PLORAS: Comments and advice from clinicians and patients on an aphasia prognosis system

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Points to consider around the impact of predictions for patients and carers:

It may be best to give a **time-range for recovery** rather than one number, e.g. 2-3 years might be better than 2 years, because this allows for variation and reduces ‘panic’ and sense of a **deadline** from the patient if they have not recovered by the 2-year anniversary of their stroke.

Potential negative impact of being told recovery will be long – need to reflect positive angle that **improvements will continue** over many years.

People have different **levels of knowledge/exposure to aphasia** – they may assume recovery is relatively quick; telling them otherwise may result in shock/ anger/ depression.

It is difficult to know **what percentages and predictions mean to patients**. Prediction models and percentages are used a lot in oncology and genetic counselling (and maybe we can learn from this).

Patients need to **know how to use their recovery time** – not just how long it’s going to take: the question of ‘how long will it take to recover’ is usually followed up by ‘how can I speed that up?’

The prediction may have a different **impact for patient versus their carer**.
Points to consider around the delivery of predictions:

There is a need to be very careful about the language used, e.g. patients may take away a different message to the one the health professional was trying to communicate – need to check for understanding and ask the patient what they think they have been told and how they feel.

Patients should be given information in as many formats as possible, e.g. written, pictorial, DVD - perhaps of another person with aphasia talking about their recovery, and even be introduced to another person who is recovering.

Patients need to feel the door to the clinic is open after a prediction is given, so that the prediction conversation is not ‘the end’. Signposting is important, e.g. give patient details of support organisations, how to access further therapy, etc.

Should involve multidisciplinary team, e.g. a doctor gives the prediction and an SLT explains in more detail what it means. Could be appropriate to involve clinical nurse specialist. Neuropsychologist’s input may be helpful, but tend to be scarce – is there any follow up counselling available or time for this when given prediction?

Need equity of service so all patients should be offered the chance of receiving a prediction regardless of perceived ‘negativity/positivity’ – it is not for us to judge when a prediction is negative as this depends on the patient’s outlook.