

North Somerset Dementia Pathway

Draft for consultation

January 2012

Core Principles;

As a person with dementia, a family member and carer living in North Somerset we can expect that;

- We will be supported to live well
- We will be treated with dignity and respect
- We will receive personalised services which are tailored to our needs and wishes
- We will receive reliable, sustainable and integrated care and support
- The services and support we receive will be of good quality
- We will receive timely interventions
- Services will be easily accessible
- We will have choice about the services, support and interventions we receive

Core Principles;

As a person with dementia, a family member or carer we can expect that;

- Our GP will actively support us and manage our physical and mental health in a holistic way
- We will be provided with information which we understand at the right time
- We will be supported to adjust to the diagnosis
- We will be supported to ensure that the person with dementia has a good death and dies in the place they want to
- We will be able to access 24 hour care and support in the event of a crisis
- The person with dementia will be supported to move into a Care Home quickly and easily if that is their choice
- The diagnosis of dementia will be given early to enable us to access the care and support we need and want
- We will be supported to make decisions about our care and our future

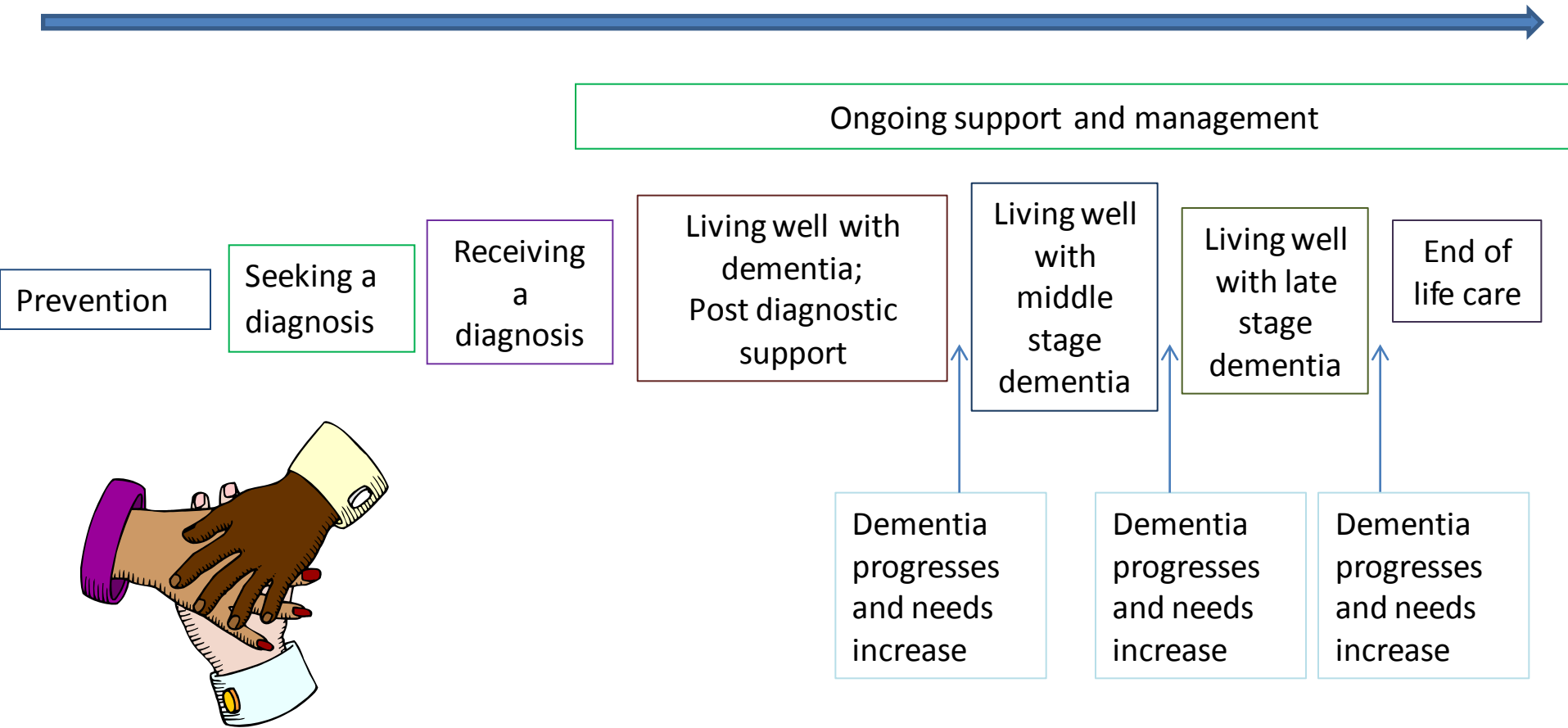
Enablers

In order to deliver the core principles and pathway the following standards will need to be in place

- Quality standards will be monitored and managed on an ongoing quality improvement basis as an integral part of performance management of services
- Clear joint working arrangements will be in place between all services supporting people with dementia, their family and carers and there will be clarity about who is providing what
- Joint protocols will be in place where appropriate
- Services will work with each other in an open and supportive way
- Information and intelligence will be shared between services supporting people with dementia, their family and carers as appropriate and consented
- Teams will have skills and knowledge in end of life care
- There will be sufficient capacity across the pathway
- Timely Continuing Health Care assessments will be provided
- A Korsikoffs pathway will be in place

North Somerset Dementia Pathway

People will move along the pathway as their own individual lives, needs and physical and mental health changes



Prevention

A range of services are provided in North Somerset in order to promote good physical and mental health and prevent the development of physical and mental health problems. These include;

- Go4Life which supports people to become healthier and fitter;
<http://www.n-somerset.gov.uk/Leisure/Go4Life/>
- Community cafes
- GP health checks

The Alzheimer's Society have also run national and local campaigns to improve awareness of dementia and encourage people who are worried about their own memory or the memory of a loved one to visit their GP

Dementia awareness sessions have been provided for staff in caring roles in North Somerset and more advanced sessions are being delivered shortly

Seeking a diagnosis

- The service user or carer may initially come into contact with services such as the police, care connect, the hospital and it becomes apparent that there are concerns about the service users memory. The service will signpost or refer to the GP
- The service user or carer may access the Forget me Not Service if available
- The service user or carer contacts the GP with concerns about the service users memory or with other concerns about physical or mental health
- The GP may refer the service user or carer to the Forget me Not Service if available
- The GP will undertake a dementia screen which includes a physical examination
- If appropriate and if the service user consents the GP will refer to the North Somerset Memory Service for a dementia assessment

The Forget me Not service is provided in some North Somerset GP practices by the Alzheimer's Society, the services consists of bookable slots with a Dementia Support Worker for initial advice about the possible signs and symptoms of dementia. The DSW feeds back to the GP regarding referral to the North Somerset Memory Service.

Receiving a Diagnosis

- The North Somerset Memory Services which is provided by Avon and Wiltshire Mental Health Trust provides an expert early intervention and diagnosis service for people with suspected or possible dementia, their family and carers. This service will provide initial post diagnostic support in order to support the service user, family and carers to adjust to the diagnosis
- The carer will receive an assessment of their needs during the diagnostic process
- A diagnosis of dementia may also be given by; the GP (particularly if the person already has late stage dementia), the Community Mental Health Team (CMHT), secondary care general hospital services, the Community Team for People with a Learning Disability and Drug and Alcohol services
- Information tailored to the individual service, user and carer will be provided during the diagnostic process

If a service user is assessed by the North Somerset Memory Services and diagnosed with Mild Cognitive Impairment, which may later develop to a dementia, they will be discharged and return to the memory service for an assessment as appropriate in the future.

Ongoing support and management

During the diagnostic process ongoing support and management will begin to be provided.

The following services are available locally and can be accessed during the course of the whole care pathway as and when appropriate for the service user, family and carers;

- Active management and support from the GP (including services provided as part of the Quality Outcomes Framework)
- Alzheimer's Society Services; Dementia Support Workers, Memory Café, tea dances, singing for the brain, groups for people with dementia, carers groups,
- Brunel Care Memory Café
- Crossroads services for carers
- The North Somerset Memory Service will provide follow up and review for as appropriate, particularly for people being treated using certain anti-dementia medications
- Rethink Mental Illness services
- Occupational Therapy Services

Ongoing support and management continued

- Physiotherapy Services
- Adult Social Care services and packages
- Information will be provided as appropriate for the service user, family and carers
- Supported housing services
- Telecare Services
- Benefits advice
- Age UK services
- Services and support around advanced directives, Lasting Power of Attorney and writing a will
- Benefits advice services, including from the Citizens Advice Bureau
- Fire prevention services

Living well with dementia; Post diagnostic support

The following post diagnostic support services are provided locally;

- Coping with Forgetfulness
- Rememberree
- Information sessions (planned to commence in 2012)

The ongoing support and management services will also be accessed as and when appropriate for the service user, family and carers.

Living well with middle stage dementia

During this part of the pathway the person with dementia, their family and carers may access the following services which are available in North Somerset;

- Meals on wheels
- Respite services
- Sitting services
- Inpatient services; Mental health or general hospital
- Enablement and Reablement services
- Day services

The ongoing support and management services will also be accessed as and when appropriate for the service user, family and carers.

Living well with late stage dementia

During this part of the pathway the person with dementia, their family and carers may access the following services which are available in North Somerset;

- Respite services
- Sitting services
- Day care services
- Domiciliary care services
- Care Homes; residential or nursing
- Specialist placement
- Mental Health Act services (particularly sections 2 & 3)
- Community Mental Health Team (including the provision of advice about the type and level of Care Home placement)
- Brokerage and care navigation services
- Continence services
- Safeguarding Vulnerable Adults, Mental Capacity Act, Deprivation of Liberty Safeguards and Best Interest Assessment services
- Physical health services (physical health needs are likely to increase during this stage)
- Continuing Health Care services
- Dietetic services
- Speech and Language Therapy Services
- Specialist services

The ongoing support and management services will also be accessed as and when appropriate for the service user, family and carers

End of life care

During this part of the pathway the person with dementia, their family and carers may access the following services which are available in North Somerset;

- End of Life Care Facilitators
- Palliative care services

During this phase active treatment will be stopped and the person with dementia, their family and carers will work jointly with care professionals to prepare for the end of the life. Symptoms will be controlled and pain will be managed to ensure that the person is comfortable. The person will be supported to die in their place of choice with dignity and respect.

Bereavement counselling and support and legal advice and support will be provided for the family and carers following the death.

The ongoing support and management services and services provided during the later stages of dementia will also be accessed as and when appropriate for the service user, family and carers.

Care Clusters – an introduction

- Care clusters is the nationally led method of paying for mental health care using an approach to assessment and provision based on the needs of the service user and carer rather than based on diagnosis or activity.
- As people are clustered based on their needs rather than the stage of their dementia the services provided in North Somerset for each of the 4 dementia related care cluster will now be described
- People with dementia could be assessed as being in any of the 21 care clusters, care clusters 18 – 21 are being focussed upon here as these clusters would be appropriate for people whose needs are primarily due to their dementia (people can receive any additional service they require not just those within the cluster they are in)
- People will be reviewed using outcome measures and they will be re-clustered (may be to same cluster) and new care plan will be developed people may step down to a lower level of support or step up to a higher level of support

Care Clusters

Avon and Wiltshire Mental Health Partnership Underpinning Values

1. working in partnership
2. respecting diversity
3. practising ethically
4. challenging inequality
5. promoting recovery
6. identifying peoples strengths and needs
7. providing service user centered care
8. making a difference
9. promoting safety and positive risk management
10. personal development and learning

Care Cluster 18

Early to moderate, receiving a diagnosis and post diagnostic support

People may be in the early stages of dementia (or who may have an organic brain disorder affecting their cognitive function) and have some memory problems, or other low level cognitive impairment but are still managing to cope reasonably well. Underlying reversible physical causes have been ruled out.

In this cluster care will be shared between the GP and North Somerset Memory Service/ CMHT/ Therapies Team

The Memory Service/CMHT/Therapies Team will interface with social Care, health care and voluntary sector services to ensure the provision of holistic, integrated and personalised care and support for the person with dementia, their family and carers.

The following services can be provided to people being assessed as being in care cluster 18;

- Social care services and packages
- Alzheimer's Society services
- Brunel care Services
- Rethink Mental Illness service
- Benefits advice from Citizens Advice Bureau

Care Cluster 18

Early to moderate, receiving a diagnosis and post diagnostic support

The Quality and Outcome measures for people agreed as being in care cluster 18 are;

- Health of the Nation Outcome Scales (scale used to measure mental health) /CAST
- Patient Reported Outcome Measure
- Service User satisfaction questionnaire
- Completion of annual health check
- Element specific outcomes
- Performance Indicators
- Essence of Care
- Real Time Patients Survey
- Memory Service National Accreditation

Assessment, treatment and support which can be provided for people who are assessed and agreed as being in care cluster 18.

Core Assessment

3 keys, Core assessment, FACS, safeguarding, Risk Assessment, diagnosis, Physical Health Screen, Neuropsychological Testing, dual diagnosis screening, Carers screen, CAST

Individualised care planning and personalisation delivery framework

Therapeutic aims

- engagement
- maximise social functioning
- maximise quality of life and physical health
- maintain appropriate contact
- symptom management
- behaviour management
- reduce risks
- prevent complications
- relapse Prevention

Memory Detection/Assessment	Enabling options	Therapeutic options	Role support options	Family/carer options	Self directed support
<p>Liaison and Triage Physical Health Screening facilitating scans needed Telephone advice and support when SU not assessed Decision on assessment level required</p> <p>Standard assessment Core assessment (as above) Neuropsychological Testing Diagnosis formulation</p> <p>Complex assessment (specialist) Neuropsychometric testing Speech and language Occupational therapy -ADL Medical differential diagnosis Diagnosis formulation and outcome decision</p>	<p>Formulation</p> <p>Health Promotion</p> <p>Crisis planning and Management</p> <p>Self Management</p> <p>Advanced Planning</p> <p>Risk Management</p> <p>Support Personal/Physical and Practical needs</p>	<p>Medication Prescribing and monitoring</p> <p>Living Well With Dementia</p> <p>Specific Psychological /Therapy Intervention</p> <p>Therapeutic Groups</p> <p>Dementia Care Mapping</p>	<p>Interagency /partnership /team liaison</p> <p>Medico-legal interventions</p> <p>Discharge Planning</p> <p>Vulnerable Adult Protection Safeguarding</p>	<p>Carers Assessment</p> <p>Carers support</p> <p>Family Intervention</p> <p>Couples work</p>	<p>Review</p> <p>GP Liaison/ Partnership</p> <p>FACS - Social Care needs support</p> <p>Signposting/ local Information support</p> <p>Discharge Planning</p>

Care Cluster 19

Post diagnostic support and ongoing support and management.
Middle stage dementia

Cluster 19 – Cognitive Impairment complicated moderate need - People who have Problems with their memory, and or other aspects of cognitive functioning resulting in moderate problems looking after themselves and maintaining social relationships. Probable risk of self neglect or harm to others and may be experiencing some anxiety or depression..

In this cluster care will be shared between the GP and North Somerset Memory Service/ CMHT/ Therapies Team

The following services can be provided to people being assessed as being in care cluster 19;

- Social Care services and packages
- Alzheimer's Society Services
- Brunel Care Services
- Telecare
- Citizens Advice Bureau
- Continuing Health Care
- Safeguarding
- Hospital admissions, mental health and general hospital
- Enablement and reablement services

Care Cluster 19

Quality & Outcome measures

- HoNOS/CAST
- Recovery Star
- Completion of annual health check
- PROM – yet to be agreed
- Element specific outcomes
- Essence of Care
- Real Time Patient Survey
- Quality Improvement Plan
- Balance Score Cards
- Quality in Health Care Governance Processes
- Medication Governance
- Quality Accounts

Assessment, treatment and support which can be provided for people who are assessed and agreed as being in care cluster 19.

Assessment

3 keys, Core assessment, FACS, safeguarding, Risk Assessment, diagnosis, Physical Health Screen, Neuropsychological Testing, dual diagnosis screening, Carers screen, CAST

Individualised care planning and personalisation delivery within CPA framework

Therapeutic aims

- engagement
- maximise social functioning
- maximise quality of life and physical health
- maintain appropriate contact
- symptom management
- behaviour management
- reduce risks
- prevent complications

Enabling options	Therapeutic options	Role support options	Family/carer options	Accommodation options	Self directed support
Formulation	Medication Prescribing and monitoring	Interagency /partnership liaison	Carers Assessment	Housing and finance support	Review
Health Promotion	Living Well With Dementia	Discharge Planning	Carers support	Residential/care home support	GP Liaison/ Partnership
Crisis Planning and Management	Life Story Work	Medico-legal interventions	Family Intervention	CHC Intervention	Signposting/ local Information support
Self Management	Risk and Behaviour Management	Vulnerable Adult/Adult Protection	Couples work		Discharge Planning
Advanced Planning/Statement	Specific Psychological /Therapy Intervention				FACS - Social Care needs support
Risk Management	Therapeutic work				
Supporting personal, physical and practical needs	Dementia Care Mapping				

Care Cluster 20

Middle – late stage dementia

Cognitive Impairment complicated high need - People with dementia who are having significant problems in looking after themselves and whose behaviour may challenge their carers or services. They may have high levels of anxiety or depression, psychotic symptoms or significant problems such as aggression or agitation. They may not be aware of their problems. They are likely to be at high risk of self-neglect or harm to, and there may be a significant risk of their care arrangements breaking down.

For people being assessed and agreed as being in care cluster 20 their responsible practitioner will be the AWP CMHT / Care Home liaison

The following services can be provided to people being assessed as being in care cluster 20;

- GP
- Hospital admissions, mental health and general hospital (falls and UTIs)
- Social care services and highest levels of packages
- Advanced statement services
- Care Homes
- Specialist Placements
- Safeguarding

Assessment, treatment and support which can be provided for people who are assessed and agreed as being in care cluster 20.

Assessment

3 keys, Core assessment, FACS, safeguarding, Risk Assessment, diagnosis, Physical Health Screen, Neuropsychological Testing, dual diagnosis screening, Carers screen, CAST

Therapeutic aims

- engagement
- maximise social functioning
- maximise quality of life and physical health
- maintain appropriate contact
- symptom management
- behaviour management
- reduce risks
- prevent complications

Enabling options	Therapeutic options	Role support options	Family/carer options	Accommodation options	Self Directed Support
Formulation	Medication Prescribing and monitoring Living Well with Dementia Life Story Work Specific Psychological Therapy/Intervention Therapeutic Interventions – Group/Individual Dementia Care Mapping	Interagency /partnership liaison	Carers Assessment	Housing and finance support Residential/care home support CHC Intervention	Review
Health Promotion			Carers support		GP Liaison/ Partnership
Crisis Planning and Management		Discharge Planning	Family Intervention		
Advanced Planning/Statement		Medico-legal interventions	Couples work	Bereavement of person Support	Discharge Planning
Challenging Behaviour Management/ Monitoring		Vulnerable Adult/Adult Protection			Residential/Care Accommodation Support
Falls management					FACS - Social Care needs support
Risk Management					
Physical health Interventions					
Supporting personal, physical and practical needs					
Specialist assessment					

Care Cluster 20

Quality & Outcome measures

- HoNOS/CAST, Recovery Star
- Completion of annual health check
- PROM – yet to be agreed
- Element specific outcomes
- Essence of Care
- Real Time Patient Survey
- Quality Improvement Plan
- Balance Score Cards
- Quality in Health Care Governance Processes
- Medication Governance
- Quality Accounts
- AIMs Accreditation of In-patient in Mental Health Services
- Productive Ward

Care Cluster 21

Frailty due to dementia or physical health middle to late stage dementia & rarely early dementia

Cluster 21 – Cognitive Impairment (High Physical/Engagement) Characterised by cognitive impairment or dementia, with significant problems looking after themselves and whose physical condition is becoming increasingly frail. There may be significant risk of care arrangements breaking down

For people being assessed and agreed as being in care cluster 21 the practitioner responsible for their care will be their GP.

The following services can be provided to people being assessed as being in care cluster 21;

- Social care home packages; large domiciliary care packages
- Care Homes; residential and nursing
- Hospice services
- Mental Capacity Act, Deprivation of Liberty Safeguards and Best Interest Assessment services
- General Hospital admissions
- Care Home liaison / CMHT services including dementia care mapping
- End of Life Care Facilitators
- Speech and Language Therapy Services
- Dietetic Services
- Physiotherapy Services
- Occupational Therapy Services
- Bereavement Support and Counselling

Assessment, treatment and support which can be provided for people who are assessed and agreed as being in care cluster 21.

Assessment
 3 keys, Core assessment, FACS, safeguarding, Risk Assessment, diagnosis, Physical Health Screen, Neuropsychological Testing, dual diagnosis screening, Carers screen, CAST

Therapeutic aims

- engagement
- maximise social functioning
- maximise quality of life and physical health
- maintain appropriate contact
- symptom management
- behaviour management
- reduce risks
- prevent complications

Enabling options	Therapeutic options	Role support options	Family/carer options	Accommodation options	Self Directed Support
Formulation	Medication Prescribing and monitoring	Interagency /partnership liaison	Carers Assessment	Housing and finance support	Review
Health Promotion					GP Liaison/Partnership
Crisis Planning and Management	Risk and behaviour Management	Discharge Planning	Carers support	Residential/care home support	Signposting/ local Information support
Challenging Behaviour Management/Monitoring					Discharge Planning
Falls management	Therapeutic Interventions	Medico-legal interventions	Family Interventions	CHC Interventions	Discharge Planning
Risk Management					Residential/Care Accommodation Support/Placement
Physical Health Interventions	Dementia Care Mapping	Vulnerable Adult/Adult Protection	Bereavement Support		FACS - Social Care needs support
Supporting personal, physical and practical needs					
Specialist assessment					

Individualised care planning and personalisation delivery within CPA framework

Care Cluster 21

Quality & Outcome measures

- HoNOS/CAST, Recovery Star
- Completion of annual health check
- PROM – yet to be agreed
- Element specific outcomes
- Essence of Care
- Real Time Patient Survey
- Quality Improvement Plan
- Balance Score Cards
- Quality in Health Care Governance Processes
- Medication Governance
- Quality Accounts
- AIMs Accreditation of In-patient in Mental Health Services
- Productive Ward

Dementia Pathway Pinch points

Identified December 2011

- Lack of capacity in Memory service for; diagnosis, follow up for medication
- Lack of clarity about the post diagnostic element of the pathway
- Financial climate
- Delayed transfers of care
- Waiting times for CHC assessments
- Appropriate services for younger people
- Lack of active support and management in some instances by the GP
- Lack of GP skills and knowledge in dementia has been nationally recognised, uptake of local GP dementia education

Action plan

Agreed in December 2011

1. Consultation on draft Dementia pathway
2. Review of post diagnostic services
3. Mapping and development of a North Somerset Korsikoffs pathway
4. Mapping of the Weston Area Health Trust inpatient dementia pathway leading to enablement and reablement dementia pathway

Other;

Transition between social care & CMHT; specifically care arrangements between Primary Care Liaison & social care
Need to be agreed and formalised.

Access Group to undertake this action