

## Letters to the editor

OVERVIEW

Please submit letters for the editor's consideration within 3 weeks of receipt of *Clinical Medicine*. Letters should ideally be limited to 350 words, and sent by email to: [clinicalmedicine@rcplondon.ac.uk](mailto:clinicalmedicine@rcplondon.ac.uk)

### Sharing acute care records with patients: potential pitfalls and areas for further research

Editor – The study by Fritz and colleagues offers valuable insights into patient and doctor perceptions of providing inpatients with contemporaneous access to full/summary medical records.<sup>1</sup> A notable finding was that 81% of patients and 41% of physicians agreed or strongly agreed that the acute care medical record should be shared. However, physicians and patients both shared legitimate concerns; the concern from physicians that medical record sharing could increase patient anxiety and uncertainty, warrants further discussion.

A key role of the medical record is to communicate in a concise but adequately detailed manner with other healthcare professionals; the language used is therefore tailored towards this professional audience. As a result, acute care records often contain medical jargon, including acronyms, abbreviations and complex medical terminology.<sup>2</sup> Understanding of this language is acquired over years of training and clinical practice. One of the reasons for using acronyms and abbreviations may be that the time pressures experienced in acute care necessitate quick documentation, leaving more time for clinical duties. Crucially, rather than clarifying aspects of care, access to this type of information may be confusing for patients, resulting in increased uncertainty, which could necessitate additional questions. However, in the study by Fritz *et al*, only 53% of patients “‘almost always’ felt they could ask questions’ of their acute physician and only 32% of patients reported actually doing so.

Acute care records are also fraught with clinical uncertainty, which is inherent to acute clinical practice, and may contain information regarding sinister differential diagnoses.<sup>3</sup> Providing full access to medical records will inevitably expose patients to this clinical uncertainty. It is therefore concerning that many patients in this study thought that communicating uncertainty in diagnosis would decrease patient trust.

The narrative in this study appears to favour summary records rather than full access; most patients favoured a summary record and reported that this may be easier to understand and less overwhelming. As doctors, one of our roles is to curate patient-friendly information to communicate important aspects of acute care in the form of a discharge summary. From my own experience as a UK foundation programme doctor, writing discharge summaries can take time and careful thought is needed to highlight pertinent information. A requirement to complete a daily acute care summary may be time consuming, placing

further pressure on clinicians who are working in an overstretched NHS. The importance of considering the resource allocation required to implement such a system is crucial in the context of the NHS.

I applaud the authors for their thought-provoking analysis and agree that further research is warranted to evaluate the impact of providing patients with increased access to their acute care records. ■

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### References

- 1 Fritz Z, Schindwein A, Slowther AM. Patient engagement or information overload: patient and physician views on sharing the medical record in the acute setting. *Clin Med* 2019;19:386–91.
- 2 Lee EH, Patel JP, Fortin AH 6th. Patient-centric medical notes: Identifying areas for improvement in the age of open medical records. *Patient Educ Couns* 2017;100:1608–11.
- 3 Wray CM, Loo LK. The diagnosis, prognosis, and treatment of medical uncertainty. *J Grad Med Educ* 2015;7:523–7.

### Post-transplant diabetes

Editor – We read with interest the article on post-transplant diabetes mellitus.<sup>1</sup> Recognition of this complication of solid organ transplantation (also called new-onset diabetes after transplantation) is very important.

We wish to highlight some additional points that are important in this topic. In the context of renal transplantation, the identification of post-transplant diabetes mellitus in a patient with end stage renal disease (ESRD) of unknown cause may point to an underlying genetic diagnosis. Remarkably, the label ESRD of unknown cause is given to around 15% of all cases of renal disease requiring renal replacement therapy.<sup>2</sup> The finding of post-transplant diabetes mellitus should prompt genetic studies in the patient for mutations in *HNF1B*, which underlie the renal cysts and diabetes syndrome. Mutations in *HNF1B* lead to very variable renal phenotypes and mutations may cause ESRD of apparent unknown cause.<sup>3</sup> A diabetes phenotype may only be revealed in cases where the pancreas is ‘stressed’, such as during pregnancy or with the commencement of steroids post transplant. Other pointers towards a diagnosis of *HNF1B* mutations include paediatric renal failure associated with congenital anomalies of the kidney and urinary tract, and a dominant pattern family history of phenotypes that may include renal tract anomalies, diabetes mellitus, gout, hypomagnesaemia and female genital tract anomalies.

In summary, in cases of post-transplant diabetes mellitus following kidney transplantation, physicians should review the underlying cause of the renal failure, take a full family history and have a low threshold to initiate *HNF1B* gene testing. ■