols, and the fastidious application and reapplication of each procedure, in the clinic, they can be found to guide, consolidate and unify care. Therefore, if each procedure of disclosure, adherence, chronic illness and transition could be described separately as technologies applied at relevant moments in the clinic, they also form a logic together that works toward a common goal in the management of care (Berg, 1997a; Latimer et al., 2006). Together these formalised procedures coalesce as an assemblage to serve a number of

## Conclusion

functions to enable that many 'outside' cultural/everyday-life associations (such as stigma, vulnerability and naivety) remain compatible with the task of virus suppression with antiretroviral medicine. For example, these procedures bring patients into knowledge, sustain a shared knowledge between patients and professionals, give guidance to each party on how to proceed, consolidate care regimes, unify medical science with practice, make compatible/integrate care requirements alongside many other outside associations, and most importantly make viral suppression possible and ensure suppressions compatibility with wider medical and patient networks. To simplify and stress the sociological aspect, all of the discussed procedures do the task in the clinic of consolidating complexity into medicine by offering each relevant party involved in HIV care with a way to proceed, and sets out a list of responsibilities that each group is tasked with upholding towards the goal of viral suppression. I do not wish to suggest that this list of functions is exhaustive, or to even say it is necessarily coherent and non-contradictory. The use of each of the procedures separately or in combination opens up a range of possibilities for managing care regimes and populations, whilst ensuring that viral suppression is to be dynamically worked towards. What is emphasised in contrast to object politics is not the simultaneous enaction of actors across multiple sites, but the sustained consolidation of possible complexities (often contradictory and dangerous if mismanaged) through procedures performed in the clinic (see the section of the literature review on object politics de Laet and Mol, 2000; Law and Singleton, 2000; Mol, 2002; Mol and Law, 2004). Each group involved must interpret, perform and maintain these procedures in order to make them functional, and so are dependent upon the scenario they are *enacted* within. The integrity and therefore purpose of the procedure changes in accordance to the clinical encounter and interpretation of protocol.

Accordingly, each procedure can be seen to combine and overlap in various ways. Disclosure brings child patients into knowledge of their HIV. The clinic begins to deal with patients from the assumption that they are in a state of innocence and need to be brought into knowledge of their HIV, and encouraged to take on responsibility for its management. The formalisation of this goal is done in the clinic and across protocol in the procedure of disclosure. Disclosure brings patients and professionals together with the aim of creating a

shared knowledge that lays out each party's responsibilities. Professionals must facilitate and build a common knowledge with patients, and patients must endeavour to internalise and comprehend what is required of them from the medicine (Committee on Pediatric AIDS, 1999b). According to this feature therefore, disclosure can be seen to unify and consolidate the medicine between the different groups necessary, from the knowledge that is discussed within the medical science around antiretroviral drugs, through the guidelines surrounding medical practice and to the knowledge prominent amongst children. Disclosure makes an attempt to unify all three branches with a common knowledge. At disclosure's boundaries, it comes into contact and links with the other procedures outlined in the logic introduced at the start of this conclusion. Within the attempt to disclose and introduce children into knowledge about their HIV, adherence is heavily stressed (Santamaria et al., 2011). Within the first sessions of disclosure, children are educated using age specific explanations about how antiretroviral medicine interacts with HIV and the immune-system. This installs comprehension amongst children from a young and impressionable age that it is of the utmost importance to adhere to their medicine. Furthermore, professionals anticipate that this knowledge that disclosure installs will be built upon and result in children becoming responsible and diligent adults. Therefore, disclosure is relevant to both how HIV is perceived as a chronic illness and the later aims of transition, doing the utmost to commence a smooth and integrated style of care management.

Adherence does the job of communicating the absolute importance of following drug requirements as close to 100% as possible. Child patients, professionals and guidelines are coordinated through negotiations of adherence in the clinic which formulate the specific tasks and responsibilities each individual must uphold. Adherence persuades children and parents to take medicine with the promise of the virus remaining dormant and otherwise 'invisible' (Gibb et al., 2003). To practitioners, formalised adherence allows them to make very clear demonstrations on what must be done to explain to patients the consequences of not adhering, to make assessments as to whether requirements have been met and, if necessary, offer possible solutions and recommendations to ensure the smooth continuation of care (this could be associated with the notion of shared knowledge in disclosure from chapter 4). To biomedicine, adherence offers an absolute measure of



requirements and allows the biochemist the opportunity of stating what dose of which isolated chemical will suppress the virus or not. Over all of these versions and purposes of adherence the overall justification presented to each party becomes the continued possibility of virus suppression and the avoidance of resistance (Merzel et al., 2008). Therefore, the accounts of adherence demonstrated in this thesis are not entirely coherent amongst different branches of medicine and patients, but it is possible to see the clear link between how these versions of adherence are coordinated between each other. Adherence unifies children, HIV, practice, guidelines and antiretroviral medicine in the task of viral suppression. Adherence is also one and the same time at the heart of all the other procedures described here. In the performance of disclosure, adherence is often the underlying or embedded message that allows practitioners to make claims about the promise of care, and for patients to have faith that their HIV will be managed in a chronic state into the future. It is also the pressing concern during transition to make the passing over of services, medical records, antiretroviral history and management of adolescence to have as little consequence as possible on a patient's continued adherence to antiretroviral medicine. Therefore, compared to the other procedures in this logic adherence is non-negotiable. In relation to disclosure and transition the application of adherence and stipulation for patients to adhere is usually the primary requirement.

Placing chronic illness alongside these other well-documented procedures may make it seem like the odd one out compared to the other three described, as it is not clearly defined as a procedure or distinct in protocol. However, from the evidence presented in chapter 7, chronic illness clearly lines up in the clinical management of paediatric HIV and has clear applications in the clinic in similar ways to disclosure, adherence and transition. In the practice of HIV care and in the literature, one bold statement often comes up over and over again, that 'HIV can now be thought of as a chronic illness' (CHIVA, 2011a). Therefore, in the clinical management of paediatric HIV, chronic illness has a definition, a set of connotations and as I have argued, a usage and purpose that becomes apparent through the process of describing HIV as chronic to children routinely over similar contexts – as would a procedure. Following through these uses of chronic illness highlights it as being relayed to patients by inviting them to place their faith in the medicine to keep HIV invisible over their entire life

course, unlimited by HIV. For practitioners, the use of chronic illness as a procedure serves a further purpose to enable them to take on large scale views of the medicine and allow practitioners to organise care and resources into projected futures. It is in this way that the role that chronic illness plays in consolidating and organising medicine together now and into the future can be seen (also see Williams, 1984). Chronic illness allows practitioners and patients to imagine a future where 'normal' life is possible and only slightly affected by medicine, and allows practitioners to imagine potential pitfalls and solutions before they arise. From this point of view chronic illness can be aligned within the demonstrated clinical logic of HIV care. Chronic illness puts into perspective the task of adherence and reinstates why it is of the utmost importance to ensure that antiretrovirals are followed 100% (also without this perspective adherence would possibly seem unassailably grim to patients). In addition, the task of disclosure is altered through considerations of chronic illness towards the deliberation that knowledge must be installed correctly to children and built upon over their entire life time. Moreover, within transition, chronic illness is present when imagining the past, present and future of a case and how it must be subsequently managed effectively in order to make patients responsible adults capable of managing their own care requirements. Therefore, from this view the unifying and consolidating obligation that the implementation of chronic illness has on paediatric HIV cannot be understated.

Finally in terms of the procedures outlined in this thesis, transition aims to bring together paediatric HIV services with general adult HIV services and so complete the patients' time as a 'child' and hand over a responsible, knowledgeable and diligent self-adhering adult (Fair et al., 2011). This is not always as straightforward as it seems however, as concepts of childhood and development concealed in the medicine do not always meet with the actual case at hand in the clinic. Transition is formalised in protocol and practice to resolve incompatibilities between services, and does so by treading the line between childhood, adulthood and adolescence. Transition in this context has two purposes: firstly to make adolescent patients take on a more individual and responsible approach to their own healthcare, and secondly to make sure that practitioners over the two services are aligned and coordinated to tailor care to individuals and ensure that care is continued seamlessly (Viner, 1999). Between these two bodies of medicine however, the adolescent patient has

## *Conclusion*

their own specific requirements that are important to acknowledge and manage within transition. Therefore, as with the other procedures, transition plays a vital part in consolidating medicine and allowing paediatrics to maintain its specialism towards children whilst keeping antiretroviral regimes operational and adhered to (White et al., 2012). Transition combines with the procedure of disclosure by converting the knowledge imparted to children at a young age to that required by a responsible, antiretroviral-adhering adult. Transition also ensures that adherence is still the inalienable goal that will be followed and upheld during the change of services. It allows a smooth continuous management of care that will be made available to chronic illness to provide an overview between practitioner and patient as to how care will unfold once they are in, and continue to receive adult care throughout their life time.

When assembled together, the procedures described in each chapter combine and overlap together in the practice and protocol of HIV medicine. The importance of this clinical logic to make medical requirements compatible with patient complexity is exemplified by the cultural sensitivity required in paediatric HIV. Through the presentation of research data it can be reasoned that there is a clinical logic guiding the formalised procedures at work in paediatric HIV medicine that shapes the administration of care. The descriptions above of procedures of consolidation and unification are not fixed however, but dynamic and also have the potential to breakdown. If each of the procedures of care are to be maintained, they must be reinstated over and again in the clinic, in protocol, over the hospital/laboratory and in the patients' homes (Latour, 1987). This gives these entities the possibility to be superseded, ignored or forgotten. It is precisely the task of those engaging in medicine to reinstate the dynamics of care over and again and formalise them into a regulated and stable protocol and practice. I argue that this is done in part through the procedures in the clinic that I have detailed above. I do not wish to argue that there is a set way in which these procedures must work or that the way in which these procedures are practiced must always follow a set pattern. The attentiveness required in the clinic for paediatric HIV highlights that it is precisely the strength of these procedures that they are adaptable, interpreted and applicable in multiple ways that ensure their effectiveness, usefulness and relevance. Entities can be combined together in ways unforeseen, and even

contradictory to the encounters described above in the ultimate pursuit of caring for those with HIV and viral suppression. The account given here is one that aims to demonstrate the dynamics that were observed and were deemed to be repetitively practiced and necessary to maintain and consolidate medicine and patients into paediatric HIV care practices (Dodier, 1998; Latimer et al., 2006; Timmermans S and Buchbinder M, 2010, 2012).

If, as stated earlier, these procedures work as part of a logic that must be constantly re-applied in a constructive and effective way to a range of adverse situations, paediatric HIV highlights the strength of the approach adopted at the clinic in practice and over the negotiations of protocol. It also reveals the 'clinic' and 'consultation' as prime technologies (especially in reference to the object politics/turn to enaction detailed in the literature review). What has often remained implicit throughout these chapters is that it is in the consultation room that the procedures of disclosure, adherence, chronic illness and transition intersect. The clinic becomes the crucible where all activities are mutually forged and centralised: through the organisation of patients attending at regular intervals, the routine taking of blood tests, administration of antiretrovirals/blood tests, routine measurements of development, discussions with patients, discussions amongst professionals, negotiations of protocol, even as the base for the CNS to carry out her community work. The list could go on as the clinic has no fully defined inventory of what its responsibilities are, it is open to the possibilities of what will be required for ongoing care (also see Dodier, 1998). I began this thesis with an analogy of how the space of the clinic necessarily moulds itself around circumstance. In the case of paediatric HIV, this process of 'moulding' seems especially exemplified. Symbolically, the research took place at a time when the old ward at UOUH was being demolished and the clinic was being relocated in a new building. The space of the clinic in the context of paediatric HIV is difficult to define, it is an ongoing process of consolidation and unification between disparate corporealities<sup>116</sup>. Within the clinic, the encounters and categorisations of paediatric HIV necessitates the formalisation of procedures such as disclosure, adherence, chronic illness and transition into

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<sup>116</sup> Mol (2002) would use the word ontologies (in the plural), the term corporealities is useful here however as it offers an interesting contrast between spirituality, essence or immateriality. We could argue that the clinic is in the process of making that which is spiritual, essential or immaterial into something tangible to which scientific medicine can be applied to.

## *Conclusion*

protocol. These formal procedures become developed and enacted through the presentation of patients over regular periods and the desire of professionals to standardise care to ensure maximum effectiveness. It is within the clinic and through regular consultations that the need for these procedures becomes salient. The formalisation of procedure can be rooted in practice and the continued relevance, applicability and unification of procedures that go towards maintaining 'useful' and 'functional' medicine (Berg, 1997a, 1997b; Timmermans and Berg, 1997, 2003).

By continuing to look retrospectively at research data, the medical forums such as CHIVA and PENTA can also hold their own versions of the procedures described here that are negotiated in the clinic. Through these forums an agency is formed and mutually constituted between what goes on at the clinic, and the impact that the recommendations, guidelines and protocol that these forums present to practice. Over these forums the clinic is brought into dialogue with other clinics and with the laboratory. Therefore, guidelines do not dictate practice. The clinic and the forum also overlap and must be maintained side by side in the formalisation and consolidation of care practices. Patients are not isolated from these discussions or practices, they actively participate in clinical practice and inform the formalisation of procedure into protocol. As stated above the negotiation between the clinic, the forum and formalised procedure is directly linked to the effectiveness of the ensuing procedures described in this thesis. The interaction between patients, the clinical management of paediatric HIV and what goes on within these paediatric HIV forums ensures that care regimes and formalised procedures can be maintained as functional networks (to use the terminology of ANT, Latour, 1987).

The use of STS combined with the clinical context presented, has perpetuated a central question throughout the thesis around how medical science is made compatible with the complex populations of children presented in practice. Stengers (2003, also see 2010, 2000) argues that the formation of medical science in the clinic must operate around the suffering body of the patient which is not able to give a reliable testimony in comparison to the objects under investigation in the natural sciences. Stengers (2003) contends that this results in the recurrent question of whether or not medical practitioners are treading the

line of the scientist or the charlatan. Stengers' analogy is useful to highlight the question of how clinical practices are ordered to negotiate the requirements of antiretroviral medicine with patient complexities as chaotic as those in paediatric HIV (or as poison or remedy as she terms it in relation to Plato's pharmakon Stengers, 2010). To Stengers' (2003) account, the question could be posed of how does one make the body of a child provide objective medical testimony. Especially in the context as has been described here of vulnerability, innocence, naivety, ethnicity, stigma and inner city life. This has been of high concern to the research chapters. Analysis can begin to contemplate the procedures and 'logic' described above for their ability to render objects compatible with scientific method. Disclosure makes bodies aware of knowledge and behaviour that will allow patients to partake in care. Adherence makes bodies conform to medical regimes. Chronic illness makes bodies contextualise and install faith in medical science. Transition makes bodies responsible for their own care. These attempts to render children as scientifically observable should not be read as a forceful imposition of power and knowledge on to child bodies but a relationship that is fostered and developed together with the aid of patients, practitioners, protocol and the laboratory. I would like to add a note of caution however with the interpretation of the rendering of children as scientific testifiers. From the consultations I observed, in many situations in the clinic, practitioners in one way or another, were only too aware of the contingency of procedures, and I hope this is obvious when reading my presentation of disclosure, adherence or transition. It is of the utmost importance to clinical staff and the writers of protocols to make these formalised procedures as flexible and applicable to patients (in this case the lives of inner city children and adolescents) as possible. Even if adherence, for example, is ultimately non-negotiable, if it is to be successful in a condition as complex as paediatric HIV, practitioners must go beyond questions of scientific method in the clinical practice of medicine. Scientific method must be made applicable to patients' lives. The clinic is the key site where complexity must be consolidated and regimes made compatible. Therefore, as has been demonstrated in research chapters, disclosure, adherence and transition must be set up to make the science of antiretroviral medicine flexible and malleable to patients' lives. Through concepts such as 'good care', the overall case outcome, the wishes of patients and 'quality of life' become clinical aims that supersede the priorities of pure scientific method. Therefore, these questions and

## *Conclusion*

considerations of rendering bodies as scientifically observable are never isolated from clinical practice and good care (Mol, 2008).

In accordance with the sensitive matter of research, this thesis has chosen to allay a representation of power as imposed from an imagined scientific hierarchy, to the clinic, then onto patients, in favour of focusing upon the ways in which the agency of all clinical actors have the ability to enact an influence multi-directionally, mutually and contradictorily. In STS this argument is implied in the conception of enactment. According to enactment power does not exist ulterior to a clinical negotiation, but must be enacted and re-enacted each time authority is implied. This means that clinical authority must be successively re-negotiated in the clinic between patients, practitioners and all other intervening agents. Even if this thesis has argued that enaction doesn't capture fully the vulnerability and stigma associated with the condition, it exposes the vulnerability and stigma of patients as having an influence on the ways in which paediatric HIV medicine must be practiced. For example, when a child patient is being practiced upon in the clinic, the agency of the child has an implication for the ways in which medicine must be practiced upon the child and the responsibilities that the practitioner must uphold in the consultation room. This diversifies the ways in which power is viewed and prohibits a simplified model of power as exercised from medical authority down to patients.

Throughout this thesis, analysis has used STS to present antagonisms between scientific method, clinical practice/protocol of paediatric HIV and the child patient. In the process, the incompatibilities of STS with paediatric HIV and the differing significances that the change of focus to paediatric HIV brings about have also been highlighted (see the literature review, especially 'object politics' Mol and Law, 2004). For example, the idea of 'translation' or 'enaction' is complicated by the breadth and immediacy of associations that the child cohort presents in the clinic at UOUH. Associations presented included childhood, adolescence, immigration, stigma, sex, public health, confidentiality, mortality, innocence, vulnerability, naivety and lack of competence (Christensen, 1998; Cohen et al., 1999). These associations emphasise the clinic as a key site to consolidate medical and cultural complexity over other STS accounts of disease and the clinic such as hypoglycaemia and

## *Conclusion*

atherosclerosis. This is in contrast to STS accounts such as Mol (2002) and Mol and Law (2004) which focus on dispersal of disease across multiple enactions and localities. The clinical encounters of paediatric HIV highlight the need for practice to develop specialised and attuned attention that remains flexible and adaptable to diverse individual cases. Paediatric HIV also highlights the immediate need for the employment of a logic at the clinic that manages patient complexity with medical requirement in order to ensure that suppression is successful. Therefore, compared to Mol's (2002) account of clinic practice where the focus is on how multiple versions of the disease and medicine are momentarily 'tamed' this thesis emphasises the sustained consolidation of a much wider notion of cultural, patient and medical complexity into clinical practice. Although the enactions taking place during practice can be seen to refer to wider associations beyond the clinic, what is emphasised is the cultural awareness required by the clinic to consolidate complexity into functional medicine. In a similar way, the notion of time or sequential ordering confuses translation/enaction in considerations of chronic illness. Translation over the life-span of an individual requires a consolidation and coordination of factors that must be done in accordance to a desired outcome in the future, relevant to a course of action in the present that will ensure that the virus is suppressed and other intervening factors in the case remain possible to manage. Life-course brings into question humanity, essentiality and the meaning of life. When engaging in practice, practitioners must act with the proviso that what is decided will make ongoing clinical management possible in the future. It points again to the attentiveness employed by the clinic to consolidate future and present complexities to the task of virus suppression. Neither of these considerations about the child or life-span fully negates the concept of translation but offer points with which to think more specifically about how it relates to the underlying context of paediatric HIV and sensitive care management.

Within STS or ANT there is a concerted attempt to systematically evade providing a normative statement. Any normative statement dealt with in STS is usually explained in terms of the statement's association to the assemblage it is enacted into (Law, 2004b). However, associations collated under paediatric HIV are so ethically charged and seen as stigmatised or vulnerable that it is difficult to imagining them only through the associations



## *Conclusion*

found in the paediatric clinic. The subject of paediatric HIV used in this thesis contributes to ANT and STS through its focus on these sensitive and potentially sensationalistic associations. The stigma and vulnerability associated with paediatric HIV serves as an impetus in the clinic for action but their value cannot be fully explained in terms of an 'enacted object' and cannot be followed as other objects are followed. Clinical enactments of paediatric HIV seem to point to further forces that out lie any imprint of that which is enacted. With paediatric HIV there exists an ethical and normative value that is beyond rationalisation with ANT/STS. This thesis has made its contribution to these highly present ethical/moral issues, not by attempting to resolve them, but through pointing to their existence and the ways in which they must be confronted and consolidated by HIV services.

The resulting argument of this thesis is significant to social theory and for those who make policy or maintain practice. The contribution it provides demonstrates how paediatric HIV relates to the populations that develop, perpetuate and maintain care. In the face of the seeming overwhelming complexity of paediatric HIV, this thesis highlights the importance of a flexible approach in practice and the need for a high regard of clinical practice in the policy making processes. It is hoped that the discussions found here emphasise to potential readers (possibly practitioners and patients) the importance of finding common ground, negotiation, flexibility and compatibility in the way those involved with the condition interact and partake in the medicine. In comparison to the prevailing sociological literature on medicine, there is a rejection in this thesis of the idea that medicine takes a solitary role in defining 'normality' and imposing it onto patients with a requisite power structure. These power structures seem to be a central assertion of Foucault through to social constructionism. Although analyses of this kind have played a central role in developing thinking around clinical practice and biomedicine in balancing out and questioning the morality of practice, I believe that the time has possibly come to readdress that balance. Therefore, the focus of this thesis has been on clinical negotiation and the multi-directionality of power when interpreting of medical doctrine. Through the use of ANT it has been possible to offer a basis to readdress clinical practice and protocol. However, paediatric HIV, practice and protocol are too complex and sensitive to be simply described as 'enacted'. It also becomes important to ask what formalised enactments of practice such

## *Conclusion*

as disclosure and adherence are encompassing moralistically in terms of vulnerability and stigma. The central strand of this thesis therefore, is not to primarily approach paediatric HIV care from the view that it must be managed, but rather that it must be made possible through consolidation, highlighting the importance of participation and the ways that practice and protocol is negotiated between clinical, medical and patient encounters.

Therefore, this thesis and the notion of consolidation will be useful to readers looking to develop an account of vulnerability, stigma and ethically sensitive topics using STS and ANT. In foresight, this project has hopefully contributed to the objective of promoting a more nuanced approach, the key role of the clinic and the indispensability of what happens there to those who must think regularly about the relationship between medicine, society and complex entities such as childhood and HIV.

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## Appendix 1.1

Information sheet for adolescent participants (ages 11 - 18)



**Title of Project:** Children living with HIV

**Contact:** Richard Boulton, PhD student at Goldsmiths University of London

**Email:** ~~Removed~~ **Tel:** ~~Removed~~

**Opening statement:** I want to tell you about a research study I am doing. A research study is a special way to find out about something. I am trying to find out more about how young people with HIV live their lives when taking medication going to the doctor a lot. I would like you to tell me how you live your life and what is important to you. If you talk to me, I can understand better how you live your life with the medicines you take and the care you receive.

**Why am I being asked to take part?** I am asking you to take part because you are a young person living with HIV. There isn't much information about children who have HIV, so the information you choose to give to me will be very useful. Your doctor passed you on to me but I haven't read anything about you that your doctor or the nurses have previously written about you.

**What will I be required to do?** This is what will happen if you are in this study: I will sit in on some sessions that you have with the doctor, recording and taking notes on what happens but not saying anything. Later on, I will also interview you and ask you some questions about yourself. It may sound a bit scary but it isn't really, it will be more like a chat than anything else. The questions I will ask you will be very simple and easy to answer. It won't be like a test more like a conversation, and you can choose not to answer any questions that you don't want to. Our conversation may last about 40 minutes, but you can stop at any time you want to. I will also send a letter out to your GP to tell

## **Appendix 1.1**

them that you will be involved in this study, it will not affect the treatment you get in anyway, and your doctor won't be able to see anything you say to me.

**Where will this take place?** All of this study will take place in the clinic at North Middlesex University Hospital.

**How often will I have to take part, and for how long?** I would like to sit in on around three of the meetings you have with your doctor, and have one interview with you of about 40 minutes. All this will take place over the next year or so.

**When will I have the opportunity to discuss my participation?** Your parents or guardians have to say it's OK for you to be in the study. After they decide, you get to choose if you want to do it too. If you don't want to be in the study, no one will be mad at you. If you want to be in the study now and change your mind later, that's OK. You can stop at any time. My contact details are on this form in case you want to discuss anything about the study. Once I have finished interviewing and sitting in on consultations and I have looked over all of the notes and recordings I have taken, a newsletter will be sent out to everyone who has participated in the study with the results of my work. If you have any comments you would like to add or discuss, you will have the opportunity to do so.

**Who will be responsible for all of the information when this study is over?** No one else will look at my notes or listen to the recordings of you. I will store it on a secure at university where nobody else will be able to look at them. I will put things I learn about you together with things I learn about other teens, so no one can tell what things came from you. When I tell other people about my research, I will not use your name, so no one can tell who I am talking about.

**What will happen to the information when this study is over?** Once the study is over, I will destroy all of the information that could identify you. Any



## **Appendix 1.1**

information that I will keep will not have your name your address or anything else that will make it possible to see who you are.

**How will you use what you find out?** The information that you give to me will be used to make a report, or a book, about young people living with HIV.

**How long is the whole study likely to last?** The study will last for about 3 years

**What if I do not wish to take part?** Participation is totally voluntary

**What if I change my mind during the study?** You are free to withdraw from the study at anytime

**Do you have any other questions?** The details of who to contact if you have any questions or concerns are on this sheet.

### **Summary**

- I would like you to take part in some social research to understand better how you live your life.
- You are being asked if I can sit in on 3 of your consultations, not saying anything.
- I would like to interview you, which will be more like a chat with no right or wrong answers for about 40 minutes.
- I will record what you say and take notes but the information you give to me will have your name taken off it so nobody can tell that it's you.
- Nobody else will hear the recording of what you say to me or the notes that I take.
- I will write some articles with the things that you say to me, but no one will be able to tell if it's you from anything I put down in an article.
- You don't have to say yes or answer any questions if you don't want to.

## Appendix 1.2

### Information sheet for Parents of Children with HIV

**Title of Project:** Children living with HIV

**Contact:** Richard Boulton , PhD student at Goldsmiths University of London

**Email:** ~~Removed~~      **Tel:** ~~Removed~~

**Goldsmiths**  
UNIVERSITY OF LONDON

**Opening statement:** I am a Sociologist from Goldsmiths University, and I am conducting a study that aims to find out how young people with HIV carry out their lives whilst having to take medication or organise their time around going to appointments. I would like your child to tell me how they live their life and what is important to them. If either you or your child choose to talk to me, I will be able to understand more fully how your child lives their life alongside the medicine and care they receive. The things that you and other families taking part will say to me will be used to make a book or an article. This will help sociologists and the doctors who care for your child and other young people living with HIV to be more familiar with the issues they face.

**Why am I being asked to take part?** I am asking you and your child to take part because they are a young person living with HIV. There isn't much information that exists on illness and childhood or children and HIV, so by talking to me your child will help people to understand these subjects better. Your child's doctor at North Middlesex has passed you on to me but I have not seen the medical records of either you or your child.

**What will I be required to do?** If you decide to take part in the study I will sit in on some sessions that you and your child have with the doctor, recording and taking notes on what happens but won't say anything.

If your child is older than 12 then I will ask if they would like to be interviewed in private, on questions about themselves, their HIV and their day-to-day life. Our conversation may last about 40 minutes, but they can stop at any time that they want to.

You, as a parent, will also be asked if you would like to be interviewed separately from your child, where you will be asked question about your child's day-to-day life and problems they have. This interview may last up to 30 mins. You can choose not to answer any questions that you don't want to. This interview will be voluntary and you may choose not to take part even if your child does take part.

**Where will this take place?** All of this study will take place in the clinic at North Middlesex University Hospital.

**How often will I have to take part, and for how long?** I would like to sit in on the meetings you and your child have with your doctor, and if applicable, have one interview with your child of about 40 minutes, and one with you lasting up to 30 mins. All this will take place over the next year or so.

**When will I have the opportunity to discuss my participation?** If at any time during the study, you wish to pull out or choose not to take part in something you can do so, my contact details are on this form in case you want to discuss anything about the study. Once I have finished interviewing and

## Appendix 1.2

sitting in on consultations and I have looked over all of the notes and recordings I have taken, a newsletter will be sent out to everyone who has participated in the study with the results of my work. If you have any comments you would like to add or discuss, you will have the opportunity to do so.

**Who will be responsible for all of the information when this study is over?** No one else will look at my notes or listen to the recordings taken, your identities will remain confidential. I will put data on a secure university hard drive where nobody else will be able to look at them. If I use any of the notes or recordings in anything I write, I will make what you said anonymous. This means that I will make sure that nobody will be able to know what you or your child said.

**What will happen to the information when this study is over?** Once the study is over, I will destroy all of the information that could identify you. Any information that I will keep will not have your name your address or anything else that will make it possible to see who you are.

**How will you use what you find out?** The information that is gathered will be used to compile a report on what is found, a group of articles and possibly a book.

**How long is the whole study likely to last?** The study will last for about 3 years

**What if I do not wish to take part?** Participation is voluntary

**What if I change my mind during the study?** You are free to withdraw from the study at anytime

**Do you have any other questions?** The details of who to contact if you have any questions concerns are on this sheet.

### Summary

- I would like your child to take part in some social research to understand the issues they face.
- You are being asked if I can sit in on your consultations not saying anything.
- I would like to interview you but more importantly, if applicable, your child, for about 40 minutes.
- I will record what you and your child says and take notes but the information you give to me will have your name taken off it so nobody can tell that it's you.
- Nobody else will hear the recording of what you say to me or the notes that I take.
- I will write some articles with the things that you say to me, but no one will be able to tell if it's you from anything I put down in an article.
- You don't have to say yes or answer any questions if you don't want to.

**Appendix 1.3**

**ADOLECENT ASSENT FORM**



**Full title of Project:** Children Living with HIV: negotiating the everyday

**Principal Investigator:** Richard Boulton, PhD student at Goldsmiths University of London

**Email:** ~~Removed~~ **Tel:** ~~Removed~~

**Agreement**

I have read and understood the information sheet.

I have decided to be in the study even though I know that I don't have to do it.

Richard Boulton has answered all my questions.

\_\_\_\_\_  
Signature of Study Participant

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature of Researcher

\_\_\_\_\_  
Date

