Digital health interventions and inequalities- the case for a new paradigm.

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Ischaemic heart disease, cerebrovascular disease (the commonest cardiovascular diseases, CVD), and diabetes mellitus (DM) represent the second, third and eleventh leading causes of disease burden (1) in England. Both CVD and DM (2) are targeted in high-level prevention policies, but variations in risk factors, diseases (3) and outcomes (4), as well as treatment and access to services, persist on the basis of ethnicity, which has long been recognised as one of the “causes of the causes” of health inequalities (5). Consideration of ethnicity in health policy has contributed to improved outcomes in ischaemic heart disease in South Asians in the last two decades in the UK (6), showing the benefits of targeted interventions. The NHS Outcomes Framework includes 11 metrics for health inequalities (7), but although ethnicity is mentioned, it is variably recorded in routine data, limiting the scope for measurement and analysis of healthcare use in black and minority ethnic (BME) individuals.

Digital health interventions (DHIs), “interventions delivered via digital technologies such as smartphones, website, text messaging” (8), could improve healthcare nationally and internationally, facilitating healthcare’s “triple aim” of better care, better health outcomes and reduced costs (9). Systematic reviews support DHIs for improving outcomes in DM (10) and CVD (11), and they are actively promoted in national policies (e.g. Diabetes Prevention Programme Digital stream, Heart Age calculator in the Cardiovascular Disease Action Plan). However, such policies could widen health inequalities through the “digital divide”, in addition to challenges in effectiveness, implementation and uptake of DHIs. Given disproportionate burden of CVD and DM faced by black and minority ethnic (BME) communities, policies aimed at CVD and DM should not further disadvantage them.

The potential for technology to worsen health inequalities is well-established (12), yet digital technology is almost universally promoted in healthcare in all settings. It is important to distinguish “inequalities” (“uneven distribution of health or health resources as a result of genetic or other factors or the lack of resources”) and “inequities” (“unfair, avoidable differences arising from external environment poor governance, corruption or cultural exclusion”, which are indefensible and warrant more urgent action (13). Most studies to-date regarding impact of ethnicity and socioeconomic status (SES) on DHIs come from North America, with little from the UK, and very little indeed from low-resource countries. Differences are expected for many reasons, including health system infrastructure and variations in ethnic diversity of populations.

Existing data suggest BME and low SES are disadvantaged whether in terms of health literacy, access to internet health resources, mhealth, patient web portals or personal health records, but data for specific DHIs, diseases and ethnic groups are lacking (14). It is unclear whether or how uptake and use of DHIs differ by ethnicity in CVD and DM. Despite associations between ethnicity, SES, CVD and DM, DHIs are rarely investigated by ethnicity and SES together. Systematic reviews to-date have estimated an overall effect size in terms of benefits of DHIs, but have not helped us understand differences between DHIs, disease areas, populations and implementation models. Actually, evaluation of DHIs often excludes BME groups, e.g.<25% of trials of telehealth interventions in DM had significant BME recruitment (15), with lower BME participation rates in countries without legislation to mandate their inclusion, such as the UK. It is highly likely that this under-representation of BME groups would lead to a unidirectional bias, which although unintentional in most cases, would result in an overestimation of the effectiveness of DHIs in BME individuals, given the higher barriers that exist in reaching such populations.
Current DHI research often dichotomises individuals into white and particular BME groups, e.g. South Asians. However, ethnicity per se is not necessarily a barrier to use of DHIs, and policies based purely on these grounds are unlikely to be fruitful in research or practice. Heterogeneity by SES, education, health beliefs, country of origin and culture needs to be incorporated in evaluation(16). Several frameworks have been proposed for evaluation of technology and innovation in healthcare, including DHIs(17). The NASSS (Non-adoption, Abandonment, Scale-Up, Spread and Sustainability) framework is evidence-based and theory-informed, and allows sufficient flexibility to inform intervention design, to plan implementation and scale-up, or to evaluate DHIs(18). However, it has not been validated or used to investigate ethnic inequalities. From apps to online risk calculators; perceptions, expectations and behaviours differ greatly between patients, public and health professionals. Different frameworks and methodologies are probably necessary to understand and optimize determinants of uptake, use and effectiveness of DHIs, e.g. behaviour change(19), sociology, health literacy, digital literacy, and complex systems. Therefore, mixed-methods approaches, properly integrating findings from different research designs, are likely to be most fruitful.

The recent National Institute of Health and Care Excellence (NICE) “Evidence Standards Framework for Digital Health Technologies” includes evidence of “challenging health inequalities” or “improving access to care among hard-to-reach populations”(20). Despite large-scale roll-out of well-funded DHI programmes across England (e.g. NHS Innovation Accelerator), pilot data (e.g. Digital Innovation Hubs, National Paediatric Diabetes Audit, Diabetes Prevention Programme, British Heart Foundation) suggest ethnicity, SES, education and other key characteristics are not routinely monitored and evaluated at design or implementation. Ethnicity is an easily measured and definable marker for a much more complex set of characteristics, including SES, education, health beliefs and culture. Understanding this interplay of factors is not just important, but essential for research and practice, because these characteristics, unlike ethnicity, are modifiable, with implications for how we design, implement, scale-up and evaluate future DHIs.

DHIs are complex interventions and solutions to the inequities and inequalities in DHIs in BME groups will require approaches at multiple levels (including individual, health services, and health system) as well as for different stakeholders (including patients, clinicians, researchers, and policymakers). In research, (i) qualitative studies are needed in order to understand barriers and facilitators in different ethnic groups; (ii) future trials should include BME groups; and (iii) evaluations of DHI initiatives must explore the impact on BME. In practice, (i) health professionals should be better trained in evidence for and use of DHIs; (ii) different groups, including BME, should be consulted at the design and implementation stages to maximize acceptability; and (iii) a framework for data collection and analysis will improve delivery and evaluation of DHIs.

References


