

Analysis of patient facing websites

D – Dementia H – Huntington’s Disease P – Parkinson’s Disease MN – Motor Neuron Disease

Area	Organisation	URL	Where are they now	Where do we want them to be
D	Dementia UK	http://www.dementiauk.org/	Some basic information on practice based research (http://www.dementiauk.org/what-we-do/around-the-country-regional-centres/west-midlands/practice-based-research/), mentioned in relation to Uniting Carers http://www.dementiauk.org/what-we-do/uniting-carers/), getting involved with research (http://www.dementiauk.org/what-we-do/uniting-carers/how-you-can-get-involved/research/). DeDNRoN – No.	Level 2
D	Alzheimer’s Research UK	http://www.alzheimersresearchuk.org/?gclid=CL7Tip7v_64CFUEOfAod4zjc4A	Do own research/fund own research. 125 projects - >£18.5m Nothing on being involved or participating in research DeNDRoN - No	Level2
D	Alzheimer’s Society	http://www.alzheimers.org.uk/site/index.php?gclid=CKDPv9rv_64CFZARfAodMynq1A	Whole section dedicated to research with links to research news, (http://www.alzheimers.org.uk/site/scripts/documents.php?categoryID=200422), Own funding body. Info on NIHR themed dementia call (http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=346) Involving people with dementia and their carers in research (http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=1109) Info on their research programme (https://www.alzheimers.org.uk/site/scripts/xforms_form.php?formID=20) Link to NIHR Portfolio and DenDRON site but no info about them on their site (http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=959&pageNumber=3) Have their own clinical research network for involvement (http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=1110) DeNDRoN – Yes –link to site only – no info on their website.	Level2
D	RP Psych	http://www.rcpsych.ac.uk/default.aspx?page=1427	Info on the disease. Has a ‘Further reading/helpful orgs’ section (http://www.rcpsych.ac.uk/default.aspx?page=1427)	Level1



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D	Dementiaweb.org.uk	http://www.dementiaweb.org.uk/index.php	Invitation to review research proposals (http://www.dementiaweb.org.uk/news/page/2/)	Level2
D	The Princess Royal Trust for Carers	http://www.carers.org/	Info on alzheimer's and dementia with a useful links section. (http://www.carers.org/help-directory/alzheimers-and-dementia) DeNDRoN-no No info on research.	Level2
D	Age UK	http://www.ageuk.org.uk/	Section on dementia with a 'further info' section (http://www.ageuk.org.uk/health-wellbeing/conditions-illnesses/dementia/help-and-support7/) Useful websites (could be used) (http://www.ageuk.org.uk/health-wellbeing/conditions-illnesses/dementia/diagnosis-and-treatment/) DeNDRoN – no Nothing on research	Level2
D	Joseph Rowntree Association	http://www.jrf.org.uk/	Info on dementia but nothing on research. DeNDRoN - no	Level2
D	Carers UK	http://www.carersuk.org/	Info on alzheimer's/dementia but nothing on research. DeNDRoN – No.	Level2
D	NHS Choices - Carers Direct	http://www.nhs.uk/careersdirect/Pages/CarersDirectHome.aspx	General information, nothing on research (http://www.nhs.uk/CarersDirect/guide/kinds/Pages/dementia-intro.aspx)	Level1
D	NHS Choices	http://www.nhs.uk/Pages/HomePage.aspx	General information (http://www.nhs.uk/conditions/Alzheimers-disease/Pages/Introduction.aspx) Clinical trials (http://www.nhs.uk/Conditions/Alzheimers-disease/Pages/clinical-trial.aspx)	Level1
D	Boots WebMD	http://www.webmd.boots.com/default.htm	General information http://www.webmd.boots.com/alzheimers/guide/alzheimer-disease-finding-help	Level1
P	Parkinson's UK	http://www.parkinsons.org.uk/	Research section (http://www.parkinsons.org.uk/research.aspx) Opportunities to take part in research, includes some portfolio studies (http://www.parkinsons.org.uk/research/get_involved_in_our_research/list_of_uk_research_studies.aspx#studies_North_East)	Level2



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			DeNDRoN-yes, 'find out more' sends to website (http://www.parkinsons.org.uk/default.aspx?page=11122)	
P	NHS Choices - Carers Direct	http://www.nhs.uk/careersdirect/Pages/CarersDirectHome.aspx	General information, nothing on research (http://www.nhs.uk/CarersDirect/guide/kinds/Pages/caring-for-someone-with-Parkinsons-disease.aspx)	Level1
P	Age UK	http://www.ageuk.org.uk/	Section on Parkinson's with a 'further info' section http://www.ageuk.org.uk/health-wellbeing/conditions-illnesses/parkinsons-disease/ Useful websites (could be used) – same url. DeNDRoN – no Nothing on research	Level2
P	NHS Choices	http://www.nhs.uk/Pages/HomePage.aspx	Info on Parkinsons (http://www.nhs.uk/Conditions/Parkinsons-disease/Pages/Livingwith.aspx) Clinical trials (http://www.nhs.uk/Conditions/Parkinsons-disease/Pages/clinical-trial.aspx)	Level1
P	Boots WebMD	http://www.webmd.boots.com/default.htm	General information (http://www.webmd.boots.com/a-to-z-guides/tc/parkinsons-disease-living-with-parkinsons-disease)	Level1
P	Brain Research Trust	http://www.brt.org.uk/	General information http://www.brt.org.uk/parkinsons-disease Research info on neurological conditions. Info on research but nothing on how to become involved.	Level2
P	Patient.co.uk	http://www.patient.co.uk	Information on Parkinson's but nothing on research http://www.patient.co.uk/health/Parkinson's-Disease.htm	Level1
P	Net Doctor	http://www.netdoctor.co.uk/	General information. Nothing on research http://www.netdoctor.co.uk/diseases/facts/parkinson.htm	Level1
H	Huntington's Disease Association	http://hda.org.uk/	Section on research but more info on studies/conferences, not about getting involved http://hda.org.uk/research/ DeNDRoN – yes, but link only – no info (http://hda.org.uk/resources/research.html)	Level2
H	HDBuzz	http://hdbuzz.net/	HD research news for global HD community.	Level2
H	Brain Research Trust	http://www.brt.org.uk/	Research info on neurological conditions. Info on research but nothing on how to become involved. DeNDRoN – no	Level2



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H	BBC	http://www.bbc.co.uk/health/physical_health/conditions	General information on HD, with an 'advice and support section which could be used (http://www.bbc.co.uk/health/physical_health/conditions/huntingtons1.shtml#advice_and_support	Level1
H	NHS Choices	http://www.nhs.uk/Pages/HomePage.aspx	General information on HD with an 'external links' section which could be used (http://www.nhs.uk/Conditions/Huntingtons-disease/Pages/Symptoms.aspx) Clinical trials (http://www.nhs.uk/Conditions/Huntingtons-disease/Pages/clinical-trial.aspx)	Level1
H	Boots WebMD	http://www.webmd.boots.com/default.htm	General information http://www.webmd.boots.com/a-to-z-guides/tc/huntingtons-disease-treating-huntingtons-disease	Level1
MN	MND Association	http://www.mndassociation.org/	Whole section on research (http://www.mndassociation.org/research/index.html) How to get involved in research (http://www.mndassociation.org/research/get_involved_in_research/index.html) Register of those who would like to be involved in collaboration with DeNDRoN (http://www.mndassociation.org/research/get_involved_in_research/register_your.html and http://www.mndassociation.org/research/for_researchers/index.html) Via 'Utilising our patient register') DeNDRoN – yes. Link to website from DeNDRoN logo at above urls. Experiences of taking part in research (http://www.mndassociation.org/research/get_involved_in_research/experiences_of.html) Link to NIHR Portal via 'Other opportunities to participate' (http://www.mndassociation.org/research/get_involved_in_research/index.html)	Level2
MN	NHS Choices	http://www.nhs.uk/Pages/HomePage.aspx	General information (http://www.nhs.uk/conditions/Motor-neurone-disease/Pages/Introduction.aspx) Clinical trials (http://www.nhs.uk/Conditions/Motor-neurone-disease/Pages/clinical-trial.aspx)	Level1
MN	Boots WebMD	http://www.webmd.boots.com/default.htm	General information http://www.webmd.boots.com/a-to-z-guides/motor-neurone-disease-directory	Level1
MN	Brain Research Trust	http://www.brt.org.uk/	Research info on neurological conditions. Info on research but nothing on how to become involved. DeNDRoN – no	Level2



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			http://www.brt.org.uk/motor-neurone-disease-mnd	
MN	BBC	http://www.bbc.co.uk/health/physical_health/conditions	General information on MND, with an 'advice and support section which could be used http://www.bbc.co.uk/health/physical_health/conditions/mnd1.shtml	Level1
MN	Brain and Spine Foundation	http://www.brainandspine.org.uk/	General information. Nothing on research. http://www.brainandspine.org.uk/information/publications/brain_and_spine_booklets/motor_neurone_disease/index.html DeNDRoN - no	Level2

Level 1 = Basic information on research / sign-posts to existing information

Level 2 = Full information / bespoke content on research with sign-posts

