

Written on the skin

The sharing of sensitive data is second nature to the young, say Brunswick's CHARIS GRESSER and GABRIELLE SILVER

HOLLY DILLON, 26, TELLS THE STORY of her skin in photos. In 2015, the Londoner launched an online health campaign, #getyourskinout, to change public perception of the chronic skin condition she's had since she was 14. The result: a brave photo documentary of her life with psoriasis. It's a visual call to action, an appeal for others to use the hashtag with their stories to inspire, support and educate.

"These little dots are always with me 24/7 whether I like it or not," Dillon wrote on her Facebook page in 2015. "They are an extension of me. A redder, spottier, alter ego that has taken me on a journey over the last 10 years."

Dillon's striking campaign breaks new ground, part of a well-documented trend of Millennials taking to social media to share their health lives. In the US in 2015, some 60 percent of Millennials with a social media account said they had shared personal health information on social media, according to Health Management Academy and RBC Capital Markets – compared to just 16 percent of people between 55 and 64.

Millennials are also more likely to use social media for health-and-wellness purposes – with their own distinctive stamp. "For Millennials, wellness is a daily, active pursuit," a Goldman Sachs study found. "They're exercising more, eating smarter and smoking less than previous generations. They're using apps to track training data." More Millennials also own wearable devices to monitor their health: 40 percent compared with closer to 20 percent of people aged 45 to 54, according to Health Management Academy and RBC Capital Markets.

Health data – a photo, a clinical record, or a heart rate – is among the most valuable, the most intimate information there is. The willingness to share it could have profound implications for science and health. But it would be a mistake to take for granted Millennials' agreement to share their health data with organizations just because they're "digital natives." In UK research for the Wellcome Trust, Ipsos MORI found that 54 percent of adults support commercial access to health data for health research, but a quarter oppose it. And young people are not



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Source: Health Management Academy and RBC Capital Markets

automatically more in favor of commercial access. That puts pressure on health organizations to create transparent policies on how data will be kept safe and how it may be used for the greater public good.

The aim should be a more informed public engagement on the uses of health data. As Dr David Agus, a professor of medicine and engineering, and author, wrote in the *New York Times*, we should applaud those willing to share their health data. "In fact, they are heroes: they are part of tomorrow's cures for themselves and their children," he wrote.

Beyond scientific value, social media sharing may help people live with chronic disease. This is a new area of research, but some already see a benefit from sharing information and fostering support.

It is, however, a complex landscape. The line between patient and consumer seems to be blurring, and the gap between private and public, shrinking. In some ways, Millennials are explorers, mapping how we live online – and sometimes how we die.

Lisa Bonchek Adams was 37 when she learned she had breast cancer. Until her death at 45, she chronicled her life with cancer in thousands of tweets and hundreds of blogs – the chemo, the pain, the fear, the conversations with her children, but also things of beauty and hope. Her final Facebook post came the day before she died. In an obituary, the *New York Times* wrote: "Ms Adams considered the sharing of her experience to be both therapeutic and altruistic, to satisfy her own need for expression and to shed light on coping with cancer."

And that, perhaps, touches on one of the mysteries of social media. It is a revolutionary tool that allows a woman to face the end of her life with thousands of online followers. At the same time, it speaks to an urge to reach out and share that is as old as medicine itself.

To this point, the Pew Research Center cited Thomas Jefferson's 1786 observation, "Who then can so softly bind up the wound of another as he who has felt the same wound himself?"

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