

## **Primary care redesign for person-centred care: delivering an international generalist revolution**

**Running title:** Primary care redesign: a generalist revolution

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## **Abstract**

Person-centred primary care is a priority for patients, practitioners and healthcare policy. Despite this, data suggests we are still not consistently achieving person-centred care – and indeed that in some areas, care may be worsening. Whole person care is the expertise of the medical generalist – an area of clinical practice that has been neglected by health policy for some time. It is internationally recognised that we need to rebalance specialist and generalist primary care. Drawing on fifteen years of scholarship within the science of medical generalism (the expertise of whole person medical care), I describe a 3-tiered approach to primary care redesign; describing changes needed at the level of the consultation, practice set up, and strategic planning. The changing needs of patients living with complex chronic illness has already started a revolution in our understanding of healthcare systems. This paper outlines work to support that paradigm shift from disease-focused to person-focused primary healthcare.

## **Summary statement**

- What is known about the topic: Person-centred healthcare focused on addressing the health needs to support daily living is a policy and practice priority; yet we still lack clarity in how to achieve it.
- What does this add: This paper outlines a 3-tiered approach to primary care redesign for person-centred care based on strengthening generalist practice in the consultation, the organisation of practice, and the strategic design of health systems.

## **Primary care redesign for person-centred care: delivering an international generalist revolution**

A quiet revolution has already started in primary care.

It remains largely hidden by a deafening crisis of concern surrounding accounts of aging populations living with the growing burden of multimorbidity; spiralling healthcare costs; and, in the UK at least, a workforce crisis where we struggle to recruit and retain the staff needed to meet growing needs.

Yet if we look a little deeper, we see another narrative thread - a story of revolution, led by the most unlikely of revolutionaries. The 80-year-old widow with multimorbidity and polypharmacy whose key priorities are maintaining her independence, so she can get to the shops and out to bingo on a Friday night. The 30-year-old living with significant learning disabilities who is repeatedly told about his risk of diabetes when he wants to talk about being a dad. The 40-year-old woman living with chronic pain and fatigue who has been told there is “no cure” and is struggling to rebuild her daily routine round a new way of living.

What these people have in common are health problems that cannot be addressed solely by a disease model of healthcare. As a result, they challenge our very understanding of how we assess healthcare need, prioritise and deliver care, and so how we design healthcare teams and systems to meet the needs of individuals and populations. They are living testament to Tinetti and Fried’s (2004) assertion that we are reaching the “end of the disease era” – that we need to evolve from a disease-oriented model of medical care to a patient-defined goal-oriented model of medical care. They are the stimulus for us to attend to the World Health Organisation (2008) call for person-centred primary care – “now more than ever”. They are the quiet revolutionaries driving a rethink of our model of primary health care.

Person-centred care - personalised healthcare which is focused on enabling daily living (Health Policy Partnership 2016) – has been a longstanding priority in health policy around the world. But a growing body of evidence – for example in the literature on treatment burden (Mair 2014) -

highlights a gap between the language of policy and the reality of practice. Perhaps most alarming in the UK was a report last year highlighting a reported decline in person-centred care in general practice (National Voices 2017) – the medical discipline which defines itself as ‘specialising in the patient’.

So how do we respond?

In this paper, I draw on the UK Society for Academic Primary Care’s model of blue sky thinking to propose a ‘Dangerous Idea’: an idea that challenges the status quo but with a commitment to action (<https://sapc.ac.uk/article/sapc-dangerous-ideas-soapbox>). Based on a critical reflection on 15 years of my own work in this area, I propose a 3-tiered approach to primary care redesign to reverse the trend in person-centred care, to address the changing healthcare needs of our population, and to respond to our quiet revolutionaries. I will outline the changes needed at the level of the consultation – the interaction between patient and professional; the organisation of practice teams; and the strategic overview of our health care system (Table 1). My account is largely grounded in a UK perspective, but evidence suggests that the proposals are relevant to an international audience. My intention is to spark the wider conversations needed, ‘now more than ever’, to deliver truly person-centred primary care.

### **Tier 1: The Consultation**

Patients highlight a perceived lack of person-centred care in their interactions with health care professionals (National Voices 2017, Reeve *et al.* 2012, Reeve and Cooper 2016a). We need to take a fresh look at the consultation – the process by which patients and professionals interact to determine and address healthcare need.

### **Addressing the decline in person-centred care: tailoring care to the individual**

Living with long term conditions can be exhausting (Carel 2008). A rich literature records a biographical account of the work living with chronic illness (Lockock and Ziebland 2015). On top of

the work of everyday life comes the burden of illness, and an increasing burden of healthcare – whether from medication, managing appointments, or the tasks of monitoring health status (Mair 2014). Primary care has long recognised this broader experience, as described within a biopsychosocial understanding of illness (Weiss 1980).

But patients tell us that although we acknowledge this wider experience of illness, we don't necessarily take it into account when we make clinical decisions (Reeve *et al.* 2012). They describe experiences of health professionals who are good at delivering personal care – empathic, relationship-based care. But that this doesn't translate into good personalised care – where clinical decisions about diagnosis and treatment are shaped around individual priorities and circumstances (ibid). The Kings Fund (2015) report on polypharmacy highlighted the importance of capacity for “compromise” between professional and patient priorities if we are to address the challenge of problematic polypharmacy. Denford *et al.*'s (2014) review of medication use provides further evidence of patients reporting a lack of such tailoring of care.

What stops health professionals from tailoring care to meet individual needs? To understand this, we must look more closely at the way that health care professionals make clinical decisions about what is wrong (diagnosis) and what needs doing (Intervention). The dominant model of clinical practice in current western healthcare is that of specialist medicine – condition- or system-specific healthcare. The specialist model currently dictates how we define 'best practice' (the timely and correct identification of disease status), and so how we train health professionals to deliver care, and design the systems that they work in. The wider literature, including my own research, highlights how and why this model of practice has become a barrier to the delivery of individually tailored care.

Person-centred care requires a clinician to tailor the use of evidence to individual circumstances (Denford *et al.* 2014), potentially requiring compromise between biomedical and individual perspectives (Kings Fund 2015) in order to deliver healthcare decisions that recognise person-centred goals focused on continued daily living (Health Policy Partnership 2016). Although Evidence-Based-Medicine (EBM) and clinical governance mechanisms encourage the use of clinical judgement, they also place clinical opinion at the bottom of a hierarchy of knowledge (Sackett *et al.* 2006). No guidance is offered to practitioners as how to distinguish between 'clinical judgement' and the form of evidence found at the bottom of EBM hierarchy of evidence – namely 'profession opinion'.

Practitioners consistently report feeling constrained in challenging the evidence, defending judgement/opinion and so tailoring care (Reeve *et al.* 2013a, 2018a).

I have previously described how scientific practice could address this barrier by recognising that generalist practice is grounded in a different epistemological framework to specialist practice (Reeve 2010). Specialist practice is deductive - theory driven practice that assesses the likelihood that a diagnostic theory can be applied to this person. Generalist practice is inductive – data driven practice in which multiple elements (all believed to be robust) are combined to infer an explanation/conclusion. What generalists have lacked is a framework to legitimise the process and output of this action – a gap which has contributed to generalist practice being overlooked (Reeve *et al.* 2013) in recent primary care redesign. Scientific practice may help address that gap.

The scientific literature, especially within qualitative and applied traditions, highlights the intellectual tasks needed to deliver trustworthy inductive interpretation (Reeve 2010). I have translated these into a guiding framework for ‘defendable-clinical-decision-making’ (ibid), and – working with GP tutors - into a consultation model for teaching (Reeve 2015). The ‘SAGE consultation model’ outlines the five steps needed to deliver effective, safe clinical decision making within an inductive model of practice. (Further details can be found in this account of the model applied to a clinical case of managing multimorbidity: <http://primarycarehub.org.uk/images/SAGE/SCM.pdf>) . The SAGE model aims to contribute to rebalancing the hierarchy of evidence, to visibly place professional wisdom back at the top of the chain (Reeve 2018b). It contributes to shifting our understanding of generalist practice from a ‘jack of all trades’ view that describes the generalist in terms of what she/he does (the range of work); to a scholarship model that understands generalist practice by how the work is done - the intellectual task of effective, safe interpretive practice.

This intellectual work happens in the context of daily practice. Surveys of professional practice highlight key enablers and barriers to the work of generalist decision making and individually tailored care (Reeve *et al.* 2013a, 2018a): including a lack of clarity in what generalist practice is, a failure to prioritise the intellectual task (and cognitive load) of generalist practice in the wider General Practice day; a lack of training; a shortage of necessary resources for practice including continuity of care and collective action; a failure to support ongoing practice through feedback and

performance assessment; and a lack of coordinated/optimised delivery of care once decisions are made and implemented.

Drawing this work together we start to recognise generalist practice as a complex intervention consisting of multiple interacting parts, defined by the distinct expertise that is whole-person-centred clinical decision making (Reeve *et al.* 2013a) - Figure 1. My own research now seeks to apply these principles to rethinking primary care design and delivery in the critical situations of prescribing practice, mental health care and acute care. My intention is to use this work to refine the generalist model as a tool to support a person-centred primary care 'revolution'.

There is still work to be done, but efforts to date prioritise four key issues in this first tier of redesign. Experience shows that it is insufficient to simply describe the principles of generalist practice – of whole person medical care – and assume that professionals can or will deliver this model to care. To deliver person-centred primary care we need to reimagine generalist practice, focusing on 4 elements:

- Recognising the distinct intellectual task that underpins the everyday pragmatism of Family Physicians and General Practitioners delivering person-centred care, recognising 'Every GP a Scholar' (Society for Academic Primary Care 2017)
- Describing that intellectual task: the five steps to trustworthy interpretive practice (Reeve 2010) and so training people in this distinct model of care
- Supporting the task of expert generalist practice through restructuring the working day (recognising issues of cognitive load, the need for multifaceted data, as well as for collective professional reflection (Gabbay and le May 2010)
- Sustaining generalist expertise through describing our own distinct model of life-long learning for professional practice. I have proposed the need to replace Evidence Based Medicine with Scholarship Based Medicine (Reeve 2018b)

## **Tier #2: The practice team**

The data highlighting barriers to delivery of whole-person-centred generalist care recognises the impact of context – the organisation of practice and practice teams – in supporting or undermining care. My second tier of change looks at the organisation of practice necessary to support delivery of generalist care.

### **Addressing the decline in person centred care: redesigning primary care teams**

We currently design teams to deliver disease focused care – described in the largely linear models of care pathways. Person-centred, generalist care, is a complex intervention – a non-linear model of care. We need to redesign teams to deliver complex interventions (Reeve *et al.* 2018a).

We still know relatively little about how to do that. In a recent systematic review, Lau et al (2015) highlight that whilst we know more about how to change individual professional behaviour to support implementation, there is a lack of evidence on the process and effectiveness of implementation of complex interventions at organisational levels – evaluating change at a whole practice level.

I have completed two studies evaluating the implementation of complex interventions within primary care – both grounded in the ideas described within Normalisation Process Theory, a sociological theory of the implementation and embedding of organisational innovations ([www.normalizationprocess.org/](http://www.normalizationprocess.org/)). One study was a prospective evaluation of introducing a new whole-person, generalist model of primary mental health care in the UK – the Bounceback project (Reeve *et al.* 2016b). The second was a retrospective analysis of the implementation of a new frailty initiative within the General Practice setting in England (Reeve *et al.* 2018a). Critical review of the findings from this work offer us useful insights into understanding the practice level changes needed to deliver a person-centred revolution in primary healthcare delivery.

A key finding from both studies was the need for models of practice that support the iterative re-design of complex interventions as an integral part of their implementation and delivery. Novel complex interventions, even when evidence-based, should not be seen as a ‘bolt-on’ to existing services, but rather as a stimulus for re-evaluation and evolution of existing models of care (Reeve *et al.* 2018a). Implementation and adaptation creates a need for extended expertise within practice



teams to support the critical development of knowledge-in-practice-in-context (Gabbay and le May 2010). Our experience supported the observations described by Evans and Scarborough (2014) of the need to ‘blur’ rather than simply ‘bridge’ the gap between clinician and research skills to optimise implementation and delivery of new interventions. All of which may require review and refinement of contractual and quality assurance mechanisms that traditionally focus on delivering a described model rather than adaptation and implementation (Reeve *et al.* 2018).

Primary healthcare systems around the world are redesigning models of practice. The current focus is on developing integrated, extended multidisciplinary teams to address the growing complexity of patient health needs – a focus on *who* is in the team. My research highlights that we also need to think again about *what they are doing* and *how they are working*; providing a framework to consider when commissioning new models of practice (Reeve *et al.* 2018).

### **Tier #3: Whole system strategic redesign**

Practice teams represent units of care delivery within a wider system of healthcare. Strategic priorities within that system determine the drivers that shape practice teams, the resources offered to them, and the performance management processes that influence ongoing delivery. To change the way we deliver care, we must look at the strategic context within which health care happens

### **Addressing the decline in Person-Centred Care: designing a system of care around a clear vision of balanced generalist-specialist care**

We see growing international consensus on the need for a revival of generalist, whole person, care – a strategic shift away from an excessive focus on the “command and control of disease” to delivery of person-centred care (WHO 2008); a rebalancing of healthcare systems (Heath 2011). We have a substantial knowledge base on the strategic design of specialist, condition-focused models of care; but lack a clear understanding of the design of generalist systems. We lack a ‘blue print’ to guide policy makers and commissioners in achieving a goal of a balanced generalist-specialist healthcare system.

Lewis's (2014) editorial started to address this gap. In this work, he recognised two emerging conceptualisations of generalist care. The first is the systems-focused model of generalism described as Integrated Care - the coordinated delivery of accessible, comprehensive potentially multi-faceted healthcare. Integrated Care seeks to overcome the healthcare burden created by fragmented models of condition-specific care – enabling the smoother navigation of a whole person (patient with multiple needs) through a complicated system. Integrated Care is the main strategic focus of most current primary care redesign; although it is also a model of care for which the evidence-base is still mixed (RAND Europe 2012).

The second approach described by Lewis (2014) is a model of personalised medical care – individual tailoring of clinical decision making, challenging the 'command and control of disease' approach to refocus healthcare outcomes on supporting individuals in living their daily lives in context. Lewis described this approach as a “revolutionary face of generalism” – “relevant to the widespread failures of the here and now, and whether and how it takes hold matters a great deal”. He was describing my own work on individually tailored clinical decision making at the heart of generalist expertise (Reeve 2010).

Taking Lewis's editorial as a starting point, Byng and I recently proposed that balanced primary care redesign needs both approaches – integrated delivery of condition-specific care, and capacity for individually tailored (personalised) care. We described a United Model of Generalism (Reeve and Byng 2017) which recognises Lewis's (2014) accounts as two axes in a single system of healthcare design (Figure 2). Our blueprint describes four new categories of healthcare defined by a person-centred need (for generalist or specialist care) and the health systems requirements to deliver care (based on simple-technical, or complex-integrated models). The blueprint provides us with a map to re-define an epidemiology of need, to describe an updated workforce model to deliver care, and so to re-balance resource and demand. We are now starting discussions with commissioners, patients and professionals to consider how we might take this work forward.

## **Concluding thoughts**

In 2008, the World Health Organisation (2008) outlined why we need to revitalise person-centred primary care, “Now More Than Ever”. Travelling forward to 2018, we see a continuing commitment across political, policy and practice contexts to that vision. But the main efforts of health services remain focused on improving the coordination and integration of existing models of care (Lewis 2014, RAND Europe 2012), rather than a true shift to a more “revolutionary view” (Lewis 2014) of individually tailored generalist care.

The changing needs of our patients are driving a paradigm shift in healthcare design from disease-focused to person-focused care (Reeve 2017). So far, a vision of redesign of care around the patient has failed to deliver this. I therefore propose that to achieve person-centred healthcare, we need to redesign healthcare around the expertise of the generalist clinician in making whole-person, goal-oriented clinical decisions.

Clinicians and scholars around the world are actively engaged in work that addresses individual elements of the ideas I have outlined (for example see Chambers et al. 2013, Spencer-Bonilla et. al. 2017, Sinnott et. al. 2017). My intention in this paper is to start conversations, collaboration and shared actions that translate scientific innovation into systems ‘revolution’. Taking this work forward will require leadership and collaboration from across the clinical and academic primary care communities (Society for Academic Primary Care 2016). I look forward to conversations arising. But any such action will only succeed if we draw on the greatest resource of all – our quiet revolutionaries. Our patients.

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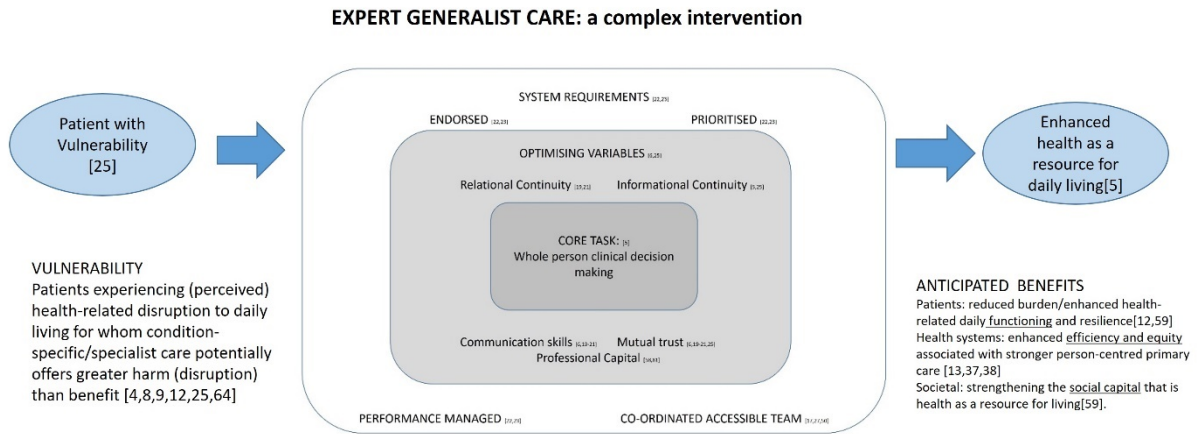
**Table 1: Outlining the 3 tiers of person-centred primary care redesign**

The problem we face...	Arising from...	Solutions lie in...
A lack of tailoring of care to individual needs (Reeve and Cooper 2016)	Defining best practice with reference to specialist care (Reeve 2018b)	<b>Revitalise Generalist decision making</b> (Reeve 2010)
A lack of teams able to develop & deliver complex interventions (Reeve <i>et al.</i> 2013)	Managed healthcare systems with inflexible contracting and performance management systems (Reeve <i>et al</i> 2018a)	<b>New models of practice</b> in professional scholarship (Reeve <i>et al</i> 2018a)
We lack a clear and consistent vision of Primary Care driving strategic planning (Reeve and Byng 2017)	Lack of strategic leadership/vision	<b>Describing new models of system design</b> eg United Generalism (Reeve and Byng 2017); and new leadership (Society for Academic Primary Care 2017)



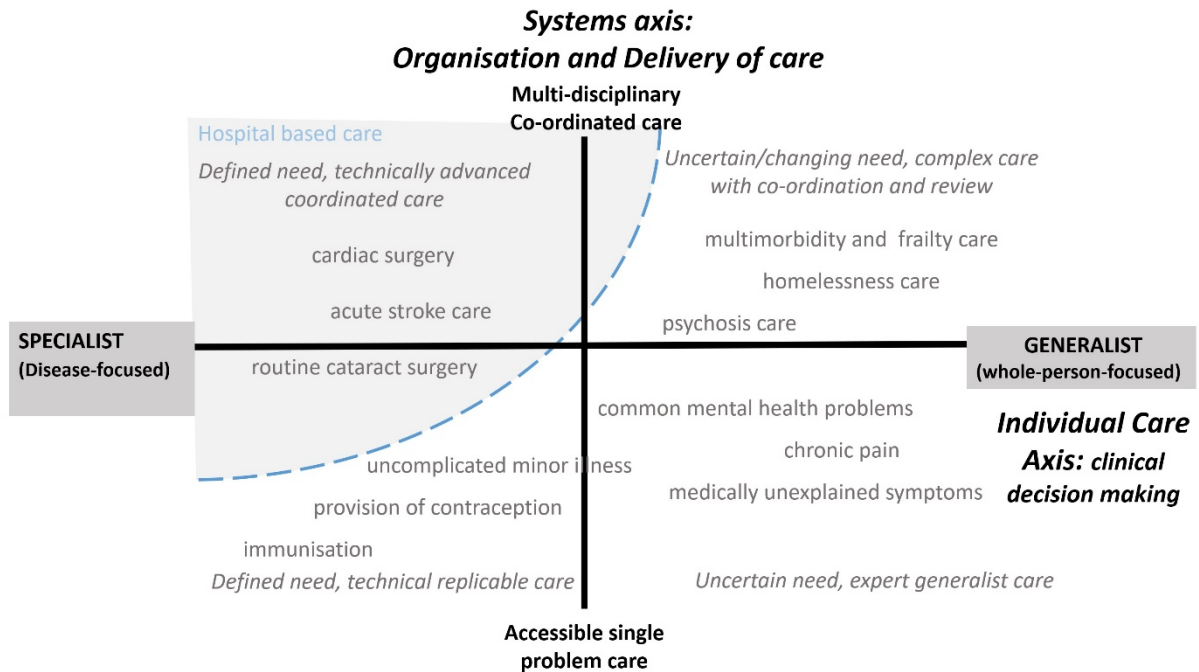
**Figure 1: Describing the complex intervention that is expert generalist care**

(Numbers in brackets refer to a full reference list available from the author)



**Figure 2: The United Model of Generalism – a blueprint for primary care redesign**

*(Amended and reproduced with permission from Reeve and Byng 2017)*



**Table 2: Considering what a generalist re-designed primary care might look like...**

<p><b>For patients</b></p>	<p>Re-focused healthcare service emphasising outcomes targeted on ‘a life for living’ – health as a means to an end, not an end in itself</p> <ul style="list-style-type: none"> <li>• Patient engagement in co-construction of solutions to health problems</li> <li>• Need defined by health related impairment to daily living (including resilience) rather than disease status (alone)</li> </ul>
<p><b>For clinicians</b></p>	<p>Revisions to training and organisation of practice to recognise/support the INTELLECTUAL TASK of expert generalist practice.</p> <ul style="list-style-type: none"> <li>• Enhanced Scholarship Training (Reeve 2018b)</li> <li>• Restructure of working day to recognise Cognitive Load of generalist task (survey)</li> <li>• Reprioritisation of resources for generalist care (Figure 1)</li> </ul>
<p><b>For systems</b></p>	<p>Reshaped around an understanding of person-centred healthcare as delivery of complex interventions, requiring us to</p> <ul style="list-style-type: none"> <li>• Redefine ‘best’ care – supporting an outcome of daily living, rather than ‘command and control’ of disease</li> <li>• Expand expertise within teams – including skills in implementation as well as delivery of interventions</li> <li>• Sustain expertise within teams (building professional capital – Gabbay and le May (2010))</li> </ul>