

## HeLa – the play

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**HeLa. Author: Adura Onashile Director: Graham Eatough; Performed by: Adura Onashile Presented by the British Council in association with QTP**

The book was powerful enough. Disturbing in its examination of the human face of the HeLa cell story, Rebecca Skloot's book, *The Immortal Life of Henrietta Lacks*, took the bioethics world by storm, quickly becoming a must-read for all those engaged in the study of medical and research ethics. The brilliant dramatisation of this story of human loss and gain to humankind by the well-known playwright and actor, Adura Onashile, is an emotional wringer. Onashile's solo performance in the play, directed by Graham Eatough and produced by Iron Oxide, has kept the audiences riveted.

The story is about Henrietta, an uneducated black woman who died of cervical cancer in 1951 in the coloured section of the Johns Hopkins Hospital in Baltimore, USA. The roles of the doctors at Johns Hopkins, the laboratory technicians, Henrietta, her sons, her daughter, Deborah, and her husband, David, are all enacted in turn by the same performer.

The play brings out touching personal details of Henrietta's life, such as her love of dancing and her family life. Her devastation on learning of her diagnosis is heart-wrenching. Adura's portrayal of Deborah's emotions, too, is skilful – her confusion over the implication of her mother's living cells and her outrage that strangers seem to "know" her mother better than she does. She believes that consent had been given only for autopsy and not for "messing" with her "sales" ("cells" in American drawl). Unable to take on the "Hopkins folks", she internalises her sorrow and takes her grief to a shrine composed of Mother's Day cards, hospital reports, a crucifix and memorabilia of her mother, touchingly displayed onstage.

The stark props used in the play – a blackboard, bare dissection table, scalpel and clip – convey the chilling reality of a clinical laboratory as it may appear to a vulnerable patient or research subject. The convulsions of the actor on the table, on which she lies curling her toes and arching her back, do more to convey the agony of the circumstances than any narrative can. It is left to the audience to interpret whether the writhing is the pain of terminal cancer or torment over the price of medical advancement. The emotive acting is aided by an evocative projection of multiplying cells on the backdrop until the entire background is filled with countless cells. Over 50 minutes you are on a roller coaster of emotions and 60 years of events, forced to encounter complex ethical issues such as respect for personhood, the meaning of autonomy in the context of poverty, and social justice in research.

The issues at the heart of the play are presented powerfully. These include the fear and ignorance of patients; the paternalistic attitude of doctors; medical advancements using HeLa cell lines derived from the tumour; and injustice in the distribution of benefits. Genetic research, research into the pathogenesis of

cancers and the development of polio vaccines, which earned Nobel prizes for the researchers, are contrasted against the sense of exclusion of the communities of contributors to such research.

Brought to India by the British Council and Q Productions, the play toured Mumbai, Delhi and Bengaluru in February 2014. At the end of every performance, an invited researcher, scientist or the playwright herself led an open discussion. Adura shared insights which she had gained from the author, with whom she had interacted while developing the play. She confessed she had not met any member of the Lacks family as they were "not reachable". Permission for the play was obtained from those who hold the copyright for the publication, not the family. In many ways, this is a replay of the very issues that are at the heart of the HeLa story, ie the issues of privacy, ownership and personhood!

The play has raised many pertinent issues at a time when we are struggling with the ethics of bio-banking and research on tissue samples. How are contributions made in "good faith" honoured in our system? How can consent be taken when it is not known how, why and by whom the tissue samples may be used? Should we not be glad about the use of some inessential cells of the body in research if they contribute to science and medicine? But then what is to be said of the commercial profits, honours, publications and promotions that benefit a few persons, the generosity of the larger community of timid contributors going unnoticed? Is it necessary that those who gain personally must acknowledge the non-specific contributions of such participants? Is mere acknowledgement enough? How practical is repeat consent when new research is planned or new outcomes realised?

The Lacks family was kept in the dark about the amazing usefulness of Henrietta's cells and the new research they generated, even when it was contacted in the 1970s for fresh blood samples. The family members were deliberately misled into believing that it was part of a health check-up. Are we content with obtaining "informed consent", represented by a signature at the end of a form, or do we make sure we obtain "understood informed consent"? Can communities be benefited if we cannot reach individual contributors? Are we sensitising young researchers, doctors and nurses in medical schools to these ethical issues?

While *HeLa* is the story of one obscure woman's contribution to science, there are millions of invisible contributors who have impacted the field of biomedical research and will continue to do so. What regulations would be appropriate in India, which is preparing for large-scale research on stored samples from bio-banks? How can we ensure ethical benefit-sharing that is part of an honest attempt to reach out to communities and bring about distributive justice, rather than just a matter of researchers meeting perfunctory requirements or fulfilling corporate social responsibility?