MND Scotland response to Health & Sport Committee’s Inquiry into Technology and Innovation in the NHS

MND Scotland welcomes the opportunity to submit evidence to the Health & Sport Committee’s Inquiry into Technology and Innovation in the NHS. In this response we have highlighted areas where we believe technology and innovation can play an important role in delivering safe, effective and person-led care to people with Motor Neurone Disease.

MND Scotland would also like to note their support for the submission by Marie Curie.

Summary

- Healthcare professionals need to be provided with an IT system that supports them to carry out their duties effectively
- Cross-boundary access to electronic records on portals in all other health board areas should be authorised, where appropriate
- Access to Anticipatory Care Plans and KIS should be enhanced and improved
- Information sharing across health boards and IJBs should be improved
- Citizens have to be confident that eHealth will protect sensitive and personal data

CARE-MND

MND Scotland has recently developed an e-based real time audit tool to capture all of the care of people with MND over Scotland - CARE-MND. The CARE-MND platform is a partnership with the Euan MacDonald Centre for MND Research.

Improving clinical care across Scotland is our highest priority. To do this we are working with healthcare professionals and auditing the provision of care nationally and by individual health board. The team is closely monitoring trends in the number of people with MND in Scotland as well as their individual clinical characteristics and care needs through the Scottish MND Register. However, the biggest hurdle we have is integrating the tool with 14 health boards - and making its use compatible and secure.
Anticipatory Care Planning and Key Information Summary

Anticipatory Care Planning is an important tool for people with MND. People with MND can lose the ability to communicate therefore it is essential that the wishes of the individual are easily accessible when providing care and support.

It is important to ensure that clinicians and other healthcare professionals have cross-boundary access to electronic records on portals in all other health board areas, where appropriate. Access to this is essential to the person first to respond to cases of emergency care to ensure that the rights of the individual are respected.

MND Scotland also believes that eKIS, in its current form, is too limited as only specific people (namely GP's) and a few “forward thinking practices” will allow District Nurses to upload this vital information about patients. The system is not user-friendly and we are reliant on GP's updating info when they have time or the inclination to do so. When it works, it does work well, however there is a huge need and demand for all Allied Health Professionals to have access to update the system.

MND Scotland also supports the statement in Marie Curie’s response to the inquiry which outlines the need for a future system to manage anticipatory care planning effectively. This system should include: “patient access; read and write access for all professionals who need it including social care, out of hours staff, care homes, hospices and district nurses”.

IT systems and Information sharing

At present MND Nurses are supporting over 450 people with MND in Scotland. The specialist nurses rely on robust and effective systems to update the records of people with MND quickly and effectively. The IT systems used by nurses and other healthcare professionals need to be “fit for purpose”.

In some cases the MND Nurses are working across different health boards. In one example a nurse is covering three health board areas; Glasgow, Ayrshire and Dumfries & Galloway. However, the nurse is unable to access patient records using the same equipment. As well as the unnecessary cost in providing an MND Nurse with 2 or 3 different laptops to cover each health board, it is not a practical way for nurses to carry out their duties.

Health and Social Care Integration also poses issues where Joint Integration boards still do not work in conjunction with health boards and therefore the sharing of information is, in some cases, very poor across both sectors.

Barriers to innovation

While there are clear benefits to e-health, MND Scotland notes seven key barriers which are outlined in the SPICe briefing on ‘eHealth in Scotland’ published in

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1 Marie Curie response to Scottish Parliament Health and Sport Committee Inquiry into Technology and Innovation in the NHS, July 2017
2 e-Health in Scotland, Scottish Parliament Information Centre, February 2013
February 2013. One of the barriers to the development of eHealth programmes, highlighted by the EU Commission, is a “lack of awareness of, and confidence in eHealth solutions among patients, citizens and healthcare professionals”.

This example highlights that digital literacy still continues to be an issue in 2017 - where many people in Scotland do not have access to the internet from their own home. MND Scotland recognises that not everyone will (or is able to) engage in eHealth and would recommend that while technology is a positive tool to engage with patients, it should not replace the core methods of patient-healthcare communication.

The public also have to be given assurances that eHealth can be delivered in a way which protects sensitive information and ensures data protection guidelines remain robust.

**Palliative and End of Life Care**

MND Scotland notes Commitment 7 of the Scottish Government’s Strategic Framework for Action on Palliative and End of Life Care which highlights the role of e-health systems.

This commitment recognises a lack of evidence on the most “effective and cost effective models” of palliative care across different care settings. MND Scotland would welcome further exploration of this. We also support and encourage the sharing of good practice across health boards to improve palliative care in a way which focuses on the outcomes of patients.

**About MND**

Motor Neurone Disease (MND) is a rapidly progressing terminal illness, which stops signals from the brain reaching the muscles. This may cause someone to lose the ability to walk, talk, eat, drink or breathe unaided. There is currently no cure or effective treatment for MND and the average life expectancy from diagnosis is just 14 months.

There are over 450 people in Scotland currently living with MND. On average over 160 new cases of MND are diagnosed each year. MND is on the increase. We do not yet know why, which is why it is so important for MND Scotland to continue investing in research.

**About MND Scotland**

MND Scotland is the only Scottish charity providing equipment, care and support to people affected by Motor Neurone Disease (MND) across Scotland, as well as funding research to find a cure.

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3 Strategic Framework for Action on Palliative and End of Life Care, Scottish Government, December 2015
Further information

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