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Longterm Conditions

Vision

People with Long Term Conditions feel empowered and supported to care for themselves in their own communities. Care will be well coordinated between partner agencies and based in the community. Clear access routes into specialist care are available when required, with particular provision for those who are vulnerable.

Definition

A Long Term Condition is defined as a condition that cannot at present be cured; but can be controlled by medication and therapies.
Current Pattern of services

The number illustrates the difference in service configuration across the three areas in ABM. Patients receive a different service or may or may not be able to access particular services depending on where they live.

In 2010-11 the total number of LTC related admissions to hospital for the ABMU Health Board was 5358, which equates to 54,421 days that LTC patients spent in hospital beds. There were 660 multiple admissions relating to LTCs, equivalent to 12% of the total number of admissions. 7016 bed days were required for these multiple admissions contributing to 13% of the total number of bed days. This illustrates the pressure on the secondary care system caused by inefficiencies in managing LTC patients. It also highlights that LTC patients continue to spend unnecessary time being re-admitted to hospital.

Specific issues with LTC services were highlighted by workstream members and are outlined below:

- There are issues with availability of community staff out of hours in ABMU. Care for LTC patients should be available 24 hours a day, 7 days a week in the community in order to stop patients having to be seen in hospital

- The current Workforce skill mix in the community does not allow for pro-active management of LTC patients. Community teams need the right competencies, confidence and flexibility to deal with patients in their own homes or in GP practice rather than admit to hospital.
Longterm Conditions

- The needs of the workforce are not reflected in training programmes to promote the development of generic skills needed to manage those with multiple chronic conditions.

- The role of the Nurse Specialist needs to be responsive to changes in demand between community and hospital care, allowing them to bridge the gap and provide specialist advice and opinion. This does not happen currently.

- There is an issue with Community staff not having the skills to be able to motivate patients to care for themselves, providing advice, education and support to empower patients.

- Secondary care clinicians are sometimes not aware of the skill mix available in community teams and voluntary sector, so they’re more inclined to hold on to these patients in secondary care.

- Collaborative working is not yet established as well as it could be between Health Board and key partners such as Local Authorities and Voluntary sector.

- Care Pathways are not based on workforce roles and responsibilities.

- There are issues with LTC patients not being managed by identified staff, resulting in a need to move to Key worker model for all LTC services.

- Issue with medicines management for those with LTCs. This is a particular problem for those with multiple LTCs due to amount of medication being taken, there needs to be holistic management.
Longterm Conditions

- We don't manage people with multiple chronic conditions appropriately due to fragmented care and little coordination between professionals and partner agencies.

- There is poor access to Information, education and specialist advice on LTCs and the availability of appropriate services.

- Current technology used is often a barrier not a facilitator for coordinated care, where staff and patients are unable to access the information they need at the right time in the right place.

- For those that have had treatment and need long term management, our appointment systems are inflexible and inefficient, e.g. follow up appointments.

- Late diagnoses of some LTCs leads to progression of disease and exacerbation, e.g. Epilepsy, Heart Failure.

- We often pump prime new concepts, without building on existing good practice models or disseminating successful outcomes.

- Care often defaults to secondary care instead of mobilising community support, which creates an unnecessary burden on unscheduled care system.

- Local Out of Hours pressures need to be addressed, to ensure responsiveness for LTC and End of Life patients.

- There is a limited safety net for the frail and vulnerable that require acute care.
• There is often duplication of assessments in community.

• Infrequent use of advance care planning for those on the End of Life pathway.

• Carers and family members are often not involved in decision making for those with LTCs.
What patients say about current LTC services

In December 2012, a patient focus group was carried out by members of the LTC workstream. Twenty five LTC patients from across the ABMU area gave their opinion on the services they experience. The following provides a summary of the issues they raised:

• Information – need to know as much as possible, causes, what it causes in the body, how to deal with it. Expert Patients Programme – no one knows about it.

• If it is long term condition which progresses in stages, it’s important to get the right information at the right time. We want to know how to deal with it.

• Access to information in GP surgeries / libraries/ community centres.

• Very important that community teams work 24/7, especially with accessing diagnostic units, where admitted on a Friday to A & E, often left with minimal care over the weekend until the Monday. 24/7 working is important across all areas.

• Community nurses on the weekend tend to be on call. Sometimes we just need reassurance. At weekends, people can feel anxious, isolated, and vulnerable.

• The use of technology to bolster community nurses is important such as telecare for reassurance, particularly in remote areas.
• The use of technology is great for many. However, for many people, their conditions can impact on memory and capability to use technology and they could be left deserted and unable to use it correctly. There needs to be a system in place which caters for everyone, where community services are joined up and cater for the majority of LTC needs.

• Follow-up appointments are a problem due to either being too unwell to attend or we attend when we’re feeling well and the next week we’re really unwell, therefore missing the opportunity to explain symptoms and waiting too long for next appointment.

• There needs to be open access to appointments or specialist opinion - to speak to someone rather than going in at a scheduled time - a role for community nurses/ specialist teams. People can be more honest if they have an assessment at home, they are more relaxed.

• The GP sees the long term effect. This is not always seen by the hospital specialist. There are key things that the GP picks up on. They see you in context, what you're like. There needs to be links between the hospital and GP – holistic information.

• With changes in the whole area, there is a need for information about which direction to go for what care. Sometimes the condition means you have to get to hospital quickly for specific treatment and this happens regularly. Often patients just wait in A+E for hours when they know they need a particular treatment from the specialist nurse or ward equipment but the system is clogged.
• A single point of access – a number to call about where to go. We’re told to ring NHS Direct, but you need to go through all your personal details. They can’t say where you need to go without going through the protocol. We need somewhere to ring just for general advice.

• I have heard of some who order repeat prescriptions for conditions, even though they don’t need it as they’re afraid it’ll be stopped and they will need it.

• People with long term conditions with no cure are not getting assessments, just continually repeated prescriptions. Nothing flags up. Are there newer, better drugs? There should be 6 monthly reviews so it doesn’t persist for years.
Principles

Principle 1
Cultural change towards person centred care - empowering people to take ownership for their health

Principle 2
Service provision and support for people with Long Term Conditions defaults to the community

Principle 3
Community strengthened to provide web of support for individuals, carers and families

Principle 4
Coordinated care through collaborative working

Principle 5
Defined route into appropriate specialist care that is safe and accessible

Principle 6
Improve Medicines Management for people with long term conditions
Objectives

Principle 1

Cultural change towards person centred care - empowering people to take ownership for their health

- We want to provide good education for LTC patients to manage their own condition

- We want to encourage all individuals with LTC to consider their options for their priorities of care / advance care planning to ensure appropriate care offered / place of care.

- We want to give professionals the tools to signpost LTC patients to good information

- We want to empower professionals to be able to support LTC patients in a holistic way

- We want to influence the media so that they work in partnership with us to promote self care

- We want to ensure LTC patients are given health literacy skills so they can understand the information and education about their condition
Principle 2

Service provision and support for people with Long Term Conditions defaults to the community

- We want to streamline care pathways so that they default to the community not to hospital
- We want to develop 24/7 working in the community so that patients have access to services close to their homes rather than having to go to hospital
- We want to develop comprehensive rehabilitation services closer to patients’ homes
- We want community teams to have the right competencies, confidence and flexibility to manage LTC patients in the community
- We want to build good relationships between community teams and specialist teams in hospitals, so they both work together in the community, providing joint clinics in GP practices and giving each other advice over the phone
- We want our specialist hospital staff to provide outreach services in the community, so that patients don’t have to go to hospital and GPs and community teams are educated at the same time.
Principle 3

Community strengthened to provide web of support for individuals, carers and families

• We want to develop a single point of access for information and support for LTC patients

• We want to work with our partners to improve social interaction: offering education, friendship and support for LTC patients through community hubs / Cafes’

• We want our professionals to be aware of support mechanisms such as social clubs, community groups so that they can signpost LTC patients to them

• We want to promote reciprocity among communities
Principle 4

Coordinated care through collaborative working

- We want to improve confidence and trust in the system for staff, service users and carers, by making sure everyone involved in the care of the patient is well informed.

- We want to ensure care in the community is supported by MDT (Multidisciplinary Team) working, with multi-agency input, such as voluntary sector, local authorities, etc.

- We want to improve the way staff can access health records, so that they are available electronically and able to be accessed by all the people who are involved in the care of LTC patients.

- We want to develop ways where LTC patients can access their own health records so they and their Carers are informed and can have meaningful discussions with health professionals.
Longterm Conditions

Principle 5

**Defined route into appropriate specialist care that is safe and accessible**

- We think it’s important to provide a safety net for the frail elderly and vulnerable people.

- We want to provide rapid access to appropriate specialist teams when things go wrong for LTC patients, e.g. quick access to diagnostics and specialty specific beds.

- We want to provide high quality ward-based care when LTC patients really need to be in hospital.

- We want to develop a pro-active discharge process back to the web of support.

- We think it’s important that ongoing care providers are well informed when LTC patients are discharged from hospital, including carers, social services, voluntary sector, etc.

- We think providing high quality End of Life care is important in anything we do and for any service we provide to LTC patients.
Principle 6

Improve Medicines Management for people with Long term conditions

• We want to ensure best practice is used to improve outcomes and reduce risk for LTC patients

• We want to provide regular medication reviews, including face to face discussions with patients

• We want to develop effective communication across interfaces (secondary care, primary care, intermediate care, care homes, social care etc)

• We want to empower LTC patients to manage their medicines through education and support

• We want everyone to play their part in improving medicines management
Future Model

Principle 1

**Cultural change towards person centred care - empowering people to take ownership for their health**

**CORE COMPONENTS OF CARE**

- ‘My Health Online’ is made available to all patients who want it and able to access it, giving them access to their own health records and ability to book appointments. Currently 14 GP practices are signed up in ABMU, we need to expand to the remaining 63 practices.

- My Health Online is then developed as a database of LTC patients for community teams and specialists in hospital to use to case manage / monitor patients

- A new consultation model established for staff, based on the ‘9 stages’ to empower patients, e.g. quality assured information, skills and knowledge, tools for self monitoring, etc.

- An LTC information resource is made available for staff to access on-line during consultations, e.g. through current NHS Direct Directory or development of Communications Hub

- Health literacy programmes established in the community (or online) for LTC patients to access, e.g. coaching sessions, expand/review expert patient programmes
- Staff are given training on self care, through mandatory training sessions, e.g. expand current self care modules across all staff groups

- Shift access to community rehab programmes for all low risk chronic conditions with management plans that include goals & outcomes, integrated into community to provide social benefits

- Conduct media campaigns for public education, take responsibility for own and family health, change attitude to NHS, promote community spirit and include in School education programmes
Principle 2

Service provision and support for people with Long Term Conditions defaults to the community

CORE COMPONENTS OF CARE

- 24/7 care provided in the community, including GPs, Specialist Nurses and community teams. This will involve an increase in the number of staff available in the community out of hours and at weekends.

- Multi-agency teams established to expand on Community Resource Team (CRT) models – standardised across ABMU. This must include access to equipment providers, specialist opinion and rapid access to diagnostics etc.

- Access to good technology, e.g. telecare, so that patient exacerbations can be monitored remotely and then managed by the CRT.

- Specialist advice lines established so that CRT and GPs can access specialist opinion from hospital based staff.

- Roles and Responsibilities (Job descriptions) of Clinical Nurse Specialists (CNS) and Community Nurses changed to reflect 24/7 working, reflecting generic skills and holistic care provision – therefore breaking down barriers of community Vs hospital care, providing a seamless interface.
- Reduction in hospital-based follow-up appointments, so responsive to patient need. Patients are more responsible for triggering specialist care; resources released to reinvest in community teams, e.g. slots made available in specialist clinics for patients who really need them; patients known to specialists. Managing expectations and reassuring patients that rapid access is available when needed

- Hospital consultants and CNS’ outreach into community clinics to provide pro-active management of LTC patients – GPs and community teams educated on a community network basis

- Access to robust Risk Stratification tools for community teams, so they feel confident managing patients in the community

- Ambulatory pathways developed so that community staff have guidelines in place

- End of Life care training provided to all staff involved in the care of LTC patients. Full compliance with End of Life pathway and advance care planning
Principle 3

Community strengthened to provide web of support for individuals, carers and families

CORE COMPONENTS OF CARE

- Providing support for patients with LTCs in a planned way through a range of social interactions, e.g. community cafes’. Needs to be on ‘industrial scale’.

- Proactive links between young and elderly – to rebuild respect and trust, e.g. expand on Swansea LA Intergenerational project through Community Networks

- Build on existing initiatives, e.g. Community First, Local Authority and Voluntary sector enterprises, befriending services etc

- Use of innovative models elsewhere, e.g. Kafka – community resilience through time banking, community social designs used in Sweden – using Community Networks

- Single Point of Access for accessing support in community, must be accessible to frail elderly, those with disabilities, etc. so range of options to access this is needed not just through Web, e.g. community cafes, libraries, social clubs etc

- Training provided to all staff to facilitate advance care planning discussions with patients with LTC.

- Training provided to all staff in End of Life care and the All Wales Integrated Care Priorities for the Last Days of Life.
Longterm Conditions

Principle 4

**Coordinated care through collaborative working**

**CORE COMPONENTS OF CARE**

- Streamlined discharge process developed, addressing the delays in getting people out of hospital and discharged home, e.g. cutting delays in accessing therapy input on wards and making sure this is provided in the community. Ensure pharmacy input earlier in the discharge process.

- Secondary care clinicians educated about skill and competency levels in community teams and quality standards held by Voluntary Sector providers, therefore increasing confidence to discharge earlier into community web of support.

- Community Resource Teams are expanded to include third sector providers such as Care and Repair, social services etc. Teams need to be co-located so that MDTs made easier and facilitates earlier interventions when patients exacerbate in the community and delays in hospital discharge.

- Cut down the artificial barriers created by finance and referral protocols – making sure there is standardised access into community teams across ABMU not different access criteria in different areas based on budgets and protocols.

- Universal access to multi agency information systems for patients and professionals. The issue of confidentiality must be addressed and broken down into useful information sharing protocols between all agencies involved in LTC care.
- All agencies have access to ‘My Health Online’ so that all providers can monitor patients in community and react to needs quickly and effectively.
Principle 5

**Defined route into appropriate specialist care that is safe and accessible**

**CORE COMPONENTS OF CARE**

- Care Pathways designed to reflect the defined routes into specialist care, i.e. the hospital best situated to accept acute exacerbations of certain conditions and those areas best suited for rapid access to diagnostics. The latter needs to be standardised access on all acute hospital sites, e.g. MRI, Endoscopy, CT etc.

- Hot Clinics established so that patient exacerbations can be managed in community with access to specialist intervention the following day in an ambulatory setting rather than admission.

- Each specialty has more control and ownership of their hospital beds, ensuring seamless access for those patients that need to go into hospital, patients known to hospital and community teams.

- Advance Care Plans in place so that if patient’s condition changes their priorities of care are known to all those involved.

- Role of the Specialist Nurse changed to reflect needs of LTC patients and care providers - access to specialist information, interface between ward based care and community team etc.
Principle 6

**Improve Medicines Management for people with Long term conditions**

**CORE COMPONENTS OF CARE**

- All staff involved in the care of LTC patients are mandated to carry out medication reviews with patients during any consultation/intervention.

- Identify those that are reporting not taking medication and provide intensive medicines management.

- Medicines awareness is included on proposed education programmes and self care coaching (principle 1).

- Medicine wastage is reduced by tackling stockpiling issues, disposal of meds at Community Pharmacies, contained prescribing bills and inappropriate meds identified during patient reviews.
Longterm Conditions

Priorities for the Future Model

• Self Care programmes established for LTC patients and their carers to access, e.g. coaching sessions and expert patient programmes, so they know how to take care of themselves and manage their own condition. The programmes should include managing medicines, health literacy and skills to manage their condition if it gets worse with information available to enable individuals to determine their own care priorities / advance care plan.

• A Single Point of Access for getting support in the community, so that those who are vulnerable, such as frail elderly, those with disabilities, etc have a range of options to access support when it’s needed not just through the Web, e.g. community cafes, libraries, social clubs etc.

• Use good Technology such as Telecare and the web-based My Health Online so that LTC patients can monitor their own conditions remotely, access their own health records and liaise with professionals without having to go to a GP practice or hospital. This technology will allow all professionals, e.g. health staff, social services, third sector to know the status of every LTC patient under their care, sharing information and support.

• 24/7 care provided in the community, including GPs, Specialist Nurses and community teams. This will mean an increase in the number of staff available in the community out of hours and at weekends.
• By strengthening our community services, LTC patients will be managed better and closer to their own homes, reducing the need for them to travel to hospitals for unnecessary follow-up appointments. A reduction in these appointments will mean specialists spend more time giving advice to GPs and community staff for patients who’s conditions are getting worse. For those that really need to be seen by a specialist, there will be slots available for them to access this care quickly.

• Community teams are expanded to include third sector providers and social services. These teams need to be based together so that they can monitor and care for LTC patients as a multi-agency team. This will facilitate earlier response when patients become very unwell in the community and address delays in getting people home from hospital.

• Care Pathways will be designed so that rapid access into specialist care is available, when LTC patients need it. This will include the most suitable hospital to address their emergency care needs, where quick access to emergency tests and scans are available and access to hospital wards specific to their condition. These pathways will also be specific to the needs of those at the End of their Life.

• The role of Specialist Nurses strengthened to provide the interface between ward based care and community teams, offering advice, support and education. The role of community professionals strengthened to provide more holistic care by using generic skills to care for patients with multiple long term conditions.
• All staff involved in the care of LTC patients carry out medication reviews with patients during any consultation/intervention. If staff identify issues with medicines then those patients should be advised/educated through intensive medicines management.
Longterm Conditions

Proposed Projects to implement the LTC Model

The above projects will be rationalised based on overlap with other work streams and timescales.
Longterm Conditions

Cross cutting components of care

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