

**Current Issues:**

## **Semantics of patient choice: how the UK national guideline for depression silences patients**

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### **Abstract**

A wide range of stakeholders, including the National Survivor User Network, the British Psychological Society and the Royal College of Psychiatrists have called for the National Institute for Health and Care Excellence (NICE, the UK body for producing national clinical guidelines) to include an up-to-date review of patient experience research in the new draft depression guideline (Thornton, 2018). In response to stakeholder concern, the Guideline Committee (GC) have postponed publication a third time, the guideline now due in December 2019. Yet the GC has also stated it will not review patient experience research. Instead, the GC has stated it will incorporate a new element of 'patient choice' but without elaborating on what this entails. Here, we attempt to untangle a number of similar sounding terms including 'patient choice' and 'patient preference'; 'patient experience research'; and 'service user involvement' in terms of how they relate to the NICE depression guideline. We argue that by conflating these concepts and implying that one will serve the purpose of another equally well, NICE risks leaving patients without a real voice, their perspectives buried in semantically void rhetorical jargon. This is pivotal because, once published, the guideline will dictate which treatments for depression patients in England and Wales can access through the National Health Service (NHS), the state-led provider of health care in the UK.

### **Choice and preference: not just semantics**

The idea of enabling recipients of services to 'choose' derived from a neoliberal 'free-market' ideology; it sought to improve public services by injecting into them consumerist market forces and bestowing 'choice' on otherwise passive recipients. The UK's NHS has been subject to 'free-market' policy drivers from successive neoliberal regimes since Thatcher's government (1979-1990). This is not to say that having 'choice' is not also potentially beneficial to patients. Indeed the current draft of the new NICE depression guideline notes:

*It is increasingly recognised that individuals wish to have a choice of psychological treatment options, and that the provision of such choice may improve treatment engagement and outcome (p43)*

Yet 'patient choice', as set out in NHS policy, does not necessarily set out to empower patients. In 2010, the government white paper 'Liberating the NHS' fused patient choice to the concept of 'control' with catchphrases like 'greater choice and control' and 'no decision about me without me'. Although this merging of terms appears seamless, the concept of 'control' derives ideologically from user-led movements demanding greater democratization of services and it is this latter sort of choice or control that has potential to empower patients rather than merely buoy up the healthcare economy (Beresford, 2002). This creates a tension in that there are different ideologies fuelling the patient choice agenda. It is therefore necessary to look beyond words in NHS policies, including NICE guidelines, and to study meaning and practice behind the rhetoric.

'Patient choice' defined by the NHS Choices Framework (2016) is a principle but not necessarily a legal right:

*The choices you have will depend on what is put in place for you by your [regional health service]...*

There is no provision to choose services outside of the local area unless "special arrangements are in place to support this". For patients experiencing depression, this means there is no legal right to choose between psychological treatments, especially if your preferred treatment is not provided within your geographical area. Although the 2018 draft depression guideline approves slightly more psychological treatments than the 2009 guideline, it still has a fairly limited range of options, further restricted by the guideline's artificial subtypes of depression. Choice of treatments is therefore likely to continue to be restricted if the guideline is published in this form. To influence patient choice, NICE would need to recommend more psychological therapies on more equal terms with a less rigid packaging of subtypes so that local services could offer more forms of therapy.

The difficulty for NICE recommending more psychological therapies is that their review methods lead to their concluding that evidence for some therapies is lacking or of limited quality. There are several methodological issues with the guideline highlighted by stakeholders (for example, ignoring long-term outcomes and quality of life outcomes) which have led to a misrepresentation of evidence for some therapies (McPherson et al, 2018). In addition, the draft guideline places treatments in order of presumed effectiveness and places disproportionate faith in experimental design, inferential statistics and meta-analytic techniques compounded by a lack of precision in the field, acknowledged in the guideline:

*...given the current limited knowledge about which factors are associated with better antidepressant or psychotherapy response, most decisions will rely upon clinical judgement and patient preference until there is further research evidence (p36)*

This admission is not reflected in the guideline's recommendations which are formulated as though there were more certainty. For example, in the case of new episodes of 'less severe' depression, the first treatment recommended is self-help (based on Cognitive Behavioural Therapy [CBT]); if this is refused or not helpful, CBT or behavioural activation can be offered; if this is refused or not helpful, interpersonal therapy can be offered; and so on down to group-CBT, counselling, then short-term psychodynamic psychotherapy. This is not the same as offering patients a clear choice of therapies and puts the onus on patients to refuse before they know there is another choice. This is important because NICE guidelines for depression are translated fairly directly into service provision in the form of a national service for psychological therapies which only provides therapies recommended by NICE. Although there may be some local variation in how the guidelines are interpreted and implemented, local providers are under "obligation in public law to have regard for the NICE guidance and to provide clear reasons for any general policy that does not follow NICE guidance" (NICE, 2014).

'Patient preference', meanwhile, refers to a separate concept in guideline development. Patient preference trials are a (relatively uncommon) variant of Randomised Controlled Trials in which patients choose which arm of the trial they enter rather than being randomised. NICE consider these to be biased because preference replaces random allocation and threatens reliability. NICE has given no indication that this stance will change and states that patient preference has already been taken into account in interpreting evidence. It seems unlikely this is what is meant by a 'new element of patient choice'; yet the concept of patient preference trials seems more relevant to the evidence review function of NICE than 'patient choice' as formulated above.

### **Patient experience research**

Above we highlighted that patient choice is an important aspiration for NHS services if driven by a genuine concern for patient empowerment. Yet, since choice occurs at the point of service delivery, it is difficult to understand which elements of the NICE guideline the GC intend to change in the current draft to better meet this objective, since they have ruled out changes to the methodological approaches criticised by stakeholders. Here we argue that since NICE has a specific evidence review remit, a review of patient experience research remains a critical task to improve the guideline's patient-centredness.

There appears to be a devaluing of patient experience research within NICE generally. For example, in 2018, in response to the stakeholder consultation on *Update to Developing NICE Guidelines: the manual*, NICE stated:

*We do not believe questions of effectiveness should be addressed by qualitative reviews as it lack[s] external validity.*

Reflecting the stance that this type of research is not valuable, the service user experience chapter of the 2009 depression guideline, now copied into the 2018 draft without update, comprised a methodologically poor unsystematic review along with a cursory analysis of handful of patient accounts collected by the GC (McPherson et al, 2018). None of the findings were incorporated into treatment recommendations; the chapter was a stand-alone part of the guideline.

Side-lining this evidence which contains the voices of thousands of patients is inadequately justified:

*..we believe that a combination of the work [on patient choice] and referring to relevant NICE guidance published since [the 2009 guideline] will be the most efficient way to deal with the concerns that have been raised. (NICE: Consultation comments and responses, October 2018)*

As noted, it is not clear what work on 'patient choice' involves and it is not obvious which other NICE guidance is being referred to. Perhaps the GC are referring to the 2011 NICE guideline *Service user experience in adult mental health*. However, this consists of a synthesis of service user experience sections from other NICE guidelines including the 2009 depression guideline which, as noted, is already copied into the 2018 draft.

### **'Exemplary' service user involvement**

Having considered the types of evidence that NICE might review to improve patient-centredness, we now consider the broader approach to patient voice in the guideline development process. The depression GC have been commended by the NICE executive for involvement of service users. This has consisted in part of having three lay members on the GC whose role is described in the guideline:

*Individuals with direct experience of services... contributed... to writing the review questions, providing advice on outcomes most relevant to service users and carers, helping to ensure that the evidence addressed their views and preferences... and bringing service user research to the attention of the GC. They ... identified recommendations from the service user and carer perspective (p15)*

There is a growing international discourse challenging the devaluing of experiential knowledge and research (Lieghio, 2013) and noting the importance of valuing and enabling user-led (survivor) research conducted under the control of people with first-hand experience of services. This type of research may be qualitative or quantitative and sometimes generates different findings to traditional research (Rose, 2003), emphasising the limitations of relying only on privileged forms of knowledge.

However, if knowledge and expertise that comes from lived experience were properly valued by the GC, patient experience research would be reviewed properly; outcomes valued by patients would be given greater priority; user-led research would be advocated; reviewing these forms of knowledge would be a core activity for guideline developers. Making it the responsibility of GC lay persons to bring service user research 'to the attention of the committee' siloes this form of knowledge so that it remains outside core guideline work. In contrast, more dominant forms of evidence are brought to the attention of the GC by a team of dedicated systematic review staff with expertise in review techniques.

In terms of lay committee members identifying recommendations relevant to service users, this reinforces the separation of the service user experience chapter from the rest of the guideline. In this sense, service user perspectives sit exclusively with lay members of the GC and impact only a limited set of recommendations which have little or no impact on the

range of treatments available. This deprioritises those perspectives and siloes them as a form of knowledge that should not infect the main parts of the guideline.

### **Conclusion**

It is unclear what work the GC intend to undertake during 2019 to fulfil their remit of including new work on 'patient choice'. Given that there are several concepts and terms that relate to patient choice, some more rhetorical than others, it seems important that the GC spell out as soon as possible what they mean in order that stakeholders may comment on the adequacy of this approach. The diverse voices of patients should have equal value in a guideline development process with a view to generating a guideline which will improve patient care and provide genuine choice and control. This would include, as a minimum, the formulation of recommendations such that the choice of treatment is offered upfront to patients, rather than left for clinicians to offer incrementally to those assertive patients who feel able to refuse enough times to move down the list of options they did not know existed at the outset. It would also include a full review of patient experience research whose findings inform treatment recommendations.

Looking to the future, NICE should aspire to develop a more democratic approach to guideline development in which lay representation on committees is not merely a means of satisfying procedural requirements. This would involve putting patients, caregivers and the public at the heart of the guideline development process rather than at the periphery, such that guidelines are co-produced with those who are most affected by them. Citizen panels, for example, could have decision making functions in selecting and defining guideline topics, setting priorities around which outcomes are examined, the forms of knowledge to be included, the methodologies to be employed and the approach to translating evidence into recommendations. Panels could receive support and training to equip them for the task and would have diverse membership in order to represent those groups who are already most marginalised and disadvantaged (Beresford, 2013). Panels would commission and consult scientific experts rather than vice versa, which would circumvent issues associated with professional and academic conflicts of interest in guideline development (Ioannidis, 2018). This shift is some way off, since NICE maintain an institutional approach which devalues experiential forms of knowledge. There is a need for a significant epistemic shift towards democratising and valuing diverse forms of knowledge and acknowledging in a more authentic way the limits to objectivity in health research.

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