

‘Why are we going round in circles measuring things instead of fixing the system’ - incorporation of patient and carer perspectives into medication safety at transitions of care.

Sara Garfield, Mike Etkind and Bryony Dean Franklin

It is widely known – among healthcare professionals as well as patient safety researchers – that transfers of care are a high-risk area in relation to patient safety.(1) And even more importantly, the experience of patients and their families suggests likewise. For example, in a research priority setting exercise focusing on safe care for adults with complex health needs, six of the top ten priorities related to transfers of care, either within or between organisations.(2) While care transitions affect all elements of a person’s care, medication safety is a particular cause for concern, with a Cochrane review finding that 56% of patients are at risk of having at least one medication discrepancy as part of standard care.(3) Accepted wisdom among many people working in the quality and safety field is that measurement is essential both to understand the risks, and to target and evaluate interventions to address them. A maxim widely cited in this field, often (possibly erroneously) attributed to Peter Drucker, sums this up as “If you can't measure it, you can't manage it”.(4)

With this in mind, the paper by Leon and colleagues in this issue of *BMJ Quality and Safety* is helpful in identifying and mapping measures that have been used to evaluate interventions to improve the safety of high-risk medicines during adults’ transfers of care.(5) The authors conducted a scoping review to establish how well existing measures reflect a comprehensive indicator framework and to identify which may be useful for real-time measurement in a digital age. They identified 162 measures from 35 studies, of which 21 studies focused on anticoagulants, four on insulin and ten on high-risk medicines as a group. Most were conducted in the USA. While most studies examined transitions from hospital to primary care, a range of other transitions were also represented. Measures were mapped against three models: “key components of an ideal transfer of care”,(6) the systems engineering initiative for patient safety (SEIPS),(7) and whether measures were lagging, leading, or real time.(8) The authors conclude that currently available measures are not sufficient to form a comprehensive indicator framework, with particular gaps around advance care planning and enlisting social support. The measures identified included some patient-reported measures: adherence, patient knowledge, understanding, beliefs, and satisfaction. Importantly however, Leon and colleagues found that there was a lack of measures that address the active role that patients perform in transfers of care.

Leon and colleagues helpfully outline some limitations of their review, largely around the limitations inherent in the included literature. Other potential limitations are that the review only included studies that actually evaluated an intervention, and so studies using one or more measures to understand the risks rather than evaluate a change in practice would have been excluded, as were papers in languages other than English. We also note that the paper does not report whether there had been any patient and public involvement in the review itself nor in the included studies.

In this editorial, we build on Leon and colleagues’ conclusion that there is a lack of measures that address the active role that patients perform in transfers of care. Specifically, we explore

the potential value of incorporating the patient and carer perspective into designing such measures and suggest how patient and public involvement may enhance future work to develop interventions in this area. We specifically include carers as well as patients, as previous work has shown that carers also have an important role to play in building resilience in medicines management during transfers of care.(9)

We suggest that in seeking to address this lack of measures addressing patient and carer roles at transfers of care, it will be important that a suitable approach to measurement is co-designed with patients and carers. Patients, and often their families and carers, are the people who directly experience transfers of care. Not only are they well-placed to offer insights into how systems and processes work from their perspective, but also how the safety of these transfers could be measured. However, there will be some key points to consider when adopting such an approach.

First, such engagement will need to be broad enough to avoid exacerbating health inequalities if specific groups of patients are excluded from this co-design process. This may be particularly the case if any measures are to be based on self-completion by patients and carers, to improve accessibility and ensure that those not able or not comfortable to complete self-reported measures are represented in the co-design process. Different groups of patients and carers may also identify practical issues around being asked to report on medication safety issues at transitions of care.

Second, choice of language will be important. For example, during our discussions while writing this editorial, our public co-author (ME) highlighted that there would be a difficult balance to be struck if considering asking patients and their carers to report on any medication safety risks. On the one hand, those who are able and confident to identify risks may gain potential safety benefits themselves as well as being able to contribute to making processes safer. On the other hand, drawing attention to the potential for systemic failings may serve to heighten worry for many at a sensitive time in their care. This again highlights the importance of eliciting a range of patient and carer perspectives. as well as identifying suitable terminology to avoid alarming those receiving care.[10]

Third, any new measures need to be developed in the context of understanding what matters to patients and carers, so that measures are relevant. While from a policy perspective, a case may be made for focusing on the more severe levels of harm, patients and carers are likely to have a broad range of views on the outcomes that are important to them in relation to social functioning, well-being, and quality of life. Patients may also feel that medication errors with very limited potential for physical harm may still cause significant psychological harm in terms of creating anxiety and lack of trust in the healthcare system.(11,12) In addition, patients are likely to have their own perspectives of what constitutes a high risk medicine. For example, Leon and colleagues' review included three categories of high-risk medicines: anticoagulants, insulins and high-risk medicines as a group. In other (not yet published) work we have carried out, patients and carers identified opioids as another particularly high-risk medicine at transitions of care, due to the potential for patients to become dependent to opioids if information about duration and future deprescribing is not clearly communicated.

In addition to involving patients and carers in co-designing measures, we suggest that researchers and quality and safety practitioners now need to focus even more on addressing the well-known shortcomings around medication safety at transfers of care, and involve patients and carers in developing solutions. On reading Leon and colleagues' paper, our public co-author found the extent of medication errors across transitions of care to be both surprising and alarming. His conclusion was that the problems are well-documented; rather than measuring them we should therefore focus on 'fixing the system'. He also disagreed with Drucker's maxim in this context.(4) This led to a discussion among our three authors around the importance of focusing on developing interventions, while recognising why it may also be important to have a way of measuring the effects of any interventions holistically, including any unintended consequences. This suggests it will be important to communicate clearly to patients and carers the contribution that they can make in developing both measures and interventions to improve medication safety.

In summary, we congratulate Leon and colleagues for identifying current measures and highlighting the need to develop additional measures that capture the active role that patients can play in their care. We suggest that further work in this area should build on this by including meaningful patient and public involvement to develop both suitable measures and appropriate solutions. This mirrors the theme for the most recent WHO World Patient Safety Day: "Engaging Patients for Patient Safety," with the strapline "Elevate the voice of patients".(13). We also suspect that our patients and carers might want us to stop going around in circles measuring things, and focus our energies on fixing the system.

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