



Memory Services National Accreditation Programme (MSNAP)

Consultation document – Standards for Memory Services

Please use this document to record proposed revisions or additions to the MSNAP standards. Feedback from peer reviews, the accreditation committee and other organisations have been collected over the past 18 months, and are included throughout. The proposed new standards resulting from this feedback are included at the beginning of this consultation document; we would also appreciate your comments on these.

MSNAP has made a commitment to including psychosocial and pharmacological standards in the standards for memory services. These have been developed and are included on pages 5 to 15 for your comment. The remaining sections include the existing assessment and diagnosis standards.

Please forward this consultation to your colleagues, professional networks, service user and carer networks – we are keen to obtain a range of opinions. Consultation responses will be discussed at the MSNAP Standards Development Group in April. The deadline for responses is 9 April 2012. Please email to Emily Doncaster (edoncaster@cru.rcpsych.ac.uk) or post to MSNAP, 4th Floor Standon House, 21 Mansell Street, London E1 8AA or fax to 020 7481 4831

Proposed additions to the 3rd edition standards

| Proposed standard | | Type | [suggested by] Comments |
|-------------------|---|------|-------------------------|
| N3 | The service offers patients the chance to participate in local and NIHR/NHS recognised research studies | | [DENDRON] |

Other suggestions/comments:

In support of proposal N3, Dementia & Neurodegenerative Diseases Research Network (DeNDRoN) would like to draw the panel's attention to a number of recent publications and policies which demonstrate the need for this standard to be included:

- The Ministerial Advisory Group for Dementia Research, supported by Paul Burstow MP, (former) Minister of State for Care Services published a report in June 2011 in which it is stated that "Collective work is needed to engender a more thoroughgoing culture of research in the field, with the ultimate aim of embedding the 'delivery' of research across the full care pathway and in all service sectors. Centrally, this will require more routine and systematic recruitment of patients and carers/controls to research at the earliest possible stage", "The National Dementia Strategy (NDS) provides new opportunities to embed 'research delivery' mechanisms in defined care pathways and to increase research activity by core care/clinical staff". http://www.dh.gov.uk/prod consum dh/groups/dh digitalassets/documents/digitalasset/dh 127904.pdf
- The 2012/13 NHS Operating Framework published in Nov 2011 by Sir David Nicholson, NHS CEO states "The promotion and conduct of research continues to be a core NHS function and continued commitment to research is vital if we are to address future challenges. Further action is needed to embed a culture that encourages and values research throughout the NHS."

 http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH 131360
- In December 2011 the Chief Executive of the NHS in England, Sir David Nicholson published the 'Innovation Health & Wealth' policy document. In that he stated that the NHS "must continue the great progress we have made in clinical research, working in partnership with the National Institute for Health Research (NIHR), and link this together with academic medicine and science and stronger partnerships with industry." http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_131784.pdf
- In December 2011, the Prime Minister David Cameron announced a package of work around the development of the Life Sciences Industry. In the subsequent paper presented by Andrew Lansley, Secretary of State for Health and David Willetts, Secretary of State for Universities & Science the government stated that "Empowering patients to participate in research is central to enabling the translation of promising treatments." http://www.bis.gov.uk/assets/biscore/innovation/docs/s/11-1429-strategy-for-uk-life-sciences
- In 2011 the Association of Medical Research Charities (AMRC), representing a number of organisations including Alzheimer's Research UK, Alzheimer's Society, MND Association, Parkinson's UK, Royal College of Surgeons of England, Academy of Medical Sciences put forward representations to the NHS Future Forum. They called for a number of improvements to the NHS these included to 1. A duty to embed and promote research throughout the system. 2. Create incentives for research 3. Develop a system that supports and strengthens meaningful patient and public involvement in research. http://www.amrc.org.uk/news 2011 building-research-into-the-structure-of-the-nhs

- The AMRC, Breast Cancer Campaign and the British Heart Foundation commissioned MORI to conduct a survey to identify how the supportive the public was of Clinical Research. They found*:
- 97% of the public think it's important for the NHS to support research into new treatments
- 92% think it's important for the NHS to support such research funded by charities
- 93% of people want their local NHS to be encouraged or required to support research
- 72% would like to be offered opportunities to be involved in trials of new medicines or treatments if they suffered from a health condition that affects their day-to-day life.
- 80% would like to consider allowing a researcher confidential access to their medical records.
- 88% would be happy to be asked to talk to researchers about their family history or give a sample of their blood to be tested in a laboratory

http://www.ipsos-mori.com/researchpublications/researcharchive/2811/Public-support-for-research-in-the-NHS.aspx

* Ipsos MORI interviewed a representative quota sample of 990 adults in Great Britain aged 15+. <u>Face-to-face</u> interviews were conducted in-home between 27 May and 2 June 2011. Data are weighted to the known profile of population of Great Britain (aged 15+).

- DeNDRoN surveyed eleven organisations that host patient registers in September October 2011. The survey has not yet been published, but it found that on average 78% of the patients approached about registering their interest in future research opportunities did so.
- In view of these statements expressed by government, the NHS, public and patients the NIHR DeNDRoN consider that everyone diagnosed with dementia or a related disorder should have the opportunity to learn about research and participate if appropriate. DeNDRoN believes that the Royal College of Psychiatrists could support this through its Memory Service National Accreditation Programme (MSNAP) by including one of the following statements in its standards for accreditation (as a proposed change to N3 presented in order of DeNDRoN preference):

- 1. "The service ensures that all patients are provided with information about opportunities to participate in high quality local and national NIHR portfolio research; and are offered the opportunity to register their interest in future research."
- 2. "The service supports delivery of high quality local and national NIHR portfolio research; and ensures all patients are offered the opportunity to register their interest in future research."
- 3. "The service ensures that all patients are provided with information about opportunities to participate in high quality local and national NIHR portfolio research."
- 4. "The service supports delivery of high quality local and national NIHR portfolio research."

Most large regions and active Trusts should be able to demonstrate compliance to this new standard. However, DeNDRoN could support Memory Services who are non-compliant through its Local Research Networks spread across all England. Support could be extended to involve these organisations in recruitment to current studies and development of local infrastructure and systems to support research. DeNDRoN would also be able to assist the MSNAP should it require assistance in reviewing compliance with the new standard or identifying metrics to standardise the measurement of compliance.