

# Do families with mental ill health have a ‘voice’?

## Gatekeeping in health and social care research

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### Introduction

This paper is prompted by the authors' experience recruiting participants for a research project focused on preventing overweight during infancy (Proactive Assessment of Obesity during Infancy (Redsell *et al.*, 2017). The research involved health visitors identifying potential participants during routine home visits to new parents. Although the protocol had clear inclusion and exclusion criteria relating to anxiety and depression, health visitors were reluctant to approach parents who they thought might have any mental health concerns. Acting as gatekeepers, they informally excluded these potential participants from the research.

The practice of researchers gaining access to participants via intermediaries was precipitated by the Data Protection Act (1998) (DPA), which specified that organisations need permission to pass on personal details to third parties. This led to the current situation in which research establishments are unable to directly contact people receiving care from health and social care organisations in order to recruit them into research projects. Consequently, it falls to client-facing professionals to identify and approach eligible participants, and to act as ‘gatekeepers’, deciding who has the opportunity to take part in research. Shortly after the DPA was introduced, Redsell & Cheater (2001) cautioned that it made research more vulnerable to recruitment bias and caused issues with external validity. This indeed seems to be the case, with reports of researchers experiencing difficulties with gatekeepers excluding people who are eligible for their study. ‘Excluded’ groups have included patients with depression (Hughes-Morley *et al.*, 2015), people who are socially disadvantaged or socially excluded (Bonevski *et al.*, 2014), ethnic minority communities (McAreevey & Das, 2013), potentially vulnerable pregnant women (Stuart *et al.*, 2015), patients with cancer (e.g. Gurwitz *et al.*, 2001) and looked-after children in a social care setting (Mezey *et al.*, 2015).

While gatekeepers are trying to protect their clients, the result is that some vulnerable people do not have the opportunity to participate – they lose their voice. With an estimated quarter of people in England experiencing a mental health problem in any year, gatekeeper exclusion of families with mental ill health has the potential to affect the external validity and hence generalisability of research in health and social care. In this

paper we explore some of the reasons behind gatekeeping, including whether research is a burden for a family, whether it might be detrimental for the vulnerable child, and whether the professionals feel exposed.

### Gatekeepers believe that research is too much of a burden for the family

*‘... some of the families I already knew had mild depression ... wouldn't respond well to participating, so yeah, I didn't ask them.’* (Health Visitor, ProAsk study)

The notion that offering the choice to participate in research could have adverse effects on some families, even where they meet the study's inclusion criteria, implies that the gatekeeping professional is being overprotective. Drawing on our own experience of recruiting participants to the ProAsk study, we proposed that mothers with a diagnosis of postnatal depression should be excluded from the study. As the gatekeepers to potential parent participants, health visitors were consulted about the protocol and advised that the exclusion criteria relating to mental ill health should be broadened so that mothers with moderate post-natal depression or anxiety scores were also excluded. These criteria were approved by the NHS Research Ethics Committee. However, during recruitment it became apparent that some health visitors were excluding mothers with *any* mental health issue; their protectiveness led to a protocol deviation which made the study sample susceptible to bias in favour of parents with no reported mental health issues.

We argue that a protective bias may be operating across both health and social care research, and seems to be a particular cause for concern where there are mental health issues. A recent systematic review of depression trials concluded that clinician gatekeepers often showed a protective bias that impacted on the recruitment of participants (Hughes-Morley *et al.*, 2015). Diggins (2016) attempted to recruit participants for research into parental mental health and child protection and found that social workers felt that participating in research would place unnecessary strain on the families. While ethical research demands that the interests of the most vulnerable in society are safeguarded, it also requires that the individual's right

to make autonomous decisions is respected. Even if the intention is to protect, a decision by gatekeepers not to offer the opportunity to take part in research necessarily results in a loss of autonomy for that person and a shift towards paternalism.

Roberts and Kim (2014) found that the overprotectiveness shown by gatekeepers in trials involving patients with mental health issues such as depression, anxiety and schizophrenia is driven by a tendency to overestimate the vulnerabilities of these patients. Although motivated by protectiveness, it has serious implications. A gatekeeper's decision not to offer an opportunity for research participation to an eligible person suggests that in the professional's judgment the potential participant lacks capacity to make the decision for him or herself. The Mental Capacity Act (2005) makes it clear that it must be established (rather than assumed) that a person lacks capacity to make a given decision. This requirement is not satisfied where a gatekeeper decides not to offer a client or patient a particular research opportunity on the basis of their intuition about conditions and circumstances. There is, however, evidence that health care professionals who identify and approach patients with mental health issues about research participation often draw on their intuition regarding the person's vulnerability rather than a formal medical assessment (Witham *et al*, 2015). Such intuitions are highly susceptible to assumptions about how mental health status might affect decision-making abilities, and make recruitment to research susceptible to unconscious and unspoken biases that are difficult to scrutinise.

The assumption that people with mental ill health are particularly vulnerable to being overwhelmed by the demands of research also relies on the belief that research participation is burdensome. Reviewing the evidence of risks and benefits of research participation for people from populations defined as vulnerable, Alexander (2010) found 100 articles that reported positive outcomes from research participation by individuals from vulnerable populations, but only one reporting negative outcomes.

The benefits of using research participants from vulnerable populations include:

- gaining new insights and information
- feeling valued
- a sense of altruism
- social contact for the socially isolated, which brings the opportunity for associated psychological benefits
- normalisation of their experience.

Alexander concludes that there is little evidence that research is especially harmful for individuals from vulnerable populations.

Research that seeks the views of people with depression, anxiety and schizophrenia who have taken part in clinical research supports this contention. Interviewed about their experiences of and attitudes towards research participation, they did not see themselves as more vulnerable than other participants and they valued being given the opportunity to take part (Roberts & Kim, 2014). Gatekeepers may be placing undue emphasis on the possible risks to their clients. In consequence, they may be both failing to recognise their

strengths and denying them the opportunity to experience the potential benefits from participating in research. Being constructed as 'helpless' by professionals risks reinforcing the loss of agency associated with depression. Effectively, gatekeeping silences patients denying choice and autonomy (Witham *et al*, 2015).

The problem with paternalistic gatekeeping to 'protect' the potential participant is that this silencing means they lose their voice, and services developed from research lack the vital contribution that these people can make.

## **Gatekeepers believe participating in research might be bad for the child**

Research involving children may be particularly vulnerable to gatekeeping. Layers of gatekeepers, from ethics committees to professionals, parents, caregivers and teachers, control access to a potential child participant (Powell & Smith, 2009). It is the ethical responsibility of these gatekeepers to protect the child. But they also have a responsibility to promote the child's right to have their freely expressed views taken into account in matters that affect them (United Nations Convention on the Rights of the Child, Article 12). Like adults with mental health concerns, gatekeepers' perceptions of children as vulnerable and lacking competence to make decisions can result in overprotection, which limits their participation in research. This problem was articulated 20 years ago by Morrow and Richards (1996) and remains as pertinent today (Tromp & Vathorst, 2015). As Luchtenberg *et al* (2015) found, young people who had participated in clinical research subsequently revealed in interviews that they had wanted to take part in clinical trials before, but had not been offered the opportunity.

Where research has accessed the voices of young people it has proven important in service development and in the success of intervention. Diggins (2016) researched the added value of learning from success in parental mental health and child welfare work and reported: 'Young carers were proud of the role they undertook in their family and some viewed caring as a positive contributory factor to their own development' (Diggins, 2016, p100). Diggins also reports that children say they hide their own difficulties from their parents because they do not want to make them feel 'more guilty' and they are worried that services might intervene and separate them. Exploring the views of children and parents enables a picture to be developed of what the children feel contributes to success, including the nature of their relationships with helping professionals. Without hearing the voice of the child, assumptions are made about what they might contribute.

## **Professionals may feel exposed by the research**

Health and social care professionals working in community settings practice in unsupervised contexts. In the space provided by professional autonomy it is difficult to make clinical judgements accountable (Grimen, 2009). As gatekeepers regulate access to potential research participants they may select participants that protect their own interests and activities (Emmel *et al*, 2007). Witham *et al* (2015) discuss gatekeepers' concerns for themselves as the main reason for not approaching potential participants with mental ill health.

Potential risks to gatekeepers include:

- harm to the gatekeeper or associates
- uninvited interference
- being misrepresented
- legal consequences.

(Clark, 2010)

Wolff (2004) suggests that a researcher's failure to gain access to participants is as illuminating about the field under study as their successes. Unsuccessful or problematic field negotiations should not necessarily be written off as failure at the personal level, nor a problem of relations, but rather seen as systemic responses to the threat of disruption. There is a clear need for researchers to develop relationships with gatekeepers so the perceived risk and uncertainty introduced by research becomes an opportunity for development and improved practice.

Researchers need to understand and directly address the gatekeeper's concerns about introducing research to service users perceived too vulnerable to be asked. The negative stereotypes of research as burdensome and threatening could be challenged by researchers highlighting the evidence of the benefits for participants, and, for non-participants, the benefits of simply being offered the choice. At the same time, researchers should not shy away from sharing with client-facing professionals the serious implications of gatekeeping for equality and social justice.

## Why is representative research important?

If research is not representative we may draw the wrong conclusions and develop poor policy. This can occur through biased or small samples. The actions of gatekeepers may result in biases into recruitment to research (Preston *et al*, 2016). This is problematic for both quantitative and qualitative research. Quantitative research seeks to study a representative sample of the population so that the results can be generalised to the wider population. If the sample is not representative the safety and effectiveness of new treatments and interventions cannot be demonstrated on important sub-groups of the population (Rugkåsa & Canvin, 2011). Within qualitative research, gatekeepers can exert an important influence over the voice of the more vulnerable participants, which influences the meanings and social understanding that qualitative research can gain. The subgroups who are not represented are often those whose experiences will be most valuable to the qualitative researcher.

It is of particular concern if people with the highest burden of illness are excluded from research. People with more than one health concern are one such group. There is evidence that gatekeepers may choose not to offer research opportunities to eligible participants because the patient has co-morbidities (Jenkinson *et al*, 2014). To illustrate this problem, even when research is designed to meet a particular and pressing need in patients with both physical and mental ill health, the additional burden of research was perceived by health care professionals as an overwhelming threat (Witham *et al*, 2015). Mental health disorders, particularly depression, are more prevalent in people with increasing numbers of physical disorders. Gatekeeping on the grounds of physical and mental health co-morbidity therefore poses a serious threat to the representativeness of research and presents a barrier to

understanding how people with the highest burden of illness experience their predicaments.

There is also evidence that gatekeepers restrict access to research participation by people from lower socio-economic groups (Bonevski *et al*, 2014). Since common health disorders are more prevalent in socially disadvantaged populations (Fryers *et al*, 2003) gatekeeping on the basis of social groups hinders the development of an evidence base that could deliver interventions and policies that reduce health inequalities.

The problems of representativeness are compounded by the use of secondary data and meta-analysis, where data sets are combined and re-analysed to establish the validity of the findings. Despite techniques to maximise representativeness, some sub-populations remain underrepresented (Frederick *et al*, 2012). Once excluded, groups are excluded again. This is important because such data can be influential for guidelines and policy; systematic reviews are seen by some as the pinnacle of evidence-based practice.

## Conclusion

The task of research is to further our understanding and to translate these findings into policy and practice. We need to understand what contributes to poor mental and physical health and we need insights into the experiences of children in troubled families. To promote parental mental health and child welfare we need to research those at risk and have to rely on gatekeepers to access these populations. There are risks in exposing people to research, and gatekeepers need to be mindful of this, but at the same time it is vital that these people have a voice and that we are able to develop policy and practice that reflects their lived experience. By highlighting some of the reasons behind gatekeeping and some of its effects, we hope to equip and encourage researchers to engage with gatekeepers and promote the potential benefits of research participation for people from vulnerable and marginalised populations.

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