Abstract

Central to ethical debates in contemporary mental health research are the rhetoric of parity of esteem, challenges underpinned by the social construct of vulnerability, and the tendency to homogenise the population diagnosed with mental health conditions. Such ethical dimensions are further complicated by the contemporary endeavour to work with 'big data' which has led to ambitious claims for discovery and knowledge. Research in mental health is challenging due to the perceived constraints of ethical principles such as the protection of autonomy, consent, risk and harms. This article discusses how ethical considerations need to be reconceptualised when using big data sets. The argument is foregrounded with an appraisal of the prevailing political discourse of parity of esteem demonstrating that ongoing disparities in services and research should also be considered when inquiry uses big data.

Key words: parity of esteem; big data research; ethics; mental health

Introduction

Tensions regarding the ethics of mental health research are multi-layered and complex. Factors such as the challenges presented by the social construct of vulnerability, issues of capacity to consent and the tendency to homogenise the population diagnosed with mental health conditions create a challenging epistemological backdrop to inquiry. Such issues are further complicated by the contemporary endeavour to work with 'Big Data' (henceforth, BD) generated by governments and institutions. Alongside this, the notion of parity of esteem, broadly conceptualised as a *mindset* which places responsibility on society to think of the whole person[1], has emerged.

The drive towards generating and using BD in mental health research and the benign intentions of parity of esteem have potential benefits. However, these developments can also be problematic in this field for political, epistemological and ethical reasons. There is a need to take a critical perspective, to remain mindful of the ethical sensitivity generated. We start by contextualising the discussion in an overview of parity of esteem which has recently dominated policy and public discourse despite there being no consensus around what it means. This discussion is connected to the challenges presented by mental health research using BD and argue that the human participant in research is at risk of being rendered invisible or at least marginalised. In the second part of the paper we appraise ethical dimensions of harm, risk and consent in the context of this kind of research to make relevant the widely adopted deontological approach to ethics with the broader issues at stake for parity of esteem.

Parity of esteem

The concept of parity of esteem as a legal right and obligation emerged from a range of legislation and policy. The Equality Act (2010)[2] set out what constituted unlawful discrimination and who had the right to challenge discrimination. If a mental health condition results in a substantial, adverse and long-term effect on the ability to carry out everyday activities (a disability) then the Act is applicable. This constitutes an important acknowledgement of the need for ‘reasonable adjustments’ by services and public institutions which includes people with mental health conditions.

There are significant inequalities experienced across the life-course for people experiencing mental health conditions and this has been recognised by Government. For example, a cross-party strategy highlighted the need for ‘parity of esteem between mental and physical health services' (No Health without Mental Health, 2011)[3] and based on this, the Health and Social Care Act (2012)[4] placed physical and mental health together in two important ways. First, it conjoined both aspects of health in relation to promotion, prevention, diagnosis and treatment (Section 1); and second, recognised the need to reduce inequalities between people with respect to the benefits they could gain from the health service (Section 4).

Despite these efforts, there remain significant disparities in the provision of care. There is clear evidence of unmet need especially for children and young people who are experiencing mental health conditions. Research shows that approximately three-in-four children with clinically diagnosable symptoms are not in receipt of care.[5] For adults, the most recent (2014) statistics on prevalence and numbers of people accessing formal services, revealed that around one-in-six adults (17%) surveyed in England met the criteria for a common mental disorder which has a broad definition and conflates people with shorter-term and more chronic conditions (NHS Digital)[6]. This excluded severe mental illness such as schizophrenia or bi-polar disorder.

Accuracy in statistics is difficult to appraise due to perceptions of ill-health and its impact which are individual and dependent on a range of social, economic, cultural and psychological factors. Accurate data on the prevalence of mental health conditions is further complicated by barriers to seeking help from formal services. This means that data often reflect the numbers and demographic profiles of those people in receipt of services (patients or service-users) but not those who may be experiencing distress in isolation. For example, there is evidence that stigma prevents adults with mental health conditions from seeking help. Recent systematic reviews have revealed the connections between mental health- related stigma and active help-seeking globally[7] and a small to moderate but clear deterrent effect of stigma on help-seeking.[8]

Inequalities in research funding

Inequalities in service provision are replicated in research, as despite mental health conditions affecting approximately 23% of the UK population, it only acquires 6% of the UK health research expenditure[9] (UK Clinical Research Collaboration, 2014). Notably, less than 30% of that mental health research is focused on young people, despite this being the most common age for onset, and its consequences lasting through into adulthood[10]. Indeed, the MQ report demonstrated that while cancer research was awarded £402 million, mental health research only acquired £112 million despite figures showing that the cost of cancer to the economy was £12,853 million compared to the £51,600 million that mental health conditions cost. In other words, cancer attracted a research spend of £178 per person affected and yet mental health only attracted £8 per person affected. This points to serious inequalities in research spending and something that must be addressed. However, the British Research Councils are slowly beginning to address the gap between mental and physical health research, arguing that mental health is a new priority. For example, the Medical Research Council[11] recently noted that the government has published a 'Framework for Mental Health Research' document that is shaping research funding strategies setting out core recommendations to improve the impact of mental health over the next decade. The focus for this is on prevention and early intervention, as well as increased engagements from patients and the public which will be hopefully be reflected in the kinds of research undertaken.

Research on mental health data needs to be appraised in the context of the political discourse of parity of esteem and cannot be viewed as separate from it. This has implications for the ethical parameters and processes that are imbued in research. It is essential to undertake more research to better understand the nuances between the manifestation of symptoms, the aetiology of conditions, the genetic profile of disorders as well as the barriers for help-seeking, but such work needs to account for the ethical issues that such sensitivities invoke. Research areas could include understanding stigma, the narratives and views of those awaiting and receiving diagnosis, the lived experience of mental health conditions and the links to the social and psychological. It is only through this integration of genetic, quantitative and qualitative research that we can truly begin to strive toward parity of esteem, so that policy and practice can be established based on best evidence, and work that is person-centred, accounting for the positions, views, and experiences of key stakeholders. With a rather disconcerting picture of disparity of esteem in mind, we now turn to more specific tensions presented when using BD in mental health research, developing a critique related to some of the taken-for-granted assumptions about its efficacy. We highlight some challenges and dilemmas before turning attention to the ethical challenges implicit in using BD to pursue knowledge in the field of mental ill- health.

Big data and mental health research

The place of data in mental health research

Big Data and use of the digital media are ever more relevant in social life, with a growth of automated "*production, use and analysis of transactional and other big data by private corporations and governments*"[12] (p.864). A central concern in our argument regarding the parity of esteem, and the ethics of mental health research, is the place of BD and the dilemmas created by its use with this population. In the digital age increasing volumes of personal data on individuals' health are available to be used for research purposes and can be 'mined' and analysed with benign intentions. NHS Digital in the UK holds patient data centrally for the benefit of patients, services and researchers. Their mental health section captures data which is routinely collected at the interface of patient care in specific categories. In addition, there are specific psychiatric databases being developed for researchers with some attention paid to the sensitivity of such data and the development of highly sophisticated systems to protect anonymity while also allowing researcher access[13].

There is, however, no consistency in the kinds of psychiatric databases which currently exist which is arguably ethically and practically problematic. In a 'snapshot' overview of mental health databases available globally, there were no definable boundaries in BD sets in mental health with some generic health databases containing mental health information with others more specialised and related solely to mental health conditions[14]. The types and range of specific and non-specific data and the lack of integration of existing sources, all present challenges for research. Even if these operational problems can be overcome, we argue that there is a need for a questioning approach to its use in mental health research and a reflective consideration of ethics.

The characteristics of data collected also limit the potential for knowledge generation. An example of this is the lack of completeness and comprehensiveness of data relating to BME populations and mental health where categories are largely defined through reference to the UK's colonial past with the risk of omitting experiences of people who would define their ethnicity differently[15]. A critical approach to the use of BD would seek out the gaps highlighting how the social shapes data collection, precision and comprehensiveness. Furthermore, social inquiry might raise epistemological issues, asking what kinds of discovery and inquiry are missing. Whilst all data (not just BD) collected for research purposes requires this kind of critical approach, the ethical dilemmas and ethical tensions raised in BD research are still emerging, especially when we consider the relationship of this with the rhetoric of parity of esteem. This means that researchers need to reflexively engage with the nature and purpose of their inquiry. We now turn to look at some specific ethical challenges presented.

Ethical dimensions of research using big data

Who is the research 'subject' in data?

BD research requires ethical reflection possibly requiring new regulatory frameworks to be devised or a consideration of how such research fits into existing frameworks[16] . Whatever the considerations might be, the use of BD for the purposes of mental health research challenges our understandings and implementation of research ethics in profound ways. Even the foundational question of identification, of who the human research 'subject' is, becomes problematic because humans are largely invisible in data. An ethically reflexive approach would nevertheless seek identification of a 'data subject' and what they are owed in ethical terms[17]. The conventional and theoretical foundations for ethical conduct in research (typically summarised as beneficence, non-maleficence, autonomy and justice)[18] are potentially problematic in BD research. This is because the 'subject' or 'participant' as an autonomous individual with agency who is required to give informed consent becomes integrated and embedded within the broader data corpus and individual contribution, and individual consent, may be problematic or lost. In other words, it may not always be clear to individuals how or when their data may be used, in what context it may be embedded or integrated, or what contribution they may be making at some potentially unidentified point in the future. This is then important in terms of ethical obligations, as BD seeks out trends rather than more focused individual contributions, raising questions as to how we might differently construct the individual hidden in the data to incorporate what is owed ethically?

Harm/benefit ratio

Research on large sets of data is different. First, research is on groups or populations with a view of generalising broad trends. Consent is altered because the individual is consenting to use of their data as part of a larger data set. The harms/benefits ratio requirement needs to be reconceptualised as it cannot be described in in relation to an individual. Protection from risk may in this context be protection from what has been referred to as "data dredging"[19] (p41) where the temptation to investigate associations in treatments is irresistible but potentially flawed when data has been collected without the primary purpose of an investigation in mind. Perhaps then protection from harm is protection from poor research practice. It is important to be mindful that susceptibility to risk is not universal[20] and neither does exposure to risk always result in harm[21] at an individual or group level.

Ethics regulation ensures that researchers are mindful of individual harms, but they are not required to consider or account for harms that may affect communities.[22] The implications for mental health research are that researchers interact with data investigating particular questions, but they are not explicitly required to consider the consequences and problems of their research and the potential of such inquiry to lead to (unintentional) further stigma. It might be argued that the ethical concern with communities of participants could be incorporated into regulatory frameworks and made a requirement of review. However, at this stage of emerging ethical and epistemological challenges in using BD there is a prior consideration. Researchers need to reflexively consider whether they are undertaking research simply because certain kinds of data exist or are easily extracted. For example, in psychiatric research, the ease of access to data on medication has resulted in extensive medication-orientated research questions. [23] Researchers are working at a distance from the communities most concerned with the research and who are unlikely to have the opportunity to shape research questions. This raises new questions about who research ‘subjects’ are and what trust means in these emerging research contexts. These ethical concerns may be resolved but require researchers to engage ‘with a rapidly changing set of research dynamics that should be addressed in context.’ [24]

Vulnerability and protection from risk

The inclusion of participants with mental health difficulties in research frequently raises concerns for ethics committees, and a common rationale for this is the protectionist position taken as these participants are usually constructed as a vulnerable group who are more likely to come to harm through participation. While we critically question treating those with mental health conditions as a homogenous group, we also consider the tensions that the notion of vulnerability raises in the context of BD, arguing that the homogenising of a population constructs and treats that population as more vulnerable than may be the case in practice.

The argued risk for this population is that those with mental health conditions may experience cognitive impairment or may find it difficult to make fully informed decisions about participation in research, and furthermore are subject to stigma and discrimination, which advances their vulnerable status. Such status is central to ethical decision-making, which has been heavily influenced by historical exploitation of these groups. However, to construct a group or population as vulnerable is complex, and there has been limited consensus in the evidence regarding how this construct should be defined.[25] Somewhat problematically, it has been used interchangeably with other concepts such as ‘hard-to-reach’, ‘sensitive groups’ or ‘hidden people’.[26]

The notion of vulnerability is indexical, not static, as it is tied to contexts[27] which need to be accounted for when positioning groups. Vulnerability is not dispositional to the person but fluid because mental health conditions affect different people in different ways. In other words, it is not simply the characteristics of individuals or groups that define the population as vulnerable, but the context of the health research and how that may be associated with vulnerabilities. Those with health difficulties may experience consent-based vulnerability, in the sense that they lack the capacity to express their autonomy, or may experience fairness-based vulnerability, as mental health diagnosis renders them as members of a group who lack opportunity or freedom leaving them susceptible to coercion.[28]

To summarise, in considering the ethics of BD research, vulnerability and its association with increased risk cannot be merely assumed or attributed to this population. This would underestimate the agency of these individuals to make their own decisions and deny the potential to influence research. Vulnerability is complex as a construct and it manifests in different ways. Indeed, it has been argued that all humans experience inherent vulnerability by the general affective and social nature of the human species that renders people at risk of psychological and physical harms.[29]

We argue that it is problematic to treat a group, such as those with mental health conditions as homogenous, and to make sweeping conceptualisations of whole groups just because they loosely share the characteristics of a 'mental health condition' is an inadequate solution for the ethical dilemmas based in research. Labelling groups as 'vulnerable', risks an unjustifiable exclusion from research.[30] A plausible solution to this challenge therefore is a view of vulnerability as etic or emic.[31] Using this perspective etic vulnerability focuses on the individual's susceptibility for harm and a risk assessed externally by others, that is, the person is either vulnerable or they are not. In contrast, an emic position would describe a position of being under threat positioning vulnerability from the perspective of the participant. This latter would counter a protectionist ethical discourse by placing the voice of participants as central to ethical considerations.

Assessing risk/benefit ratio: the risk of 'more of the same'

Harms and benefits might be less obvious or transparent than the convention of weighing up risk and benefit when using data. Harm may not be direct. Nevertheless, potential difficulties arise if populations are treated as homogenous and knowledge about conditions continues to be driven by narrow conceptualisations of the nature of mental ill-health. To date, inquiry appears to reflect a continued medical approach. The potential for change is clear but a search conducted by the authors of the associated Clinical Record Interactive Search (CRIS)[32] (publications between 2009 and 2018 reveals limited investigation of social factors or even demographics with a strong focus on treatment, onset and the co-morbidity of substance misuse or physical conditions and mental disorder. While this is worthwhile research, the nature of studies should introduce a note of caution. It is difficult to clearly identify benefits for those whose data has formed part of research. Arguably, the potential for making notable discoveries using data that has not been collected for (specific) research purposes is '*grossly overrated'*.[33] Research is shaped by the kinds of data which exist and the interests of researchers. In addition, if data is not collected for specific research purposes, we need some assurances that the research is worthwhile. Put bluntly, better research requires better research data – not 'spurious analyses with junk' (p41).

Research is not necessarily seeking answers to questions that participants want answers for. A good example of this is in autism research where 56% of research studies focus on brain, biology and cognition, and 15% on aetiology, with very little in funds spent elsewhere.[34] For some, this is argued to be insufficient as parents of autistic children want more research in areas that help them support their children and address problem behaviours.[35] Others have taken a stronger position arguing that genetic testing and identifying the genetics associated with autism may put mothers under pressure to terminate pregnancies.[36] which reflects a new wave of eugenics.[37] Continued research for a schizophrenia gene presents similar disturbing ethical questions.[38] Social and economic aspects of mental health are less frequently the subject of inquiry. People living with mental health conditions which have affected their quality of life may view social barriers, stigma, isolation, exclusion and the associated limiting consequences of these, as at least as important as symptom control. There is a risk of losing the human behind the data and the real risk may be research that would be considered iatrogenic to those living with mental health conditions.

With parity of esteem in mind, researchers need to consider epistemological and methodological elements of investigations if findings are to present the possibility of challenge inequalities in mental health. A significant ethical question for researchers is whether the existence and content of data sets shape research questions rather than questions emanating from populations experiencing difficulties. There is a risk that BD research elides important questions of disparity and the complex interconnections of mental ill-health with psychological and social factors constraining our understanding of mental health.

Consenting to research

Finally, we turn to specific consent issues. Mental health research which directly involves people experiencing mental health conditions is limited. This can in part be explained by a focus on biological, genetics and outcomes-driven research calls and as we have shown the barriers presented by ethical regulation of research involving vulnerable groups. The obstacle presented by consent requirements is particularly problematic. A significant difficulty is that informed consent as a principle potentially excludes large groups of people, including for example those who are viewed as mentally unstable or disabled.[39] This exclusion of those deemed incompetent to consent may lead to their lives being concealed and limit the extension of knowledge which may be of benefit. In research the *a priori* assumptions of vulnerability in relation to informed consent can be 'deeply silencing'.[40] A way forward would be to enable a reasonable assessment of the level of protection needed. Current ethical regulation arguably privileges consent above all other ethical considerations and has been described as an 'ethical panacea counteracting the potential danger of paternalistic and autocratic practices' [41] We are not arguing that consent should be dispensed with but that regulatory processes permit a reasonable debate about consent in context. In other words, viewing consent as fluid and iterative rather than a one-off event[42].

There are important and alternative ways that consent might be considered in relation to BD. In his discussion of consent in the use of data which has not been collected for research purposes (often referred to as 'routinely available'), Ioannidis argues that dispensing with consent constitutes an oxymoron in that research is claimed to simultaneously be non-interventionist and 'routine', presenting little impact on patients whilst resulting research and analyses of data are viewed as highly important and influential. Mental health data is potentially sensitive because stigma and its consequences create an uncertain and often unsafe world for prospective participants who understandably value their privacy. Consequently, we regard consent as important albeit different in BD research. This is because participants are consenting to research which they may have no agency to influence or shape. For this reason, the continuation of assertive opt-in rather than the necessity of an assertion to opt-out remains important. We acknowledge the efforts made to include service-users/patients in how data should be accessed but this does not always amount to influencing inquiry.[1]

Discussion and Conclusions: A (dis)parity of esteem and change in data research

Seeing BD research in mental health in the context of prevailing political discourse about parity of esteem has permitted a pragmatic analysis of BD research. We have argued that the continuing inequalities in individual outcomes are mirrored in research in mental health. Furthermore, whilst there are clear inequalities in the ways in which mental and physical health are funded, parity of esteem is much discussed but ill-articulated and this in turn has effects on research, its procedures and ethical processes. There are also assumptions made about the possibilities presented by BD research in mental health which are perhaps overly optimistic. Again, there is an absence of a coherent vision of what we want data to provide in terms of knowledge about mental health. Finally, there are some ethical dimensions which demand further examination. The particular ethical challenges implicit in using BD to pursue knowledge of mental ill- health are presented by what we have argued is the narrow scope of research which does not reflect the interests of service-users who continue as marginalised or even invisible in the data as human ‘subjects. The potential impact of this is a clear “recovery gap” between what service-users and carers value as important in recovery and social inclusion and what services prioritise as outcomes.[43] Underlying assumptions about the kind of services

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[1] An exception is a recent consultation to set priorities for research. D. Robotham, T. Wykes, D. Rose, L. Doughty, S. Strange, J. Neale and M. Hotopf (2016) Service user and carer priorities in a Biomedical Research Centre for mental health, Journal of Mental Health DOI: 10.3109/09638237.2016.1167862

and interventions needed continue to shape research and will inevitably influence the questions investigated when using BD sets. Innovative re-imagining of services, intervention and treatments will require more than the availability of data but would depend upon skilled researcher interpretation. Psychological and social research needs to think through ways in which it can positively use BD in ways which take us beyond biomedical explanations. Consent also needs to be reconceptualised perhaps categorising the types of research potential participants opt in to.

The terms *'naturally occurring'* and *'routinely available'* data both occur in the literature surrounding the use of data for research and present alternative ways of examining research problems in mental health. The focus is practice-based evidence as real-world data is favoured over those generated via BD. Difficulties remain in that the language used constructs data as obvious, natural and routine as if it were unproblematic. However, data is never neutral and must be accounted for in any dissemination. Even data collected from naturally occurring activities carries ethical and pragmatic implications for its usage. In short, 'naturally occurring data' usually means data which exists independently of the researcher and which the researcher has not influenced; that is, it consists of recordings or observations of naturally occurring activities that occur routinely in practice and are not generated only for the research project, like a questionnaire or interview might be[44],[45]. Naturally occurring and routinely available data are not collected with research questions in mind. However, this does not make the data corpus neutral as if it is being used for research purposes, then a research agenda, and ethical constraints will have influenced its collection. Furthermore, the assembling of these naturally occurring activities will likely have been collected for other purposes and therefore what exists has been influenced by social, political and medical contexts. For example, increasingly, data is frequently collected to meet the needs of institutional audit or to demonstrate accountability. Consequently, accrued data can address some questions but not others.

Pre-existing and routinely collected data have potential, but inquiry needs to incorporate psychosocial aspects of people's experiences. Following analysis of data, interpretation should be cognisant of some of the altered ethical considerations presented here. This would mean researchers being reflexive about the questions posed and we suggest a conscious consideration of the ethical dimensions outlined in this article. The invisibility of lived experience, the contested meaning of vulnerability which may deny agency, and the consequences of research replicating ineffective practice responses to problems.

We have suggested that the ethical principles of research need to be considered but perhaps with different emphases. For example, protection of participants may be protection from spurious research. Autonomy is altered in BD research where it might be reconfigured as relational or collective with consent considerations taking account of a community of participants rather than individuals. The weighing up of the risk and harm ratio is also challenged especially if we reconfigure benefit and harm for communities of 'patients. We have described the problematic construction of risk when applied to communities of people with diagnoses as if homogenous. Risk and harm are altered concepts when considered in BD research because the potential person-centred assessments of vulnerability and potential risks are difficult to attain when looking at large sets of data where the individual is elided. Achieving parity of esteem requires a change in approach to BD research and more work and guidance is needed for researchers in this area. For example, an ethical toolkit or decision-making tool could be developed to help guide BD researchers in reflexively approaching ethics in their work and to encourage critical consideration of the issues we have laid out. The democratisation of research using BD is required, where the perspectives of those with lived experiences is assimilated into inquiry thereby shaping knowledge and advances in practice.

Disclosure statement

There are no conflicts of interest to report.

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