



# DEFINING AND NEGOTIATING THE SOCIAL VALUE OF RESEARCH IN PUBLIC HEALTH FACILITIES: PERCEPTIONS OF STAKEHOLDERS IN A RESEARCH-ACTIVE PROVINCE OF SOUTH AFRICA

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## Keywords

social value,  
collateral benefits,  
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## ABSTRACT

*This article reports on qualitative research conducted in KwaZulu-Natal, South Africa, among researchers and gate-keepers of health facilities in the province. Results suggest disparate but not irreconcilable perceptions of the social value of research in provincial health facilities. This study found that researchers tended to emphasize the contribution of research to the generation of knowledge and to the health of future patients while gate-keepers of health facilities tended to emphasize its contribution to the healthcare system and to current patients. Furthermore, relations between research stakeholders were perceived to be somewhat fragile, making it difficult for stakeholders to achieve consensus about the social value of research, as well as on ways to maximize value. Interventions to negotiate a shared perspective on the social value of research would appear to be warranted, and the findings of this study suggest some focus areas for such intervention.*

## BACKGROUND

The social value of research has emerged in recent decades as an important criterion for ethical research. In early guidelines the social value of research was only briefly alluded to and the reader was left to operationalize the concept. Amongst earlier ethics guidelines, it is perhaps the Nuremberg Code (1947)<sup>1</sup> which best identifies social value as desirable, and defines valuable research most clearly as that which yields ‘fruitful results for the good of society, unprocurable by other methods or means of study, and not random and unnecessary in nature’. Although not expressly identified as the standard of social value, this definition is echoed in the International Ethics Guidelines for Biomedical Research

involving Human Subjects (‘CIOMS guidelines’) of 2002,<sup>2</sup> as a requirement for ethical research, while the new draft (not yet finalized) explicitly lists social value as the first guidance point for ethical research.<sup>3</sup>

In recent years, the concept of social value has been more clearly articulated and elaborated upon as an ethical requirement of research in the frame-

<sup>2</sup> Council for International Organizations of Medical Sciences (CIOMS) (2002). International Ethical Guidelines for Biomedical Research Involving Human Subjects. Available at [http://www.cioms.ch/publications/guidelines/guidelines\\_nov\\_2002\\_blurb.htm](http://www.cioms.ch/publications/guidelines/guidelines_nov_2002_blurb.htm) Accessed on 2 November 2016.

<sup>3</sup> Council for International Organizations of Medical Sciences (CIOMS) (2015). International Ethical Guidelines for Biomedical Research Involving Human Subjects. Available from <http://www.cioms.ch/index.php/12-newsflash/394-the-public-consultation-on-ethical-guidelines-is-now-closed>

<sup>1</sup> The Nuremberg Code 1947. *BMJ* 1996; 313: 1448.

work provided by Emanuel and others.<sup>4</sup> Within this framework, the concept has evolved over time. In the first iteration,<sup>5</sup> the social value of research was defined as being the ‘enhancements of health or knowledge... derived from the research’ which reflects the implied definitions in major international guidelines such as the Nuremberg Code<sup>6</sup> and CIOMS guidelines.<sup>7</sup>

In subsequent elaborations of Emanuel’s framework<sup>8</sup> the essence of this first definition of social value was retained but important qualifications were introduced in the benchmarks (discussed in more detail later). These benchmarks recognize that social value is likely to be conceptualized and measured differently by different beneficiaries of research, and that value in research is not a constant – it can both be enhanced and undermined by factors within or external to the research process. The benchmarks are crucially important for specifying social value and reflect the complexity of applying any ethical standard in various socio-cultural contexts, including the standard of social value. It could be argued that there are objective indicators of whether research has social value, such as disability and quality adjusted life years, or whether it corresponds to national health priorities. Yet it is also possible, even likely, that various research stakeholders will judge the social value of a study differently, pointing to the elements of value that are subject to social context.<sup>9</sup> Such differing judgements may reflect the interests of specific social groups that may have diverging perspectives, needs and priorities.<sup>10</sup>

<sup>4</sup> E.J. Emanuel, D. Wendler & C. Grady. What makes clinical research ethical? *JAMA* 2000; 283: 2701–2711; E.J. Emanuel et al. What makes clinical research in developing countries ethical? The benchmarks of ethical research. *J Infect Dis* 2004; 189: 930–937; E.J. Emanuel, D. Wendler & C. Grady. 2008. An ethical framework for biomedical research. In *The Oxford Textbook of Clinical Research Ethics*, E.J. Emanuel et al. New York: Oxford University Press.

<sup>5</sup> Emanuel, Wendler & Grady. 2000, *op. cit.* note 4.

<sup>6</sup> The Nuremberg Code 1947. *BMJ* 1996; 313: 1448.

<sup>7</sup> Council for International Organizations of Medical Sciences (CIOMS) (2002). International Ethical Guidelines for Biomedical Research Involving Human Subjects. Available at [http://www.cioms.ch/publications/guidelines/guidelines\\_nov\\_2002\\_blurb.htm](http://www.cioms.ch/publications/guidelines/guidelines_nov_2002_blurb.htm) [accessed 2 November 2001].

<sup>8</sup> Emanuel et al. 2004, *op. cit.* note 4; Emanuel, Wendler & Grady 2008, *op. cit.* note 4.

<sup>9</sup> P.W. Geissler 2011. Studying Trial Communities: Anthropological and Historical Inquiries into Ethos, Politics and Economy of Medical Research in Africa. In *Evidence, Ethos and Experiment: the Anthropology and History of Medical Research in Africa*. P.W. Geissler & C. Molyneux, eds. New York: Berghahn Books; 2011. Available from: <http://www.ncbi.nlm.nih.gov/books/NBK184571/>

<sup>10</sup> D.R. Wassenaar & N. Mamotte. 2012. Ethical issues and ethics reviews in social science research. In *The Oxford handbook of international psychological ethics*. M. Leach et al., eds. New York: Oxford University Press: 268–282.

There is much literature on the importance, and *process*, of eliciting such views from various stakeholders or ‘communities’, particularly in relation to HIV research.<sup>11</sup> There have also been several studies investigating the related concept of research benefits.<sup>12</sup> To date, however, much of the literature has tended to define the inherent value of research according to its contribution to new knowledge, and this has been the point of departure for empirical studies on this subject.<sup>13</sup> Our study underscores that this ‘traditional’ definition of value is not always shared by key research stakeholders, and interrogates the opinions of both researchers and non-researchers around this concept.

<sup>11</sup> M.O. Folayan et al. Debating Ethics in HIV Research: Gaps between Policy and Practice in Nigeria. *Dev World Bioeth* 2015; 15(3): 214–225; M.O. Folayan, K.S. Oyedemi & O.A. Fatusi OA. Community Members’ Engagement with and Involvement in Genomic Research: Lessons to Learn from the Field. *Dev World Bioeth* 2015; 15(1): 1–7; D. Allman, M.H. Ditmore & K. Kaplan. Improving Ethical and Participatory Practice for Marginalized Populations in Biomedical HIV Prevention Trials: Lessons from Thailand. *PLOS ONE* 2014; 9(6): e100058. doi:10.1371/journal.pone.0100058; K.F. King et al. Community engagement and the human infrastructure of global health research. *BMC Med Ethics* 2014; 15: 84. DOI: 10.1186/1472-6939-15-84; J. Koen et al. ‘It Looks Like You Just Want Them When Things Get Rough’: Civil Society Perspectives on Negative Trial Results and Stakeholder Engagement in HIV Prevention Trials. *Dev World Bioeth* 2013; 13(3): 138–148; K.M. MacQueen et al. 2012. Stakeholder Engagement Toolkit for HIV Prevention Trials. FHI 360. Available at <https://www.fhi360.org/resource/stakeholder-engagement-toolkit-hiv-prevention-trials>; UNAIDS/AVAC (2011). Good participatory practice: Guidelines for biomedical HIV prevention trials. Joint United Nations Programme on HIV/AIDS (UNAIDS). Geneva, Switzerland. Available at [http://www.unaids.org/en/resources/documents/2011/20110629\\_JC1853\\_GPP\\_Guidelines\\_2011%20OK](http://www.unaids.org/en/resources/documents/2011/20110629_JC1853_GPP_Guidelines_2011%20OK); M. Ukpong & K. Peterson 2009. Oral Tenofovir Controversy II: Voices from the Field: A series of reports of the Oral Tenofovir Trials from the perspectives of Active Community Voices engaged on the field in Cambodia, Cameroon, Nigeria, Thailand and Malawi. *NHVMAS* 2009; P.O.Tindana et al. Grand Challenges in Global Health: Community Engagement in Research in Developing Countries. *PLoS Med* 2007; 4(9): e273. doi:10.1371/journal.pmed.0040273

<sup>12</sup> D.M. Kamuya et al. ‘When they see us, it’s like they have seen the benefits!’: experiences of study benefits negotiations in community-based studies on the Kenyan coast. *BMC Med Ethics*. 2014; 15: 90. doi: 10.1186/1472-6939-15-90; G.M. Lairumbi et al. Forms of benefit sharing in global health research undertaken in resource poor settings: a qualitative study of stakeholders’ views in Kenya. *Philos Ethics Humanit Med*. 2012 Jan 17; 7: 7. doi: 10.1186/1747-5341-7-7; G.M. Lairumbi et al. Stakeholders understanding of the concept of benefit sharing in health research in Kenya: a qualitative study. *BMC Med Ethics*. 2011; 12: 20. doi: 10.1186/1472-6939-12-20; S. Molyneux et al. Benefits and payments for research participants: Experiences and views from a research centre on the Kenyan coast. *BMC Med Ethics* 2012; 13: 13; DOI: 10.1186/1472-6939-13-13

<sup>13</sup> G.M. Lairumbi et al. (2008). Promoting the social value of research in Kenya: Examining the practical aspects of collaborative partnerships using an ethical framework. *Soc Sci Med* 2008; 67: 734–747

## AIMS

This article reports on a subset of data from a qualitative study exploring perceptions of research conducted in provincial health facilities in KwaZulu-Natal, South Africa.<sup>14</sup> KwaZulu-Natal is an appropriate location for such research, because its population is heterogeneous, and it has for the past few decades been the focus of intense health research activity, primarily in the fields of HIV/AIDS and TB. Research in this province has informed clinical treatment protocols and the development of new treatments for these diseases.<sup>15</sup>

The study participants were managers in the provincial government's Department of Health (DoH), and researchers both internal and external to the Department. DoH managers control access by researchers to provincial health facilities and are among those stakeholders who are likely to use the results of research.<sup>16</sup> Varying notions of 'valuable' research in provincial health facilities emerged as a key theme, as reported and discussed below.

## METHODS

Semi-structured in-depth interviews were conducted with two critical stakeholder groups: firstly, researchers (both those external to the DoH who conduct health research within DoH facilities as well as doctors employed by the DoH who conduct research as part of their clinical work) and secondly, managers of health programmes or health facilities ('gate-keepers' – DoH employees who provide permission for researchers to access these health facilities in order to conduct their research).

Purposive sampling was used, which involves choosing participants who may provide rich, diverse and relevant information about the study question.<sup>17</sup> Health managers from high-volume research facilities or programmes, and researchers active in provincial health facilities were invited to take part in the study. There was only one refusal to participate. All interviews were conducted by

the principal investigator. Sixteen interviews in total were conducted – seven with health managers and nine with researchers.

Interviewees were asked about their perceptions and experiences of research in provincial health facilities, including their perceptions about 'good', 'useful' or 'valuable' research in such facilities, their perceptions about the importance of research in such facilities, their perceptions about whether research in such facilities improved health/health care, and their perceptions about what factors facilitated or undermined such research. Individual informed consent was obtained for interviews, and interviews were recorded with the informed consent of interviewees, and transcribed. The study was located broadly in an interpretivist perspective which focusses on the meanings and perceptions people attach to conduct.<sup>18</sup> Transcripts were analysed using Thematic Analysis.<sup>19</sup> Codes were assigned to text that were deductive (i.e. emerged from relevant literature and ethical guidance such as the Good Participatory Practice Guidelines for Biomedical HIV prevention trials),<sup>20</sup> as well as inductive insofar as they emerged from engagement with the transcripts. Codes that shared a relationship were linked to create coherent categories or code-clusters or themes – namely a 'patterned response' that captures key aspects of the data in relation to the study question.<sup>21</sup> The first and second authors coded several transcripts independently, and discussed their emerging codes to inform the development of a joint coding scheme, which was used to code later transcripts. It has been argued that if the approach is interpretivist then strict inter-rater reliability checks are not appropriate;<sup>22</sup> rather, efforts were made to resolve coding differences by 'reconciliation discussions'.<sup>23</sup> The exact number of interviewees holding a certain view was generally not reported,<sup>24</sup> because this was an exploratory qualitative study; instead the

<sup>14</sup> E. Lutge E. Perceptions and practices regarding research in provincial health facilities in KwaZulu-Natal, South Africa. Thesis for partial fulfilment of Masters of Social Science in Research Ethics through the University of KwaZulu-Natal

<sup>15</sup> F. Tanser et al. High Coverage of ART Associated with Decline in Risk of HIV Acquisition in Rural KwaZulu-Natal, South Africa. *Science* 2013; 339 (6122): 966–971. [DOI:10.1126/science.1228160]; Q.A. Karim et al. Effectiveness and safety prevention of HIV infection in women. *Science* 2010; 329(5996): 1168–1174.

<sup>16</sup> S. Singh & D.R. Wassenaar. Contextualising the role of the gate-keeper in social science research. *S Afr J BL* 2016; 9(1): 42–46. DOI:7196/SAJBL.465.

<sup>17</sup> A. Tong, P. Sainsbury & J. Craig. Consolidated criteria for reporting qualitative research (COREQ): A 32-item checklist for interviews and focus groups. *Int J Qual Healthcare* 2007; 19(6): 349–357.

<sup>18</sup> P. Ulin, E. Robinson, E. Tolley & E. McNeill. 2002. *Qualitative methods: A field guide for applied research in sexual and reproductive health*. Research Triangle Park, NC: Family Health International.

<sup>19</sup> V. Braun & V. Clarke. Using thematic analysis in psychology. *Qual Res Psychol* 2006; 3 (2): 77–101. ISSN 1478-0887,

<sup>20</sup> UNAIDS/AVAC (2011). Good participatory practice: Guidelines for biomedical HIV prevention trials. Joint United Nations Programme on HIV/AIDS (UNAIDS). Geneva, Switzerland. Available at [http://www.unaids.org/en/resources/documents/2011/20110629\\_JC1853\\_GPP\\_Guidelines\\_2011%20OK](http://www.unaids.org/en/resources/documents/2011/20110629_JC1853_GPP_Guidelines_2011%20OK)

<sup>21</sup> J. Green et al. Generating best evidence from qualitative research: the role of data analysis. *Aust N Z J Public Health* 2007; 31(6): 545–50.

<sup>22</sup> L. Yardley. 2008. Demonstrating validity in qualitative psychology. In *Qualitative psychology: A practical guide to research methods*. J. Smith, ed. London: Sage: 235–268.

<sup>23</sup> R. Boyatzis. 1998. *Transforming qualitative information: Thematic analysis and code development*. London: Sage: 152.

<sup>24</sup> M.N. Marshall. Sampling for qualitative research. *Fam Pract.* 1996; 13(6): 522–525.

reporting convention of 'some', 'many', 'most' or 'all' was used.

The study was approved by the Human Sciences Research Ethics Committee of the University of KwaZulu-Natal (reference HSS/1570/014M) and by the KwaZulu-Natal DoH (reference HRKM333/14).

## RESULTS

Study findings are set out under two main, related themes below.

### Theme 1: Varying perceptions of the social value of research

This theme reports on participants' perceptions about what makes research in public health facilities valuable. All interviewees perceived that research in public health facilities was potentially socially valuable. Respondents were generally enthusiastic about the potential for research to improve health and health care, as this researcher and health manager say:

*(Health Research is) extremely important. I think it makes [a] massive difference to public health (Researcher, interview 2).*

*We have benefitted directly as a province. Clinical outcomes have improved as a result of research – these improvements we can prove are as a result of research (Health Manager, interview 6).*

However, the elements of research perceived as most valuable tended to vary according to the role of the interviewee. More specifically, most researchers tended to perceive the social value of research in provincial health facilities as residing in its contribution to knowledge, and to future beneficiaries through its effect on policies and protocols, as exemplified in the following quote:

*I mean, we're in the business of providing evidence that will inform policies and decisions so it's critical. (Researcher, interview 3).*

On the other hand, many health managers tended to assign weight to other kinds of perceived benefits, such as human resource development and capacity-building for health workers, as well as building infrastructure. As one health manager said:

*But for me it will even improve the health system more if the skills are also imparted on the people that do day to day work' (Health Manager, interview 1).*

Almost all health managers perceived research as less valuable when it appeared to detract from the healthcare system by using resources meant for current (non-research) patients:

*I think the biggest problem ... [is] where they assume that once the research is approved they can use resources of the hospital for the research and the sponsorship doesn't get used up and I tend to wonder where that money then goes... (Health Manager, interview 7).*

*...we always have a problem with beds for patients but then I discovered there are a number of beds that are reserved for just clinical trials and I don't think that's fair (Health Manager, interview 1).*

Some health managers perceived the value of research in provincial health facilities as located in the potential benefits to the healthcare system, i.e., they tended to value research that would lead to improved operations, improved functioning of the healthcare system or improved patient outcomes:

*The positive (research project) is where operational research is conducted, where it will make us re-think the way we do things (...) I love (these research projects) because they are also simple and even simpler to implement the recommendations. [Health Manager, interview 1].*

*Research and practice and clinical outcomes go hand in glove – if you leave out one and think you can survive without it we will have problems' [Health manager, interview 6].*

Over half the researchers recognized concerns about resource-use and the importance of investing in health infrastructure and support for patients (such as computers for hospital wards, blankets for patients).

*If we are running a research project in the facility we provide our own staff, we provide our own resources, and in fact almost on a compassionate basis - we provide additional resources to the facilities' (Researcher, interview 3).*

However, about a third of researchers questioned the degree to which expectations of material investment were appropriate and questioned the limits of such investments:

*I'm not a bank and I am unable to utilize the sponsor as a bank ... I completely understand that somebody is coming with fancy whatever it is - nice computers and we [the researchers] have an office and their [government] staff is crowded and so I do know that it's a fine balance to work (Researcher, interview 10).*

Almost half the researchers perceived that certain gate-keepers to health facilities appeared not to value research in the same way, or according to the same criteria that they did (i.e., they did not attach as much importance to the knowledge-generation component). For example, one researcher said:

*Last thing that I find er extremely frustrating is er there's not a a sense of importance er associated with research... (Physician researcher, interview 2).*

## Theme 2: Relationships between researchers and gate-keepers

This theme reports on perceptions of the relationships between researchers and the gate-keepers of health facilities in the province.

Inter-stakeholder relationships were characterized as somewhat mistrustful, which appeared partly linked to differences in perceptions about the value of research. Some of the researchers interviewed felt that gate-keepers to health facilities did not value research in the same way that they did. For example, these researchers said:

*There's often conflict between research staff and facility staff because it [research] is seen as an extraneous activity so it's always been an issue. (Researcher, interview 5).*

*...it's sort of antagonism towards researchers and to some extent it's being carried on ... just a slight antagonism to the researchers instead of embracing them (Researcher, interview 12).*

The different value assigned to research by some gate-keepers might be attributable to inadequate understanding of the research's scientific merits and purpose, as reported by one gate-keeper and echoed by two researchers. This inadequate understanding reportedly impacted managers' ability to engage with researchers and to impact on the health research agenda, as shown in the quotes below:

*...because for me it's one of those things where I'm like 'why are we even doing this' but then again [it's] just me - as a programme person I have not much research experience. (Health Manager, interview 1).*

*They [health workers and managers]...they don't understand that [the study results] so we need to, as researchers, to come up with a better way of explaining things and I'm not sure if that's necessarily possible' (Researcher, interview 3, page 6).*

Certain health managers also questioned researchers' motivations in conducting the research in the first place:

*I think from all research that are coming probably about 25-30% truly have an intent of improving services or having some sort of benefit for the department whereas that remaining 75% or so is mainly to get the MMed or that primary degree... (Health manager, interview 7).*

*They are doing their career pathway... (Health manager, interview 8).*

Researchers were reportedly perceived as having generous budgets yet could not be trusted to distribute

resources appropriately (*'So the perception is that it's a money making business...'* (Researcher, interview 5).

In some cases, both researchers and health managers bemoaned the poor dissemination of research results to and by senior health officials, and blamed each other for this.

*So from my experience I have received only three report(s) out of maybe 100 research (projects) and mainly (they come) from [names one organization], the one I spoke about ... (Health Manager, interview 8).*

*We don't get any feedback whatsoever. No one ever does ... Unfortunately they even go and publish information but we as the people who gave permission for the study don't even get to see the outcome of the research (Health manager, interview 7).*

*... when it gets published we send ah the publication to the facility but no one actually reads that (Researcher, interview 5).*

Thus, most participants interviewed here perceived relations between researchers and facility managers in provincial health facilities as characterized by some mistrust. Some of the strain in relationships appeared linked to varying perceptions about what makes research in public health facilities valuable, and what benefits accrue to various parties as a result of research.

## DISCUSSION

This study found that researchers and facility managers tended to have different perceptions about what makes research in public health facilities valuable. These varying perceptions seemed linked to strained relations between them, which may impact on these stakeholders' ability to negotiate a shared vision of socially valuable research, and to develop and execute robust results-dissemination plans. These two main findings are discussed in terms of the theoretical literature and other studies below.

### Varying perceptions of social value

Many researchers tended to emphasize the benefit to future persons arising from information yielded by research, while many health facility managers ('gate-keepers') tended to invoke the importance of human-capital development and infrastructure development associated with research. This resonates with a distinction drawn by King<sup>25</sup> who noted various forms of benefit arising from research, including benefit that accrues to *future persons and society* arising from the research

<sup>25</sup> N. King N. Defining and Describing Benefit Appropriately in Clinical Trials. *J Law Med Ethics* 2000; 28: 332-343.

results (termed ‘aspirational’ benefit) as well as benefits that accrue to *participants* from the research protocol (e.g. better clinical monitoring/diagnostic tests) or from extras (e.g. free care) (termed ‘collateral’ benefit). King noted that participants’ motivations for enrolling in research may sometimes be rooted in desire for ‘collateral’ benefits. Our findings suggest that facility managers’ motivations for supporting research may *also* be somewhat rooted in the hope of collateral benefits – not for themselves directly but rather for the healthcare system within which they work. While so-called ‘collateral benefits’ were not assigned the same primacy of importance by most researchers in this study, several researchers recognized this perspective and reported trying to build some capacity or infrastructure-development into their research. However, some researchers questioned whether expectations in this regard were always reasonable, and this may also have undermined the quality of their relationships with gate-keepers.

Empirical studies in other low resource settings show that the ‘collateral benefit’ of research may be valued as highly as its ‘aspirational benefit’ by stakeholders such as the leaders of institutions involved in research,<sup>26</sup> and by fieldworkers in research projects.<sup>27</sup> In these qualitative studies, the distribution of benefits through research was considered vitally important as a means to address social justice. Lairumbi and colleagues<sup>28</sup> further argue that the benefits of research may be seen as a ‘lens through which to reflect on the social values that may be expected to inform the ethical acceptability of global health research in poor settings’.

Benefits such as capacity-building and infrastructure-development are included in accounts of *social value* in later versions of the Emanuel framework. More specifically, in the 2004<sup>29</sup> and 2008<sup>30</sup> versions it is stated that socially valuable research should not detract from existing health services and infrastructure, and should, if possible, supplement the existing health system through ‘the provision of additional resources, equipment, medications, or training...’ Also, in the 2004 and 2008 versions, they underscore the principle of ‘collaborative partnerships’ as a requirement for ethical research and as necessary for research to achieve its social value. They

define ‘collaborative partnerships’ as (amongst others) shared responsibility for assessing the social value of research, and sharing of benefits. So called ‘collateral benefits’, such as building infrastructure and human capital, are therefore viewed by Emanuel and colleagues as an intrinsic part of the *social value* of research as well as of the ‘*collaborative partnerships*’ between those undertaking the research.<sup>31</sup>

The idea that such benefits *should* be part of the value calculation of research resonates with empirical viewpoints described here, namely that benefits such as training and infrastructure development are a key part of valuable research. That is, this study found that so-called ‘collateral’ benefits are viewed as an inherently valuable component of research by important role-players in public health facility research. As for Lairumbi<sup>32</sup> and Kamuya<sup>33</sup> in Kenya, the importance assigned to such benefits is perhaps understandable in the context of the resource-constrained public health environment in countries like South Africa,<sup>34</sup> and in the context of profound economic inequality as seen in South Africa.<sup>35</sup> Perceptions of the ample resources of researchers and their institutions may incline health managers to emphasize sharing of such resources as an essential part of the research process. Some commentators have argued that research initiatives should attempt to offset at least some health injustices<sup>36</sup> and take steps to ameliorate inequitable social circumstances;<sup>37</sup> these opinions resonate with the views advanced by some stakeholders in this study.

Some of the views advanced here echo recommendations made in a framework called the ‘Fair Benefits’ approach – namely that ‘communities’ (admittedly not ‘gate-keepers’ *per se*) *should* bargain with investigators for a wide range of benefits<sup>38</sup> including ‘collateral health services’ (additional services for the population) and ‘capacity development’ (improved infrastructure, and training of personnel) – to ensure that the research does not exploit ‘communities’. However, this approach is

<sup>26</sup> G.M. Lairumbi et al. Forms of benefit sharing in global health research undertaken in resource poor settings: a qualitative study of stakeholders’ views in Kenya. *Philos Ethics Humanit Med.* 2012; 7: 7. doi: 10.1186/1747-5341-7-7.

<sup>27</sup> Kamuya DM, Marsh V, Njuguna P, Munywoki P, Parker M, Molyneux S. ‘When they see us, it’s like they have seen the benefits!’: experiences of study benefits negotiations in community-based studies on the Kenyan coast. *BMC Med Ethics.* 2014; 15: 90. doi: 10.1186/1472-6939-15-90.

<sup>28</sup> Lairumbi et al., *op. cit.* note 26.

<sup>29</sup> Emanuel et al. 2004, *op. cit.* note 4.

<sup>30</sup> Emanuel et al. 2008, *op. cit.* note 4.

<sup>31</sup> Emanuel et al. 2004, *op. cit.* note 4; Emanuel et al. 2008, *op. cit.* note 4.

<sup>32</sup> Lairumbi et al. *op. cit.* note 26.

<sup>33</sup> Kamuya et al. *op. cit.* note 27.

<sup>34</sup> B.M. Mayosi & S.R. Benatar. Health and health care in South Africa–20 years after Mandela. *N Engl J Med.* 2014; 371(14): 1344–53. doi: 10.1056/NEJMsrl405012. Epub 2014 Sep 29.

<sup>35</sup> Leibbrandt M, Woolard I, Finn I, Argent J. (2010). ‘Trends in South African Income Distribution and Poverty since the Fall of Apartheid’, Papers, No. 101, OECD Publishing. <https://doi.org/10.1787/5kms0t7p1ms-en>. Available at [http://www.oecd-ilibrary.income-distribution-and-poverty-since-the-fall-of-apartheid\\_5kms0t7p1ms-en](http://www.oecd-ilibrary.income-distribution-and-poverty-since-the-fall-of-apartheid_5kms0t7p1ms-en) Accessed on 20th October 2015.

<sup>36</sup> S.R. Benatar & P. Singer P. Responsibilities in international research: a new look revisited. *J Med Ethics* 2010; 36(4): 194–7.

<sup>37</sup> Emanuel 2000, *op. cit.* note 4.

<sup>38</sup> Participants. Moral standards for research in developing countries: From ‘reasonable availability’ to ‘fair benefits’. *Hastings Cent Rep* 2004; 34(3): 17–27.

somewhat controversial and continues to be debated in the literature.<sup>39</sup>

The findings of our study contribute to the debate on whether and how collateral benefits should count in the ethical evaluation of research. They provide support for the idea that at least some key stakeholders place considerable value on collateral benefits in their evaluation of what justifies the conduct of research in low- and middle-income countries. Our findings suggest that for research in public health facilities in KwaZulu-Natal to be perceived as valuable by core stakeholders, both 'aspirational' and 'collateral' benefits should be articulated and accommodated. This approach would satisfy many of our study interviewees and their representatives, and it would also satisfy international benchmarks.<sup>40</sup> We submit that a project that only delivers 'collateral' benefits with no knowledge gains may not qualify as research (for which the aspirational benefit of new knowledge is the *raison d'être*), yet, where collateral benefits are not realized, this may constitute insufficient benefit in relation to risks and burdens assumed, particularly because many research interventions may not be proven effective, nor become available in the health setting.<sup>41</sup>

Viewpoints on what makes research valuable appear to vary among stakeholders, as do definitions of valuable research in the literature. Stakeholders in this study and possibly in other low-resource settings may benefit from the opportunity to discuss the 'aspirational' and 'collateral' value of research,<sup>42</sup> how these could be reconciled, and the limits that should reasonably be placed on such expected benefits. Significant 'moral imagination'<sup>43</sup> in doing so will be required on the part of researchers and senior health service officials overseeing public facilities that host research, and also of research ethics committees that review related research proposals.

### Relationships between researchers and gate-keepers

Relationships between researchers and health managers in this study were characterized as somewhat mistrustful. Health managers' views of researchers may be partly anchored in knowledge of past exploitative research that

took place in South Africa,<sup>44</sup> or even in perceptions that researchers are part of a social elite.<sup>45</sup> It is also possible that health managers possess lower levels of research literacy than researchers<sup>46</sup> which might undermine their assessment of the knowledge-generation value of research.

Collaborative partnerships have been proposed as the ideal vehicles for negotiating how to maximize social value of research for various potential beneficiaries.<sup>47</sup> Recent ethics guidelines<sup>48</sup> emphasize trust-building as critical to the participatory practices of researchers. This aspirational guidance asserts that research teams should canvass stakeholders early when developing a research concept, should assess their needs and priorities, and should discuss key aspects of the research with them as well as ensure that findings are promptly disseminated. Gate-keepers and researchers may benefit from opportunities to understand each other's priorities, pressures and commitments, and to build more positive relations. It is likely that when different perceptions of what is valuable in research are discussed and debated in a transparent manner, this would build understanding of the motivations and needs of partners, and contribute to more harmonious relations and socially valuable outcomes.

One qualitative exploration<sup>49</sup> of the views of researchers, policy-makers and funders found that stakeholders perceived results dissemination to be critical in enhancing social value. Our study suggests that, in this setting, more structured mechanisms for dissemination of research findings to gate-keepers are required, including processes within health systems to consider the implications for revision of local services and policies. Failure to disseminate research findings adequately and to implement them, where feasible, justifies perceptions that the value of research in such settings is not realized as fully as it should be. As Emanuel et al<sup>50</sup> describe, the process

<sup>39</sup> A. London & K. Zollman. Research at the auction block: Problems for the Fair Benefits approach to international research. *Hastings Cent Rep* 2010; 40 (4): 34-45; U. Schüklenk. For-profit clinical trials in developing countries – those troublesome patient benefits. *Am J Bioeth* 2010; 10(6), 52-53; R.K. Lie. 2010. The Fair Benefits Approach Revisited. *Hastings Cent Rep* 40(4): 3-3. Project MUSE. Available at: <https://muse.jhu.edu/>

<sup>40</sup> Emanuel 2004, *op. cit.* note 4.

<sup>41</sup> Participants, *op. cit.* note 38.

<sup>42</sup> Lairumbi et al. *op. cit.* note 26.

<sup>43</sup> S.R. Benatar. Moral imagination: The missing component in global health. *PLoS Med* 2005; 2(12): e400.

<sup>44</sup> N. Barsdorf & D. Wassenaar. Racial differences in public perceptions of voluntariness of medical research participants in South Africa. *Soc Sci Med* 2005; 60(5):1087-98.

<sup>45</sup> N.A. Christakis. Ethics are local: engaging cross-cultural variation in the ethics for clinical research. *Soc Sci Med*. 1992; 35(9): 1079-91; S. Benatar. Reflections and recommendations on research ethics in developing countries. *Soc Sci Med* 2002; 54: 1131-1141.

<sup>46</sup> D. Allman, M.H. Ditmore & K. Kaplan. Improving Ethical and Participatory Practice for Marginalized Populations in Biomedical HIV Prevention Trials: Lessons from Thailand. *PLOS ONE* 2014; 9(6): e100058. doi:10.1371/journal.pone.0100058

<sup>47</sup> Emanuel 2004, *op. cit.* note 4.

<sup>48</sup> UNAIDS/AVAC, 2011. Good participatory practice: Guidelines for biomedical HIV prevention trials. Joint United Nations Programme on HIV/AIDS (UNAIDS). Geneva, Switzerland. Available at [http://www.unaids.org/en/resources/documents/2011/20110629\\_JC1853\\_GPP\\_Guidelines\\_2011%20OK](http://www.unaids.org/en/resources/documents/2011/20110629_JC1853_GPP_Guidelines_2011%20OK)

<sup>49</sup> G.M. Lairumbi et al. Promoting the social value of research in Kenya: Examining the practical aspects of collaborative partnerships using an ethical framework. *Soc Sci Med* 2008; 67: 734-747

of implementing research results is typically 'complex, incremental and haphazard'. Competent results dissemination strategies may go some way to offsetting mistrust, in addition to realizing the impact of research.

## LIMITATIONS OF THIS STUDY

This study aimed to investigate stakeholder perceptions about research in provincial health facilities in KwaZulu-Natal, and was not specifically focussed on the social value of research. However, the issue of how 'value' is perceived emerged as a key theme during data analysis. A limitation is that these participants were not asked to comment on the value of a common standardized research protocol, which might have illuminated whether they assign different value to the same research protocol. Also, the sample for this study included managers ('gate-keepers') of health facilities in KwaZulu-Natal, and researchers who conduct research in these facilities. Other key stakeholders' views (e.g. those of research volunteers, communities and members of research ethics committees) were not canvassed. Furthermore, the sample size for the study is small, and was drawn from one geographic location. While the findings may not be directly applicable to other settings it is hoped that they may have relevance in contexts with similarities to this one.

## CONCLUSIONS

This study found that key stakeholders involved in research in provincial health facilities in KwaZulu-Natal, South Africa, disagreed about what gives research social value, with researchers tending to emphasize the importance of 'aspirational' benefits and health managers tending to put greater weight on the 'collateral' benefits of research. It will be important for these groups to share their perspectives with each other, to have opportunities

to debate the merits of their perspectives, and to strive to reach a shared understanding of valuable research in provincial health settings. A forum for robust discussion and communication between these groups may be helpful to allow them to negotiate a shared view of valued research in such settings. This may also enable these research stakeholders to build more collaborative and trusting relationships that maximize value for all concerned. This effort may require a champion with harmonization of these research stakeholder views as a primary objective.

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<sup>50</sup> Emanuel 2004, *op. cit.* note 4.