

## Characteristics of LTCs (with comments from the open round)

These are the characteristics of LTCs highlighted by the expert group in the pre-workshop 'open round' of comments. The comments are reproduced verbatim to illustrate the different perspectives on the characteristics.



Potentially relevant characteristics and the spectrum	
Presence or absence of on-going symptoms	
Asymptomatic < ----- > Persistent symptoms	
Presence or absence of symptoms	<ul style="list-style-type: none"> <li><u>Presence or absence of symptoms</u>: for example an asymptomatic condition such as hypertension may benefit from a different approach to a condition with persistent symptoms such as multiple sclerosis</li> </ul>
	Presence or absence of symptoms (may make a difference for person engaging with lifestyle changes and SM support depending on whether conditions impacts on their life day-to-day)
	Symptomatic or not
	Can be symptomatic or asymptomatic
	Symptomatic/asymptomatic
Specific symptoms	Prevalence of mental & emotional symptoms for those with LTC's
	Pain based symptoms which impact mobility such as muscular skeletal and breathing problems
	Presence and degree of pain
	Degree of fatigue

Impact of symptoms on lifestyle	
Normal activities (including work) < ----- > Severely limited (including housebound)	
Severity of condition	Severity of condition
	Level of disease severity
	Severity of symptoms across LTC's as measured by impact on QOL and usage of healthcare resources
	Conditions which have pronounced physical and cognitive, mental health, emotional effects
Impact of symptoms	Effect of symptoms
	Impact on function or on global self-rated health (which might be a combination of the other factors described previously).
	Overall QOL for various LTC's
	Impact on physical, emotional, occupational and social functioning
	Impact on work or capacity to work
	Impact of LTC's on workforce participation

<b>Risk of future progression/mortality necessitating (self) monitoring</b>	
Unlikely/not serious < ----- > common/potentially fatal	
Risk of (early) death	Probability of serious deterioration/early death
	Potential for serious complication including premature death
	Impact on early mortality
	Life limiting versus life-threatening (similar to 'potential for serious long term complications')
Progressive	Progressive
	Degree to which disease course results in progressive loss of health
	That are degenerative and/or terminal, be that with or without treatment
	Probability of progression to severe form of condition, and the potential impact of this for co-morbidities, such as depression
Monitoring	Degree to which condition should be monitored (for either disease progression or from the point of view of safety because of treatment)
	Degree to which there are objective diagnostic tests (e.g. not in back pain, fibromyalgia)
	Degree to which there are objective tests providing information on biological health (e.g. blood pressure, HbA1c)
<b>Risk of significant complications or co-morbidity necessitating (self) monitoring</b>	
Unlikely/not serious < ----- > Likely/significant	
Complications	<ul style="list-style-type: none"> <li><u>Potential for serious long term complications</u>: for example diabetes, if poorly managed, may be associated with long term complications whereas osteoarthritis may deteriorate over time but is not associated with life threatening long term complications</li> </ul>
	Serious complications; Foot disease leading to amputation, retinopathy leading to blindness, Nephropathy, neuropathy, cardio vascular disease, peripheral vascular disease, erectile dysfunction, gastroparesis.
	Risk for the future
Common co-morbidities	LTCS needing anticipation/surveillance for other complications e.g. Myotonic dystrophy leading to diabetes, PKD and stroke, HNPCC and bowel cancer, dysplastic naevi and melanoma
	Common co-morbidities - cluster together LTCs which tend to manifest with other conditions
	That have diverse consequences/affect multiple functions within and between medical domains (e.g., physical, mental, social)
Complications of Rx	Where polypharmacy/medication may lead to complication e.g. methotrexate and Rh arthritis

<b>Significant variability / risk of (serious/high cost) exacerbations</b>	
Minimal variability < ----- > Highly variable	
Stable or variable	<ul style="list-style-type: none"> <li><u>Degree of variability in symptoms</u>: for example a variable condition such as asthma might need a different model of care to an on-going condition like osteoarthritis with less variability</li> </ul>
	Relapsing / stable
	Predictability
	Pattern of fluctuation in terms of severity and frequency
	Characteristics of symptoms and their severity (this is actually similar to "Potential implication of flare-ups" above, so please use this if preferred)
	Awareness or recognising signs and symptoms e.g. COPD exacerbations (seen more in winter months as prone to chest infections)
	Potential for flare up
	Symptoms vary over time depending on external and internal context
	Constant problems/only during exacerbations/variants on these extremes

Risk of severe exacerbations or events	<ul style="list-style-type: none"> <li><u>Potential implication of flare-ups:</u> for example a severe exacerbation of COPD might be fatal, an exacerbation of inflammatory bowel disease might result in time off work, a flare up of eczema might just be a nuisance.</li> </ul>
	Potential for high cost exacerbations – which is a subset of ‘flare ups’ and ‘complications’ but with a greater service and economic focus
	Ambulatory care sensitive (ACS) condition; Diabetes is classed as an ACS by the DH as it is a condition that needs emergency medical intervention if there is no daily management including insulin tablets or injections. Failure to manage diabetes appropriately can cause the following; Hypoglycaemia, Hyperosmolar Hyperglycaemic State & Diabetic Ketoacidosis which can be fatal if not treated quickly and appropriately. The National Commissioning Board’s priority is to reduce ACS emergency admissions as they are costly to the NHS.
	Degree to which exacerbations are life threatening
	Degree to which exacerbations require hospital admission
	Degree to which exacerbations result in permanent loss of health

<b>Potential of treatment/(self) management to improve symptoms</b>	
Limited benefit < ----- > Very effective treatment	
Control of symptoms	Completely controlled by medication e.g. thyroid and hormonal conditions
	Completely controlled by self-management e.g. diet controlled diabetes, IBS, obesity?
	Degree to which medical management can alleviate symptoms
Evidence-based clinical interventions	Amenability to medical treatments – obviously this changes with time, but the perceived need for self-management interventions may differ if medical management is advanced.
	Degree to which you can influence condition through treatment, lifestyle choices and self-management
	Availability of effective/cost-effective interventions
	Degree to which ‘lifestyle’ interventions have the most impact on LTC (e.g. smoking cessation, physical activity, alcohol harm reduction, weight loss) e.g. compare COPD with Multiple Sclerosis
	Current treatment options available and their efficacy (e.g. asthma treatments are very successful in controlling disease for the majority of patients, if they are used properly - the challenge is ensuring that patients use their medication properly. Other LTCs may not have such effective treatment options available).
	Degree to which provider can influence outcomes

<b>Potential of treatment/(self) management to be disease modifying</b>	
Limited benefit < ----- > Very effective treatment	
Disease modifying	Whether the condition is modified by the treatment, for example is dementia considered a long term condition?
	Whether treatment has the potential to be disease modifying/symptomatic
	Degree to which medical management can modify disease course
Standards of care	Implications of bad management
	The effectiveness of treatments available, but which for some reason are often not adequately provided

<b>Impact on ability to self-manage and/or requiring significant assistance from (informal) carers</b>	
Self-caring < ----- > Highly dependent	
Ability to self-manage	Impact on ability to self-manage
	Mental capacity to engage: need for carer involvement
	Disability and/or Cognitive impairment (degree to which you can care for yourself, or be cared for by others)
	Mobility: capacity to access / move to services
	Impact on mobility
	Impact on dexterity
	Impact on cognition
	Impact on communication
	Mobility and/or psychological limitations (e.g. cannot leave house because not well or scared)
	Whether the LTC (or its treatment) causes mental/physical impairment (which could affect ability/willingness to self-manage)
	Potential for functional and psychosocial impact which could lead to in some conditions loss of function and motivation leading to loss of employment, risk of isolation, risk of addictions and self-harm
	Number of debilitating effects of the condition, multiple effects may complicate the ability to live independently
	Need for and impact on carers
The need for substantial carer support e.g. dementia	
Needing help from others	
Impact on carers	
Effect on others / or not	
Conditions which can be more effectively managed with the aid of family/carers/supporters	

<b>Who provides care: predominantly self-management or reliant on professional input</b>	
Largely self-care < ----- > High level of professional care	
Balance between professional and self-care	Degree to which they personally rather than the professional can influence outcomes
	Regularity of contact with Health Care Workers (HCWs)
	Warrants occasional health service intervention and considerable daily self care
	Requiring medical/healthcare/social care support or not, and magnitude of these (e.g. Obesity without co-morbidity is just about you and rarely see HCP for this; cross a biochemical line and get diabetes, suddenly you have people wagging fingers, treatments, support etc.
	Degree to which routine care can be delivered by different members of healthcare team e.g. community pharmacists/AHPs/nurses/GPs/specialists/specialist nurses
	Who is the main 'actor' for support - in diabetes the person is usually the main actor making lifestyle changes, taking their treatments (even if HCP the main actor in prescribing) and incorporating all this into their lives; in the frail, elderly it is likely that HCPs and services have a much greater role (although person will still have a role as well)

Multi-professional care	Cost implications for health and social care - cluster together LTCs which tend to require a response from both health and social care
	that require primarily multi-professional and team-based treatments (e.g., HIV), vs primarily single-profession treatments (e.g., migraine)
	that require case-management
Requires specialist input	Essential specialist care; Retinopathy checks, blood tests for HBA1C, annual reviews, blood pressure checks, cholesterol checks, foot checks and referred to podiatrist if necessary, kidney function monitoring, weight monitoring, smoking cessation, care planning, psychological support.
	Preconception & pregnancy; specialist care is required in preconception planning, throughout pregnancy and post natal care too. Tight control is needed and more regular appointments are required to ensure that there are no problems for mother and baby such as retinopathy and birth defects. Gestational diabetes care is important to monitor too and may develop into Type 2 later on in life.

<b>Degree of complexity of medical/clinical/social/lifestyle self-care regimes</b>	
Simple tasks < ----- > Complex daily regimes	
Medicines management and complex clinical regimes	Medicines management; Injecting insulin, tablets, insulin pump or medications for comorbidities. Education needed when making changes and reviews to ensure good patient outcomes
	Complexity : groups of more than one condition , or groups of different symptoms , i.e. maybe complex from medical point of view (multi – comorbidity)
	Inclusion of a technical aspect into otherwise generic care e.g. insulin / bladder care etc. : or grouped as ‘need specialist’ vs. don’t need specialist
	Implication of monitoring symptoms (e.g. daily, weekly, monthly, 6-monthly etc.)
	Effectiveness and importance of treatment, for example, in cystic fibrosis, the treatment of antibiotic nebulisers is quite simple yet time consuming and often not undertaken by teenagers with disastrous consequences
	that require direct self-treatment (e.g., self-injection) vs. indirect self-treatment (e.g., health-maintenance affecting symptoms)
	that require self-regulation of physical, mental, or social aspects (e.g., self-regulation of arousal in epilepsy, self-regulation of behaviour in HIV)
	Medication management/Poly pharmacy in terms of self-monitoring and concordance
Regular treatment	Medication management (medication required to take daily e.g. hypertension as opposed to take when needed e.g. chronic pain, preventive (daily) and reliever (as and when) inhalers in asthma)
Complexity of daily regimes	Complexity of daily routines
	The most important is the extent to which the individual has to develop self-management skills in determining the success of care, this is particularly true for example of Type 1 diabetes, where the treatment is full of limitations and the patient (or their parents) needs to provide a very high
	level of skill and competence way beyond that possessed by the non-specialist doctor. This contrasts with for example hypertension where the patient just swallows a few tablets.
	Degree of self-management support required: for e.g.: Hypertension might need information provision and compliance with medication whereas Chronic low back pain might need lot more engagement on patient’s behalf over and above information and compliance with meds.

Coordination of complex services	Complexity: in need of coordination of services or not : complex form the delivery point of view
	Conditions which require collaboration with other providers to enable effective support

<b>Genetics/familial nature of condition</b>	
No significant familial component < ----- > Clear genetic condition	
Inherited disorders	Conditions which are genetically inherited
	Genetic differences between LTCs: Those that are highly penetrant e.g. BRCA1/2 v those that are less e.g. hemochromatosis
Inherited risk factors	Can run in families – due to mix of risk factors and or genetics
	LTCs where family history is important e.g. inherited cardiac conditions, familial hypercholesteramia
Genetic classification	Unsure genetic component but suggestion of tailored/stratified medicine approaches in the future
	Increasingly genetic classification of diseases e.g. Diabetes , breast cancer hypertension

<b>Age of onset</b>	
Onset in childhood < ----- > Onset as adult	
Age of onset/age affected	Age
	Age: modification of disease by age
	Age: differing expectations / priorities with age
	Typical age of onset
	Onset at different ages but lasting for life
	Age group of people effected by the LTC (this may inform appropriate management approaches)
Children and teenagers	Paediatric; More frequent blood tests for HBA1C, weight, height, general health checks, psychological support, education, dietetic support
	Resistance of teenagers in certain conditions to undertake self-management and the relevance of this omission (disastrous in CF and Type 1 diabetes)
	Transitional services; It is vital that these services offer a seamless transfer of care to ensure patient engagement. Children usually stop attending appointments in this time and present later on with complications

<b>Presence of co-morbidities (including depression)</b>	
No co-morbid conditions < ----- > Significant co-morbidity	
Increasing burden of disease and care	Presence of co-morbidities
	Synergies and discordance of conditions or their management – of relevance where patients have more than one condition, as self-management for some conditions may be common, whereas in other areas the requirements for one condition may clash with another
	Similarity of symptoms or body systems involved (e.g. vascular, breathlessness, musculo skeletal, neurological etc. groupings)
	Degree of crossover with other LTCs (e.g. diabetes, or osteoarthritis and hypertension – thinking burden of care in comorbidity)
	Communality of symptoms across LTC's – e.g. symptom burden of kidney and EOL patients similar
	Co-morbid conditions which implicate the burden of care.
	Co-morbidities and their implications on drugs etc.
Mental health	Increased likelihood of mental ill-health often caused by fear
	Association with depression, reflecting the importance of depression as a comorbidity in the WHO study of Moussavi et al (2007). However, this is dependent on there being variability between disorders in the likelihood of depression.

<b>Stigma/social class/medically unexplained symptoms</b>	
No stigma/inequity issues < ----- > Stigma	
Stigmatised conditions	Stigma and public attitudes to the disorder, which may impact on the perceived importance of self-management and willingness to engage with services. Dixon-Woods' concept of 'candidacy' may be relevant here
	Presence of social stigma associated with the condition
	Stigma associated with a condition, which may impact on initial identification, and subsequent treatment concordance and adherence; may include specific ethnic or cultural issues regarding illness and disease

	Stigma (from the perspective of the patient and how a service might be organised in order to take account of sensitive issues, for example HIV )
	that entail stigmatisation (e.g., chronic infections, obesity) affecting treatment-success and health-outcomes
Doubtful medical legitimacy	How uncertain the condition is in terms of legitimacy e.g. uncertain conditions which invoke a response that this different by clinicians and how people think about it (e.g. CF, IBS etc.)
	Medically unexplained symptoms such as IBS and ME
Embarrassing	Embarrassing symptoms such as bowel conditions, incontinence and skin conditions
Social demography and inequalities	The social class gradient of the group most likely to experience the condition e.g. COPD
	Demographics of populations most affected
	Existing health inequalities

<b>Prevalence (burden to healthcare system/society)</b>	
Rare condition < ----- > Common condition	
Prevalence	Prevalence
	Overall Prevalence/incidence – burden of disease on society and health services
	Number of people effected by the LTC – may help us to prioritise.
	Size of the patient/user population -
Rare diseases	LTCs classified as a rare disease e.g. in UK 6000 diseases classified as such
Cost	Cost to society/health system

<b>Evidence base / existing tools /skills required</b>	
No evidence about self-management < ----- > Extensive evidence base	
Evidence	The strength of the existing evidence-base that self-management is effective/cost-effective
Theory	Health beliefs; use Leventhal's common sense theory as framework (i.e. beliefs about 'identity', 'cause' 'time line', 'consequence', 'curability/controllability') : see attached matrix slide : This will affect skills needed by staff
Existing tools	Existence of self-management tools for the LTC (may alter recommendations)