

Subject: **Scottish Huntington's Association**

Purpose: To seek the approval of the Integrated Joint Board to re Contract with the Scottish Huntington's Association for a further three years.

Recommendation: The Integrated Joint Board directs North Ayrshire Council, on behalf of North, South and East Ayrshire Health and Social Care Partnerships and NHS Ayrshire and Arran, to lead on the procurement of the service from the Scottish Huntington's Association.

Glossary of Terms : *No acronyms used.*

1.	EXECUTIVE SUMMARY
1.1	The Scottish Huntington's Association is the only Charitable Organisation in Scotland which provides dedicated support to Patients, their family and carers whose lives are affected by Huntington's Disease.
1.2	The Ayrshire Huntington's Disease Service provides specialist nursing support to the Huntington's Disease Management clinic; one to one support for the individual with Huntington's Disease or at risk of Huntington's Disease and their family/carers in their own home, and liaises with multi- disciplinary teams within statutory services and other voluntary partners in the delivery of a holistic health and social care service to Patients, their family and carers. Training is also provided to staff in statutory services and other environments, for example Nursing Homes,
1.3	The current Agreement between North, South and East Ayrshire Health and Social Care Partnerships and NHS Ayrshire and Arran ends on the 31 March 2018 and the recommendation is that an Agreement be entered into for a further three year period.
2.	BACKGROUND
2.1	Huntington's Disease is an inherited progressive disorder of the brain that leads to uncontrolled physical movements, emotional instability, loss of intellectual faculties and ultimately death. Huntington's disease can affect an individual at any age.
2.2	There is an Agreement in place between North, South and East Ayrshire Health and Social Care Partnerships and NHS Ayrshire and Arran (the Commissioners) which ends 31 March 2018.

2.3	The Service is monitored quarterly by a steering group chaired by the NHS Ayrshire and Arran's clinical lead for Huntington's; representatives of the Douglas Grant Rehabilitation Centre; Allied Health Professionals; Ayrshire Hospice; a genetics representative from Queen Elizabeth Hospital, Glasgow; and Community Services management and commissioning representatives from the three Ayrshire Health and Social Care Partnerships.
2.4	Considerable additionality is achieved for the Commissioners and individuals with Huntington's Disease and their family/carers through the wider resources of the Scottish Huntington's Association. For example the Commissioners benefit through participation on the National Care Framework and the Scottish Huntington Associations ability to access grants and provide additional resources to enhance the service delivered pan Ayrshire. Additionality is provided to individuals with Huntington's Disease and their family /carers, for example, through Huntington's Youth Worker and activities arranged for the children of those with Huntington's Disease; carers events; and financial well being reviews. In the period October to December 2017, inclusive, there were improvements in the finances of three new service users amounting to £20,063.
3.	PROPOSALS
3.1	The Integrated Joint Board approves the procurement of a specialist Huntington's Disease Service for a further period of three years, 1 April 2018 – 31 March 2021.
	The preferred procurement route to be the Single Tender Action Request Procedure putting forward a case to direct award to the Scottish Huntington's Association based on uniqueness of provision.
3.2	<u>Anticipated Outcomes</u>
	<p>The outcomes are:</p> <ul style="list-style-type: none"> • Implementation of the Patient Pathway through the Scottish Huntington Association nurses interventions with statutory organisations and other voluntary organisations as appropriate. • Advice will have been offered on the Genetic Assessment and Diagnostic process. • Patients living with Huntington's Disease will have continuously improved management of their condition. • Patients, their family and carers will have improved resilience and be able to manage behaviour changes and other challenges of living with Huntington's Disease. • Patients, their family and carers will be in receipt of an integrated Health and Social Care Assessment. • Patients are included in the community as part of their support plans. • Maximisation of financial income for Patients, their family and carers. • Education and Training in relation to Huntington's Disease will have been delivered.

3.3	<u>Measuring Impact</u>										
	<p>Measures will include:</p> <ul style="list-style-type: none"> • Linked activities with Health and Social Care – data collection regarding number of type of activities e.g. statutory services case conferences/reviews; community programme approach meetings and Child and Adult Support and Protection. • Collection of data on the number of symptomatic patients, family, carers and people living at genetic risk who have contact with the service is maintained with appropriate consent being obtained. • Recording of activity in association with the above including: assessments and follow up visits; carer visit; case conferences; hospital admissions; Huntington's Disease Management Clinic patients seen; liaison visits; training given; referral to other services and Partnership meetings. • Patients and their family/carers will report on their satisfaction with the service and the information and advice they have received. • Data collection regarding maintenance of patients in the community. • Audits of the Service/Huntington's Disease Management Clinic will take place every three years. The subsequent report will be fed back to inform current and future service requirements. • Patients and their family/carers will report that they feel more able to continue to cope with managing behaviour changes/challenges associated with Huntington's Disease. • Recording of training provided, to whom and evaluation of same. 										
4.	IMPLICATIONS										
Financial :	<p>The service provided by the Scottish Huntington's Association is currently funded per financial year as follows:-</p> <table> <tr> <td>NHS Ayrshire and Arran</td> <td>£20,000</td> </tr> <tr> <td>North Ayrshire Council</td> <td>£15,000</td> </tr> <tr> <td>East Ayrshire Council</td> <td>£15,000</td> </tr> <tr> <td>South Ayrshire Council</td> <td>£15,000</td> </tr> <tr> <td>Total</td> <td>£65,000</td> </tr> </table> <p>NHS Ayrshire and Arran additionally provide funding for a Huntington's Consultant post and provide office accommodation for the Scottish Huntington's Association Nurses.</p> <p>It is proposed that funding remains at the above levels for the next three years of the Agreement.</p>	NHS Ayrshire and Arran	£20,000	North Ayrshire Council	£15,000	East Ayrshire Council	£15,000	South Ayrshire Council	£15,000	Total	£65,000
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Total	£65,000										
Human Resources :	There are no Human Resource implications for NAHSCP staff.										
Legal :	The Procurement will be carried out in line with the Public Contracts (Scotland) Regulations 2015 and North Ayrshire Councils Standing Orders.										
Equality :	<p>There are no equality issues to be considered.</p> <p>Equality in employment and service delivery will be in accordance with statute and covered within the terms and conditions of the Agreement.</p>										
Environmental & Sustainability :	There are no environmental /sustainability implications in connection with this proposal.										

Key Priorities :	The service fits with North Ayrshire Health and Social Care Partnerships Strategic Plan 2015-18, specifically: <ul style="list-style-type: none"> ➤ Bringing services together. ➤ Early intervention. ➤ Improving Mental Health and Wellbeing.
Risk Implications :	There is the risk that should continued funding for this service not be available that patients and their family/carers would receive a fragmented service with increased pressure on existing statutory resources. The service provided by the Scottish Huntington's Association is the linchpin enabling a holistic service to patients and their family/carers and co-ordination/support for statutory services.
Community Benefits :	These would be non core and revolve around training provided on Huntington's Disease and its management and patients continued participation in the community.

Direction Required to Council, Health Board or Both	Direction to :-	
	1. No Direction Required	
	2. North Ayrshire Council	
	3. NHS Ayrshire & Arran	
	4. North Ayrshire Council and NHS Ayrshire & Arran	✓

5.	CONSULTATION
5.1	Consultation has taken place between the three Ayrshire Health and Social Care Partnerships and Scottish Huntington's Association.
6.	CONCLUSION
6.1	It is recommended that the Integrated Joint Board approve the continued procurement of this service for the next three financial years, that is, 1 April 2018 to 31 March 2021.

For more information please contact Stuart Gaw, Senior Manager, Integrated Care and Re-ablement Services on 01294 400616 or stuart.gaw@aapct.scot.nhs.uk

DIRECTION

From North Ayrshire Integration Joint Board

1.	Reference Number	15032018-	
2.	Date Direction Issued by IJB	15 th March 2018	
3.	Date Direction takes effect	15 th March 2018	
4.	Direction to	North Ayrshire Council	
		NHS Ayrshire & Arran	
		Both	✓
5.	Does this direction supercede, amend or cancel a previous direction – if yes, include the reference numbers(s)	Yes	
		No	No
6.	Functions covered by the direction	Huntington's Disease Service to people with Huntington's Disease or at risk of Huntington's Disease, their family and carers as outlined in the report to the Integrated Joint Board.	
7.	Full text of direction	NHS Ayrshire and Arran and North Ayrshire Council are directed to re-commission the Huntington's Disease Service for the three year period 1 April 2018 to 31 March 2021. The annual cost to NHS Ayrshire and Arran is £20,000 and the annual cost to North Ayrshire Council is £15,000. This is a pan Ayrshire service and North and South Ayrshire Councils contributions will be £15,000 each per annum. Total annual cost of service being £65,000 (refer section 4 Finance of the attached report)	
8.	<i>Budget allocated by Integration Joint Board to carry out direction</i>	£35,000 per annum (refer section 4 Finance of the attached report)	
9.	Performance Monitoring Arrangements	The Agreement will be monitored by a Steering Group (refer section 2.3 of the attached report)	
10.	Date of Review of Direction (if applicable)	January 2019.	