

# QUALITATIVE EVIDENCE SYNTHESIS CAN INFORM RECOMMENDATIONS IN NICE CLINICAL GUIDELINES

Christopher Carroll

School of Health and Related Research (ScHARR), University of Sheffield, UK

## ABSTRACT

The published evidence used to underpin National Institute of Health and Care Excellence (NICE) clinical guidelines is almost exclusively quantitative. This is understandable as the principal focus is efficacy and safety: the aim is to establish what works. However, clinical practice is arguably also best informed by evidence that explores how and why patients make the decisions they do. Qualitative evidence can help with this. A synthesis of qualitative studies can paint a rich, subtle and extremely useful picture of patient experience and their views, beliefs and priorities. This paper makes a case for integrating this type of evidence into the development of clinical guidelines.

## METHODS

In this paper, the NICE clinical guideline of chronic kidney disease will be used as an example. This condition has been chosen because it has been the subject of recent NICE clinical guidelines and qualitative evidence synthesis. It therefore offers an appropriate “test case” for assessing the potential value of qualitative evidence synthesis for clinical guidelines. There are other relevant examples but, due to the limits of this presentation, only chronic kidney disease is considered here. This is followed by a worked example, which demonstrates how synthesised qualitative evidence has already informed and enhanced a NICE clinical guideline for stroke. Such an example is rare. The qualitative evidence synthesis cited below reports a wide range of findings, but only a small number of its key themes are covered here.

## RESULTS

This **NICE Chronic Kidney Disease (CKD) clinical guideline (CG182)(1)** makes almost no use of qualitative evidence. Its recommendations stress the importance of treatment decision-making being based on a good understanding of the condition and being shared between clinician and patient. The current guideline recommends that education and information provision should be “appropriate” or “tailored to” the severity of the condition, but there is no detail of what might be appropriate – or how to discover this. A recent qualitative evidence synthesis of 18 studies **(2)** provides exactly this evidence (see **Box**). It describes and explains in detail the decision-making process of this population. It highlights the real and perceived constraints that patients feel affect their choices, and explains how their preferences change depending on where they are in the treatment pathway. The synthesis findings can therefore enhance the recommendations by providing more specific advice relating to the nature of patients’ decision-making

Clinical Guideline recommendation	A finding from a qualitative evidence synthesis
<p><b>1.4.1</b> Offer people with CKD education and information tailored to the severity and cause of CKD, the associated complications and the risk of progression.</p> <p><b>1.4.3</b> Offer people with CKD high-quality information or education programmes as appropriate to the severity of their condition to allow time for them to fully understand and make informed choices about their treatment.</p>	<p><i>The four themes that emerged from this synthesis of primary studies (confronting mortality, lack of choice, gaining information about options, and weighing alternatives) were relevant to decision making across all treatments for chronic kidney disease. Many patients perceived they had limited choices in treatment. When choice was offered, preferences for peritoneal dialysis were based around privacy, freedom, and flexibility, whereas preferences for haemodialysis were attributed to a planned schedule, regular social contact, and previous knowledge of the therapy .... Overall, patients were less concerned about their longevity with a specific treatment and more concerned about its impact on their quality of life</i></p>

Christopher Carroll

School of Health and Related Research (ScHARR), University of Sheffield, UK

## RESULTS CONTINUED

The issue of goal-setting for stroke rehabilitation offers an example of how the synthesis of qualitative evidence has already enhanced recommendations. The influence is quite transparent when cross-referencing the methods and evidence used in developing the guideline (3) with the actual, final **NICE Stroke Clinical Guideline (CG162)**.(4) The development involved using published evidence from a relevant synthesis of qualitative evidence (5) and integrating this with the quantitative evidence. The qualitative evidence synthesis suggested that patients and family members felt goal-setting was seen as relatively unimportant, and wholly the remit of the health professional, and that it needed to be more structured. The findings informed a series of evidence statements (6.2.3), which in turn informed the recommendations (6.2.5). These recommendations then appeared in the final **NICE Clinical Guideline (CG162)**, which required that goal-setting be conducted at specific meetings and be meaningful, relevant, challenging but achievable, time sensitive (reviewed regularly), and involve ample input from the patient and their family and/or carers. In other words, the qualitative evidence synthesis not only stressed the importance of shared-decision making, but also how it should be done. As a result, it was integrated in detail into the recommendations.

## CONCLUSIONS

Decision-making is increasingly required to be "shared" with the patient, and information and advice are required to be "appropriate". However, simply recommending this approach does not mean it is necessarily going to address issues of importance to patients; issues that are raised and detailed by qualitative evidence synthesis. Clinical Guidelines and their recommendations can make use of this evidence base; they can be more informed, richer and context-specific. There are many hundreds of published qualitative evidence syntheses, so the evidence is available. Such evidence syntheses are generally more useful than single qualitative studies, unless the latter is both high-quality and highly specific to the group, condition and service in question. Regarding context, it might be that the evidence synthesised comes from settings that are not always applicable to the NHS, so this needs to be taken into account, in the same way as it is with trial evidence. The proposed approach might also be more useful for some conditions than for others, but even pharmaceuticals encounter issues of adherence that might be addressed if clinical guidelines recommended highlighting particular issues from the qualitative evidence. However, as the examples described above indicate, such evidence synthesis, carefully considered and integrated, offer a highly useful addition to the expert and patient opinion currently used in the guideline development process.

## REFERENCES

- (1) Chronic kidney disease: early identification and management of chronic kidney disease in adults in primary and secondary care. Issued: July 2014. NICE clinical guideline 182. 2014. London, National Institute of Health and Care Excellence (NICE).
- (2) Morton R et al. The views of patients and carers in treatment decision-making for chronic kidney disease: systematic review and thematic synthesis of qualitative studies. *British Medical Journal* 2010; 340:c112.
- (3) National Clinical Guideline Centre. Stroke rehabilitation: Long-term rehabilitation after stroke. Final Full Guideline. Issued: May 2013. Clinical guideline 162. Methods, evidence and recommendations. 2013. National Clinical Guideline Centre.
- (4) Stroke rehabilitation: Long-term rehabilitation after stroke. Issued: June 2013. NICE clinical guideline 162. 2013. London, National Institute of Health and Care Excellence (NICE).
- (5) Rosewilliam S, Roskell CA, Pandyan AD. A systematic review and synthesis of the quantitative and qualitative evidence behind patient-centred goal setting in stroke rehabilitation. *Clinical Rehabilitation* 2011; 25(6):501-514