

Addressing the MS Care paradox: Practical solutions.

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Topic: 17: Digital health and global networks

Abstract text: Introduction:

At ECTRIMS 2021, we presented the 70 centre UK MS Service and DMT prescribing audit [1]. This uncovered an MS care paradox: an *increasing* ability to affect MS patient outcomes, but a *diminishing* ability to deliver MS outcomes. This is due to; shortages of resources and alignment, inability to influence change, suboptimal utilisation of available data and lack of accountability and responsibility failures at all levels.

Objectives: Here we describe actions taken post audit to address the paradox.

Methods: The audit results were discussed with NHS organisations, third sector (patient charities) and others. Potential projects were proposed, discussed and refined. A set of deliverable projects actionable by the UK MS community were identified.

Funding models that maximise the benefits of funding were considered.

Results:

The projects, for which funding has been sought, are:

- Clarifying roles and responsibilities of MS team members
- Website, to facilitate communication and good practice repository
- Where's the care? – UK MS care map development
- Recording care – MS team documentation
- Measuring outcomes – MS expectation frameworks (for Patients and teams)
- Maximising core activities – making blueteq (England web-based drug reimbursement forms) and prescribing databases indispensable
- Advancing data value – improving Hospital Episode Statistics (HES) data quality and routine use
- Ensuring the future – making MS an attractive career option

A ring-fenced entity (Transforming MS 4 All) was established within an existing not-for-profit community interest company (CiC).

Conclusions:

We believe that the challenges faced by UK MS services are not unique and that the proposed solutions are transferrable worldwide. These deliverable, impactful projects should improve UK MS care. Managing governance and finances under a not for profit organisation, enables transparency, accountability and reinvestment of funding, to sustain services. Nevertheless, much more is needed.

Reference

1 UK MS services in crisis? An audit of 70 Centres exposes the MS care paradox. J Hobart, J Mathews D Rog and the Raising the Bar MS study group. ECTRIMS 2021 E poster

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