

Accepted version

Title: A data-based participatory approach for health equity and digital inclusion: prioritising stakeholders

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Funding statement:

This work was supported by the Arts and Humanities Research Council (Grant number AH/S004564/1).

Abstract

This article starts from the premise that projects informed by data science can address social concerns, beyond prioritising the design of efficient products, or services. How can we bring the stakeholders and their situated realities back into the picture? It is argued that data-based, participatory interventions can improve health equity and digital inclusion while avoiding the pitfalls of top-down, technocratic methods. A participatory framework puts users, patients, and citizens as stakeholders at the centre of the process, and can offer complex, sustainable benefits, which go beyond simply the experience of participation or the development of an innovative design solution. A significant benefit for example is the development of skills, which should not be seen as a by-product of the participatory processes, but a central element of empowering marginalized or excluded communities to participate in public life. By drawing from different examples in various domains, the article discusses what can be learnt from implementations of schemes using data science for social good (DSSG), human-centric design, arts and wellbeing, to argue for a data-centric, creative and participatory approach to address health equity and digital inclusion in tandem.

1) Introduction

This article starts from the premise that projects informed by data science¹ can address social concerns, beyond prioritising the design of efficient products, or services. How can we bring the stakeholders and their situated realities back into the picture? It is argued that data-based, participatory interventions can improve health equity and digital inclusion while avoiding the pitfalls of top-down, technocratic methods. A participatory framework puts users, patients, and citizens as stakeholders at the heart of the process, and can offer complex, sustainable benefits, which go beyond the experience of participation or the development of an innovative design solution. A significant benefit for example is the development of skills, which should be understood as a central element of empowering marginalized or excluded communities to participate in public life. By drawing from different examples in various domains, the article discusses what can be learnt from implementations of schemes using data science for social good (DSSG), human-centric design, arts and wellbeing, and digital inclusion approaches.

First, we outline definitions of health and wellbeing data, while highlighting some critical issues that relate to the collection and use of these data, such as privacy, data ownership and sharing, and public trust. The article then moves on to present how the disciplinary field of data science for social good (DSSG) has been implemented by looking at various applications, and discusses how the guiding principle of efficiency optimization and automated decision-making may be counter-productive when it comes to more human-centered experiences with technology. In order to further explore the need for a participatory data-based framework in which capacity building is a central tenet, we explore digital inclusion and its relevance to health inequalities, with reference to research that shows how socioeconomic factors continue to determine how citizens, patients and healthcare consumers process health information. Then we also touch upon how global health crises such as COVID-19, are also communication crises, with people belonging in vulnerable groups doubly disadvantaged because the lack digital skills. From this discussion, the article develops a case for a participatory approach to data-based projects that aim to advance health and wellbeing, while maintaining a focus on the social and lived experiences of the stakeholders.

Background

It is well established that socioeconomic determinants play an important role in health and wellbeing (Bartley 2016, Wilkinson 1997). Art and music education are often understood as indicators of socioeconomic privilege. There is international acceptance and evidence that shows that participation in the creative arts can help to promote well-being and health in communities. Participatory or public health art projects can be particularly beneficial for disadvantaged groups while engagement with the arts can improve the value for money of the health and social care systems (APPG 2017). The World Health Organisation 2019 report on the benefits of arts on health and wellbeing has recognized the value of culturally diverse arts programmes and arts-based health communication for disadvantaged minorities (Fancourt and Finn 2019). Critical public health literature has also highlighted the role of advanced health literacy in improving health outcomes and reducing health inequalities. Critical health literacy is considered key to empowerment, as it not only improves people's capacity to use health information, but also helps them gain greater control over life events (Nutbeam 2000). But health literacy today includes the capacity to efficiently use digital health technologies and being able to critically analyse information presented online. Scholars in digital health studies have identified how poor health in socioeconomically disadvantaged population relates to the lack of digital skills and health literacy (Newman at

al 2015). In Britain, 12.6 million people lack digital skills and they are most likely to suffer from poor health, while in most cases they also belong in disadvantaged social groups (in terms of age, disability, income and unemployment) (Tinder 2016). Projects such as the NHS Widening Digital Participation have aimed to enable digital inclusion and to address health inequalities. However, these two areas – art participation for health and wellbeing, and digital inclusion for health and wellbeing – have not as yet been brought together. There are good reasons to think of these two areas in tandem:

First, the adoption of personalised digital health environments (e.g. self-management mobile apps), big data (e.g. surveillance of infectious outbreaks) and AI algorithms that inform decisions about social and health care (e.g. IBM Watson Health for social care management) all raise important issues about data and privacy. Medicine and health today create new forms of technological embodiment, as they are increasingly experienced through digital and informational technologies (Miah and Rich 2008). Meanwhile, health promotion and communication has also moved to a digitised era, with health organisations using texts and social media in order to educate about health risks and prevention (Lupton 2015). Public health communication models however often follow a linear model of communication, in which public health education campaigns and media coverage of health issues lead to changes in behaviours and awareness (Hornik 2002). Often these campaigns and materials are unsuitable for the larger public. Health literacy scholars and community-focused initiatives have noted how health outcomes are not only a matter of suitability of information and design, but dependent on the capacity of audiences to obtain and process information, which is in turn associated with social, cultural and economic factors (Freedman et al 2009; Rudd 2015). Public health campaigns may also raise subtle ethical dilemmas that can be important when it comes to the potential effects of public health communication interventions on individuals and society as a whole (Guttman and Salmon, 2004). Such ethical issues include consent for the use of personal care data (e.g. the controversial NHS Care.data) and participation in research using web 2.0 technologies. In these cases, health communication and literacy can play an important role in building trust. But a systematic approach to how public health communication can be enriched by community-based participatory forms to account for the ethical, social and cultural issues in the era of big data and personalised medicine is missing. Second, as technologies change, there are new questions that art and humanities research can help us address in relation to health and wellbeing. “Arts and humanities can provide insights into how we may innovate responsibly,” according to Gary Grubb (AHRC 2017). Arts-based inquiry that involves public and personal health data analysis can be an innovative intervention for public health projects. As is argued in this article, creativity and data-based, participatory interventions can improve health equity and digital inclusion.

Health and wellbeing data

What do we mean by health and wellbeing data in this context? Health and wellbeing data take lots of different forms. They can be found in formalized medical records, which traditionally have been collected by professionals during consultations, and take the form of notes and samples. However, increasingly patient-generated health data (PGHD) are collected through the use of mobile devices and are consequently used for decision-making (see Figueiredo and Chen 2020 for an overview). Health data collection increasingly takes place in mundane everyday activities beyond the clinical setting. Often lifestyle and wellbeing data (such as diet, exercise, sleep and fertility tracking, and allied biomedical data such as heart rate) are gathered by individuals to inform self-care practices, without the intention of sharing with healthcare professionals. Therefore, in this article health and

wellbeing data is a term reflecting a plethora of practices, and highlights the diversity of identities:

- **Patient data:** information on someone's own health and wellbeing used by a health body for decision-making (such as a general practitioner surgery or hospital). This might include medication records, in the form of medical notes, or blood pressure readings, for example. It also includes PGHD collected using digital technologies within heterogeneous settings.
- **Individually collected data,** not specifically collected to be shared with health professionals, for example, through wearable devices and mobile phone apps that track heart rate or exercise patterns. Here the individual occupies identities other than healthcare consumer or patient, for example through the quantified self lenses.
- **Data collected by third parties,** for example by a third sector or community groups, by employers, and by companies such as health insurers.

Health datafication is a phenomenon whereby everyday data are drawn from ordinary people from a wide range of everyday practices, including in-store purchases, browser history, restaurant reservation and wearable trackers². These data, also known as 'alternative data' or 'shadow health records', encompass preferred healthcare providers and medical information. Research shows that 19 out of 24 health-related apps available through the Android platform shared user data to third and even fourth parties (Grundy et al, 2019). The global market in healthcare data comprises of data holders (sometimes called 'data brokers') who gather de-identified data from healthcare systems, pharmacies and other sources, and sell it on to buyers interested in analysing large data sets. Multiple corporations are increasingly interested in non-clinical health-related data that are being used in automated decision-making with an impact on health and insurance provision. Buyers include government bodies, marketing agencies, and research organisations³.

There are both benefits and risks associated with working with health and wellbeing data. Working with data can provide researchers and organisations with new insights related to public health, and form the essential evidence that supports new directions in managing health conditions. For example, data might allow governments to identify links between health and poverty, or help individuals to notice what lifestyle changes could result in a healthier life. For third sector organisations, such as charities and non-governmental organisations (NGOs), data analysis can fuel strategic planning and advocacy work. And digital and mobile communications provide new opportunities to respond quickly to global health crises.

But health datafication also presents new challenges, because it disrupts our understandings of agency and ownership of medical data (Ostherr 2020), while it normalizes self-care through the use of self-monitoring technologies (Fotopoulou and O'Riordan, 2017). The challenges for individuals within this context are wide-ranging. Shifts in attitudes slowly take shape in regulatory regimes but regulatory protection often falls short of what is required, in part because the data are generated across a broad range of contexts, which fall outside of legislative reach (Rosenblat et al, 2014). In the UK, there are strict controls around how and why companies can access and use national patient data (See Understanding Patient Data, 2018). But models of data ownership and sharing differ hugely across the private companies offering internet solutions, wearables and app technologies. For example, a 2018 study

found that the majority of 959,000 apps from the US and UK Google Play stores transferred data to third parties, and that many of these operated on a transnational basis (and therefore not necessarily in adherence to the legal system of the country of use) (Binns et al, 2018). In the meantime, next generation wearable electronics are fast advancing to integrate artificial intelligence (AI) and Internet of Things (IoT) promising broad applications in personalised healthcare monitoring and treatment (Shi et al 2020). In this context, data holders and aggregators may exploit the ethical tension between the value of big data for the social good – with the potential for better treatments – and the clear issues related to personal privacy and, in some regions, access to such treatments. “Nudging” people to adopt healthier behaviours, which is one of such controversial uses of healthcare data, has been criticized because it turns policy makers away from addressing structural factors (Prainsack 2020). And finally keeping up with the regulatory environment and healthcare marketplace, both of which move quickly, can be a tall order for individuals.⁴

So, although the use of health and wellbeing data can be potentially transformative for the healthcare sector, health datafication continues to present a minefield in relation to a number of critical issues, such as privacy, data ownership and sharing, and public trust. This extends to social care as data systems that are being used to inform decisions in childcare welfare systems are far from neutral (Redden Dencik and Warne 2020). The noted lack of representation from underprivileged groups in datasets can also lead to amplification of health inequalities, especially in public health systems where big data are used for automated decision-making about social security and healthcare (Lee and Viswanath 2020). The public needs to participate in discussions about what happens to their data, and datasets used in AI systems for receiving social security and healthcare need to reflect the diversity of social life. But because these discussions are often perceived to be highly technical, better left with experts and policy makers, this article argues that common approaches to digital health literacy and digital inclusion need to be rethought. Patients, healthcare consumers and citizens more broadly can approach these critical issues through participation, experience and skills training, while small community organisations in the health and wellbeing sector can benefit from using data to communicate with stakeholders. But how much training, what form can it take, and for whom? The next section looks at developments in the field of data science for the social good (DSSG), and the potential for developing skills in data science through participation.

Good data for the social good – stakeholders, skills holders and data holders

Data science for social good (DSSG) is a relatively new disciplinary area in data science, principally applied to tackle social issues such as humanitarian crises, global outbreaks of disease, and ecological catastrophes. DSSG asks: how can data science be used to address social concerns? As a sociotechnical domain, it stems from the increased demand for evidence-based policies. With the advent of big data and AI, emphasis has progressively been placed on identifying patterns, while decision-making increasingly relies on automated processes (Niño et al 2017). There is a wealth of impactful DSSG projects around the world. For example, big data are being harnessed in order to achieve the Sustainable Development Goals set by the United Nations for 2030 (Benjamins et al., 2018). The Swedish non-profit organisation Flowminder provides data analyses of mobile data, satellite and household survey data, in order to improve health and wellbeing in low- and middle-income countries. As part of their major strand of work in precision epidemiology, they used mobile phone operator data to help towards the elimination of malaria, to monitor real-time outbreak responses to cholera, and to map the spread of other infectious diseases globally.⁵ This type

of work has also encouraged the growth of innovative collaborations for the formation of data archives. For instance, a DataKind project⁶ created a 'data warehouse', an automated reporting system, and an accessible data visualization dashboard in an attempt to 'de-silo' patient data across different agencies and medical centres. However, the failure of Google Flu⁷ revealed how the use of big data for the common good is complex, specifically because of the challenges of creating models of collaboration amongst industry, government, academics, and general do-gooders to use big data archives to produce insights for the public good (Lazer and Kennedy 2015). Similarly, the challenges of implementing structures of data sharing for the public good in a fashion that respects individual privacy was evident during the Ebola epidemic.

One of the key difficulties in the implementation and design of DSSG is locating who the stakeholders are. And this is because often the stakeholders closest to the issues (or 'problem holders') are different to the data holders (those who are closest to the data collected and analysed) and very often distinctive to the skills holders (Niño et al 2017). One example of how this dissonance can be bridged is modeled by a project led by the South Australia Health and Medical Research Unit, supported by the Fay Fuller Foundation. The social issue that this DSSG project aims to tackle is the low health and socioeconomic levels that Aboriginal communities face in comparison to the rest of the Australian population. As is the case with other DSSG initiative, the project created a data warehouse: it included a range of health and cultural indicators from 18 geographical areas across South Australia, by and for Aboriginal people. It was designed to provide Aboriginal communities with their own data, allowing them to drive their mode of engagement with service providers, as well as monitor performance of government systems on their health and social outcomes over time (Schreiner, 2018). This way data science involves end users (what we will also call here 'problem holders', following Niño and colleagues) in order to empower them to make decisions and hold the government to account. In this example the problem holders are also the data holders, but these communities when left on their own devices will still lack the capacity to further analyse their datasets and shape policy.

Skills building in the DSSG sector predominantly aims to provide data scientist with an alternative, more ethical, career option to the commercial sector. For example, the UK-based 'Data Science for Social Good' Fellowship, an annual, three-month programme seeking to train aspiring data scientists on data mining, machine learning, and big data management funds projects with social impact. One of the funded projects, 'Reducing Recidivism and Improving Outcomes for People with Complex Health Needs' in Kansas, created a data archive aggregated from both police departments and public health centres, to improve predictive assessments of the likelihood of individuals re-entering the criminal justice system where there was a combined history of offending and mental illness.

A similar project allowed the creation of a Social Determinants of Health Database, which aggregated social data from agencies serving the Camden community (e.g. employment status, educational attainment, homelessness, and law enforcement records), with health data (Graham et al., 2016). Analysis thus far has illuminated the correlation between social care and health data and shown that high hospital use was correlated with housing instability, substance abuse, mental health status, and involvement in the criminal justice system (Graham et al., 2016). These cases also bring up certain ethical issues: the use of criminal and health data to model criminal justice forecasts may reinforce structurally embedded injustice and bias, or may contribute to further profiling of certain demographic groups that are already disadvantaged⁸. Standardised good practice that allows the use of data analysis for social purposes while avoiding harm to the populations to which the data

refers is still missing (Niño et al 2017). When dealing with sensitive personal data and vulnerable social groups, it is essential to construct working definitions of the 'social good' in partnership with stakeholders and those who provide the data in the first place.

Although these DSSG initiatives are unquestionably beneficial, it is apparent how the guiding principle remains efficiency optimization and automated decision-making. But an overarching principle of contemporary computer science and design is to enable more human-centered experiences with technology (Zegura et al 2018). It becomes therefore important to ask how can a data science project address social concerns and inform policy beyond prioritising the design of efficient products, or services.

Of course, data science fellowships are addressed at those already highly skilled in data analytics. Data scientists are in many cases not the data holders, and the 'problem holders' may not come out of the project any wiser. What about the capacity of problem holders and wider audiences to tackle information presented about them and based on data they provide? What about their ability to evaluate advanced healthcare solutions that use data science, such as AI fuelled predictive tools? In the context of health datafication, without basic data literacy for citizens, healthcare consumers, service users and patients, tackling important health and wellbeing run the danger of shifting to the hands of data brokers rather than the interest of public health. The next section discusses some of the new challenges that health datafication poses for digital inclusion.

But as is shown below, DSSG projects often focus on efficiency optimization as both their end goal and their guiding principle, while both the stakeholders and their sociocultural contexts tend to vanish from the picture. How can we bring the stakeholders and their situated realities back into the picture?

3) Digital inclusion, health datafication and health communication

Research has shown that the capacity of audiences to obtain and process health information plays a central role in adhering to behavioural changes that improve wellbeing (Freedman et al 2009; Rudd 2015). Such capacity is linked to media literacy and advanced critical health literacy, and more lately, to complex literacies necessary for using digital health technologies (Fotopoulou, 2020). However, as is examined below, socioeconomic factors continue to determine how citizens and patients process health information, while participation is at the heart of digital inclusion (Barraket et al. 2017).

Social, cultural and economic factors may present barriers to accessing and understanding health information in the first place. Public health communication has traditionally followed a linear model. It relies on public health educational campaigns and media coverage of health issues, which aim to raise awareness and motivate changes in behaviours (Hornik 2002), such as smoking cessation interventions (Anguiano et al., 2017). But often these campaigns and informational material are unsuitable for certain audiences from disadvantaged communities, such as low-income communities or those who are difficult to reach. It is still striking how those identified as digitally excluded are more likely to be elderly, disabled, on low incomes, lack tertiary education, live in rural or remote communities, live with disabilities, be from culturally and linguistically diverse backgrounds, or be unemployed (Borg et al 2019). Behavioural interventions with the use of consumer information technologies in health disparity populations considerable lags behind the general population (Bakken et al. 2019). A survey of smartphone ownership in the UK showed that although less than half of all respondents over the age of 55 owned such a

device in 2016, the figure rose to 70 percent in 2020 (Statista 2020). In the European region studies of digital development of households and individuals (and digital divide) takes broadband Internet access for granted and calculates households and individuals' daily use of advanced services, such as e-commerce, e-banking and e-government services (Lucendo-Monedero et al 2019). Digital inequalities of access according to gender still persist, especially in the global south (Henwood and Wyatt 2019). As non-user populations in the UK, the Netherlands, and Sweden seem to have become more concentrated in vulnerable groups, also termed as the 'digital underclass' (Helsper and Reisdorf 2016), it comes as no surprise to see that health information is predominately sought by those well-educated, and in employment (Van Deursen et al 2015).

Three primary barriers to digital inclusion have been identified: access, skill and attitude (Borg et al 2019). When thinking about digital health and data-based public health campaigns we need to take these barriers into account, as well as the particularities of the concentration of non-users. This is especially important since social media have become the go-to solution in public health communication and health, aiming educate about health risks and prevention (Lupton 2015), while governments and health providers around the world have been keen to engage with digital health technologies⁹. For example, in 2017, the National Institute for Health and Care Excellence (NICE) used Snapchat 'snotty nose' filters to raise awareness around the spread of infection and drug resistance, while Public Health England and Durex used Instagram and Snapchat to promote condom use (PR Week, 2017; Campaign Live, 2017). But only 1.9% of Instagram users are over 65, and only 3.4% of users are 55-64 (Clement 2020). Similarly, Snapchat is a platform used predominately amongst younger demographics, with 71% of Snapchat's users under 25 years old (Statistic Brain Research Institute, 2016), who also happen to be experts in digital technologies. Public health campaigns using Snapchat and Instagram, and emerging social media platforms like TikTok, hence discount audiences of older age and those who belong in other demographics identified as the 'digital underclass' by default.

What is more, the application of technological and digital health solutions may not yield much when these solutions fail to take into account culturally situated realities and socioeconomic contexts (Sun 2012). For example, the MomConnect programme in South Africa delivered weekly text messages to pregnant and post-partum women with relevant health information (Livingston Mehl et al., 2017), but failed to engage the most marginalised women (Hrynich and Waldman, 2017). In the case of the Zika outbreak in Latin America, a range of technocratic solutions was tried out, but these were predominately tool-based. For example, serious games were recommended in the Zika Playbook as a tool to enhance public awareness of Zika (implemented by the International Development Bank and Governance); other solutions, such as online forums and two-way SMS communication, and even drones and adaptive vehicles were recommended, in order to support long-term medical care and to remove trash from hard-to-reach areas respectively. But high-risk populations and epicenters of Zika did not enjoy the same access to infrastructure and technologies. (Ding 2020). Researchers have also noted that during the ZIKA pandemic not everyone had access to tracking devices – who are the data poor and data rich (Ostherr 2020)? Taking into account these situated realities and understanding how vulnerable populations access technologies is essential.

In the context of the COVID-19 pandemic, researchers have recently argued that global health crises are also communication crises because people belonging in vulnerable groups are also those on the wrong side of the digital divide, and as result, doubly disadvantaged (Xie et al, 2020). Health inequities can further intensify when some population segments can

“shelter in place” with remote work, e-health, and online education, while others lack access to the resources to make staying at home possible (Jackson et al. 2020). It is clear that misinformation about the virus circulating in social media, especially Twitter and Facebook, and sensationalist reporting have generated mistrust in the general public, while the WHO has played a key role in dispelling key myths (Smith et al 2020). Social media are tools that still have not become routine practices in many governmental agencies regarding public health in the countries studied. Social media of course have the potential to aid disaster communication during both public health and natural crises, and this involves spreading accurate information and dispelling misinformation (Eckert et al 2018, Palen et al, 2018). Social media platforms have also played a key role in creating bridges between volunteers and people in need of food supplies and protective gear in the COVID-19 crisis. But public attention tends to concentrate on social media influencers. These are healthcare leaders with a large number of followers who influence public attitudes. Although they may increase awareness about health and wellbeing, they can potentially also spread misinformation (Gottlieb & Dyer, 2020). This does not necessarily mean that audiences will receive messages uncritically, and perform the expected behaviours, as official public health organisations fear, but it does raise the debate as to whether content moderation should be introduced, which however requires huge resources and is not always possible. What these developments importantly show is that public engagement happens in real time. An opportunity thus emerges, to work with audiences and public health organisations in order to enable their critical capacity to evaluate the legitimacy of health information and to manage the enormous flows of data and misinformation that disseminate in disaster and crises conditions, as well as communicate their own experiences. Research on digital health literacy have warned against the reproduction of existent health inequalities that result from the introduction of more opaque technologies in the health sector (Azzopardi-Muscat and Sørensen 2019). The Digital Health Literacy Instrument (DHLI) for example recommends the advancement of operational skills, navigation skills, information searching, evaluating reliability, determining relevance, adding self-generated content, and protecting privacy (van der Vaart et al 2017). Adopting a media and cultural studies approach to health communication (Dutta 2008, Lewis & Lewis 2014, Seale 2003), we assume here that attitudes, values and understandings about health do not travel from experts in a top-down way, but are actively shaped by audiences in our media-saturated environments. What this paper further argues is towards a participatory approach that involves creative solutions.

4) Participation, arts and health

In order to realise the benefits of using data technologies and social media for better health we need to rethink the conditions on the ground, and how these can be implemented. As data science, AI and automation are increasingly used in governmental services, digital inclusion challenges need to be addressed further (Park and Humphry 2019). In their analysis of an intelligent avatar interface called Nadia, which was designed to assist disabled people gain access to disability support, Park and Humphry (2019) indicate how automated systems can reinforce punitive policies of existing healthcare and social service regimes at the design stage. It becomes clear then that instead of pursuing top-down, technocratic methods, health equity and digital inclusion can be improved through participatory interventions.

Participation can take different forms. In the context of human-centered design there are strong links between social justice (with health equity as a priority) and technical communication (Borg et al). Participatory, user-centered design can play an important role in user empowerment and ethical engagement with users in civic, educational, and industrial settings (Johnson, 1998; Scott, 2008).

In emerging sustainability living labs around the world, participation of end-users within the processes and dynamics of daily life is seen as a key method in evaluating technology-centric services, products and other solutions (Herrera, 2017). The “user as designer” principle of social innovation employs creative research methods, which are “characterized as disruptive, practice-based, iterative and intuitive in its approach, and open in terms of its results” (Van Dijk et al 2011). Artists and designers working at the institute of Art, Science and Technology Waag Society (Amsterdam, the Netherlands) for example have developed projects such as Labyrinth Psychotica, an “empathy tool’ that helps people understand the subjective experiences of psychosis (see www.labyrinthpsychotica.org). Fablab Cares followed open innovation principles and fostered collaboration between designers and individuals with physical impairments in order to develop low-cost healthcare technologies, such as the Low Cost lower knee prosthesis in Indonesia. More recently, the digital social innovation strand of Waag has focused on how stakeholders can create solutions for their own healthcare and contribute significantly to the empowerment of patients (Phillips, 2019). Elsewhere, similar approaches have been employed in healthcare innovation labs, with the promise to actively engage patients and users in the design of treatment solutions, such as the interactive digital cartography of cancer patients’ care pathways (APPG on Arts, Health and Wellbeing, 2017; and see www.helix.com).

Often studies examining this type of participatory design project primarily focus on issues that pertain to product development, and do little to help with understanding matters such as ethics, uneven power relations between researchers and stakeholders, counter-narratives, social dynamics and expectations by participants. A notable exception is the reflection on the “Make the Breast Pump Not Suck” Hackathon held in the US in 2018 (Hope et al., 2019). Hope and colleagues (2019) discuss how the event involved users, designers, academics and commercial companies and focused on building relationships rather than deliver a solution or product. In order to help designers reflect on how to build in equity into their work, the organisers run an equity and design workshop introducing design terminology, while they targeted 70% of non-white participants (Hope et al., 2019). Tseklevs and colleagues (2020) prefer the term participatory co-creation than co-design when talking about engaging people with dementia, prioritising playfulness to stimulate imagination. Another interesting reflection comes from Malmo in Sweden, where there is a consideration around education and skills, and a view of hacking friendships and agonistic experimentation (Hillgren 2013). Understanding counter-narratives, social engagement and the themes that emerge from participatory projects is important in order to gauge trust towards official channels of health communication.

Beyond participatory approaches to innovation and design for healthcare innovation, there is a long tradition of participatory art projects aiming to benefit health and wellbeing, and which are not technology-driven and do not rely on digital resources. The benefit of participatory arts through schemes such as Arts on Prescription and social prescribing¹⁰ has been well documented (Poulos et al 2019, Ward et al 2020), not only for patients, but also care workers (Wilson et al 2016). Participatory arts projects¹¹ place emphasis on the patient’s lived experience, in line with the narrative turn in health care (Sharf, Harter, Yamasaki, & Haidet, 2011). The emphasis here is placed on co-production of artwork based on personal stories of illness and disability. Narrators piece together experiences of illness and/or disability to make sense of present conditions and envision otherwise, while placing these experiences in context (McNiff, 2004, Rickett et al 2011, Woods et al, 2019, Davis 1995). Making vulnerable “bodies audibly and visibly present” (Harter, 2013, p. 332) through artwork can have a powerful emotional effect on audiences, which can lead to changes in

public attitudes and perspectives towards certain target groups or conditions. The production of such counter-narratives that may question official public health communication can stimulate necessary public debate about health and wellbeing. Such counter-narratives have migrated online, and in conditions of pandemic lockdowns, such as COVID-19 at the time of writing, there is increased artistic production (Marandet, Barratt, and Fotopoulou 2020). Participatory arts projects are also immensely beneficial for those who take part in them, with stated outcomes ranging from enriched participant mental and physical wellbeing, to more cohesive communities. For example, researchers found that people who had experienced serious illness showed significant improvement in wellbeing after participating in an Australian poetry-writing programme (Rickett et al, 2011). Similarly, research shows that interventions aiming to engage people suffering from dementia and their carers and were based in art-galleries have helped to foster social inclusion and social engagement, improved the relationship between patient and carer, and enhanced participants' sense of personhood (Camic et al. 2013). Studies have revealed that after engagement in participatory arts projects, communities also perceive elderly people to be more valued members in society (Mental Health Foundation, 2011). However, there is still work to be done in terms of clearly evidencing and evaluating art interventions for health and wellbeing. For example, reviews of art therapy interventions show that it is often difficult to draw conclusions about causality (Kelly et al 2015). Nonetheless, the literature predominately reports on the benefits of participation in the arts for both mental and physical health (Jensen and Bonde 2018).

In Brighton and Hove, where the research that informs this article took place (project *Art/Data/Health: data as creative material for health and wellbeing*, <https://www.artdatahealth.org>) people are more likely to engage with the arts than in the rest of the UK. But this frequently excludes people living in areas of social deprivation, people with disability and carers. In fact, health behaviours and healthcare services play only a small role in health outcomes; research from Public Health England shows that the most important factors that influences health and wellbeing rests in socioeconomic situation (Hill 2018). The Brighton and Hove Public Health strategy therefore targets those excluded through a range of participatory arts and health initiatives, e.g. social prescribing, culture settings and festivals. Such participation can be potentially hugely favorable for digital inclusion too, since direct experience and collaborative learning can address the significant skills barrier noted in reviews (Borg et al 2019).

Today scientific data and statistics of all sorts are being used in infographics, data journalism, design and art in order to create meaning from the deluge of big data. "Data is a versatile, material of our times. It can be shared, transformed, filtered, analysed and expressed. Data art, design and visualisation, whether analytical or expressive has the uniqueness and serendipity of your endeavours embedded within it" (Kultur Design 2018). There are several cutting-edge critical and insightful representations of data, such as the *Anti-eviction Mapping Project* (documenting the gentrification process in the San Francisco Bay area), the wearable data objects depicting air pollution by Stefanie Posavec, the *Data as Culture* project of the Open Data Institute, and the award-winning project *Dear Data* by Giorgia Lupi. Data visualisation has become mainstream as it makes use of the accuracy of data in specific contexts but have also been questioned ideological assumptions, social impact and framing of events. Within academia, a growing number of scholars critically approach processes of data generation and visualisation and have argued for fairer and more transparent processes that are sensitive to social justice issues (Hill et al. 2016). Jasanoff (2017) considers the potential of data analysis and visualisations to engage citizens in actionable change and to affect policy and law, while others focus on how data representations can help stakeholders

to comprehend large amounts of data and to identify patterns (Papaloi & Gouscos 2013). However, as an emergent area of study, there is no implementation of data-based art in public health initiatives or in community-based initiatives that aim at health literacy for marginalised population. So although art, health and community engagement initiatives have been successful, using data hasn't been practiced. This article argues that it is important to consider both cultural participation and digital inclusion when addressing health and wellbeing, and that we need new ways of advancing digital, creative and health skills in tandem. Previous work has shown how art-centered inquiry to promote *critical data literacy* (Fotopoulou, 2020; Bhargava et al., 2016; D'Ignazio & Bhargava 2016).

To conclude this section, it has been argued that the notion of participation for health and wellbeing takes different forms and has different priorities in a number of applied areas. Participatory design approaches and living labs, public health initiatives such as social prescribing, arts for health and wellbeing events, often focus on the personal benefits to participants, on developing a creative output that will influence public opinion, on developing an innovative product or design solution. In all cases a participatory framework understands the user/patient/citizen as the initiator of the process. By bringing these different strands together this paper argues that community-based, data-based participatory projects can offer complex benefits when they are sustainable and go beyond the experience of participation or the development of a design solution. Developing skills needs not be a by-product of these processes but a key factor that empower and enables socially deprived citizens to participate in public life.

Conclusion

In this complex landscape, and within the profoundly volatile landscape of the COVID-19 crisis, public communication for better health and wellbeing demands more than measures to enable online information seeking. The article has so far discussed how participatory approaches can potentially address key barriers to digital inclusion, which continue to disproportionately affect vulnerable groups and older people. Social support, inclusive design and collaborative learning are all key enablers to digital inclusion (Borg et al 2019), but participatory data science and design projects also empower stakeholder communities through direct experience and active thinking about what affects them. The motivation to take part in health-related projects is the perceived benefits beyond the personal level, for the general good (Callari et al, 2019). This can be of great importance when it comes to crises such as pandemics, where the public actively participates as producers of communication through social media, and not merely as receivers of official public health information.

In the context of health datafication, and as social security and public health services globally increasingly rely on the use of health data in AI systems and automation, public participation becomes doubly necessary. First, patients and others using health and wellbeing services need to be skilled and informed enough about privacy and data, in order to make decisions about their own data uses, and to be able to evaluate health and scientific information.

Second, beyond the scope of digital inclusion that this article investigates, there is a remarkable lack of diversity in relation to the strategies of data collection and AI design. As Lee and Viswanath (2020) note in an article on Data Absenteeism and Chauvinism in the Context of Health Disparities Research, the lack of representation from underprivileged groups is an ironic phenomenon in a data-rich society. But there are significant data gaps in

relation to LGBTQ+ groups, which are linked to health disparities (LGBT Data Collection, 2015). This scarcity leads to invisibility of certain identities, and as Costanza-Chock (2019) notes in relation to AI systems such as wave scanning in airports, even erasure of trans identities. Researchers have made concrete recommendations to mitigate bias and discrimination in AI systems (West et al, 2019). It is however important to engage community organisations in understanding and collecting different types of data that mitigate the underrepresentation of underprivileged and stigmatised groups and help shape new intervention strategies (Phillips II 2019). At the organisational level, the research project informing this article aimed to offer organisations with a skills toolkit for data science training, focusing on data management and building trust in data processes through creative exercises. A further wider aim has been to motivate audiences to understand collective themes about health and wellbeing through a combination of experiential individual stories and statistical data about health and wellbeing. Still, from an organisational perspective, using big data to address health disparities may be perceived as a costly long-term investment, and many community organisations working with underprivileged groups do not have the resources to do so (Lee and Viswanath 2020), for example the staff who know how best to turn data into insights to benefit the organisation operationally. Still, by engaging disadvantaged populations in a creative process that uses data, research can democratise the applications of the arts and humanities, and contribute to the advancement of participants' digital and creative capacities and resources beyond specialist professionals. Through this discussion it has been argued that data-based, participatory interventions can improve health equity and digital inclusion while avoiding the pitfalls of top-down, technocratic methods when the focus remains with the stakeholders and their lived experiences.

Funding

The project *ART/ DATA/HEALTH: data as creative material for health and wellbeing* was funded by the Arts and Humanities Research Council (AH/S004564/1 2019-2021).

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¹ Data science has developed in the last two decades due to technological advances and the vast amount of data collected, but it has its roots in scientific data gathering methods. It “encompasses a set of principles, problem definitions, algorithms, and processes of extracting non-obvious and useful patterns from large data sets” (Kelleher and Tierney, 2018: 1). These patterns may help classify things, or identify abnormal events.

² Apple, Fitbit, Xiaomi, Garmin, and Huawei (the top five wearables companies worldwide).

³ For example, the US health information technology firm Iqvia (formerly IMS Health), one of the biggest companies in the health data market, generated \$8 billion in revenue in 2017 (Arndt, 2018). Overall from an estimated global value of \$14.25 billion in 2017, the health data sector is expected to grow to \$68.75 billions by 2025 (BIS Healthcare, 2018).

⁴ Industry faces similar challenges from the delivery angle, seeking to find a balance between the security and availability of data. Technological innovations such as decentralised blockchains (a kind of ‘digital ledger’ tracking where data has come from and how it has been exchanged) and homomorphic encryption (which allows data to be analysed without being decrypted) may help.

⁵ Unusual mobile phone use patterns can be correlated to natural disasters and other events such as terrorist attacks (Benjamins et al., 2018).

⁶ DataKind (www.datakind.org) brings together volunteer data scientists with social change organisations across the globe, aiming to maximise social impact through cutting-edge data solutions

⁷ Google Flu Trends started in 2008 when researchers decided to explore the potential for predicting flu outbreaks based on people’s web searches. When people are sick with the flu, there is a surge of flu related searches, which provides instant signals of overall flu. The paper published in Nature demonstrated that search data, if properly tuned to the flu tracking information from the Centers for Disease Control and Prevention, could produce accurate estimates of flu prevalence two weeks earlier than the CDC’s data. Reflecting on this failure, researchers identified a number of problematic practices in its use. The reliance on statistical patterns (such as a correlation between internet searches for flu symptom and flu outbreaks) rather than on causal links has thus been shown to be unreliable (Harford, 2014).

⁸ The Global Data Ethics Project by Data for Democracy deals with issues such as privacy, transparency, consent, bias, diversity and ethical imagination, while it provides a guide to data practitioners, based on an ethical framework of five pillars: fairness, openness, reliability, trust and social benefit. (<https://www.datafordemocracy.org/project/global-data-ethics-project>).

⁹ Digital health covers a wide array of technologies, ranging from mobile phones (mhealth) including texts and apps, emails, gaming and social media to virtual and augmented reality and wearable devices.

¹⁰ Social prescribing allows health and social care professionals to refer people with non-medical issues, such as loneliness, to art programmes and activities. See more: <https://www.england.nhs.uk/personalisedcare/social-prescribing/>

¹¹ Participatory arts projects are distinct from those that seek to improve environments of healthcare as well as from art therapy practice, although many initiatives seek to combine elements of the three.