"The Importance of Information: the HIFA2015 campaign and South Africa"

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Abstract

This dissertation will explore the emphasis of information as a key health resource in the Information age. Health information campaign HIFA2015 will be the case study, South Africa will be the country focus, and Lalonde's (1974) health field concept will be the framework in the analysis, with reference to wider concepts such as, globalisation, information poverty and the digital divide. It will use an interpretivist model and qualitative methods will be used to collect data.

<u>Acknowledgements</u>

<u>Introduction</u>

Poverty is not a new phenomenon; it is defined as the disparities in necessary human needs. For example, adequate, safe shelter to live in, food, clean water, healthcare, education and sanitation. Poverty is present in all countries. However, it is the Third World, the underdeveloped and developing countries, that this universal condition is most prevalent and most intense. They are without fundamental capital to improve their human needs. The majority of people in the developing world live in complete poverty, and this contributes to profound forms of social exclusion. Poverty and social exclusion are interconnected; those who live in poverty generally also experience social exclusion.

The technological revolution, resulting from the first industrial revolution and beginning as early as the 18th Century, has transformed society through innovative progress in, for example, technology, manufacturing and science. One of the most significant characteristics of the revolution is the accelerated growth of information and communication technologies (ICTs), in particular the Internet, connecting millions of people worldwide. It is often argued we have entered a new age, defined by this transformation in ICTs, known as the 'Information Age'. It has been asserted that ICTs offer the possibility of ridding the world of its suffering and poverty (Shirky, 2009). However, it is frequently debated that lack of access to such ICTs especially for people and whole countries already heavily poverty stricken, in fact further puts them at a disadvantage. "Technology per se does not solve social problems. But the availability and use of information and communication technologies are a pre-requisite for economic and social development in our world." (Castells, 1999: 3)

Therefore, it is arguable that the technological revolution has created another type of poverty, defined by this lack of access. Not only is the developing world the victim of conventional poverty but also the victim of 'information poverty' (Norris, 2001). For example, they have inadequate access to healthcare. But now as a result of the Information Age, lack of access to ICTs equates to lack of access to health *'information'*. This puts them in further destitution. They are unable to receive the necessary health information to better their health systems, which would contribute to improving their poverty levels and as described by the United Nations Development Programme (2011) overall improve human development. Therefore, this lack of information exemplifies a key form of inequality in the Information Age. The UNDP state that- "Human development is about people, about expanding their choices to lead lives they value." (2002: 13) Without adequate information, informed choice is

impossible.

The 'have' and 'have-nots' are characterised in this current digitalized, technology fuelled era as those who are connected to ICTs and those who are not. This concept is known as the digital divide. The gap needs to be bridged, otherwise, as technological innovation continues, whole countries, societies and people excluded will be left behind with the possibility of never catching up. Globalisation and the Information Age are bringing the world together but a large proportion of the world's population are excluded. Unless these issues are properly addressed, poverty and suffering will continue to segregate the disconnected.

The research will include a case study of global campaign HIFA2015, Healthcare Information For All by 2015. The aim of the study will be to identify the necessity of such a campaign which is solely focused around equalising health information distribution. The case study of HIFA2015 will hope to open up questions about the double-sided process of globalisation, the emphasis of information as a key resource, and the role the digital divide plays in hindering access. Therefore, information on its own simply cannot be enough; there are other crucial interlinked factors such as infrastructure and content which need to be considered. Information requires a range of other factors to be in place before it can be used efficiently. It needs to be thought about in different contexts because it has many meanings. Firstly, it is a possible medical resource (Lalonde, 1974), and contains accurate procedural information, something that needs to be used in order to displace traditional practices in local 'knowledges'. Secondly, it is something that needs to be adequately disseminated through reliable infrastructures. Thirdly, it needs to be thought of in terms of its content and made specific to local needs; information differs from user to user. Lastly, information is also something needed by the campaign itself to monitor progress and effectiveness through feedback, etc. This is because modernity is a reflexive process, it is constantly reviewing itself, this is known as 'reflexive modernity' (Giddens, 1990). Therefore, health information needs to be looked at outside of just a medical context to fully understand its purpose, for example within a sociology health model.

The work of credible theorists in this field will be explored, for example, Manuel Castells, an influential sociologist who has made a significant contribution to our understanding of issues surrounding the Information Society, the Network Society, globalisation and the power of communication. The work of Pippa Norris will also be considered; her writings are centred on the digital divide and the implications of this concept. The publications provided by

UNDP, especially the Human Development Report will also be useful in this research.

This project will be submitted to the campaign to help HIFA2015 build evidence on health information needs, through their expanding 'knowledge base'. This has been agreed with the campaign Co-ordinator, Dr Neil Pakenham-Walsh. Therefore, the wider aim of the study is a contribution to the research of the campaign, especially in the submission of the literature review, focusing on the analysis of key work on the Information age and the digital divide. HIFA2015 will benefit from this research, but more importantly so will those in the developing world for whom HIFA2015 is intended to benefit. Because the more the issue is recognised and made a focus of advocacy, the closer we will get to narrowing information gaps and improve the quality of life for the world's poorest people. The distribution of information is something that is often taken for granted in developed societies. Therefore, this will be a part of an overall progression to help bring all disconnected people out of information segregation.

1.2 An Introduction to HIFA2015

HIFA2015 is a health information campaign. Information is the key word here. Rather than putting the emphasis entirely on global *health* for all, although this will ultimately benefit from the campaign and is significant in wider health development goals, the emphasis of HIFA2015 lies predominately in information, knowledge and communication. HIFA2015 is a contributing campaign to the "Millennium Development Goals". "Achievement of this goal [i.e. information] is critical to attain the Millennium Development goals: reducing child mortality by two-thirds; reducing maternal mortality by three-quarters; and combating HIV/AIDS, tuberculosis and malaria." (HIFA2015, 2008: 1) However, health information is unequally distributed. Addressing these inequalities could contribute significantly to resolving bigger global development issues.

In the words of HIFA2015: "By 2015, every person worldwide will have access to an informed healthcare provider. People will no longer be dying for lack of knowledge." (HIFA2015.org, 2011) The discourse used here is striking. HIFA2015 are highlighting the importance of information to save lives. The juxtaposition between death and knowledge signifies the consequence of this problem; people can die from something as intangible as missing or false information. Alongside attempting to solve the wider issues of health in developing countries, the gaps in information distribution need to be bridged.

HIFA2015 have over '4000 members and 1800 organisations in 157 countries worldwide' (HIFA2015.org, 2011). The members vary from doctors, health workers, social scientists, researchers, etc to those of the public with a general interest in achieving this goal (Ibid). The campaign is also linked to the goals of the 'Global Health Workforce Alliance'. They are working to improve the shortage of health workers, especially in lower income countries. "The critical shortage is recognised as one of the most fundamental constraints to achieving progress on health and reaching health and development goals." (Global Health Workforce Alliance, 2011) However, HIFA2015 not only argue that the gap in healthcare workers needs to be improved, but also that gaps in *health information* needed for healthcare workers to provide a better health service also and simultaneously need improvement. Indeed, the goal of health for all can only be met if information is freely and readily available for all. HIFA2015 highlight that thousands die daily from treatable causes. It can then be argued that the biggest cause of death in the developing world is the lack of basic, essential knowledge needed to stop rising mortality rates. This is essentially why the campaign is needed and how it discursively justifies itself in terms of its focus.

HIFA2015 has a partner campaign CHILD2015, with similar aims. Their goal is for 'every child worldwide to also have access to an *informed* healthcare provider by 2015'. HIFA2015 recognise the need for such a campaign in the current global circumstances and acknowledge that the use of ICTs can enhance wellbeing in many ways- in this instance by focusing on the way that information reaches healthcare providers and by focusing on the serious issues which mean this is not always the case.

> "We live in the 'information age' but the reality is that most healthcare providers continue to lack the information they need to deliver basic health care. Indeed, there is little evidence that the majority of caregivers and health workers at primary and district levels are any better informed than they were 10 years ago. This lack of progress is directly attributable to ineffective coordination and communication among the many stakeholder groups involved at international, national and local levels, resulting in duplication and waste of effort and resources. As a result loss of life and suffering continue unabated, jeopardising the achievement of the Millennium Development Goals." (HIFA2015, 2008: 2)

HIFA2015 define their goal by using the criteria from the framework 'S M A R T': specific,

measurable, agreed-upon, realistic, and time-bound. Their goal therefore reflects this framework (Ibid). HIFA2015 state their definition of a healthcare provider is used in a broad sense; all providers of healthcare are included in the definition. Rather than creating restrictions by only focusing on 'formal healthcare workers', the definition extends from professionals in hospitals to local community health centres. "The term is not absolute: what is needed will vary depending on the carer, the person receiving care, and the situation. The bottom line is that the person who requires health care is not put at risk simply because of lack of appropriate life-saving information." (HIFA2015, 2008: 3) Therefore, this will decrease the chances of "dying of lack of information" and work towards amending information poverty.

<u>Methodology</u>

Contemporary society is saturated with global campaigns with a wide range of motives, aims/ goals and structures. Predominately most campaigns are implemented to help raise money, give aid and support to those in desperate need worldwide, most with a specific demographic. So why study HIFA2015? HIFA2015 is highly relevant when considered within a specific contemporary context; it fits into broader issues surrounding ideas about globalisation and the emergence of what Castells terms the 'Information age' (Castells, 1997). HIFA2015 is of particular interest as it is focused on disparities in access, which is a core problem for theories of the digital divide. To narrow the research focus further, it was necessary to choose a specific developing country. Although HIFA2015 aim to equalise health information for all, for this purpose, South Africa will be used to particularize the research. This helped to assess the relationship between HIFA2015 and South Africa and to place HIFA2015's overall emphasis on health information within a specific context.

'Inductive reasoning' was the framework for the research; it follows the 'bottom up' approach. It begins with specific observations and findings, theory is then applied to the results leading to general arguments and then a conclusion. By using this framework it allows the research to be more exploratory and flexible, as opposed to 'deductive reasoning' which aims to achieve specific conclusions led by a particular tried and tested hypothesis. Therefore, the research is not testing a distinct hypothesis but instead the emphasis will be placed on 'understanding' and 'empathy' for examining the chosen organisation and its context.

The research will be representative of an Interpretivist model, also known as antipositivism or post-positivism. This approach is characterised by using predominately qualitative research methods, opposing that of positivism which is centred on quantitative methods. The research will incorporate a "Verstehen" perspective, a term coined by German sociologist Max Weber (1864-1920). "Verstehen" is a German term meaning "understanding", or "comprehension". However, in late-nineteenth-century German academic circles it came to be associated with the view that social phenomena have to be understood "from within". This approach to social inquiry tended to be qualitative rather than quantitative and was opposed by positivists who stressed external, experimental, and quantitative knowledge." (Martin, 2000: 2) The Verstehen perspective will be used on the interview data collected from professionals/ members of the campaign in order to adequately consider how they think and feel about the

project, exploring them from 'within' and by analysing their own frames of reference. It will help understand perceptions about healthcare and its relationship with information/ knowledge, personal development and the meanings and values of the campaign in a local context. Therefore, a qualitative approach was felt to be more useful as it will focus on the value-laden discourses and the meanings that professionals within the organisation ascribe to their practice. This form of research usually accumulates subjective results from participants and 'Micro' samples are used; small scale research, a small sample in society used to achieve richer qualitative results. This is opposite to 'Macro' samples, which is large scale research, looking at larger samples in society which is therefore more useful in compiling quantitative results. The qualitative approach allows for the results to be evaluated in more depth.

The study is composed of a mixture of primary and secondary research. The secondary research includes, for example, exploring the theories of sociologists and anthropologists found in a variety of books, journals, articles etc. These theories will provide guidance, they are crucial in the evaluation of the findings as having a framework to compare and contrast is critical in social research. Statistics from, for example, the MobileMonday report were also used. Statistics are a useful piece of secondary data, being able to quantify phenomena assists with putting a perspective on social theory. As a member of HIFA2015, access to the campaign's archives and publications become easily attainable.

The primary research includes a mix of methods. The campaign itself, the social context, and its function were considered using critical discourse analysis (CDA) of literature produced by the campaign and through the analysis of interview data. CDA is valuable in applying a social text to the wider context of any given society. Norman Fairclough (2003) argues that CDA is a type of critical social research, which he states is essential for improving the human condition.

> "Critical social research begins from questions such as these: how do existing societies provide people with the possibilities and resources for rich and fulfilling lives, how on the other hand do they deny people these possibilities and resources? What is it about existing societies that produces poverty, deprivation, misery, and insecurity in people's lives? What possibilities are there for social change which would reduce these problems and enhance the quality of the lives of human beings? The aim of critical social research is better understanding of how societies work and produce both beneficial and

detrimental effects, and of how the detrimental effects can be mitigated if not eliminated." (Fairclough, 2003: 202-203)

Interviews were the main research method used. The interviews were unstructured which allowed for more in-depth answers. The interviewees are the Co-ordinator of HIFA2015, Dr Neil Pakenham-Walsh and consultant paediatrician, Dr Edward Synge who is also a member of HIFA2015/ CHILD2015 (see appendix 4/ 5). A rapport was built beforehand with the interviewees because of previous meetings attended; this potentially provided more reliable, valid data. Deeper meaning can be probed from the answers given due to the nature of unstructured interviews; this also eliminates any chance of misunderstanding as all questions can be elaborated on if necessary. The discourse from the interviews will help to critically understand how HIFA2015 have responded to the digital divide, operate within and have become a part of the Information age, the position of South Africa, what challenges they face, and how they hope to implement their strategy.

Questionnaires were also used as a form of primary research. They were sent out via email to one hundred and ten South Africa representatives who are also HIFA2015 members. The questionnaires were sent to as many South Africa members whose details were available because questionnaires tend to have a low response rate. They were sent with the intention of finding out what the implications are for lack of health information for those in South Africa, how or if HIFA2015 are invoking changes, how or if progress is measured and their view on the progress of healthcare in South Africa (see appendix 2/ 3). In terms of analysis the questionnaires could be used to either support or contrast the findings from the interviews. The questions were open-ended, so in this sense they were also primarily aimed at producing qualitative data (see appendix 1).

The questionnaires hoped to provide useful results. It was a way to get the thoughts and opinions from South African members directly surrounded by issues of information poverty and therefore reliable data could be collected. It can become very difficult to gather this kind of data without a platform such as HIFA2015, where they are bringing together people from the developed and developing world. However, the distance from disconnected groups can also be useful to evaluate and should be considered; this in itself provides useful conclusions. How can we truly research this problem if it cannot be fully accessed? HIFA2015 are trying to bridge this divide in communication, they are trying to make this target group more accessible by connecting the members', who symbolize the local people. Reaching the

representatives is a step towards overcoming the problem. The limitations of the method itself should be regarded. Questionnaires lack opportunity to elaborate on the answers given. Questions cannot be clarified, which implies there can be potential for the questions to be misunderstood.

Finally, attending HIFA2015's 26th Steering Group Meeting and HIFA Challenge Working Group meeting, held at the British Medical Association was another form of primary research (see appendix 6). This allowed for overt participant observation as the subjects were aware of the intentions of the research. This method provided an inside look into the campaign that could not be reached by any other method, as it allowed an insight into the organising of the campaign while it was happening. This increases the validity of the findings. Questions could be asked for clarification, an important aspect which only overt participant observation can offer as opposed to covert. The results from this meeting helped to form the questions for the interviews, in particular for Dr Neil Pakenham-Walsh.

Literature Review

There are four interlinked concepts, which are characteristic of the twenty-first century, either positively or negatively. These concepts are globalisation, the Information Age, Information poverty (which stems from underdevelopment) and the digital divide. These concepts all play an important role in information distribution or in the case of the developing world the lack of, therefore affecting the diffusion of health information. As globalisation is at the core of each of these concepts, it will be useful to start here.

Globalisation is symbolic of the contemporary world; it is based on the idea that the world is increasingly connected through various, economic, political, cultural and social networks. These networks have developed from the technological revolution where innovations were made on a mass scale. Using the work of Armand Mattelart, Tony Schirato and Jen Webb, argue that, "....globalization has a hegemonic role in organizing and decoding the meaning of the world." (2003: 1) Therefore, globalisation has become an important concept in defining how the modern person lives and the modern world operates.

However, Schirato and Webb (2003) also state that globalisation is an ambiguous term; usually represented as an ill-defined theory, making it difficult to explain in concrete terms. They argue that the concept cannot have one definitive meaning as there are various interpretations that have been developed by writers, some in favour of it and others against. Firstly, they argue that some writers see globalisation as the ultimate characteristic of modernization or postmodernization and with that comes great opportunities for development and freedom, metaphorically speaking. While others see it as the root cause of maintaining differences in development and promoting inequalities. "For some, globalization means freedom, while others see it as a prison. For some it means prosperity, while for others it guarantees the poverty of the developing world." (Ibid: 2) Therefore, this is linked to what Schirato and Webb call the 'politics of naming' which globalisation creates. Some writers define globalization in terms of Westernisation which through the global imposition of neo-liberal economic models has excluded those in poverty and their needs. In this sense the term 'globalisation' masks an essential power dynamic. "The politics of naming thus simultaneously creates one reality, and forecloses another." (Schirato and Webb, 2003: 6)

Another interesting point raised by Schirato and Webb (2003) is based on the work of David Held and Anthony McGrew who argue that theories about globalisation can be divided into

two main arguments, 'globalist' and 'sceptics'. "Globalists, they argue, are believers, in the sense that for them 'globalization is a real and significant historical development' (2000:2) – the effect of real structural changes in the past few centuries. The sceptics, on the other hand, consider that what we are experiencing at present is simply a continuation of trends that developed in the period of European colonial expansion, [which] peaked during the period 1870-1914...." (Ibid: 7)

Some writers argue that globalisation is significant in improving the quality of people's lives (Friedman, 2007). If so, one of these aspects could be health. Through global networks, better resources are available for those who can afford it and are included in the process of globalisation. However, as I will argue here this is a different case for the developing world in which we can see that Manuel Castells' arguments about uneven development of networks means that a 'digital divide' opens up. For this reason there is a big problem in receiving health information. Therefore, the benefits of globalisation do not extend to the whole world. Castells examines the significance of this and the social consequences of the technological revolution.

Castells' concept of the Information Age is especially important, as the functions and processes of this concept have substantial consequences on the distribution of information. The term is reflective of the information society but extends its representations to a new global status; a concept which affects everyone around the world in different ways. Being a part of the 'technology generation', surrounded by vast amounts of ICTs, readily available to use at all times, we can become ignorant and negligent of the implications of a growing reliance on ICTs. The Internet in particular is remaking the world. Access to, flow and exchange of information/ knowledge is now instantaneous, it is no longer restricted by time and space. Castells argues that the Information Age is made up of an extensive range of social trends. For example, the most important social trend he claims is 'the diffusion and deepening of the information technology revolution', but also, 'the restructuring of capitalism', 'the process of globalisation', 'the crisis of democratic politics', etc, (ed. Webster, 2004: 138). These social trends can be used as a guideline to understanding this concept, which is also exclusionary; it has the ability to reject those who do not participate in any use of ICTs. This is what Castells (1999) calls the 'other side of the Information age', which he says consists of 'inequality, poverty, misery and social exclusion'. Therefore, Castells (2001) argues, "So, in that sense, we have unleashed extraordinary creativity and

technological innovation but the contradictions of development are sharper than ever." (Castells, 2001: 19)

We can use Castells' arguments of the 'double-sided' information age, to identify factors that can affect receiving health information. Poverty plays a very decisive role; some will argue that it can be crippling to all aspects of life. Elena Murelli states that living in poverty goes beyond the lack of resources; it extends to having "*little or no adequate knowledge.*" (2002: 4) Castells (1997, 1999) has described that poverty has become so extreme that he proposes a 'Fourth World' of exclusion. He argues that most parts of Africa, Asia and Latin America make up the Fourth World. "Poverty is an institutionally defined norm establishing the level of income that a society considers necessary to live according to an accepted standard. Misery, or extreme poverty, is an institutionally defined level that establishes the lowest material standard of living, making survival problematic." (Castells, 1999: 7)

The Information age, has led to what some call the 'knowledge economy'. Terry Flew (2007) describes a shift from industrial society to the knowledge economy happening from the 20th century. There is such a strong emphasis on the power of information that being excluded can have detrimental effects. Information needs to be addressed critically. It is often argued ICTs are required for sufficient access to information. However, there are other factors that are essential to allow information to be effective. For example, considering the local; information is not a 'one size fits all model'. There are variations between content needs for different societies. Tessa Edejer (2000) argues there is a 'twin barrier' of access, 'literacy and language'. This is why she explains it is absolutely crucial in having a process in which information is made more accessible from the global to the local. "This is the point where local intermediaries, on the web or on the ground, can read, translate, and convert the information into content that is relevant to the local context." (Edejer, 2000: 798) Castells (2009) also argues that this is where power lies in the Information Age and therefore in networks, the ability "to include everything valuable in the global while excluding the devalued local." (2009: 50) He continues to say there is a division between the global, which is 'the space of flows' and the local, which is 'the space of places' (Castells, 2009).

Information poverty is a term which Pippa Norris (2001) argues is reflective of the digital divide. This division is between the 'information-rich' and those who are disconnected, the 'information-poor'. Castells (1999) in his discussion paper for the United Nations Research Institute for Social Development (UNRISD) puts forth some very significant arguments in

relation to these issues. Within the paper, Castells claims, "The entire realm of human activity depends on the power of information, in a sequence of technological innovation that accelerates its pace by month." (Castells, 1999: 2) He is essentially describing ICTs as 'a strategic tool' for what he states as the manipulation of life. Therefore, he argues those privileged in entering the Information age from childhood have the ability to create and progress in wealth and knowledge, faster than ever before and at an unprecedented degree, but ICTs are drastically uneven around the world (Ibid). However, Nicholas Garnham (1998) argues that Castells is perhaps too deterministic in his view of the power of ICTs and technological innovation. Garnham states, "The first, in some ways the most important for Castells, and at the same time the weakest, relates to globalization and finance capital. But all of them exaggerate the novelty of networks as forms of social and economic organization within which power is exercised, and thus at the same time exaggerate both the extent and the novelty of the impact of ICTs." (ed. Webster, 2004: 173)

Castells' ideas link to development theories, and to the question of how ICTs can make an impact in transforming the development process for Third World countries. He describes the development categories as being a result of each other but ultimately as a result of society.

> "In a nutshell, cultural and educational development conditions technological development, which conditions economic development, which conditions social development, and this stimulates cultural and educational development once more. This can be a virtuous circle of development or a downward spiral of underdevelopment. And the direction of the process will not be decided by technology but by society, through its conflictive dynamics." (Castells, 1999: 4)

To understand trends in poverty and inequality the digital divide should be considered. Pippa Norris (2001) argues that this concept is an important phenomenon with different dimensions. She describes three types of the digital divide; the 'global', 'social' and 'democratic' divide. "The *global divide* refers to the divergence of Internet access between industrialized and developing societies. The *social divide* concerns the gap between information rich and poor in each nation. And finally within the online community, the *democratic divide* signifies the difference between those who do, and do not, use the panoply of digital resources to engage, mobilize and participate in public life." (Norris, 2001: 4) This concept is appropriate in determining the extent of the divide in any society and what has the biggest impact on

information gaps. For example, with the social divide what determinants of society have resulted in a digital split in a nation?

The digital divide is a consequence of globalisation and the Information age. UNDP (2001) argue that "the digital divide follows the income divide." (2001: 27) People who have higher incomes can participate more in technology, therefore the digital divide is also intertwined with issues of poverty. UNDP state that technology has the potential if used correctly to diminish poverty. Therefore, UNDP (2001) argue that technology should not just be a 'reward for development' but used as a means for development. "...many technologies are tools of human development that enable people to increase their incomes, live longer, be healthier, enjoy a better standard of living, participate more in their communities and lead more creative lives." (UNDP, 2001: 27)

However, Benjamin M. Compaine (2001) poses the question, "information gaps: myth or reality?" (2001: 105) "The concept of an information gap is ill-defined from the start. It may refer to the access individuals have to information or the ability of individuals to have the tools – intellectual or tangible – to manipulate, analyse, and synthesize information." (ed. Compaine, 2001: 106) He uses Herbert Schiller's arguments to strengthen his own and both question theories surrounding the Information gap. Schiller says "...*for whose benefit and under whose control will it [ICTs] be implemented?"* (ed. Compaine, 2001: 106). Therefore, in who's best interest is the Information age as the developing world is disconnected. A cycle is created by the lack of companies investing ICTs into developing countries, because they are seen as 'devalued', so they cannot participate, deepening the divide and social exclusion, leaving them in information poverty.

Background

<u>Brief history of South Africa and apartheid</u>

It is not possible to consider South Africa, their health systems and position in the Information age without taking into context its extensive and rich history. South Africa is a very culturally diverse country and similarly to most post-colonial countries has deep colonial roots, which have had a huge impact on the country, politically, socially, culturally and economically. The history of South Africa is complex. The country has experienced segregation, racialization and suppression to such an extreme extent and was subject to an official policy of 'apartheid', until 1994.

Although the country is enduring many changes, Robert Ross (2008) argues the past is still a heavy burden for the majority of its people. The majority of the people are Black, migrating from Northern Africa and the minority are White, whose ancestors were European- British and Dutch colonists. "The rate of social and political change is now greater than ever before. Nevertheless, South Africans of the early twenty-first century are having to work within, and to cope with, the heritage of their past, both recent and distant." (Ross, 2008: 2) Ross also states that South Africa is an 'ex-colonial country'; however, a pre-colonial way of thinking in society is still very much a part of how people lead their lives. Therefore, it can be said that many of the native South Africans still live by their pre-colonial traditions and values, despite the western domination by colonialism. Ross (2008) also writes that South Africa's history can be quite difficult to define in comparison to other African countries. He argues most authors just prefer to write about the effects of the Republic of South Africa and its European colonial rule in government but on the other hand, the focus needs to be on the whole Southern region and include countries, Botswana, Lesotho, Swaziland, Namibia and Mozambique. For this reason he says it is sometimes difficult to refer to South Africa as a 'single country'. "The country has eleven recognised official languages. Its divisions are so great that, within South Africa, calling the country single is more of a routine statement, or a pious hope, than a statement of fact." (Ross, 2008: 1)

To understand the divisions of South Africa, one of the most significant and detrimental aspects of their history has to be considered, this is known as apartheid. There was European control and White dominance long before apartheid. But when apartheid was introduced the country took on a racial division like no other the world has seen. Apartheid began in 1948 and was legislated by the National Party (Afrikaner Nationalists); it lasted up until 1994 when

the first universally democratic elections were held. It became a constitutional democracy through the election of the African National Congress (ANC) into power and by the Presidency of Nelson Mandela, who was released from prison in 1990. The country was emancipated from apartheid laws. Martin Meredith in his book, 'The State of Africa: A History of Fifty Years of Independence' argues, "To ensure that South Africa's whites retained power permanently, white politicians constructed the most elaborate racial edifice the world has ever seen." (2006: 117) The native, indigenous people had their rights of land stripped from them, along with this came strategic social exclusion. "Every facet of their life - residence, employment, education, public amenities and politics - was regulated to keep them in a strictly subordinate role. In the name of apartheid, more than three million people were uprooted from their homes to satisfy government planners; millions more were imprisoned for infringing apartheid regulations." (Ibid: 117)

There are two healthcare systems in South Africa, private and public. The public is used by the majority of South Africans, Black or of mixed race descent, and who live in rural areas. The private is used by the White minority, who live in urban areas, the more developed, industrial areas. The private health system is far more established and stable, with huge amounts of funding from the government being invested into it in comparison to the public service. "...one that is largely publicly funded that serves most South Africans and a privately funded health care system that serves the small percentage of people who are able to afford it, mainly Whites and Asians. During apartheid, most of the national health expenditure was allocated to building a medical infrastructure that would be used by urban inhabitants and the privately insured." (Kon and Lackan, 2008: 2272) Therefore, this difference in health service also includes inequalities in infrastructure in the provinces. The health sector in South Africa is very uneven because of historical inequalities. The private sector boomed in the 1980s, during apartheid, as the White population were threatened by the thought of possible desegregation. Investment is key here, all White hospitals were built and new technology and ICTs were introduced (Ibid).

<u>Synthesis: Findings, Analysis, Discussion</u>

<u>5.1 Marc Lalonde's Health Field Concept</u>

It is crucial to consider the sociology of health to fully understand the field. This is because there are sociological indicators or social determinants which can make a significant impact on any health problem that are outside of the medical cause, for example, lifestyle and environment (Lalonde, 1974). Sociology of health takes into account the relationship between health and society. What are the influences of society and its structure on healthcare? This is relevant to exploring the lack of health information and the reasons behind it, because there are factors in developing societies which will restrict distribution. It could be argued that these are some of the issues that HIFA2015 try to understand in relation to their campaign strategy. The sociological indicators of health can also be applied when examining the information needs of South Africa. Marc Lalonde's (1974) 'Health Field Concept' will be used as a framework to understand the sociology of health. "The concept was designed with two aims in view: to provide a greater understanding of what contributes to sickness and death, and to facilitate the identification of courses of action that might be taken to improve health." (Lalonde, 1974: 35)

The health field concept is moving away from what Lalonde describes as the traditional view of the health field, which only focuses on the influence of science and medicine on the quality of healthcare. Lalonde argues that there is a shift from a predominant focus on science to social factors. "The traditional or generally-accepted view of the health field is that the art or science of medicine has been the fount from which all improvements in health have flowed, and popular belief equates the level of health with the quality of medicine." (Lalonde, 1974: 11) Therefore, there are limitations to the traditional view that health improves due to advancements in medical technologies – social factors (including health education and information campaigns) play a vital role. This forms the basis of campaigns within developing countries and is an important factor in shaping campaigns such as HIFA2015.

Lalonde's health field concept is supportive in exploring South Africa's health system, health policy and why like so many developing countries have disease related epidemics. "Any health problem can be traced to one, or a combination of the four elements. This comprehensiveness is important because it ensures that all aspects of health will be given due consideration and that all who contribute to health, individually and collectively, patient, physician, scientist and government, are aware of their roles and their influence on the level

of health." (Lalonde, 1974: 33) Therefore, lack of health information is a health problem as it influences morbidity and mortality rates. The four elements in the framework, coined by Lalonde are: Human biology, Environment, Lifestyle and Health care organization. Thus, it can be argued that mortality and morbidity caused by lack of health information can be traced to one or more of these four elements.

Lalonde argues that 'lifestyle' is the one element where the individual has 'more or less' the most control over in comparison to the others, and where information campaigns can often be highly effective. It is connected to the life the individual chooses to lead and in some cases can actually be harmful to their health. However, lifestyle choices can be influenced by environment and society, so in that case they can have a direct influence on each other. The fourth aspect of the concept, health care organisation is "...generally defined as the health care system" – which includes a range of medical resources (Lalonde, 1974: 32). This can be argued to have the most relevance to the distribution of health information. In the almost 40 years since Lalonde's work, information has come to be regarded as more of a resource than ever. The following sections will consider in detail how HIFA2015 operationalises 'information' as a medical resource.

5.2 HIFA2015 and Communication Power

HIFA2015 is based in the UK; it is administered by non-profit organisation 'Global Healthcare Information Network' (GHI-net). HIFA2015 is not only a campaign, but itself can be described as a network, a platform for discussing the needs of information/ knowledge in developing countries and a means for collectively addressing a complicated health problem. Dr Neil Pakenham-Walsh is determined to keep the motives clear, "...HIFA itself is not a health information provider it's a campaign and a knowledge network for discussion about how to transfer and filter healthcare information..." (Line 181-183) HIFA2015 have a strategy in which they hope to achieve this. The strategy is described as a 'cycle' consisting of "Communication: promoting international, regional and national cooperation", "Understanding: building a picture of information needs and how to meet them" and "Advocacy: promoting sustainable solutions to achieve HIFA2015". (HIFA2015, 2008: 1) From these three components HIFA2015 then aim to take the evidence forward to stakeholders, who have the funding to put the plans into effect.

The communication approach from the strategy is centred on exactly what it says: an opportunity for communication. It allows the members of the campaign to interact, share,

critique and evaluate this health problem, through two email forums, HIFA2015 and CHILD2015. "Members plan campaign strategy, and exchange experience and expertise on health information priorities, activities and trends. HIFA2015 members also facilitate, manage, and participate in face-to-face meetings and conferences worldwide, promoting and exploring issues around the availability of healthcare information in developing countries." (HIFA2015, 2008: 7) The second stage of the strategy 'Understanding', is to take the information needs discussed from the forums and put the most useful parts into the HIFA2015 knowledge base. The knowledge base contains ideas and initiatives from a variety of countries, as members stretch to many corners of the world and more importantly from the developing world. The third part of the cycle 'Advocacy' involves what the campaign describes as 'Agenda for Action'. From discussing the information needs, to extracting the most essential details, to advocacy, where these ideas can be transformed into action. This is where the organisations that support HIFA2015 and the individual members (and their organisations) play a major role; they are the key in transferring and implementing the initiatives further. For example, "...broad priority areas for action: understanding information and learning needs; improving the availability of existing materials; and developing new reference and learning materials." (HIFA2015, 2008: 10) However, as much as there are strengths there are inevitably weaknesses too in HIFA2015's strategic approach.

It can be argued the campaign is now establishing itself as a key contributing network within Castells' theory of the network society. Castells describes the rise in ICTs, the instantaneous exchange of information on a global scale combined with changing social practices and new ways of working has led to a new global economy, which he calls 'Informational capitalism'. Castells argues the most characteristic and the most dominant social structure, as a result of this new global economy 'Informational capitalism', is the network society.

Castells (2009) emphasizes the significance of global networks. He argues, "The core activities that shape and control human life in every corner of the planet are organized in global networks." (Castells, 2009: 25) However, Castells is clear in outlining that the revolution of ICTs did not solely create the network society, but without ICTs the network society would not exist. The enormity of the need for networks to share Information worldwide, within countries, across countries, can have distinguishing effects in how we define developed and developing societies in the modern world. The network society as Castells (2009) outlines is based around a binary opposition. "The network society works on the basis of a binary logic of inclusion/ exclusion..." (Castells, 2009: 26) HIFA2015 are

therefore attempting to change this structure of inclusion/ exclusion by using networks as a method to bring people together, i.e. the 'HIFA2015 community', and use these networks as a means to address information needs. HIFA2015 'Global networks' are collectively made up of: HIFA2015, CHILD2015, HIFA-pt (Portuguese), HIFA-EVIPNET-Fr (French) and HIFA-policy. The first country focused network, HIFA-Zambia, will be launched on the 5th May 2011. Across these networks the members are connected as they serve the basis for the email forum discussions and thus the 'communication' factor of the strategy.

This communication is essential for the campaign and its purpose. Vincent Shaw (2005) in the Bulletin of the World Health Organization argues that there needs to be a 'health information system reform' particularly in South Africa to accommodate for information as an important resource. "Health services are increasingly under pressure to develop information systems that are responsive to changing health needs and appropriate to service objectives." (Shaw, 2005: 632) He outlines that this could be done through achieving 'an essential data set'. Therefore, this could be helped by the HIFA2015 strategy, through discussing and addressing information needs of a particular area, 'an essential data set' is created which is used in unison across the area, for what Shaw describes is needed to 'monitor and evaluate' services and therefore information. Information distribution is a complex issue and although it is a key resource it is often tied up in its abstract form but instead it needs to be utilised with other factors to survive.

Dr Neil Pakenham-Walsh (2011) during his interview described where the inspiration for starting a campaign for health information developed. He explains it was not just the effect of one thing but three things that occurred in a 'sequential order'. As a medical student he visited a hospital in Djelfa, in Algeria, where he saw the 'total lack of reference and learning materials in the hospital'. Secondly, working as a clinical officer in rural Peru and Ecuador he experienced what these conditions were like for an 'isolated' health worker because he was working under the same conditions. And thirdly, during a conference in 1994 at the British Medical Association he realised the need for health workers all over the world to have a platform where they are able to communicate with each other. "[In the] conference at the British Medical Association about health information in the developing world...the point that really struck me was that there were lots of people doing lots of things to try to improve health information but there wasn't any mechanism for people to talk to each other." (Line 8-11) From this point Dr Pakenham-Walsh got approached to co-author a shortened version of the paper 'Can we achieve health information for all by 2015?' ".....in the paper we call on

WHO to champion the goal of health information for all and to lead the campaign and they wrote a reply to that and in 2005 I set up a new organisation called 'Global Healthcare Information Network' to form the organisational basis for the campaign, which was then launched in 2006." (Line: 19-22)

This piece of literature is valuable to understanding HIFA2015 as it was a founding step in creating the campaign. Godlee et al in 'Can we achieve health information for all by 2015?' outline that at the brink of the information age "...there was optimism that, by 2004, all – or nearly all – health professionals in developing countries would have access to the information they needed to provide the most effective health care possible with the resources available." (2004: 1) There was a global expectation, trust and enthusiasm that the new knowledge economy/ Information age could rid the poorer nations of their hindrance to achieving effective healthcare. Information, exclusively, was often thought of as a limitless possibility. Godlee et al argue, "Although other factors such as lack of drugs and infrastructure might hinder provision of health care, this would not be the case with information." (2004: 1) However, infrastructure can in fact be an obstruction to information. Without infrastructure to support information flow access is not possible, for example, phone lines to maintain an Internet connection. Factors that can affect information dissemination require just as much attention. Is the focus on information too narrow? Information cannot survive without infrastructure, which is affected by decisions about allocation of *material* resources.

5.3 Environment and Lifestyle

How does this need to be addressed in South Africa? As Lalonde (1974) argues the individual has no control over the environment, "Individuals cannot, by themselves, ensure that foods, drugs, cosmetics, devices, water supply, etc, are safe and uncontaminated....that the spread of communicable diseases is prevented...and that the social environment, including the rapid changes in it, do not have harmful effects on health." (Lalonde, 1974: 32) The political and racial segregation of apartheid laws was and some will argue still is reflective of South Africa's healthcare systems. White South Africans and Black South Africans experienced very different health services; due to apartheid the Black majority became isolated and neglected. In 1994, South Africa was faced with the challenge of reorganising the constitution to include Black South Africans back into social life, lifting the previous restrictions that they faced, which involved including them into the health systems. "When apartheid ended....many saw it as an opportunity to redress inequalities that underpinned the

country's health care system. As a middle-income country, South Africa has provided world-class care for White elites....while denying many in the majority populations' access to appropriate health care services." (Stuckler et al, 2011: 165) Stuckler et al (2011) describe this ongoing separation and inequality of health services as 'spatial segregation'.

Lyn Hanmer, who works for the 'South African Medical Research Council; e-health Research and Innovation Platform', agreed in her questionnaire that lack of resources was a big problem. She says speaking of South Africa: "[There is] potential for inappropriate accessing of scarce healthcare resources, and the alternative: the danger of not accessing health services early enough." (Hanmer, 2011: 2) However, the White population were living in very contrasting conditions. Dr Edward Synge in his interview explains, "....South Africa when it was run under very unjust conditions became quite rapidly an industrialised country, which of course is very lucky in natural resources, with gold and so forth, and so has run very efficiently because it ran very efficiently for the White people and was a much more undeveloped, preindustrial, skeleton sort of system for the Black people." (Line 54-58)

The reintegration of Black South Africans into the health system is still proving challenging. Now what this means for the distribution of health information is that the infrastructure is not quite as stable in rural areas and due to isolation information flow is limited. Resulting in different levels of health information distribution made available for Black and Whites. The 'Bantustan' areas were completely cut off from any investment in infrastructure building to support their abandoned health system, therefore, intentionally keeping them underdeveloped. However post-apartheid, health was declared under the presidency of Nelson Mandela and the ANC as a constitutional right and needed to be equalised. But the progress has been slow, and instead Stuckler et al (2011) in their research on healthcare capacity and funding in South Africa, argue an 'Infrastructure-Inequality Trap' has developed. This is related to capacity, the more developed provinces out of the nine that make up South Africa receive the most funding because they have the infrastructure; for example, to adequately use and support new health ICTs and technological advances in medicine. "Regions with a greater capacity to spend funds received more funding and created more infrastructure than those with greater health needs. Historical infrastructure inequalities may have created an infrastructure-inequality trap, in which the distribution of funds to those with greater "absorptive capacity" exacerbates inequalities." (Stuckler et al, 2011: 165) The biggest consequence of the infrastructure-inequality trap is distribution of information. Therefore, creating a cycle; ultimately poorer Black South Africans who already experience high levels of poverty are

now also unable to benefit from infrastructure capabilities to receive a higher level of healthcare. This is an example of information poverty and the digital divide, these are both complex things and the campaign argue there is no simple answer.

However, even with this in mind Dr Synge in his interview described the health systems of South Africa to actually be quite good but run very unequally. Dr Synge emphasises this is a vast contrast to other Sub-Saharan African countries. "...as South Africa has changed, so the factors are already industrialised and developed has meant that those systems were already in place they just needed to be extended and in many in other Sub-Saharan country in great poverty, wouldn't have had the infrastructure." (Line 58-62) Therefore, due to apartheid and European conquest, modernity was brought and invested into specific areas of the country (now the wealthiest provinces and most industrialised) transforming them to be part of the modern world. The rise in ICTs could be supported by the infrastructure already in place in the urban provinces, with a greater White population. So there is clearly a 'global divide' between the developed and developing world but also a 'social divide' or a 'social stratification' within South Africa. The social divide within countries is determined by factors, such as, what Last Moyo (2008) describes as 'socio-demographic barriers'. These include 'class, income, education, gender, age and race' (eds. Creeber and Martin: 127). The inequalities between race in South Africa is clearly affecting quality of health and therefore life.

Dr Synge makes an analogy of South Africa's health system to their road systems. This comparison can be used to emphasis and exemplify the private health sector as more developed than the primary/ public or district level healthcare. He says: "...one of the amazing things about South Africa is the state of the roads, they're superb and they go on for miles and miles. Other African countries the roads are tracks, you know....roads are quite a good sign of the whole thing really, they have these highways that are of North American standard and all highways have smaller roads going off them, so you get a smaller road and a smaller road and its very characteristic of South Africa....So, what I'm saying is that the system is there from before the end of apartheid for having highly educated people, industrialised ways of doing things, good management and a bit of an ethos..." (Line 62-72) Therefore South Africa's historical identity is responsible for their growing industrialised country. The structure and framework is there, it is just needs to be disseminated equally to all areas. If this is achieved then greater opportunities will open up for health information

distribution. Dr Synge explains that this process is already in place, he says, 'it is still fairly fast for any kind of human change that I've ever seen'. He describes the system as having huge potential but the country has to deal with very difficult historical problems but although there is negative reporting about the health system it is heading in the right direction (Synge, 2011).

5.4 E-health Solutions

One of the most interesting discussions that emerged from the HIFA2015 forum was the use of 'e-health solutions' to bridge information gaps. When Dr Pakenham-Walsh was asked how he would define e-health solutions he replied: "Well, I think e-health is the use of ICTs, information technologies or and healthcare generally. With regards to health information and availability of use of health information, I think the two most important areas are, Internet in general and mobile phones in particular in recent years, it seems that mobile phones have a huge potential and they've exploded in terms of the number of mobile phones across low income countries.....e-health also includes the use of...you know traditional technology, such as radio, television and so on and those also...continue to have an important role especially for the public." (Line 145-152) Ruxwana et al argue speaking of South Africa, "Information and Communication Technology (ICT) solutions (e.g. e-health, telemedicine, e-education) are often viewed as vehicles to bridge the digital divide between rural and urban healthcare centres and to resolve shortcomings in the rural health sector." (2010a: 17) The UNDP Human Development Report (2001) emphasis how technology can be used to improve human development, the report expresses a strong need for technology to improve people's lives. "People all over the world have high hopes that these new technologies will lead to healthier lives, greater social freedoms, increased knowledge and more productive livelihoods. There is a great rush to be part of the network age..." (UNDP, 2001: 1) However, the report also argues that "technological change, like all change, poses risks", and that there could be damaging effects and "without innovative public policy, these technologies could become a source of exclusion, not a tool of progress." (Ibid: 1)

But e-health solutions are sustained through ICTs, so yet again we come across a recurrent trend that the most significant barrier to health information is the physical access. Dr Pakenham-Walsh when speaking of the biggest challenges in achieving the HIFA2015 goal, from the point of view of information, he mentioned that technological issues in developing

countries are a huge obstacle. He argued that the lack of connectivity is hindering health information although he says it is clearly improving. If improved it could be one of the most prominent advancements. However, using South Africa or Africa in general as an example we can see that connecting people to the Internet is a complex task. Castells (1999) uses irony to describe the position of Africa in the Information age; he describes them as being subject to a 'technological apartheid', which could be extended to many other areas of the world. Castells (1999) argues that this is a difficult problem to overcome when the developing world face vastly different challenges than those in developed societies. For example, he states "...one third of the world's population still has to survive on the equivalent of one dollar per day." (Castells, 1999: 3) Therefore, people who live in poverty would probably not consider being connected to the Internet a priority, but instead value their basic human needs first. However, Murelli (2002) is much more optimistic with the prospect of the Internet as a means to bridge the information gap. She argues, "Above all, the Internet can become a *crucial channel for the diffusion of essential information in those places where poverty implies not only lack of economic means but also lack of accurate information.*" (2002: 3)

5.5 E-health: Mobile Phones

The use of the Internet as an e-health solution for achieving equal access to information is often represented as the easiest option. However, this is more complicated than is anticipated. In recent years there has been a surprising rise in mobile phones in developing countries. In an article for BBC News Business titled, 'Mhealth: Mobile technology brings healthcare home', they argue the possibility of mobile medicine to improve healthcare. "Mobile healthcare is really starting to take traction and if you consider the high penetration of mobiles globally then they really are the future." For the developing world, the implications of mobile healthcare are huge. In Sub-Saharan Africa, 70% of people have a mobile phone." (BBC News, 2010) The statistics here are incredible considering these are some of the poorest places in the world.

Dr Madanmohan Rao, a Research Project Director for MobileMonday, also identifies that "....there are more than 500 million mobile phone subscribers in Africa now, up from 246 million in 2008. In 2000, the number of mobile phones first exceeded that of fixed telephones." (2011: 5) The report also goes on to identify South Africa as one of the four biggest mobile phone markets in Africa. These statistics show a huge increase in mobile

phones in Africa in the last three years with the numbers still currently rising. This particular report was discussed in the HIFA2015 forum. The members are currently initiating that there is a huge potential for mobile phones, and that they should be used as a mechanism to improve health information. They have been sharing ideas of how this can be implemented. For example, they have suggested being able to download a free health information 'app' or the phones to be pre-loaded with a specific chip which will provide free basic health information.

This fits into the 'understanding' element of their strategy. They have identified an initiative in rising mobile phones; this can then be pushed and turned into an advocacy plan of action. This is supported by Castells (1997, 2001) who had intimated that 'medical technology' and 'Internet based health care' could potentially bring down mortality rates. He has a strong belief in the potential of ICTs. "....what is critical is Internet-based agriculture, Internet-based services, Internet-based health, Internet-based education, particularly for developing countries that need a faster process of development." (Castells, 2001: 12) However, Castells is not being too deterministic because he stresses this is not an easy process to "jump from the current state of dereliction and under-development to an Internet-led economy", or an ICT led economy for that matter (Ibid: 12). Mobile phones can also provide wireless access to the Internet, increasing their overall potential for health information dissemination. Therefore, we can see that the platform for delivery of information is changing. As technology is adapting HIFA2015 are responding to these changes through the information feedback loop- this is picked up through consistently reviewing.

5.6 Content and 'the local'

However, we must consider: how useful is information? Another problem that was discovered through this research was that misinformation or information overload is just as harmful as lack of information. This is again also the result of lifestyle and environment. But it can be argued that this also fits into Lalonde's 'Health Care Organization' category. In the context of South Africa, which is also reflective of many other African countries, traditional healers are often used as a healthcare alternative. Their methods are based on superstition and tradition. For example, the lack of an adequate healthcare system or healthcare organisation for Black South Africans has contributed to the spread of HIV/ AIDS especially in Bantustan

areas, through a mixture of superstition and misinformation about prevention of this disease, i.e. the benefits of contraception (Mitton, 2000).

This relates also to Lalonde's Human Biology element. Lack of information and the use of misinformation have contributed greatly to the HIV/ AIDS epidemic. For example, HIV transmission from mother to child is a big cause for spreading the disease, through birth and also through breast milk. But if mothers were more informed this is preventable. Jennifer Mitton (2000) argues, "As there is no cure for HIV/ AIDS, and presently no vaccine, this epidemic must be controlled through health promotion. It is therefore necessary to look at health not only within a biomedical context, such as the development of an effective vaccination, but also in relation to the broader determinants of health." (2000: 18) Dr Pakenham-Walsh states that poverty is one of the biggest determinants of health. Therefore, a proven effective tool for health promotion which HIFA2015 argue is the most successful is information. But Dr Pakenham-Walsh also argues that regardless of poverty everyone should have access to information, in general and for health, because it is a human right, and 'HIFA2015 is based on human rights'. We can see here how information is not simply regarded as 'neutral' for HIFA2015, it is a value-laden concept which is strongly linked to an overall conception of rights – to information itself as a basic human right.

South Africa is an extreme example of how this human right is not properly exercised, mainly because disease is spreading from lack of information and from misinformation. This can be exemplified by Dr Pakenham-Walsh, another big challenge in achieving the HIFA2015 goal he described in his interview is the 'content' of information. The separation of useful information from the false is essential. He explains:

"....the content problems relate to the issue that every person, every healthcare provider or every group of healthcare provider needs a particular type of content that's packaged in a particular way that is relevant to their needs and is reliable. And that's a big issue. I mean there is a lot of content that is being available to healthcare providers or is being used by healthcare providers but it's either unreliable, i.e. for example it may be poorly put together or it may not be actually based on proper appreciation of the underlying evidence or it may be irrelevant. And it may just simply be talking about things that the healthcare provider is unable to implement." (Line 49-56)

This was another similarity in the interview with Dr Synge, he too emphasised that 'false knowledge' was harmful. This is why HIFA2015 are absolute in distinguishing their definition of an *'informed'* healthcare provider. Dr Synge says "... [The health workers] need to have some equipment and some training and somewhat training starts to be knowledge. But they may well in real life have false knowledge, people don't usually just say I don't know, they usually actually have knowledge but it may be false and they won't be able to do the right thing if they don't have the correct knowledge. An 'informed' health worker is somebody who has sufficient knowledge to perform optimally the particular task they were assigned to do." (Line 38-44) Healthcare organization can help create more reliable information dissemination by properly adapting information to suit the recipient's needs. Therefore, this means taking the information from the global and transferring it appropriately to the local communities. Health information has to be made suitable to the purpose it must serve.

What this means for South Africa is information has to accommodate the needs of the primary health sector especially, making the information easily attainable and comprehendible. In the interviews the word 'filtering' was used to describe this process, however, Dr Pakenham-Walsh expressed that this term could have a misleading expression. He agreed with the importance of such a process but with 'nuances'. He argues: "I wouldn't so much use the term 'filtering' but simply to say what is it that can make it easier for people to find what is relevant and that can often mean helping using ICTs, for example, so that people can search on areas that are going to be relevant to them and in different languages. But...there's a suggestion with the term filtering that we might be....saying right we take this content and we only give access to, for the end user, [a] little bit of it. So, I don't think...there's [anything] to be gained...from some kind of blockage of information flows." (Line 157-164)

However, without relevant 'filtering' of information flow, opportunity for access to irrelevant information is more likely and could be problematic. So it could be argued that this process is crucial. Having said that, although Dr Pakenham-Walsh was not so much in favour of the term 'filtering' he mentions that any sort of process which helps the user find efficiently what they are looking for is beneficial. This is because he describes another big problem with information is information overload. "....and so for almost everybody except for the most isolated there is indeed a huge overload of information that they can get hold of, especially if you have access to the Internet. And it's difficult, if not impossible for people to work out

what is actually reliable information and what is actually misleading information, difficult in developed countries and developing countries. So anything that helps people to understand what is reliable for them is important and also anything that helps them to get what is relevant is important." (Line 169-174) Castells (2009) argues that the global network society is a huge dominating force to people outside of the networks, for example, local communities, but in an exclusionary way. "In this sense, the global overwhelms the local – unless the local becomes connected to the global as a node in alternative global networks constructed by social movements." (Castells, 2009: 26) Unless the information is properly addressing the needs of the local people, the global will always be intrusive and of little use; this 'filtering' process is about integrating local people into the global.

In relation to HIFA2015 implementing a process of transferring and 'filtering' knowledge to locals, Dr Pakenham-Walsh explains that many of the individual members and their organisations usually take responsibility for this. HIFA2015 itself does not directly work with such a process. However, Dr Synge agrees with the need to filter information, but points out that there are problems with the use of the forums that need to be addressed. "....on the Internet forums, HIFA2015 and CHILD2015; you'll find that although the remit of the organisation is really about finding out what knowledge is needed and where even you can get it and how to diffuse it and distribute it and so on. You'll find actually a lot of the discussion is not about that; it's about the actual content of the knowledge." (Line 136-139) He argues that this will inevitably happen, because of how successful the forums are the members will use the network as an opportunity to talk about more than health information needs. There are often disagreements in the forums about the most successful and practical way to address treatment of particular illnesses. But this type of discussion is not what HIFA2015 are trying to establish. Therefore, going back to his analogy of the road system and health information, Dr Synge describes the process of 'filtering' for information distribution as very difficult. "So this filtering is the hardest possible part of it and I mean we've got to try haven't we, but you know...designing a kind of network of road systems is one thing but when you've actually got to decide what to put on the road it gets much harder. Filtering is still obviously very important but it's very difficult to get agreement about it." (Line 167-171) Dr Peter Cooper, Paediatrician and Neonatologist and a South African HIFA2015 member, in his questionnaire argues that this process has a long way to go in South Africa. He explains that health organisation is not properly addressed, therefore health information "does not reach everyone that it should" (Cooper, 2011).

Lalonde (1974) states that most of the attention has been placed on healthcare organisation to improve health; but he argues that if the first three aspects (human biology, environment and lifestyle) were taken more carefully into consideration, many deaths and sickness would be preventable. HIFA2015 also promote the exploration into social causes of illness and death. A very interesting point from the HIFA2015 Steering Group Meeting was the use of 'social autopsy' to determine cause of death. This will help identify if information could play a significant role in the prevention of such deaths. Dr Pakenham-Walsh was asked to elaborate on this concept and its importance in the interview. He explains that there is a clear distinction between a 'social autopsy' and a traditional medical autopsy. "So, what's different about social autopsy is you're finding out what it is, what was it that was actually happening that led step by step towards that person ending up dying." (Line 100-102) Therefore, what social factors contributed to that person's death? This is a subsidiary tool in determining information needs.

Dr Pakenham-Walsh used the example of a child who has died from diarrhoea. He explains interviews can be done with the family or health provider to determine why the child died, because diarrhoea is very easily treatable. However, he stresses there are 'sensitivities' with conducting this type of research but it could help to correctly identify the lack of information or if misinformation was used. As he says, if a child had fluids mistakenly withdrawn while they were sick this could be fatal. "So, it's very important because to understand social autopsy, to understand why people are dying is in many ways as important if not more so than to understand whether people [are] dying of diarrhoea or pneumonia, you know the medical diagnosis. Because if you understand what the steps are that are leading to death, there might well be things that...could...be changed within those steps that would have prevented the death happening. And those things may include, simply the person responsible for healthcare actually knowing what to do at the time." (Line 122-128) This relates back to Lalonde (1974), although his ideas developed in the seventies they are still relevant today. Society is constantly changing, new innovations and technologies emerging, healthcare is also adapting so therefore social factors of health will always be significant.

5.7 Challenges of HIFA2015

Addressing health information needs is without a doubt extremely difficult. There are variations across and between the developing and developed world. Richard Horton argues, "Information exchange is critical for development of health systems. The Information needs

of less-developed countries are especially challenging...." (2000: 2231) This can cause problems in measuring the progress of HIFA2015 as information is difficult to measure. Dr Pakenham-Walsh stresses that this is the case when evaluating progress, "....there is no single index...that you can assign to any country to say this is where there are with regards to access to health information." (Line 25-27) Instead he says there are 'proxy indicators' or 'indirect indicators' which can provide a vague outline of how accessible information is. For example, "....you can have measurements of how active different countries are in terms of their research output; you can have numbers that tell you what proportion of the population is connected to the internet. But they're really sort of quite distant to what we would like to have and there are very few data that are routinely picked up by countries that we can monitor that really show us what progress is being made." (Line 28-32) The best that can be done is educating and raising awareness of the benefits but at the same time campaigning for infrastructural improvements too.

Through the research it was discovered that there is not a direct focus on South Africa with HIFA2015. In fact, the only country focus so far will be HIFA-Zambia. Therefore, this highlights the ambitiousness of the campaign and the complex problem of identifying information needs 'for all'. However, the language focus direction the campaign has taken for the global networks (e.g. HIFA-Portuguese etc) is probably more realistic. Having the networks divided by language is still appropriate; incorporating language in information dissemination should be an important focus too. Dr Synge states: "The essential idea behind HIFA2015 is one of those ideas that can seem so obvious, that it's hardly worth saying and yet like a lot of things that seem obvious that means it gets ignored. And so, if you think about all the things that people have recognised that you need for health are, medical staff or health stuff generally, yes, medicine, yes, things in the environment, such as clean water, yes, and also all these things don't really work if you don't have knowledge." (Line 17-22) Therefore, information is the foundation of health.

HIFA2015 are faced with huge challenges in achieving their goal. Dr Pakenham-Walsh argues: "...there's a lack of understanding about health information needs of different groups of healthcare provider and how to meet those needs. So, there's an awful lot of people who are producing information without an understanding of the target audience, and then the third area is that there is lack of commitment by funding agencies and governments to actually tackling this problem....." (Line 40-44) This was another key similarity in the two interviews,

the need for funding, especially so the campaign could put more of their advocacy ideas into effect. At the moment the advocacy element of the campaign seems to be the weakest.

However, HIFA2015 are constantly trying to improve their strategy. This was observed in the Steering Group meeting. At the moment an evaluation of the campaign is being done and Dr Pakenham-Walsh agreed that this was needed for them to keep to their targets. "...we need it to be able to improve the campaign so we need to find out what is it in the campaign that is working well and what's working not so well so that we can improve it in the future. We also need it to demonstrate hopefully that we are having a positive impact on individual members and also on hopefully the actual health information situation globally and in different countries because if we can demonstrate that impact then of course we will be much more likely to attract increased funding in the future which is what we need...." (Line 204-210) He also explains that their approach is 'innovative', and describes HIFA2015 as an example of 'communications for development'. Dr Pakenham-Walsh describes this approach as testing the affectability of "...bringing together thousands of people to discuss and address a complex health challenge." He says if proved successful this approach can be 'replicated for other areas of health and international development'.

This is exemplifying why information itself is also important to the campaign. The continual need for evaluation creates information feedback loops. The campaign needs feedback as a means to measure their progress. This information becomes a cycle and it relates to Anthony Giddens concept of 'reflexive modernity', as he argues society becomes increasingly more self-aware. It is the idea of endlessly adapting and modifying. The campaign is constantly adjusting ideas and strategy, 'reflecting' on these ideas as they go along. This is because within modernity information/ knowledge comes not from a divine cause, but instead from systems changing and reflecting on the process of change. Therefore, information is 'hyper-reflexive'. Giddens also argues that knowledge considered in 'reflexive social activities' is determined by four elements. One of those is: "*The circulating of social knowledge in the double hermeneutic*. Knowledge reflexively applied to the conditions of system reproduction intrinsically alters the circumstances to which it originally referred." (Giddens, 1990: 54) Therefore, information has a reflexive nature, as new things are learnt information is modifiable.

<u>Conclusion</u>

This research has shown that information has many meanings and functions, not only is it a medical resource and a complex characteristic of the Information age but also a resource itself to the campaign, allowing it to adapt to new circumstances through processes of reflexive monitoring. A few of the difficulties that South Africa faces in the distribution of health information were presented by using Lalonde's health field concept as a framework. Sociological factors of health have been found to impact hugely on unequal health information in South Africa. For example, historical inequalities because of racial divisions, infrastructure and adapting content. An emphasis on social factors was also found in HIFA2015, especially their concept of 'social autopsy'. A few possible solutions were discussed as initiatives to bridge the health information gap, such as connectivity through the Internet and the use of mobile phones. However, dissemination of health information is a complicated issue and requires large amounts of funding to push advocacy ideas. This is where HIFA2015 struggle to turn their strategy into action.

However, what has been useful and what can possibly help HIFA2015 is using the four elements of Lalonde's health field concept to properly analyse the need for adequate health information of a particular area. For example, through the research it has been discovered that in fact South Africa in their environment have good infrastructure implemented by the Europeans to support ICTs, but it is not equally extended to all provinces. This could become a real area of focus. What has been found from their lifestyle is that mobile phones should be an effective priority, as statistics have shown the developing world has a large market. HIFA2015 can use this research to create a country focus for South Africa as a part of their 'global networks'. This will provide the opportunity to address the issues raised and to discuss in-depth between South African policy makers and stakeholders about how to implement changes; this research could be a starting point. South Africa has huge potential to have health information equalised in comparison to other developing countries and this can be pushed through HIFA2015's strategy, especially as the networks are a fundamental communication tool.

Although there is hope for ICTs such as the Internet and mobile phones, the research also found that the receiver still has to known what to do with the information. For example, a key issue discussed was 'information overload'. Too much information is also a problem, which hinders the effectiveness. Along with this, came the problem of content. The information has

to be relevant and reliable for its purpose but this can differ between users, making this kind of problem extremely complex. As a consequence of content, misinformation was discussed, and it was highlighted that this could also be just as harmful as lack of information. Therefore, information overload and content are very significant. The information has to be relevant to the local, and there must be a process for including the local's needs into the global.

The interviews and participant observation at the HIFA2015 Steering Group meeting were successful; the results were valuable and provided a rich set of data. The questionnaires were disappointing as there was a low response rate. It was not a sufficient sample and the results were too brief to be able to compare against one another in regards to the South African member's views on the issues raised. Because of this the questionnaires played only a small part in the overall analysis. However, this is another reason for HIFA2015 to push a country focus for a South African global network as these are some areas which require further research.

In a wider context, the areas that need further investigation and are necessary if HIFA2015 are to achieve their goal is, firstly how health information is measured. As Dr Pakenham-Walsh outlined there is no single index at the moment to measure this but there should be at least a standardised set of indicators to be able to see if health information is received effectively which could be set by using the 'proxy indicators'. This will help assess all countries as to where they are in terms of connectivity and infrastructure support. Secondly, the issue of funding for the campaign should be addressed, which is a difficult problem in itself, but one which needs elevation if every person is to have health information by 2015. As mentioned information was declared a human right and should be given the attention it deserves worldwide.

Another limitation of this research was the huge amount of detailed data collected from the interviews, the length of the project simply could not accommodate all of it and much could still be done with the data in terms of further analysis. HIFA2015's goal is ambitious, but the campaign as a case study has highlighted the extent of the problems they face in achieving it. Information has been shown to be hugely important in contemporary society and as a term which has many meanings within different contexts. Therefore, it requires a huge amount of detailed preparation for access to be freely available. There are barriers and underlying problems with reliability etc and as ICTs continue to expand through the growing

Information age with many excluded, this poses the risk of restricting the flow of health information for development. However, this needs be a shared responsibility to include everyone in the Information age, and HIFA2015 have been influential in raising this awareness.

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Appendices

Appendix 1: Questionnaire questions for the South African members:

1. If applicable, what is the name and description of your organisation or profession?

2. How is HIFA2015 implementing healthcare information to South Africa?

3. What are the outcomes/ benefits of HIFA2015 working to improve the quality and reliability of healthcare information in South Africa?

4. What are the specific problems people in South Africa face due to lack of essential, adequate healthcare information?

5. What is the process of transferring health information collected from the global to the local communities?

6. How effective would you rate HIFA2015's position in improving healthcare information on a scale of 1 to 10 (1 being the lowest and 10 being the highest) for
   A. South Africa
   B. All developing countries
   And why?

7. In your opinion, what is the most successful healthcare information source for South Africa? And why?

8. What are the e-health solutions in South Africa? Are they effective? And why?

9. What progress has been made in South Africa in regards to distribution of health care information?

10. In your opinion, will HIFA2015 achieve its goal for every person worldwide to have access to an informed healthcare provider by 2015? And why?

Appendix 2: Peter Cooper's questionnaire response:

1. **If applicable, what is the name and description of your organisation or profession?** I am a paediatrician/neonatologist attached to the University above

2. **How is HIFA2015 implementing healthcare information to South Africa?** Currently very informal as far as I am aware getting only to those on the distribution list

3. **What are the outcomes/ benefits of HIFA2015 working to improve the quality and reliability of healthcare information in South Africa?** I don't think the impact is significant at this stage

4. **What are the specific problems people in South Africa face due to lack of essential, adequate healthcare information?** Increased morbidity and mortality across all sectors

5. **What is the process of transferring health information collected from the global to the local communities?** Teaching institutions and health depts. carry out a lot of CME for doctors & nurses, but not organized sufficiently and does not reach everyone that it should

6. **How effective would you rate HIFA2015's position in improving healthcare information on a scale of 1 to 10 (1 being the lowest and 10 being the highest) for**

A. **South Africa** 2

B. **All developing countries?** 4

And why? I don't know enough about the overall effects to comment adequately

6. **In your opinion, what is the most successful healthcare information source for South Africa? And why?** As what is happening as described above as it maintains communication between different levels of care. However, much more needs to be done.

7. **What are the e-health solutions in South Africa? Are they effective? And why?** Not much happening at present, but a lot of potential as demonstrated by some research studies using cell phones etc.

8. **What progress has been made in South Africa in regards to distribution of health care information?** As described above

9. **In your opinion, will HIFA2015 achieve its goal for every person worldwide to have access to an informed healthcare provider by 2015? And why?** No – I think it is a great goal but will take a lot longer

1. **If applicable, what is the name and description of your organisation or profession?** South African Medical Research Council; eHealth Research and Innovation Platform.

2. **How is HIFA2015 implementing healthcare information to South Africa?** There are individual members of HIFA2015 in South Africa; not sure how many and where!

3. **What are the outcomes/ benefits of HIFA2015 working to improve the quality and reliability of healthcare information in South Africa?** The wide range of participants who can offer comment and advice and suggestions is a major benefit, but difficult to quantify. The understanding of the importance of healthcare information is key. I suspect though that we are largely preaching to the converted.

4. **What are the specific problems people in South Africa face due to lack of essential, adequate healthcare information?** I have not done specific research on this, but the issues would be the same as in many other places: potential for inappropriate accessing of scarce healthcare resources, and the alternative: the danger of not accessing health services early enough.

5. **What is the process of transferring health information collected from the global to the local communities?** There are multiple initiatives through government and through NGOs such as Lovelife. At the MRC, a colleague runs an excellent research-based programme to disseminate information on AIDS to multiple audiences, using multiple methods. Details can be found on www.afroaidsinfo.org.

6. **How effective would you rate HIFA2015's position in improving healthcare information on a scale of 1 to 10 (1 being the lowest and 10 being the highest) for**

A. **South Africa** 3

B. **All developing countries** 3

And why? Coverage and effectiveness depend on knowledge of the resource, and access to email. These remain challenges in many developing environments.

7**. In your opinion, what is the most successful healthcare information source for South Africa? And why?** Lovelife, since it uses multiple mechanisms (including non-electronic), has a wide footprint, is well funded and endorsed by government.

8. **What are the e-health solutions in South Africa? Are they effective? And why?** There are multiple initiatives including a country-wide district health information system (DHIS) which collects facility-level data; facility-level health information systems which support mainly administrative and management processes (in some but not all of the nine provinces, and in many private facilities); multiple systems to support the rollout of ART; comprehensive laboratory information systems (but not typically linked to other systems), among others.

Effectiveness varies depending on the appropriateness of the systems; training and management of users to ensure data quality and completeness; management and user attitudes to the information systems; reliable access to the required infrastructure, including networks.

9. **What progress has been made in South Africa in regards to distribution of health care information?** The multiple programmes and initiatives are making great effort to improve distribution of health care information, but I do not have information on how effective these are overall. I am not aware of any projects to assess coverage, which is not to say that there are none.

10. **In your opinion, will HIFA2015 achieve its goal for every person worldwide to have access to an informed healthcare provider by 2015? And why?** Not unless all healthcare workers have easy access to electronic resources. Even in South Africa, this will be difficult.

Appendix 4: Transcript of the interview with Dr Edward Synge, including questions:

1. Firstly, please provide details of your medical background?

Medical background, well, I qualified in 1968 and trained as a specialist in paediatrics, so I first did some paediatrics in 1969 so 40 years or so as a paediatrician.

2. How have you been involved in campaign HIFA2015 and CHILD2015?

5   Yes, well as I paediatrician I belong to the Royal College of Paediatrics and Child Health, and closely associated with something called the International Child Health Group and I'd always thought as I was once the editor of the magazine for the International Child Health Group, and I had some sort of part in the committee, and I always thought, this is goes back to the 1990s, that we needed some kind of internet link among ourselves. And through that

10   group, I think Neil Pakenham-Walsh probably came to talk to us and Professor Steve Allen, he wasn't a professor then but he is now he's at Swansea, particularly mentioned Neil. And so then Neil Presented the CHILD2015 as a way of us all talking to each other all over the world to the International Child Health Group. So, and then invited me to be on the CHILD2015 Steering group and then the HIFA2015 Steering group and so on.

15   **3. From a medical perspective, why is the equalisation of healthcare information essential for those in the developing world? How can it make a difference?**

The essential idea behind HIFA2015 is one of those ideas that can seem so obvious, that it's hardly worth saying and yet like a lot of things that seem obvious that means it gets ignored. And, so if you think about all the things that people have recognised that you need for health,

20   are, medical staff or you know health stuff generally, yes, medicine, yes, things in the environment, such as clean water, yes, and also all these things don't really work if you don't have knowledge. And, the fact is there are many health workers and carers and so on who simply don't have the knowledge of what to do, so if you take something like water aid, which have recognised the importance of water, and is a big NGO. Well we all need water

25   but of course we also need information to know what to do with the water, basically, that's a very simple example. And it might seem terribly obvious. But in the case of something like if a child has malaria, well, malaria is treatable but is not effectively treatable if you don't know how to recognise that it is malaria and if you don't know what you should do with it if its malaria, and if you should get hold of the correct medication for malaria and what will

30   happen when you give it and so on and so forth. So that was the essential idea about

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providing one of the components for health for all. From a paediatric point of view, I think most paediatricians will probably think that we have a responsibility towards all children not just particular children in your neighbourhood and so on, so there's a very...I think paediatricians have always been rather in the forefront of the idea of international health.

4. How would you describe an 'informed' healthcare worker?

Well, someone who has the necessary, correct information to maximise, if you like, or to fulfil the full potential of what they're capable of doing. I mean the health worker needs to be the same facility as the person whose sick, it's again obvious, they need to have some equipment and some training and somewhat training starts to be knowledge. But they may well in real life have false knowledge, people don't usually just say I don't know, they usually actually have knowledge but it may be false and they won't be able to do the right thing if they don't have the correct knowledge. An 'informed' health worker is somebody who has sufficient knowledge to perform optimally the particular task they were assigned to do.

5. From your experience working in South Africa, how would you describe the current health systems?

In South Africa? Well, in many ways extremely good, but that's a very long question, a long question to answer, because you can't deal with it without taking into account the history of South Africa which is famously very divided. That you had a relatively small number of relatively wealthy, privileged people whose skin was white and descended from Dutch and Portuguese and English and so on. And a much larger group of people whose skin was black and also you need to include the labourers who were brought in from India to work under nearly slave conditions, so called the inventions labour in order to cut sugar cane and things like that, so you had this very divided country. However, on the other hand South Africa when it was run under very unjust conditions became quite rapidly an industrialised country, which of course is very lucky in natural resources, with gold and so forth, and so has run very efficiently because it ran very effectiently for the white people and was a much more undeveloped, preindustrial, skeleton sort of system for the black people. However, as South Africa has changed, so the factors are already industrialised and developed has meant that those systems were already in place they just needed to be extended and in many in other Sub-Saharan country in great poverty, wouldn't have had, wouldn't have had the infrastructure and one of the amazing things about South Africa is the state of the roads,

they're superb and they go on for miles and miles. Other African countries the roads are tracks, you know. As we of course we eventually, roads are quite a good sign of the whole

65   thing really, they have these highways that are, you know of North American standard and all highways have smaller roads going off them don't they, so get a smaller road and a smaller road and its very characteristic of South Africa that they're given a code of numbers so you have a national, you know the N1 is effectively a freeway, then you have the R numbers and then you get down to little tiny roads and then you get down to dirt tracks, like anywhere else,

70   it's a big country. So, what I'm saying is that the system is there from before the end of apartheid for having highly educated people, industrialised ways of doing things, good management and a bit of an ethos if we can sort of solve every problem if not just get on with it, you know, the white people might not like the racist white people, they've never been sort of whingers in their tradition and stuff, and even for all the unattractive parts of it, even the

75   Africana mentality, you know the idea of the bowers who went in their carts over the mountains and things with just their Bibles and so forth but of course the ultimate in racism but at the same time we have to give them their due that they're not whinging people who give up, that spirit is there. And so, I think that that spirit is also diffusing, it's just like the roads you have in hospitals, say you have your big hospitals and them some really bad

80   understaffed, you know impoverished places in the country. But, the highly organised way of doing things, which in my personal opinion is rather superior to Britain in many ways, cause Britain is a nation of whingers, 'we can't do it and this is why', is truly spreading out from the industrialised base that was there under undesirable circumstances before, and although everybody was being patient with the pace of it and so forth, it's still fairly fast for any kind

85   of human change that I've ever seen and you know black people are given the managerial jobs and so forth. And sometimes even the whinging of the white people can be a bit, as of course I've said they're not whingers but they might complain a bit, if somebody is displaced by a black man, a black woman from a managerial position it may not always be just but it has to be done and it isn't going too badly, the white people are not whinging too much about

90   it. So, I think that the whole health system has huge potential cause they're dealing with very, very difficult problems and is fast spreading out like my analogy of the road system, it's as if the tracks are being turned into roads, you know little hospitals are being turned into bigger hospitals and so on. So, although you might hear negative reporting about it, I mean I think it's also of course a huge human achievement and it's really a very good health system.

95   **So, you think it's better compared to the other Sub-Saharan health systems?**

It certainly is it started off with something there, even if that something was in the hands of the white people and it shouldn't have been but it was at least there. Whereas in other countries it was never there, and the only people who tried to substitute for it are World Bank and United Nations type of workers, who live in compounds and drive enormous white four
100 wheel drive vehicles, and don't really get into the system at all. So, South Africa is much better in that respect.

6. HIFA2015's current working group challenge for 2011 is related to mother and family caregivers, statistics show that 80% of child deaths occur at home. In your opinion how will improving healthcare information reduce this risk?

105 Right ok. Well, obviously for each as we've said about the informed healthcare worker, for each person to have knowledge appropriate to the task, I said assigned it sounds rather sort of bureaucratic, I mean given you know, the job your given. If you have a baby, you're given a job, it doesn't mean the governments kind of told you, but you still have to do it...And you need the knowledge you have, which is a lot to do with when to ask somebody else. So those
110 80 percent of deaths occurring at home, it's not that they, you know the treatment for whatever killed the child could've been given at home but the knowledge would allow somebody to say this child is too sick to stay in the home. You see what I mean, so that knowledge is appropriate, so in that sense, the mother or grandmother or father is a healthcare provider and the information you need is you know this child looks very sick. And, also of
115 course a lot of information about nutrition that families need and again that can be an area of very false information, you know, accidents are very common cause of death with children in the home, so some people need knowledge about safety. But it's all knowledge.

So, it branches from just professionals into the home?

Absolutely! Yes so, everybody appropriate to the job they have. And, I think it's, I mean I
120 haven't got any figures on the top of my head, I've not sort of prepared it, but I don't think you'll find 80 percent of children in Britain die at home. And obviously the number of deaths is much smaller anyway, but even the proportion of them, I mean it's is really pretty unusual for a child to die at home. I think we could even go so far as to say it would be better if slightly more children died at home because those children who die in a very highly
125 organised industrialised place tend to die for things in which we have all the knowledge in the world we haven't got it yet. So if somebody has cancer and they've had five courses, five attempts of treatment and you give up on the sixth, it's better for that child to actually die at

home, it's rather sad that they die in hospital. So I think you'll find of the very small number of child deaths that we have an even tiny proportion of those die at home, so I think it's reasonable to think that with increased information that the proportion of children who die at home will be, in poor countries, will be reduced.

7. It is often argued a key part of information distribution is the filtering of information to suit the varying needs of the local communities from the information deprived countries. Do you agree or disagree with the importance of this? And why?

I agree with it but I think it's also seems to be two problems that we haven't really solved. I mean you...on the Internet forums, HIFA2015 and CHILD2015; you'll find that although the remit of the organisation is really about finding out what knowledge is needed and where even you can get it and how to diffuse it and distribute it and so on. You'll find actually a lot of the discussion is not about that; it's about the actual content of the knowledge. That's not what HIFA is supposed to be about but it inevitably happens because the thing about the Internet forum is that it's one of the most effective and liked Internet forums in health that there is, that is truly global. So you can't be surprised really that you'll want to use it as a network to talk about more than just health information and when you see these arguments do occur you see that there is sort of uncertainty about, you know about us, it's not like we just got some knowledge and now we want to spread it out, if I went back to my roads in South Africa, you know it's easy enough to get the roads out if you can because want do you need, some sort of surveying equipment, you know tar to put on the surface and some bulldozers and you just go there you know. In this case it's more like we're not quite sure how to make a road, do you see what I mean? So I mean for example there's a sort of argument recently about nutrition, how to treat malnutrition and there is people who aren't agreed about it, they weren't really understanding it so even we you know the HIFA people and CHILD people were very uncertain and argue among ourselves so we're not in a very good position to hand out.....So it is important but actually we also don't quite know how to do it.

So it's still a long way to go?

Well I haven't got the answer to that one because, what I would understand filtering to mean is that for children with diarrhoea say, which is one of the common causes of death of children because they die of dehydration, there is some you know harmful practices, like not giving the child any fluids because it would just make them poo more so let's stop all the fluids, that's harmful to the child, I think we're all agreed on that. So you want to filter that

160　out and you want to let go through well this is the best way to do it but then you come to details, like well should they get salts out of a packet, a special packet and mix it up with a quantity of water, now how do you measure the water? Is it like pints? Well not everybody seems to understand, you know some people think a pint is an ordinary beer bottle, a little beer bottle and some people think it's huge and so that all goes wrong, so then you'll say oh

165　no it's hopeless, you know let's give them, let's say you use a pinch of salt and a hand full of sugar but then if you let that message out somebody's going to put in a hand full of salt and a pinch of sugar instead of the other way around, which would be very bad for the baby. So this filtering is the hardest possible part of it and I mean we've got to try haven't we, but you know sort of designing a kind of network of road systems is one thing but when you've

170　actually got to decide what to put on the road it gets much harder. Filtering is still obviously very important but it's very difficult to get agreement about it.

8. In your opinion, what improvements can be made to HIFA2015/ CHILD2015 if they are to achieve their goal?

Well there is absolutely no doubt that what's really needed is at the moment is money. I mean

175　if you look at what's the....HIFA has certainly got some great strengths cause it's arisen from a few individuals and they're are not all in Britain by any means and librarians in Africa and India and it has formed this community which is not, which is a very good contrast to many things, it's not a set of people from industrialised countries telling other people what to do you know, it's a much more coligent, collaborative, equal kind of thing. So it's come from,

180　you could call it the ground up and so that's a big strength unfortunately it goes with weakness because things that come from the top-down actually have funded you know, the World Bank or something I mean they have enormous amount of money, and that's not their problem their problem is getting it to the ground you know. So in some ways HIFA is almost upside down compared with other projects. So in order to sort of get its balance it needs

185　central funding at the top you know, it's really the weaknesses that just a few people who are not being paid and have to find time from other things they do but trying to run it on nothing you know. It would need a few paid researchers, a bit of administrator staff, you don't want it top heavy like with an enormous steel and glass tower somewhere you know, full of people running around doing some quality control, accounting and things it's the complete opposite

190　of that. However, it needs some, it needs to attract some core funding, that's its big problem.

9. Again, from you experience working in South Africa what specific illnesses/ diseases have the potential to have the risk lowered through improved healthcare information?

195   Well the big killings of childhood, pneumonia, diarrhoea...maternity things you know, so mother don't die in childbirth as well as children themselves...malaria, some big infectious diseases, accidents are extremely important an obviously you'd hope some other things, HIV, tuberculosis, these are big diseases in which knowledge certainly plays a part and the chronic non clinical diseases like diabetes and so on not so clear really, it's not so clear how we can

200   actually practically prevent those. So I think the, I would personally go for sort of hoping for the clear cut and infectious ones first, you know diarrhoea and pneumonia and the accidents and maternal health would be first things, I mean one of the things that make a very big difference to child health is female literacy because you can see it has a connection with information but it's not a health information campaign to have schooling for everybody, so

205   it'll be completely impossibly and ridiculous for a small organisation can't do that, so the campaign to have all the women in the world literate which is a lot to do with culture and even religion a bit and so on and the equality for women and so on, these things are really really important and would make a huge difference to health. But I don't think its HIFA's brief to do that and if it tried to do too much it would actually achieve nothing probably. So it

210   needs to still keep its focus on what it's formed to deal with which is health information.

10. HIFA2015 is a campaign that shows initiative in improving the overall quality of all human beings. How important would you rate healthcare information in relation to improving human development? And Why?

215

Well, health itself improves human development. I think it's sort of two things, I think health itself, you know sick people can't develop things very well but also I think the mere process of learning, because after all inquiring information means learning doesn't it. So I think it has a wider affect even learning specifically about health, you're also learning about learning,

220   learning to change previously held beliefs things like that, so I think that in that sense it's all part of human development too. In other words, I'm saying the process of learning, of changing, of seeing different points of view which in this case is in the health field, it could be in another sector you could also say, suppose it was something different supposing we were talking about agriculture, you could say well development depends on specifically on

225 agriculture, you grow more potatoes then you have more potatoes....you grow flowers in Kenya and then you can sell them and so on. That's direct development but also the process of learning the technology of better potato production, more productive farming is also part of development itself, its part of the learning. So there are just as much outside of the agricultural sector just like some of what comes out of this is outside the health sector. So

230 although you don't, I mean I was saying in my previous reply that you need to maintain some focus on the subject and not sort of get into female literacy, you know let the educationalists do that, that's in their sector we're health they're education, at the same time when you concentrate on your own thing it does diffuse into other sectors. So you know health, improvement of health information does actually spill over into the education sector, well

235 improvement of agriculture spills over into the health sector and the education sector. So, actually these things need to go into different sectors, you just won't make that your primary aim it will happen anyway. So I think anything that is about humans teaching each other and learning from each other is intellectual development, which is development.

Appendix 5: Transcript of interview with Dr Neil Pakenham-Walsh, including questions:

1.   What is the background inspiration for beginning a healthcare information campaign?

Well, see three things that come to mind are sort of in sequential order because it's not one thing. When I was a medical student I went to visit a hospital in Djelfa, in Algeria. And I was actually visiting my mother, who was teaching English. It's a town on the edge of the desert
5   about 50 miles south of Algiers and I was really taken back by the total lack of reference and learning materials in the hospital. Then in 1986 and '87, I did some periods of being a rural clinical officer in rural Peru and Ecuador and I sort of experienced what it was like to be an isolated health worker. And then in 1994, I went to a conference at the British Medical Association about health information in the developing world and the point that really struck
10   me was that there were lots of people doing lots of different things to try to improve health information but there wasn't any mechanism for people to talk to each other. This was something at was picked up by others at the conference, and I was lucky enough to get the job to be the co-ordinator for a network at the 'International Network for the Availability of Scientific Publications' and we got some funding from Danida, which is the Danish
15   government. And then, in 2004 I was asked by Fiona Godlee to co-author a paper for, it was originally commissioned by WHO, and we wrote a shortened version for The Lancet and it was called 'Can we achieve health information for all'.

Yes, I've read that,

Yes, and in the paper we cause on WHO to champion the goal of health information for all
20   and to lead the campaign and they wrote a reply to that and in 2005 I set up a new organisation called 'Global Healthcare Information Network' to form the organisational basis for the campaign, which was then launched in 2006.

2.   How is progress within specific countries measured in relation to improving the distribution of healthcare information?

25   I think the short answer to that is it isn't. There are no, there is no single index of, there is no single number that you can assign to any country to say this is where there are with regards to access to health information. There are some, what you might call proxy indicators that sort of indirect indicators, I mean for example, you can have measurements of how active different countries are in terms of their research output, you can have numbers that tell you

30 what proportion of the population is connected to the internet. But they're really sort of quite distant to what we would like to have and there are very few data that are routinely picked up by countries that we can monitor that really show us what progress is being made.

3. What are the biggest challenges in achieving the HIFA2015 goal, for every person worldwide to have access to an informed healthcare provider?

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Thinking of this is two areas. One is, the areas that HIFA is particularly trying to tackle and that is that there is a general lack of communication between all the different stakeholders involved in information flow. So, there, an HIFA too, in a lack of a discussion platform for health professionals to exchange experience with publishers and librarians about how to
40 tackle this issue, it's a complicated issue. Similarly, there's a lack of understanding about health information needs of different groups of healthcare provider and how to meet those needs. So, there's an awful lot of people who are producing information without an understanding of the target audience, and then the third area is that there is lack of commitment by funding agencies and governments to actually tackling this problem of lack
45 of access to health information. So, those are the areas HIFA is especially looking at, but obviously there are some underlying big issues. I mean, from a point of view of information, I think the two main things are, technical problems and content problems. And the technical problems include things like, the connectivity or lack of it in developing countries, although that is clearly improving and the content problems relate to the issue that every person, every
50 health care provider or every group of health care provider needs a particular type of content that's packaged in a particular way that is relevant to their needs and is reliable. And that's a big issue. I mean there is a lot of content that is being available to health care providers or is being used by health care providers but it's either unreliable, i.e. for example it may be poorly put together or it may not be actually based on proper appreciation of the underlying
55 evidence or it may be irrelevant. And it may just simply be talking about things that the health care provider is unable to implement. I mean, most extreme is that you might have a text book that describes CT scans or something when being used in a primary health care setting. And of course, underlying all of this is the big social determinants of health, global poverty and so on, you have to keep in mind that those big issues are obviously a major, you
60 know are the underlying cause of all the other issues. So, yes, that's how I'd answer that one.

4. What progress has been made so far by HIFA2015 in improving information equality for all?

65 Well this is a little bit like question two. I think we don't know actually, because we don't have the adequate data to be able to measure a base line of information equality, so the...but an evaluation is being done, I mean it's worth pointing out here that an evaluation is being done at the moment, funded by the Rockefeller Foundation and the evaluation is attempting to look at what, the evaluators are attempting to look at what impact HIFA2015 itself is
70 having on improving access to information but it's really a difficult area to look at. It's well known that this whole business of impact of information with any initiative is a difficult thing to measure.

5. From the Steering Group meeting I heard about a virtual room being implemented,
75 **could you provide more details? And what are the hopes for the virtual room?**

This is a base for web conferencing, so it's being provided for us by the University of Iowa, and we can use the space free of charge and invite other people to join us on the website and we can have a discussion in real time with HIFA members or whoever. And, we can give
80 powerpoint presentations at the same time. It's a way of bringing HIFA members together to talk in real time rather than just by email.

6. What are the challenges the campaign faces as a non-profit organisation?

First the organisation is Global Healthcare Information Network, that's the legal entity that
85 runs the campaign. So the campaign is a project. The main challenge is it needs more staff. At the moment, there's just me, as a paid member of staff and we estimate that we need at least two or three staff to be able to roll out the strategy, because we have a strategy but we're simply unable to roll it out in full because of lack of staff. The strategy consists of running forums, which we're doing ok. Secondly, it consists of building a knowledge base on
90 information needs and how to meet them and that is...it's very limited because we don't have the staff to be able to pull that together, although it's happening this year. And the third area is in advocacy work and we've done some of that but again it's very limited because of lack of staff. It's quite an ambitious project, and we need three, we really need three full time staff equivalent to be able to delivery it properly.

95 **7. Another interesting point picked up in the Steering Group meeting was the idea of a 'social autopsy' could you further define this concept? And its importance/ relevance?**

Yes, a social autopsy is a description of what happens to a person in the hours or days or weeks leading up to their death. So, it's different from a typical autopsy that is simply
100 looking for the cause of death, you know the medical cause of death. So, what's different about social autopsy is you're finding out what it is, what was it that was actually happening that led step by step towards that person ending up dying. So for example, if you have a child that, a small child that is brought in dead, dying on the way to a clinic through dehydration due to diarrhoea, you could do a social autopsy on that child by interviewing the mother and
105 parents. Obviously there are a few sensitivities to this kind of work but it would be theoretically possible to pick up, for example, that a couple of days before the death the child had developed diarrhoea and the mother mistakenly believed that they should withhold fluids when the child does develop diarrhoea rather than actually provide more fluids or to maintain fluids, which is what you should do. So, that would make the child worse. It may be that the
110 mother at that stage did not recognise how ill the child really was, so she just carried on looking after the child, withholding the fluids and the child got even worse. Then the mother could think, well I must take this child to see somebody or the family may say we must take the child to see somebody but they may go to a traditional healer who gives the wrong treatment. And then at the end of the day, they may finally find a health worker but the health
115 worker may not recognise the severity of the problem or whatever. And so it's just there are all kinds of things that can cause, can make it more likely that somebody dies as a result of falling ill. I mean, if you look at a, if a mother in the UK gets into trouble during child birth then still it's extremely unlikely she'll die because they're health care providers that are around who know what to do and there is equipment that will help to save her life. But of
120 course in a rural village it's a different issue, and so the chances of dying in a rural area are vastly increased because of lots of other factors, not just knowledge obviously, but issues to do with transport and all sorts of things. So, it's very important because to understand social autopsy, to understand why people are dying is in many ways as important if not more so than to understand whether people they're dying of diarrhoea or pneumonia, you know the
125 medical diagnosis. Because if you understand what the steps are that are leading to death, there might well be things that you could, things that could be changed within those steps that

would have prevented the death happening. And those things may include, simply the person responsible for health care actually knowing what to do at the time.

8. In your opinion, what is the most successful healthcare information source for developing countries? Would this also differ between countries?

I'd say there's no single or most successful information source because every different group of health workers needs a different information source, so there's nothing that suits everyone. But I think the thing that comes closest to it is probably "Where There Is No Doctor", which is a publication for primary health care in low income countries and it's published in many different languages. I think, yes it does differ between countries but it also differs according to language and according to the level of healthcare you're talking about i.e. primary health care, district level and tertiary level and of course it depends according to the level of resources that are available in any place and it varies according to the educational level of the user. I mean, there's a big difference between the health information that a community health worker with only primary level education might have as compared with a nurse or a doctor.

What was the name of that publication?

"Where There Is No Doctor".

9. What is your opinion towards ehealth solutions? Can they be defined? Are they successful?

Well I think ehealth is the use of ICTs, information technologies or and health care generally. With regards to health information and availability of use of health information, I think the two most important areas are, Internet in general and mobile phones in particular in recent years, it seems that mobile phones have a huge potential and they've exploded in terms of the number of mobile phones across low income countries. It's, other technologies...I mean ehealth also includes the use of technology such as radio, but you know traditional technology, such as radio, television and so on and those also have an important, continue to have an important role especially for the public.

10. It is often argued a key part of information distribution is the filtering of information to suit the varying needs of the local communities from the information deprived countries. Do you agree or disagree with the importance of this? And why?

62

Yes, but it's...but with nuances. It's important that people are able to find what is relevant to them and I think that, I wouldn't so much use the term 'filtering' but simply to say what is it that can make it easier for people to find what is relevant and that can often mean helping using ICTs, for example, so that people can search on areas that are going to be relevant to

160   them and in different languages. But filtering suggests that, well there's a suggestion with the term filtering that we might be talking about, saying right we take this content and we only give access to, for the end user, we only give access to this little bit of it. So, I don't think there's any, there's nothing to be gained I don't think from some kind of blockage of information flows. But, if you think from the point of view of the needs of the user then....I

165   seem to be lost in my mind with this one. I mean, essentially it's all about understanding and meeting the information needs of the user, they need to be able to find the information that they need at any given time, so anything that can help them to do that is a good thing and I think it's worth pointing out that one of the big problems of information is information overload and so for almost everybody expect for the most isolated there is indeed a huge

170   overload of information that they can get hold of, especially if you have access to the Internet. And it's difficult, if not impossible for people to work out what is actually reliable information and what is actually misleading information, difficult in developed countries and developing countries. So anything that helps people to understand what is reliable for them is important and also anything that helps them to get what is relevant is important. If they don't

175   speak English, then it's helpful if there is a way of enabling them to find materials in their own language, for example.

11. Does HIFA2015 have a process of transferring and filtering healthcare information from the global to the local communities?

The members, many of the members are involved in this kind of work, the individual

180   members and their organisations. It's worth pointing out that there is over 2000 organisations represented across HIFA, but HIFA itself is not a health information provider it's a campaign and a knowledge network for discussion about how to transfer and filter health care information if you like.

12. What are the overall benefits of improved healthcare information?

185   If you're a health worker or somebody responsible for the care of somebody else who requires health care, then you need certain things to be fulfilled in order to be able to provide effective care for that person and we use the term 'seismic' as an acronym for the needs of a

healthcare provider to provide effective care and that's down to: skills, equipment, information, structural support, medicines, incentives and communication facilities. Now if
190 you a health care provider and you don't, and you lacking in one or more of those areas, you will be comprised in your ability to provide effective care and one of those items was information so a health care provider needs to have access to health care information in order to be able to provide effective care. So that information may be in the form of actual something they can refer to at the point of care or it may indeed be something they have
195 previously referred to or picked up in some way and it has then instilled their knowledge in their mind. So there's information that is external or their own knowledge which involves previous exposure to information and if that information has been false, you know there are lots of miss and incorrect beliefs about health in various cultures well worldwide. If the...you know so information can be actually harmful as well as beneficial with respect to the final
200 outcomes of what happens to the patient as a result of the behaviour of health care provider based on their beliefs and their knowledge.

13. How important is the monitoring and evaluation aspect of the campaign in keeping on target with the goals?

Well, it is very important obviously, we need it to be able to improve the campaign so we
205 need to find out what is it in the campaign that is working well and what's working not so well so that we can improve it in the future. We also need it to demonstrate hopefully that we are having a positive impact on individual members and also on hopefully the actual health information situation globally and in different countries because if we can demonstrate that impact then of course we will be much more likely to attract increased funding in the future
210 which is what we need to be able to push up our staffing to two or three people. And also we're...our whole approach is quite innovative in that we are, we're basically testing an approach whereby we're bringing together thousands of people to discuss and address a complex health challenge and if we can show that this approach is effective then this kind of approach could be replicated/ adapted for other areas of health and international
215 development. So in other words there is a whole area of global interest which is probably up your street Sophie, which is to do with communications for development and HIFA2015 is an example of a communications for development initiative looking at the possibility of bringing together a large number of people to help address a complex problem. And this is where it comes back to our strategy because we think that in order for people to contribute
220 meaningfully to address a big complex problem like this you need to have, some point you

need to bring people together and have them discuss the issues. Secondly you need to be able to actually identify the useful things that people are saying in those discussions and organise those things in a way that could be used by other people, by researchers and by other health information services in the future and that's the aim of our knowledge base. Our knowledge base is aiming to capture the key points that are being made in the HIFA2015 discussions by different stakeholders and to put those into a database that is organised in such a way that it will build a picture that can be tapped into by researchers, policy makers and information professionals.

14. HIFA2015 is a campaign that shows initiative in improving the overall quality of life for all human beings. How important would you rate healthcare information in relation to improving human development? And why?

Well this links a little bit with a previous question, question twelve I think. HIFA2015 is based on human rights. Now one of the most important human rights is the right of access to healthcare and inherent in that is not just any healthcare because it's clear that a lot of people especially in developing countries and especially the poor, even if they do have access to healthcare the quality of that healthcare maybe...sometimes is ineffective and sometimes can actually cause even more harm to those people. And this is something that is shocking and unacceptable globally, so improving the availability and use of relevant and reliable healthcare knowledge is a critical part of enabling health workers, healthcare providers to deliver the effective care that is the right of every human being and it seems to me and many others that it's a great injustice that we spend so much on medical research and health in the developed world and that so little of the benefits of health research actually reach people who need them and leading in turn to huge differences in the quality of care and early death for many children and adults. I think availability and use of healthcare information has a huge role to play in that.

15. Lastly, could you provide details of your other organisation GHI-net? And what is the relationship between GHI-net and HIFA2015?

GHI-net was the organisation that was established in 2005, as the organisational basis for HIFA2015. So HIFA2015 is a project administered by GHI-net.

So do GHI-net deal also with healthcare information or broader issues of healthcare?

Well we have a vision mission and all that in relation to our...I mean the main purpose of
255 establishing GHI-net was to simply form an organisational basis for the campaign. Because
you can't form a campaign out of thin air you have to have an organisational basis for it. But
we also specialise if you like in the area of fostering networks and so as you'll have seen
we've now been involved in fostering global networks, several different networks so there's
HIFA2015 which is administered by GHI-net, CHILD2015 is administered by in
260 collaboration with the international child health group of the Royal College of Paediatrics and
there's HIFA-Portuguese and HIFA-Evipnet-French which are both collaborations with
WHO and then we're about to launch HIFA-Zambia in collaboration with the Zambia UK
Health Workforce Alliance. So GHI-net is a tiny organisation, it's just myself and two other
directors, one of them is Rachel Stancliffe who used to work for 'Update Software' which
265 produced the clock room collaboration and she's now herself director of the 'Greener
Healthcare Campaign' based in Oxford and the other director is Fred Bukachi who...you'll be
meeting both of them on the 9th May [HIFA2015 conference] and Fred used to live in the
UK, which is how I got to know him, he's a cardiologist from Kenya and he's been back in
Kenya for the last couple of years and he's got a special interest in the use of information
270 technologies in health. So we've known and worked with each other for ages, when I used to
work for INASP, the International Network for Availability of Scientific Publications, we did
a lot of work together with other people as well, you know obviously, so in 2005 after the
publication of the article 'Can we achieve health information for all', we decided that is was
time for us to get something sorted out and get this campaign off the ground.

Appendix 6: Notes gathered from overt participant observation at the 26th Steering Group Meeting:

HIFA-Portuguese

- Steadily growing, Neil as moderator
- Proactively inviting people to join
- Locate health information, and training in librarianship
- 8 Portuguese speaking countries
- Training of trainers initiative
- Challenge for the year – increase the number of members, increase in the countries with a low number of representatives
- Objectives- create a people who are representing both discussions
- Sometimes the discussions are too diverse- needs to be refined
- Representatives from all the 5 countries in Africa
- 2 pages in the e-journal – publish on a regular basis
- 3 medical journals in Portuguese countries
- Building more infrastructure- low connectivity but will be able to publish
- Electronic journal in information communication in health
- Country representative initiative
- Complex
- Pushing HIFA representatives in countries

HIFA-Evipnet-French

- 136 members at the moment
- Distribution of research- better organised
- How to find a way to promote research at district level
- Good sharing between the countries

- Monitoring and evaluation- assessing the value of HIFA2015 on information, communication and advocacy on health issues
- Large email forums HIFA-pt and HIFA-Evipnet-French
- Share methodologies on how to produce journals for policy makers
- Qualitative research, to disseminate this type of research

- How to spread this information
- Not just international and national level but also those on the ground (local level)
- More ways of promoting research on the ground
- Reduce the minimum of understanding

HIFA Event May 9th 2011

- Put a cap on the 150 mark for attendance
- Exhibition material for supporting organisations
- When to invite the media
- Contact 'The Lancet'
- BMA news to cover the event
- Funding- will cost a total of £4000

HIFA-Zambia

- 50/60 people attending the launch
- Moderator training
- This launch is the first country focus, global network within a country focus
- If works well could be adapted to other countries- anyone with an interest in improving healthcare information
- HIFA challenge (annual challenge)

The Knowledge Base

- Collaboration with the Norwegians
- Project to run through till September
- Change in the functions of HIFA knowledge base- put in the HIFA lumps (re-organised information from the email forums)
- Advocacy effects have previously been quite weak- as an extra data source
- Compliments- coming from the messages rather than the published literature
- Innovative approach, new kind of data- organising data would be more powerful and one of the first campaigns to do

HIFA- monitoring and evaluation

- Evaluation- fill in the survey

- This is how they monitor their progress

- Focused on progress/ process and informative evaluation

- Mid-term report around the time of the event

Fundraising and Marketing

- Donations are always welcome

- What is the next stage of the Rockefeller initiative?

- Maybe a corporate supporting organisation structure....?

- All supporting organisations comes with perceived strings even if they try to disguise it

- HIFA global networks as an over arching brand

- Build our own capacity for press releasing

- Interesting how the dynamics change when profit is not an incentive

- The campaign is based around the work of volunteers, how to keep the momentum up?

- Amazing how the campaign has grown, from non-profit

HIFA Challenge Working Group Meeting:

- "Social autopsy"- evaluation of the contribution to a death, the (social?) events surrounding a death, these deaths are usually preventable

- An area of particular interest, in the healthcare needs of the developing world, is chosen every year to be the challenge- what the impact is, of not having the basic healthcare knowledge

- Deaths occurring because the caregiver did not know when and where to seek help

- Previous challenges- 2008, 2009, 2010

- Literature Review- formulate a research strategy, the information needs of mothers and caregivers (current challenge) and how to meet them

- Recognise it is a big, with low capacity, heavy workload for the campaign volunteers

- The campaign wants to broaden dialogue with supporting organisations

Forward Planning

- Lit review for current challenge

- 'Social autopsy'

- International patients association/ organisation

- Reach out to Mums net (based in the UK?) but probably have partners in the UK
- National family care giving association
- Gathering contacts, HIFA2015 itself is building a global network of networks
- HIFA 2011 challenge is to do with insuring that if a child, or mothers are sick in the home, they will have the correct knowledge to make live saving decisions
- Empowering citizens to have the knowledge to make sufficient decisions to potentially save lives
- 'Meeting the information needs of the home'
- Each challenge needs a leader- someone who has a professional background in the subject area to be the leader and over see the progression
- All challenges run up to 2015
- Have to keep the momentum up
- Draft templates what constitutes a challenge to give to all the challenge leaders as guidelines
- Build an advocacy paper for each challenge based on the literature review and the discussions from the forums
- Virtual room- members can communicate in an instant forum in real time
- Build an email discussion forum based on HIFA2015 challenges
- An opportunity of development
- Just begin with working on implementing these changes to two of the challenges to not overwhelm the work load
- Engage and energise
- 104 supporting organisations, a supporting organisation is one who publicly supports the campaign
- Build a criteria for supporting organisations to be able to differentiate between those who are committed from those who are less committed