

## EDITORIAL INTRODUCTION

# Person-centeredness in health and social care - what exactly is it that patients and their carers want?

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### Keywords

Health services research, justifications for person-centered care, measurement, methodology, patient-centered care, patient experience, patient involvement/engagement in care, patients and carers, person-centered health and social care, progress

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Accepted for publication: 23 March 2018

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## Introduction

Writing in the *British Medical Journal* (BMJ) some 18 years ago, Little and colleagues considered how a patient-centered approach to consultation in primary care should be taken forward [1]. The central tenet of their paper, that the best way of measuring patient-centeredness is to seek an assessment of it from patients themselves, is as valid now in 2018 as it was in 2001, and remains of fundamental importance to progress in the field. Yet the extent to which patients are systematically consulted on their care needs and experiences, the results analysed and assimilated and executive action taken in consequence, is limited at best. Indeed, despite the inexorable rise of the patient as a sovereign consumer of health and social care services, with all of the powers and privileges such a status technically affords [2-9], the ability of patients to act as prime movers of person-centered change within care systems has remained largely underexplored, if not, by default, disallowed.

For sure, the patient's voice has become extraordinarily politically powerful [10,11], but there remains significant confusion as to how exactly patients are, methodologically, to drive the quality of services forward. If, for clarification, we refer to the dominant discourse, then it appears substantially the case that beneficial, patient-mediated effects on the person-centeredness of care services, will be delivered through dynamic patient involvement in decision-making at every level of health services activity - from basic research, through service development, to a final evaluation of health and social care outcomes as part of a full and proper consideration of the *value of services*

in terms of the extent of human resources employed and the quantity of hard currency invested [12-25].

While no universally agreed definition of person-centered care (PCC) currently exists, the principles of such care and its domains have been the subject of much study [26-31]. However, both historically and currently, investigations in PCC have been, and are, overwhelmingly, professionally driven by academics and clinicians, without an explicit recruitment and involvement of patients themselves in research and publication processes. But, as Stewart has emphasised, and as we ourselves agree, it is the patient who should be the final judge of PCC and the primary authority in what PCC is and what it is not [32]. This dictates the involvement of patients in basic research as well as eliciting their conclusions on the value of resulting health and social care outcomes. While the BMJ, for example, has laudably made the inclusion of patients in research and publication wherever possible a matter of editorial policy [33,34], in reality only a start has been made at propagating policies of these types and endowing them with the necessary 'teeth' within the healthcare publishing industry more generally. At the time of writing, there is much noise when people talk of PCC, but this continues to consist largely of 'virtue signalling', with its associated moral posturing. Much effort will therefore need to be expended by patient advocates, clinicians, researchers, policymakers, publishers and governments, to bring about the cultural change which will allow patient involvement, at all levels of modern healthcare activity, to move from an atypical feature to a normative characteristic.

Who would argue against the need to move person-centered care, the ambition to treat patients as persons [35],

“from rhetoric to methods, through implementation to outcomes”, especially given the three principal justifications for PCC, recently articulated [36]? If, returning to Stewart [32], we believe the patient to be the ultimate arbiter or what is and what is not person-centered care, then the time has come, and is long overdue, to engage patients and their carers much more dynamically in health services evaluation and development, and to ask the question: ‘Person-centeredness in health and social care - what exactly is it that patients and their carers want?’

## National Voices: ‘*Person-centered care in 2017. Evidence from service users*’

In a preliminary answer to such a question we must take a careful look at an important report recently published by National Voices, a UK coalition of charities that advocates for people being in control of their health and care. The report, entitled ‘*Person-centered care in 2017. Evidence from service users*’ [37], is a rich source of patient and carer perspectives [38] drawn from a plethora of information sources which put the current state of play, at least in the UK NHS, into vivid perspective. Whether or not the results recorded reflect the current status of development of PCC across Europe and, more distantly, elsewhere, remains to be seen. But the general methodological approach taken by the researchers could certainly be replicated elsewhere with minimal difficulty, with such an exercise highly likely to generate fascinating results, as well as multiple blueprints for change.

The key findings of the report [37], of which there are nine in broad summary, are instructive. We learn the following:

1. Person-centered care is inadequately measured and that it is not current possible to adequately measure or assess person-centered care across services.
2. A mixed picture is evident: people’s experiences can be highly variable. From the patchy data available it appears some aspects of person-centred care are being consistently achieved, but people’s experiences can be highly variable.
3. Some aspects of person-centred care have improved. For example, 76% of inpatients who had an operation or procedure said that what would happen was ‘completely’ explained and 87% of general practice patients said their GP was good at listening to them.
4. There has been progress towards involvement in decisions and being in control. Here, 78% of cancer patients were definitely as involved as much as they wanted to be in decisions about their treatment and 33% of people using adult social care said they had as much control over their daily lives as they wanted; another 44% had ‘adequate’ control.

5. The steady progress in person-centeredness of care is now deteriorating, both for general practice and inpatient care.

6. There is little evidence of personalised care and support planning. Only 3% of people with a long-term condition said they had a written care plan.

7. The coordination of care is not measured. A 64% rise in delayed transfers out of hospital in the last five years was noted, with 46% of inpatients saying that they did not get enough further support to recover or manage their condition after leaving hospital.

8. Family involvement is not central and most carers need better support. Some 68% of carers said that their GP knew they were a carer, but did not do anything differently as a result. Additionally, 23% of carers said they had received a social care assessment.

9. There are some indicators of inequality between racial groups.

What are we to make of these observations and what are we to do in response? The conclusions of the report are forthright, to which the reader is referred [37]. In our view, dynamic action is absolutely the order of the day and the development of specific models of person-centered care for specific clinical single, co- and multi-morbid, socially complex conditions, has become the most urgent priority within modern health and social care systems [36,39,40].

## Conclusion

Much is wrong within modern health services and much work is needed to put what is wrong right again. Is there a danger that we may lose the momentum to implement PCH in operational practice, remaining preferentially content to engage in endless discussions of its philosophy only? We think so, the result of the report we discuss confirming the same, at least for the UK. Contemplating this, it should be clear to all those colleagues working to advance the person-centeredness of health and social care services that they are called to a particular urgency of action. Complacency is the opposite of what is required in these circumstances. Co-ordinated efforts among all of the multiple stakeholders in PCC are central here [35,36]. Accordingly, we call on colleagues who are not already members of the European Society for Person Centered Healthcare, to join the ranks of the Society [41] and work with us to make person-centered health and social care a reality.

## Conflicts of Interest

The authors declare no conflicts of interest

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