

Humanising Digital Healthcare to Build Capacity by Harnessing the Power of Patient Data

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Abstract : Patient-generated health data should be seen as the expression of the experience of patients, including the outcomes reflecting the impact a treatment or service had on their physical health and wellness. We discuss how the healthcare system can reach a place where digital is a determinant of health - where data is generated by patients and is respected and which acknowledges their contribution to science. We explore the biggest barriers facing this. The International Experience Exchange with Patient Organisation's Position Paper is based on a global patient survey conducted in Q3 2021 that received 304 responses. Results were discussed and validated by the 15 patient experts and supplemented with literature research. Results are a subset of this. Our research showed patient communities want to influence how their data is generated, shared, and used. Our study concludes that a reasonable framework is needed to protect the integrity of patient data and minimise abuse, and build trust. Results also demonstrated a need for patient communities to have more influence and control over how health data is generated, shared, and used. The results clearly highlight that the community feels there is a lack of clear policies on sharing data.

Keywords : digital health, equitable access, humanise healthcare, patient data

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