Educating the next generation of researchers on open and collaborative data sharing

Erinma Ochu & Michaela Parnell - University of Salford

Erinma Ochu, Salford University Lecturer and Figshare Ambassador, is helping to shape the future of data sharing and collaboration by encouraging her students to take an interest in innovative methods of knowledge creation and sharing research beyond academia.

Erinma set up the online Science Communication and Future Media Masters program at the University of Salford. Students develop skills in science communication and science storytelling and learn to apply these skills in sectors beyond academia. Part of the course is to hear directly from organizations working in the sci comm space in the form of a podcast conversation, facilitated by Erinma, with questions from students. Figshare's Megan Hardeman participated in one such webinar on open science and sparked the interest of student Michaela Parnell.

Michaela shared content from her recent exhibit at the 2018 Manchester Science Festival Community Science Showcase via a Figshare repository created by The University's library. For the exhibit, Michaela crowdsourced art and storytelling from patients with Hidradenitis Suppurativa (HS). HS is a chronic, relapsing, systemic inflammatory condition that causes sterile, deep-seated, painful nodules which appear as boils and abscesses. It causes significant morbidity, pain, disfigurement and has profound impacts upon the suffers psychologically, physiologically and emotionally.[1]

These resources were translated into eight languages - a crowdsourcing effort Michaela led through a Facebook international HS community.[2]

Michaela then went on to write a case study for one of her student assignments. And, as part of a wider campaign, the HS community have been sharing and downloading the stories stored in the Community Science Showcase repository.
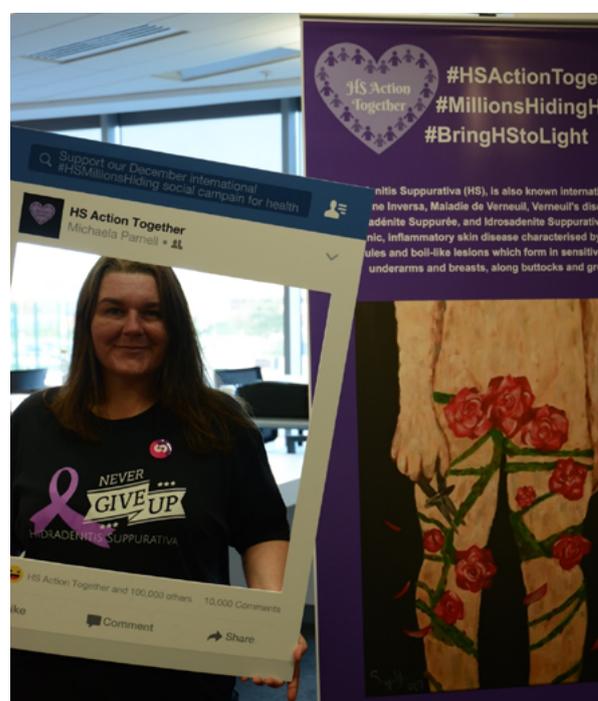
Michaela Parnell at her exhibit at the 2018 Manchester Science Festival Community Science Showcase.

Ayres, Bill (2018); Community Science Library Showcase @ MSF18 - University of Salford. MCUK Library. figshare. Fileset.

https://doi.org/10.17866/rd.salford.7321421.v1

The next step for Michaela is to create an app and a platform for researchers and the community to interact and share knowledge in order to educate and inform those with HS and encourage researchers to listen to and learn from HS perspectives. This community will consist of HS patients, research organizations and policy makers. "That can be built

upon by developing online video, audio, and traditional pedagogical training and learning materials," said Michaela. "Figshare can facilitate the dissemination of these materials to the digital international HS community as part of an educational programme to empower HS patients in ways that are important and matter to them to enable upstream engagement and innovation."

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"Patients can inform the research agenda and make it accessible to a wider audience by creating an open sharing, citable digital library archive of research and research outputs created on Figshare but accessible via the HS platform," said Michaela.[3]

Erinma also works with the National Co-ordinating Centre for Public Engagement (NCCPE) and invited practitioners, including Michaela to present her work to Wellcome research centres who are developing their public engagement strategies with support from the NCCPE. She has now been invited by the NCCPE to document her project in their Research for All Journal, which is open access.

"Trained originally as a biologist, Michaela is using her scientific knowledge and her digital skills to enable patients and their lived experience to inform and shape health research," said Erinma.

"This is critical to providing equitable access to healthcare. So, creating a trusted platform for scientists, clinicians and HS advocates to share knowledge, is a big, positive step in that direction. Building these kinds of communities, to mobilise knowledge through sharing, can make a real difference to improving health research and improving the lives of people around the world. My research and teaching is focused on collaborative inquiry and helping people from different backgrounds to come together and learn. She's also using the course as a platform to put her ideas into practice, which as a lecturer, is exciting to see."

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Erinma continues to spread the message of open data sharing and collaborative research through social media, via community events, online training and an open access book for practitioners and policymakers.

Michaela will also be presenting her collaborative research and advocating for the HS community at a US conference. Figshare will continue to be a place for the community to share and have their contributions valued.

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[1] Jayarajan, R., and Bulinska, A. (2017). HIDRADENITIS SUPPURATIVA (ACNE INVERSA): A REVIEW OF AETIOPATHOGENESIS AND MANAGEMENT. EMJ Dermatol. 5(1), 66-73.

[2,3] Amazing Things Happen When We Work Together (https://link.medium.com/cuNhJwyZIU)