PRISMS

PRACTICAL SYSTEMATIC REVIEW OF SELF MANAGEMENT SUPPORT FOR LONG TERM CONDITIONS

Components of Self-Management

These are the components of SM 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 components.

Components	
Training /education	
• For staff/HCPs	Training and education for staff e.g., Shared decision making – MAGIC programme
	Training for health care professionals
	Dedicated staff training
	Ability of staff and staff training to deliver programmes
	that these programmes require as much education of clinicians and commissioners as of patients, including the fact that self-management includes the ability to influence the effectiveness of services received. E.g., ...
	that these interventions require skill and knowledge that is not picked up on a weekend course by a physician or nurse, and that these need to be strategically developed and supervised by those most skilled in behavioural and communication-based interventions, typically psychologists
• For users	On Line/paper based **progressive education** e.g., educare or Diabetes UK

	Telephone coaching
	Telephone support
	Objective advice and support to support people to remain at or return to work
	Programs to support patients at risk of LTCs to remain mentally, emotionally and physically healthy
	Symptom Management programs covering M, & P, symptoms
	Education
	Structured education
	Systematic education programmes – definitely important but we must remember that what works for one patient may not work for another.
	Provisions of structured self-management education programmes via internet, telephone, one to one or in small groups by health care professional and lay member
	Lifestyle behaviour change programs especially around activity, weight, diet etc.
	self-management typically requires learned skills - and that poorly learned skills can be counter-productive
	Follow up patients to reinforce or remind them about keys self-management skills acquired by health care professional or lay member
	Peer-led healthcare programmes including buddying, coaching, teaching, sharing experience and knowledge and friendship like Expert Patient or British Lung Foundation
	Individual home-based programmes led by multi-disciplinary teams of professionals – disease specific e.g. pulmonary rehabilitation
	Group programmes led by multi-disciplinary teams of professionals – disease specific e.g.

	pulmonary rehabilitation managed remotely – e.g. cardiac rehab online
	Group programmes led by multi-disciplinary teams of professionals – symptom specific e.g. breathlessness programmes – pulmonary/cardiac rehab
Access to information	
	Relevant information regarding your conditions, services and treatments
	Information prescriptions (tailored advice and information 'prescribed' for people with LTCs)
	Access to medical records - and the ability to keep a diary of symptoms and / or update personal record.
	Patient-held records (physical or virtual)
	Access to information prior to consultation (such as test results in diabetes)
	Timely and accessible information – not just written and not just one off
	The expert patient carrying 'health passports' e.g. sickle cell patients. Health passports also used for learning disabilities
	Provision of online results to enable better self-management
	Access to information and services for day to day living e.g. provision of blue badge, access to exercise centres that patients with COPD can join after completing pulmonary rehabilitation and self-management programmes
	Personalised decision support
Monitoring	
• Web based	Remote monitoring and support

	Web monitoring – e.g. Just Checking
• Telecare	Telecare equipment
	Telemonitoring
	Use of low cost telehealth interventions - e.g. online avatars for people with depression (asks questions about their mood, and responds with personalised suggestions/advice)
	Use of text based approaches - reminding people to take medication, appointments, how to access out of hours services
	Computer and mobile phone technology for support, monitoring and education
	Internet & mobile support, i.e. that support can be accessed / used via a wide range of technology
	Use of mobile phone 'apps' to help people manage their condition e.g. monitor glucose levels, blood pressure
	Much better use of telephone based systems - telephone consultations to check symptoms;
	Home monitoring e.g. BP of course,
	Tools that enable people to track their own health status (a particular challenge for musculoskeletal disorders where there are not biomarkers – PROMs will need to feature heavily)
• Feedback	Personal monitoring and feedback – e.g. diabetes testing, INR
	Provision of rapid feedback
Environmental adaptations	
	Adaptations
	Aids and devices and how to make the best use of them

Care planning	
	Written action plans
	'Written' actions plans – important to consider different languages spoken in the UK and the use of pictorial/ graphic plans rather than text-heavy plans to communicate effectively. This is important fro both English-speakers and non-English-speakers.
	personalised care planning
	Care Planning; as detailed in the Year of Care project patients should work in partnership with healthcare professionals to decide goals, treatment options and undertake shared decision making
	Care planning including personalised plans written in books, online records e.g. http://www.microsoft.com/en-us/healthvault/
	Clear, personalised guidance for people with an LTC as to when to self-manage a flare, and when to seek clinical input
Access to a specialist team	
	Access to a specialist team
	Access to community support, e.g. paediatric teams, diabetes nurses, district nurses etc
	High quality professional support is essential (for which there is an evidence base) and cannot be provided by a 'generic LTC nurse'.
	Access to a named care co-ordinator and contact number/email.
	Urgent access to specialist clinical support during times of a flare
	24-7 symptom management expertise available

	On demand access to expert support: telephone helplines, telemonitoring
	Flexible access to expert support – certainly important to maximise the breadth of people who can be supported
Emotional/ social/psychological support	
	Emotional & psychological support; on how to cope to live with diabetes
• Peer support	Peer support or buddy groups - especially around the area of treatment choice - Condition-specific support groups - Online peer support through forums, message boards etc - Befriending
• Lay support	Lay support Lay outreach workers working in association with patients
	participation in peer-based patient-advocacy groups is essential in the case of poorly responsive health-services (e.g. highly skilled and expert patients who suffer poor services need to be able to organise to insist on quality services)
• Professional/peer	Motivational and psychological support to assist behaviour change
	Symptom Management programs covering E and Spiritual symptoms
	Provision of psychological and social care to complement medical aspects of SM.
	Links to mental health services for people with physical LTCs - in a preventative capacity
Users having financial Control	

	Given financial control
	Personal health budgets
	Personally-chosen programmes selected from trusted providers e.g. pilates teachers, nutritionist, homeopathy, using personal budgets or private funding
	Flexible funding mechanisms that give similar priority to non-medical interventions that support self-management, such as supported living equipment and home modification
Financial incentives	
	Financial incentives pay for performance in relation to self management support
• **National incentives**	QoF/service focus/ – obviously this changes with time, but the perceived need for self-management interventions may differ if or incentivised.
'Large scale' public health initiatives	
	'Large scale' public health initiatives
	Local authority programmes to create hope and optimism eg walking programmes, green gyms, children-older people joint programmes
	Public health approaches such as nutrition, exercise, tobacco and alcohol controls and family or population-based interventions

Key features/ characteristics	
Patient centeredness	
	Patient involvement; people with diabetes should be involved in the commissioning of services and patient experience should be reflected in commissioning decisions
	Degree to which intervention is focused on patient (self-defined) versus provider goals (e.g. adherence to medication). The former may increase acceptability and motivation, but may be somewhat more diffuse in their effects
	Opportunity to prepare for consultations and decide what would like from service
	This implies that personalised care planning is just a challenge – but it is potentially also the solution to the conundrum that you raise – how to provide support for self management for everyone– with a common framework for the service **and** a completely tailored and individualised outcome for the individual
	Flexibility for people to build their own programme of support around their own needs with the support of health-care professionals
	Identify patient's understanding of condition and needs prior to supporting patients with provision of written action plans, self-management programmes etc
	Tailored self-management programmes which use a mixture of face to face, online or telephone support - developed alongside the user.
Complexity	
	Complexity of the intervention (there might be a number of proxies for this, including total cost, number of professionals involved, duration)
	Scope, in terms of the range of behaviours targeted. It is not clear whether self-management interventions are better when they target multiple behaviours or a smaller number

	The complexity and relevance of the input from the professional, for example in flexible insulin therapy (essential in Type 1 diabetes), high quality professional support is essential (for which there is an evidence base) and cannot be provided by a 'generic LTC nurse'. This has never been grasped by many who provision such support.
Multidisciplinarity	
	Group healthcare programmes led by multi-disciplinary teams of professionals – disease specific e.g. pulmonary rehabilitation
Disruption to individual	
	Interventions which have more or less impact on the individual (as opposed to conditions which have more or less impact). A relevant concept here would be May's 'minimally disruptive medicine'
Involvement of carers/families	
	Active involvement of carers/families
	Family and carer support and education
	Administration of medicines by carers, roles and responsibilities
	Role of providing support and information to carers as well as to patient themselves.
	Education and training for carers
	The level of support needed by families.
Generic/Disease specific	
	Interventions that may impact on multiple conditions versus those that will only impact on one

	(related to previous entry)
	Applicability/adaptability to more than one comorbidity
	Interventions taking account of multimorbidity (related to previous entry, but here we have interventions that are DESIGNED to take account of multimorbidity and the challenges that it raises, compared to those which may simply impact on multiple conditions)
Duration	
	One-off interventions (e.g. EPP) versus those using long-term and ongoing support (e.g. telehealth)
	Time allocated
Accessibility	
	Accessibility
	Language and cultural differences
	Language services if English not first language
	Information provided that takes into account varying levels of health literacy
	IT infrastructure – for booking/managing appointments, prescriptions, medicines monitoring
	Good and trusted connectivity to primary and secondary care recording systems
	Technologies which may make self-management more convenient or easier to use e.g. mobile phone technologies, ‘Apps’ etc
	A comprehensive self management educational, information and supportive framework available via a suitable provider, accessed via equipment that can access the cloud where all these materials can be located. We are working with 2 universities to give access via Internet enabled

	PC's laptops, tablets, ipads, iphones, smartphones, and Internet accessing TV.
Integration into mainstream healthcare	
	How this is integrated into overall healthcare and support – best example is structured education courses that support people to develop the knowledge, skills and confidence to self-manage their condition that then go back into a healthcare system where the HCP doesn't listen to the patient, belittles their suggestions, 'doctor knows best' and person loses confidence or gets extremely frustrated. Most studies have explored tiny fragments in isolation and then are surprised about lack of impact - somehow need to separate this out if possible.
	Complementary medical care programs to support self-care
	Forming Links with carers, social services or community nurses to provide support to patients who are housebound
	Use of multidisciplinary teams which include social care and mental health (can help with access to practical support, adapting home, providing carer respite etc, managing anxiety etc).
	Tailoring to local healthcare economies – e.g. providers, specific environmental issues
• Feedback to services	independent assessment by service-users of the quality and efficacy of services can be life-saving, thus feedback to services about delivery-variables directly related to health-effectiveness is essential if health-services are to be effective and long-term
• Links to existing community organisations	Links to existing community organisations
	The Presence of "expert" patient support organisations through which self management can be supported
	Underpinned by relevant patient or user organisation where available and appropriate

Outcomes	
	confidence and self efficacy
	Condition-specific knowledge and skills
	Generic knowledge and skills (e.g. : navigating health services, dealing with generic symptoms such as tiredness, breathlessness)
	Health Literacy

Unallocated	
	Managing portals e.g. gastrostomies, home dialysis, etc
	Principles of Reablement
	Availability of facilities where people can undertake structured physical activity in a supported environment
	Social prescriptions (prescribing stop smoking support, exercise classes, group therapy, befriending services)
	Interventions focused on process goals (increasing empowerment) versus treat to target (specific targets to reduce HbA1c, for example). As above, there may be tradeoffs between acceptability and effectiveness
	Legislative issues; relating to employment, driving etc
	Principles of Reablement
	Media used to support self-management – which formats are important e.g. printed materials (booklets, posters, summary sheets), medication reminder devices/alarms etc, telephone

	helplines etc.
	Transition/adolescence is an important time when many most individuals fail to self manage adequately