# HIV clinic-based audio project emphasizes the power of patient voices

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The voice on the recording was low and calm as the speaker recounted the telephone call that brought the news he was infected with the human immunodeficiency virus (HIV) that causes AIDS: "My heart just stopped for a little bit and next thing you know I was on the floor flat on my face boohooing, crying like a baby."

Yet the message was hopeful when the recording ended less than 10 minutes later. "Don't feel like this is the end of you . . . because it is just God setting you up for something greater," the anonymous speaker tells an unseen audience.

The St. Jude Children's Research Hospital VOICES project that captured the patient's voice and story is the focus of the "A Piece of My Mind" column in the July 22 edition of the *Journal of the American Medical Association (JAMA)*. The project uses contemporary technology to tap an ancient and powerful clinical tool—the patient's own story—as a way to empower and inspire patients, teach empathy and improve [health care](#).

VOICES began in 2012 as a way for HIV-infected St. Jude patients, ages 18 to 24, to anonymously share the experience of being HIV positive with other patients, health care providers and students. Today, this password-protected archive includes recordings from 18 patients recounting the stories they wanted to tell—the shock of diagnosis, the importance of medication adherence and a healthy lifestyle, the social stigma of HIV or their refusal to let the diagnosis limit their dreams or

define who they are.

"This project has confirmed our belief in the power of patient voices and patient stories," said corresponding author Aditya Gaur, M.D., an associate member of the St. Jude Department of Infectious Diseases. The narratives have empowered participants and have given health care providers another tool for helping patients struggling with issues like medication adherence. The project has also given clinicians and students a glimpse into the emotional impact of HIV, allowing them to learn the challenges patients face in navigating the health care system or to receive feedback on the clinical environment.

"This project provides another layer of understanding that is not available to every clinician or student, particularly in today's medical environment when there is often limited time to build rapport with patients and students often receive information about patients second hand through the medical records or other members of the health care team," Gaur said. Kathryn Cantrell, formerly of St. Jude and now of the University of Massachusetts, Boston, is the first author and Sylvia Sutton, a St. Jude social worker, is co-author of the essay.

St. Jude has been involved in HIV and AIDS research and treatment since 1987. Today the hospital's multidisciplinary HIV/AIDS program cares for more than 275 HIV-infected children and youth. The VOICES project is currently limited to youth, who are approached about possible participation by a member of their health care team. The recordings average about five minutes in length and occur after patients provide written consent. The patient determines the content.

The resulting audio files are stripped of patient identification, catalogued by themes like disclosure, coping and relationships, and transcribed to make it easier for clinicians to access the library to help other patients with similar concerns.

The recordings underscore the importance of listening to patients, Gaur said. "If you really want to know a patient," he said, "you have to listen."

Provided by St. Jude Children's Research Hospital