Healthy London Partnership



Steps towards implementing self-care:

A resource for local commissioners

Contents

i.	Foreword	3
ii.	What self-care means for Londoners	5
iii.	Executive summary	8
1.	What do we mean by self-care?	10
2.	Why does self-care matter ñ the business case	16
3.	Digital support and engagement	19
4.	Implementation	26
	i) Identifying the target populationii) Operating model and funding sources to support self-care	26 26
5.	Monitoring, evaluating, demonstrating value	29
6.	Enablers	31
	 i) Health self ef cacy and patient activation ii) Health literacy iii) Workforce development 	31 31 31
7.	Useful Websites	34
8.	References	36
	pendix A: Using the EAST framework to help implementationpendix B: Interventions relating to the self-care continuum	39 41

Foreword

London is a vibrant city with diverse communities, assets and a deep reservoir of social capital. However, London also has significant inequalities in wealth, mental and physical health. In aspiring to be the world's healthiest major global city, the London Health Commission's report Better Health for London (Mayor of London 2015)¹ calls for coordinated action to enable Londoners to do more to look after themselves. This aspiration strongly aligns with NHS England's vision for change, as set out in Chapter 2 of the Five Year Forward View (NHS England 2014)², and its focus on how people powered health can be achieved through the 'renewable energy of communities'.

Since April 2015, Healthy London Partnership has galvanised leadership, forged strong links with national, regional and local partners and focused on evolving the evidence-base to demonstrate the value of person-centred and community-centred approaches.

All five London Sustainability and Transformation plans (or STPs) identified a focus on self-care, prevention and social prescribing as a means of implementing a range of person and community-centred approaches. Whilst commitments to digital-enabled self-care are important components of London's Local Digital Roadmaps.

The health and care system can do much more to support people to make informed choices and to be more active in managing their own health, wellbeing and care. The Healthy London Partnership is committed to working with local people, communities and agencies across the capital to help London to achieve the following vision.

A future vision for London

Londoners are more proactive in their care and report improved outcomes due to shared decision-making. Supported by a vibrant and diverse supply market and new digitally-enabled processes, self-care becomes the norm. New Care Models empower Londoners to take control of their health and wellbeing drawing upon a wider network of support made available by family, friends, voluntary and community groups, as well as health and care services when needed. This results in:

- a) Care decisions are shared, helping people to make informed choices. Citizens are routinely and systematically involved as active partners with clinicians in clarifying care, treatment or support options and choosing a preferred course of action. Decision aids are widely utilised to help citizens and clinicians think through the pros and cons of different care, treatment or support options.
- b) Care planning and self-management is hardwired into how care is delivered. Meaningful care planning takes place for people with long-term conditions or ongoing care needs which guides the choices and actions of an individual and their professional team. This care plan is digital and can be shared between care settings and is owned by, and useful for, patients, their families or carers. People living with long-term health conditions or care needs are offered support to improve their confidence and their capacity to manage their own health and wellbeing. This is achieved through greater take-up of evidence based approaches such as self- management education, peer support, health coaching and group based activities.

¹ https://www.london.gov.uk/sites/default/files/better_health_for_london_-_one_year_on.pdf

² https://www.england.nhs.uk/wp-content/uploads/2014/10/5yfv-web.pdf

A resource for local commissioners

- c) Social action beyond the NHS helps people improve their health and manage their wellbeing. Clinical Commissioning Group (CCG) and local authority commissioners support the local population in building community capacity and resilience. Social prescribing schemes and other community-based support are widely available to the public. Strong partnerships between the NHS, other statutory partners and voluntary groups deliver health prevention and support for patients, carers and their families. Shared local leadership promotes community-based activities aiming to strengthen local skills, knowledge and resilience to improve health and wellbeing.
- d) Personal Health Budgets and integrated personal budgets, including NHS and social care funding, are available to everyone who could benefit (in line with NHS Mandate requirements³). In each CCG area at least 1-2 people per 1,000 of the population has a personal health budget (PHB) or integrated personal budget incorporating NHS & social care funding. PHBs should be in place for NHS Continuing Healthcare and Continuing Care, people with high cost packages of support (e.g. people with a learning disability); and in specific areas where the model will deliver a positive impact (e.g. end of life care, mental health).

e) Support in 2017/18

Healthy London Partnership intends to build on this resource in 2017 when additional resources and support will be available following further collaboration with NHS England, Public Health England, the Social Prescribing Network, Greater London Authority, London Councils, London branches of the Association of Directors of Adult Social Services (ADASS) and Association of Directors of Public Health (ADPH) and of course with input from local STPs, Clinical Commissioning Groups (CCGs), Local Authorities, the voluntary and community sector and lay partners.

We do hope you find this resource helpful.

Graham MacKenzie

SRO Proactive Care Programme Healthy London Partnership

Grehow Markenze

Chief Officer

Wandsworth Clinical Commissioning Group

Jane Barnacle

SRO Proactive care Programme Healthy London Partnership

JaneBarrace

Regional Director – Patients & Information NHS England (London region)

³ https://www.gov.uk/government/publications/nhs-mandate-2016-to-2017

What self-care means for Londoners

If a range of self-care support were more widely available it could make a difference to peoples' lives in the following ways.



Thomas, 12 from Newham

Thomas is 12. He is an adventurous young person who loves exploring the outdoors. His confidence is knocked by a recent asthma diagnosis. He is spending less time outside with his friends. His GP advises his dad Frank to contact the local social prescribing scheme. After a phone conversation and an assessment with his link worker, Frank and Thomas better understand the local opportunities which are available. They decide that a peer support group, led by a sports fanatic coach in her early 20s who also has asthma is a good fit for Thomas. He now loves weekly canoe sessions in the Royal Dock at Newham and is gaining confidence in himself and in using his inhaler.



Maysie, 86 from Barnet

Maysie is 86. She is blind and partially deaf. She is unsteady on her feet, but still gets out once a week with help using a walking a stick. She is widowed and lives alone, but sees her daughter and her family every week. Maysie is becoming withdrawn and showing signs of depression. Her GP arranges for her to meet a social prescriber from Age UK. She loved reading and so they arrange for weekly visits from a volunteer from the local blind association who comes to read to her, and for the library to drop off a selection of talking books (she can hear them if they play at full blast on her headphones). They speak with Maysie's daughter, who then encourages her friends to visit more. Maysie begins to contact people and go out with them at least once a week to a lunch club at the Salvation Army and her mood picks up.



Jenny, 75 from Merton

Jenny is 75 and lives with her husband. She has a heart condition, type 2 diabetes and is unsteady on her feet. The house is now dated, and the fixtures and fittings are sometimes hazardous. She has fallen twice, but did not suffer serious injury and she and her husband decided not to do anything about it. The London Fire Brigade conducted a "Fire, safe and well" visit and noticed her unsteadiness and the hazards in the house. They referred Jenny to an Expert Patient Programme and arranged for the hazards in the home to be fixed (e.g. new hand rail on the stairs). At the Expert Patient Programme she met others who had a range of long term conditions, and was taught exercises to manage her balance better. Jenny also received information about a range of resources she could use, including the local falls clinic. She now manages her balance better and uses a walking stick to go out to play Bingo and have afternoon teas, on alternate weeks, with her husband. She has not fallen for 6 months.

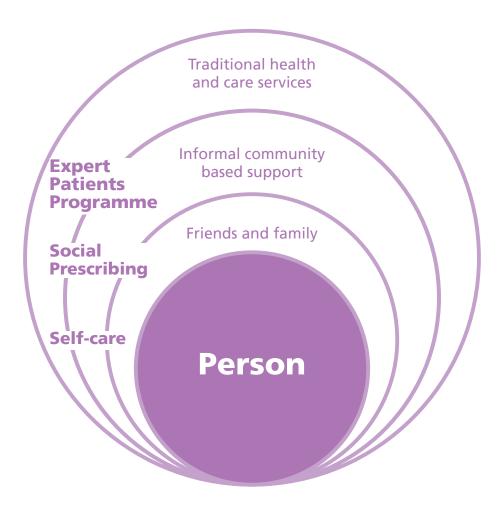


Figure One: The relationship between people, person-centred approaches and appropriate support



Sanjita, 46 from Hammersmith & Fulham

Sanjita lives in a poor part of her borough. She is overweight and smokes. She lives with her parents who are getting old. She does not see much of a future for herself and has only ever had part time unskilled jobs. She went to her GP who referred her to her local Improving Access to Psychological Therapies service. She found that helpful, and is now thinking she would like to do more with her life. Her GP therefore referred her to a local health coach. The coach worked with Sanjita to agree her goals, and how she would work towards them. They found a local women's walking group, to help her make connections with other people and motivated her to start reducing her intake of snacks and fatty foods. Some of the other women had given up smoking and encouraged her to do the same, so she referred herself to the stop smoking service. Sanjita is now feeling healthier and happier, and has begun volunteering once a week at a lunch club for older people at her local community centre.



Sophie, 32 from Greenwich

Sophie has a learning disability, and currently lives at home with her parents. She is not working. She is a little overweight. She would like a job (paid or voluntary), more friends, a boyfriend and her own place to live. With support she has successfully applied for a personal health budget. With help from her family and professionals she has decided to spend the budget on some personal assistant time, going to a day centre, and horse riding which she enjoys. Through the day centre and horse riding she has increased her social networks (but not found a boyfriend yet) and been able to undertake free IT lessons to develop her skills for work. She is happier and feeling healthier, and thinks her prospects for future employment and relationships are good.



Jagedish, 55 from Harrow

Jagedish is a 55 year old man who was made redundant 6 months ago and has not been able to find other work. He has been accruing debts trying to manage, and his wife is putting pressure on him to find work which he is struggling to do. He is becoming more depressed. He experienced severe chest pain and was worried he may be having a heart attack. He went to A&E where no heart conditions were found and the Hospital booked him to see his GP. The GP asked him to see the practice social prescriber. At that meeting, Jagedish stated his clear goal of returning to work. After consulting an online directory they found 2 organisations in his area who help people to find work and a debt advice service. He went to one of the employment services and is now undertaking training to update his employability skills. He has also contacted the debt advice service on the phone, and restructured his repayments to make them more manageable. His wife is happy as she can see he is trying to find work. Jagedish has used the online directory with his wife to find a local women's group she now goes to weekly and enjoys.

Executive summary

London has committed to promoting the health and wellbeing of its citizens⁴. This includes helping people to look after their own health better, and making it easier to use health services when needed. All of London's Sustainability and Transformation Plans (STPs) include increased self-care and prevention.

This document has been developed by the Healthy London Partnership with the help of a wide range of stakeholders from around London and the UK. It is designed to help local leaders to implement their STPs. It is intended to be practical, easily accessible, and to stimulate local leaders to work closely with appropriate partners to increase the number of people who are effectively caring for themselves. Examples are cited without any endorsement, but to indicate to commissioners a variety of ways in which outcomes can be achieved.

It will be the basis for support that the Healthy London Partnership will provide to local health and care economies. It is also intended to be valuable to all of those who are interested in self-care (from whichever perspective). It has been developed with a companion resource for social prescribing⁵, and they both refer to each other. It should be used in conjunction with the personalisation and self-care programme Case for Change⁶. It is not a document set in stone. The intention is that it will develop over time so that as new challenges are identified, or new solutions found, they can be shared to help everyone improve.

What is self-care and why does it matter?

People can play a central role to protect themselves from ill health, by improving or maintaining healthy lifestyles or by choosing the most appropriate treatment and managing long term conditions. The term self-care used throughout this document is based on a definition used by the Self-Care Forum:

'Empowering people with the confidence and information to look after themselves when they can, and visit the GP when they need to, which (sic) gives people greater control of their own health and encourages healthy behaviours that help prevent ill health in the long-term' Self-Care Forum⁷

There is a growing body of evidence showing that a diverse and wide range of person-centred and community-centred approaches leads to improved outcomes and significant benefits for individuals, services and communities (Realising the Value 2016)⁸. This has been demonstrated through improved mental and physical wellbeing, contributing towards NHS financial sustainability and wider social outcomes.

Section 1 in this resource describes different interventions with their potential outcomes which help people to care more for themselves.

In section 2 we set out the business case for self-care. From a citizen's perspective, benefits can include improved self-reported health and well-being and reduced isolation, anxiety and/or depression. Self-care is also important for commissioners. All Sustainability and Transformation Plans in London include

- 4 https://www.london.gov.uk/sites/default/files/better_health_for_london_-_one_year_on.pdf
- 5 https://www.healthylondon.org/latest/publications/steps-towards-implementing-self-care
- 6 https://www.myhealth.london.nhs.uk/system/files/Case%20for%20Change%20Summary%2011.pdf
- 7 http://www.selfcareforum.org/about-us/what-do-we-mean-by-self-care-and-why-is-good-for-people/
- 8 http://www.nesta.org.uk/publications/heart-health-realising-value-people-and-communities

A resource for local commissioners

reference to self-care, prevention and social prescribing. Financial modelling showed that self-care can reduce hospital admissions by 25-30%, saving up to £430 million a year by 2020/21 for London⁹. Further financial modelling commissioned by the Healthy London Partnership found that implementing expert patient programmes can achieve savings ranging between 8% to 35% ¹⁰. Other system benefits from self-care include the more effective use of primary care resources and reduced 'over treatment'.

In section 3 we show how digital support and engagement for self-care can enable information sharing, shared decision-making and more efficient transactions (e.g. booking appointments and referrals to services). Online personal care and support plans, access to information such as NHS Choices and local online directories of services can empower and enable people to choose the right care. Digitally-enabled self-care is a growing area of interest and commitments have been reinforced through local digital roadmaps which support STP implementation. A number of potential risks and governance issues are explored in this section.

Implementation is the focus of section 4. When developing systems for self-care, identifying the target population is important. This can be done through gathering local evidence (e.g. Joint Strategic Needs Assessment), strategic plans (e.g. STPs) and risk stratification. People with long-term conditions or with disability are a suitable population to start with. The next step is to establish the service specification and to engage with local GP practices and the voluntary sector. This will also include establishing a sustainable funding source (e.g. Best Practice Tariffs and capitated budgets).

Good service development and delivery require a sound monitoring and evaluation process, demonstrating the benefits and value which are realised over time. A comprehensive framework to assist with this is presented in Section 5.

Section 6 sets out a number of important enablers of self-care. These include health self-efficacy and patient activation, health literacy and workforce development and training.

A list of useful websites are summarised in section 7 and a list of references are included in section 8. Finally, the EAST Framework to help implementation developed by the Behavioural Insights Team is included in Appendix A. Appendix B provides a visual of the interventions relating to the self-care continuum.

Acknowledgements

The Healthy London Partnership team members that have developed this resource include Shaun Crowe, Brendan McLoughlin, Helen Davies and Jason Tong.

⁹ https://www.london.gov.uk/sites/default/files/better_health_for_london_-_one_year_on.pdf

¹⁰ https://www.healthylondon.org/sites/default/files/Presentation%20-%20Social%20prescribing%20and%20expert%20patient%20programmes%20 modelling.pdf

1. What do we mean by self-care?

Self-care is about:

"Empowering people with the confidence and information to look after themselves when they can, and visit the GP when they need to, which (sic) gives people greater control of their own health and encourages healthy behaviours that help prevent ill health in the long-term." Self-Care Forum¹¹

NHS England has worked with Nesta, the Health Foundation, the National Association of Voluntary and Community Action and others to develop a vision and implementation plans for self-care. Their delivery model is shown in figure two below.

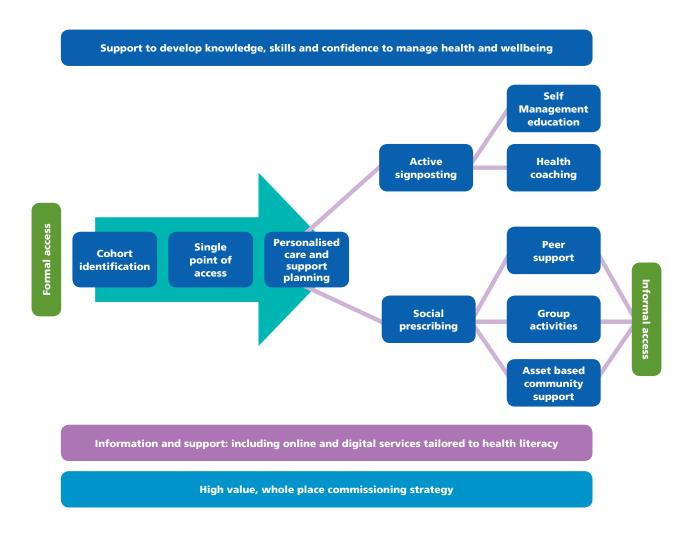


Figure Two: A new relationship with people and communities as championed by Realising the Value (2016)

¹¹ http://www.selfcareforum.org/about-us/what-do-we-mean-by-self-care-and-why-is-good-for-people/

A resource for local commissioners

The above model (Figure 2) shows how people can be helped to care for their own health through:

- Personalised holistic care plans to achieve personal goals developed collaboratively and with shared decision-making between clinicians and the patient
- Expert Patient Programmes/Self-management Education
- Peer Support
- Health coaching
- Personal health budgets
- Community based resources (e.g. through social prescribing)

Prior to its publication the HLP case for change for personalisation and self-care¹² had brought these together under three common themes and suggested local leaders work on:

- Self management
- Community based resources
- Enablers

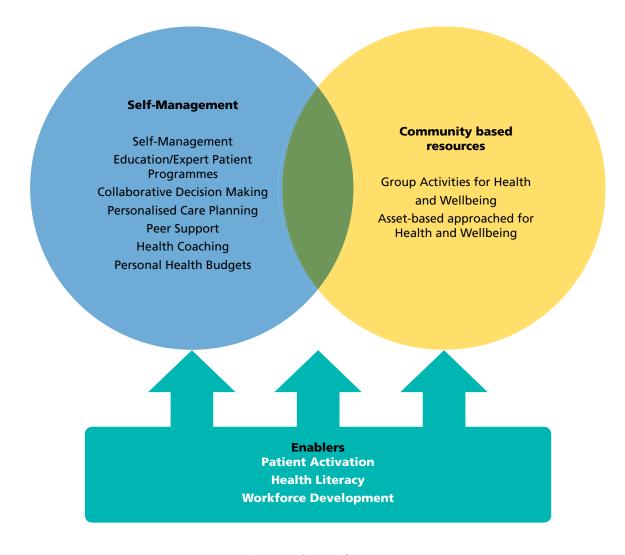


Figure Three: Themes for self-care implementation

¹² https://www.myhealth.london.nhs.uk/system/files/Case%20for%20Change%20Summary%2011.pdf

A resource for local commissioners

These themes resonated with London's health and care leadership and informed the development of STPs, with commitments to social prescribing, prevention and self-care included in STPs and local digital roadmaps across London.

Enablers of self-care

Self-care will be enabled by:

- Improving patient activation/self-efficacy
- Improving health literacy
- Developing the workforce (including easy access to training for clinicians and patients)

More information is in section 6.

Elements of self-care

1. Personalised care planning and shared decision making

Personalised Care Planning is "a collaborative process used in chronic condition management in which patients and clinicians identify and discuss problems caused by or related to the patient's condition, and develop a plan for tackling these. In essence it is a conversation, or series of conversations, in which they jointly agree goals and actions for managing the patient's condition" (Coulter et al 2015)¹³. It requires current clinical information, relevant to a person's condition, with information about all the options available to them, to agree a treatment route which best suits their needs and preferences.

Person-centred care is concerned with (Humphries & Curry 2011)¹⁴:

- Peoples' access to services through information, advice and referral
- Peoples' journey through the health and social care system and the pathways they use
- Peoples' overall experience and outcomes
- Peoples' ability to influence their own experience of the system

Outcomes include:

- Reduced hospital admissions and shorter lengths of stay
- Reduced need for crisis interventions or A&E attendance
- Improved relationships with health-care providers

In addition, person-centred planning enables staff to learn what matters to individuals they are seeking to help, find out more about what 'good' looks like from different perspectives, and better understand how individual people communicate their choices and make decisions (Sanderson & Lewis 2012).

Information about personalised care and support plans is available at: https://www.england.nhs.uk/wp-content/uploads/2016/04/core-info-care-support-planning-1.pdf

2. Expert Patient Programmes/Self-Management Education

Education initiatives increase health literacy and support more active involvement in disease management. Improved outcomes are achieved with comprehensive expert patient programmes/self-management education which 'complements traditional patient education in supporting patients to live the best possible quality of life with their chronic condition' (Bodenheimer et al 2002).

¹³ https://www.ncbi.nlm.nih.gov/pubmed/25733495

 $[\]underline{14\ https://www.kingsfund.org.uk/sites/files/kf/integrating-health-social-care-where-next-kings-fund-march-2011_0.pdf}$

A resource for local commissioners

The focus is on:

- Self-efficacy
- Motivational approaches
- Goal-setting
- Breaking "symptom cycles"
- Problem-solving skills
- Elements of peer support

Outcomes include:

- Increased self-efficacy/activation
- Improved knowledge
- Improved self-care
- Improved symptom management
- Improved stress, coping, and quality of life

Most CCGs will have existing expert patient programmes. These could be developed and expanded to support increased self-care.

3. Peer support and health coaching

Peer support

"A system of mutual aid based on principles of respect, shared responsibility and empathic understanding of the other's situation. This understanding stems from a common experience, based on the belief that someone who has faced and overcome adversity can offer support, encouragement, hope and guidance to others who face similar situations" (Campos FAL et al 2014)¹⁵.

In a review of the evidence for peer support (Nesta 2013a)¹⁶, Nesta and the Regional Voices network found the best evidence to be for:

- Face-to-face groups. Run regularly, such as every week for three months, by trained peers which focus on:
 - o Emotional support
 - o Sharing experiences
 - o Education
 - o Specific activities such as exercise or social activities
- One-to-one support (likely to be volunteers) provided face-to-face or by telephone. This may result in reciprocal benefits for supporters and include:
 - o Information provision
 - o Emotional support
 - o Befriending
 - o Discussions
- Online platforms such as discussion forums. People may use them for just a limited time. These have been found to be particularly useful for:
 - o Improving knowledge
 - o Reducing anxiety

 $^{15\} https://www.researchgate.net/publication/278402488_Peer_support_for_people_with_mental_illness$

¹⁶ http://www.nesta.org.uk/publications/people-helping-people-peer-support-changes-lives

A resource for local commissioners

Outcomes from peer support include:

- o Reduced anxiety
- o Reduced social isolation
- o Improved health outcomes and behaviour

Examples of online peer support include:

- Big White Wall (https://www.bigwhitewall.com/landing-pages/landingV3.aspx?ReturnUrl=%2f#. V4UAWU900dU)
- Diabetes UK Forum (https://www.diabetes.org.uk/How_we_help/Community/Diabetes-Support-Forum/)
- British Heart Foundation (http://community.bhf.org.uk/forum)
- elefriends (https://www.elefriends.org.uk/)
- I had cancer (https://www.ihadcancer.com/)

Health coaching

"A partnership and different type of conversation ... that guides and prompts patients to be more active participants in their care and behaviour change". A valuable resource is the Better Conversation, Better Health website¹⁷.

It is a person-centred process that entails:

- Goal setting determined by the person
- Self-discovery
- Content education
- Mechanisms for developing accountability in health behaviours

Outcomes of health coaching include:

- Improved self-efficacy
- High levels of satisfaction
- Greater understanding of conditions
- Reduced lengths of stay in hospital
- Reduced contact with clinicians

Health coaches can range from clinicians e.g. a practice nurse, to lay volunteers. All would need training. Being Well Salford is an example of such a service¹⁸.

4. Personal Health Budgets

Personal Health budgets may be in the form of:

- Managed bank account which is a Direct Payment with a third party doing the banking and paperwork
- Individual Service Fund which is where a service holds the money for the client, but the client still has the contract with the service directly (rather than being a notional allocation within a block contract)
- Individual Budget, which is where a variety of funding streams are put into the one 'bucket' and used to plan all the care and support necessary
- Combination of these arrangements

¹⁷ http://www.betterconversation.co.uk/

¹⁸ https://www.beingwellsalford.com/

A resource for local commissioners

Using a personalised care and support plan the person should be given help to decide their health and wellbeing goals, and set out how the budget should best be spent to achieve them. They are intended to:

- Offer choice, control and flexibility to the budget holder
- Allow budget-holders to define the health and wellbeing outcomes they want to achieve and provide them with the means to do so
- Recognise both the clinical expertise of practitioners and the individual expertise and preferences of people

Potential benefits include:

- Improvements in independence, choice, control and well-being
- Improved quality and continuity of care
- Ability to remain at home rather than receiving long-term care in a residential or nursing setting
- Increased independence and reduced social isolation
- Improved relationships with family and informal care-givers
- Positive impact on carers' self-reported quality of life

There is a national drive to increase take up of personal health budgets. Many commissioners are reviewing their local situation including the barriers and plan to increase the number of people receiving health budgets. Healthy London Partnership's focus has been to understand what matters to existing and potential new recipients of personal health budgets and support local take up. Our engagement with individuals, carers and family members has indicated that the wider availability of digital care plans, as a means of capturing and updating people's goals and preferences, could improve shared decision-making as well as make the process of managing personal health budgets more efficient. The partnership has worked with 5 community organisations and over 50 users, carers and family members in developing use cases and user stories for personalised digital care plans and personal health budgets.

5. Use of community based resources

A wide range of resources exist within communities which can help someone to manage their health or illness better. They have often developed organically in relation to issues facing communities or individuals, and address what is known as "social health" (i.e. the range of factors which are not physical or psychological in origin but which can affect a person's health such as debt or isolation). Resources can include self-help groups, horticultural projects, and lunch clubs. A separate document has been produced by the Healthy London Partnership on Social Prescribing¹⁹ which deals in more detail with these resources and how best to access and use them.

2. Why does self-care matter? The business case

Self-care has strong ethical, economic and practical arguments for it.

The citizens' perspective

Representatives of patient, carer and public interest groups highlight that "standard treatment interventions – often reactive, episodic and narrowly medical – are increasingly out of kilter with the needs of the growing number of people with multiple, chronic health problems and disabilities. They deserve a more holistic, personalised offer, one that meets their needs, but also builds capacity to retain control and independence, and continue to achieve a good quality of life" (National Voices 2014)²⁰.

Benefits and outcomes

For the individual they include:

- Improved self-reported health and wellbeing
- Increased confidence, knowledge, and self-efficacy related to managing health challenges and symptoms
- Improved symptom control and management
- Reduced isolation, anxiety and/or depression
- Improved satisfaction with care and treatment
- Increased self-monitoring of symptoms and self-directed action in response to problems
- Improved relationships with health-care providers

For the service they include:

- Reduced pressure on and use of health and social care
- Reduced hospitalisation & A&E attendance
- More effective / efficient use of primary care
- Better outcomes
- Increased concordance with drug treatments
- Reduced "over-treatment"
- Reduced compensation and litigation costs (Patient Information Forum 2013)²¹

Return on investment

In the current climate of financial challenge facing public services, these arguments will be strengthened and stand greater chance of CCG board approval if the business case highlights the potential savings and benefits to the NHS as a result of NHS investment. Investing in self-care will produce longer term returns as people are better educated to stay healthy and reduce the risk of developing health conditions which consume NHS resources.

A resource for local commissioners

The Wanless review (Wanless 2002)²² estimates that potentially for every £100 spent on fully engaging people in their health care £50 would be saved. Nesta (Nesta 2013a)²³ estimates that effective interventions to 'redefine consultations' and provide access to peer support potentially reduces the cost of delivering healthcare by 7% of the commissioning budget.

The London Health Commission (2014) estimate self-empowerment and education potentially reduces hospital admissions by 25-30%

- Individualised care plans potentially reduces hospitalisation by around 23%
- Engaging Londoners in their own health (in line with Wanless), could potentially save up to £430m a year by 2020/21²⁴

Expert Patient Programmes (or Chronic Disease Self-Management Programmes) have many favourable economic evaluations (Nesta 2013b)²⁴. One study estimated potential savings of over 10:1 in 6 months (Lorig KR et al 1999)²⁶.

Nesta has estimated that teaching people with long-term conditions to manage their own care potentially saves between £0.2 and £0.4 billion nationally (Realising the Value 2016) 27 .

The Healthy London Partnership commissioned i5Health to model potential savings to the NHS in London and its constituent CCGs for Expert Patient Programmes. This indicates potentially significant savings can be made if these programmes are commissioned and made available to those who could benefit, ranging from approximately 8% to approximately 35%. An extract from the results is presented in table one below which concerns self-management for chronic conditions courses, and shows potential savings to London of over 10% per annum (final column).

commissioning	Initiative	Outcome	Assumption	Fin Year	Current Spend			Opportunity/Reduction		
Opportunity					Patients	Activity	Cost	Patients	Activity	Cost
Expert Patient Programme	Self- Management for Chronic Conditions	Non- elective admissions reduction and better patient outcomes	A six week self-management course for anyone living with any long-term health condition or impairment to educate patients on dealing with pain and fatigue; Managing depression and other difficult emotions; Preventing falls and improving balance; Relaxation and exercise; Dietary recommendations; Physical activity; Communicating with family, friends, health professionals and social services.	13/14	179,852	242,564	343,601, 889	42,710	45,545	37,653, 339
				14/15	181,946	249,420	330,703, 894	45,822	51,660	37,337, 310
				15/16	183,813	240,876	348,252, 104	47,281	49,863	38,396, 781

Table One: Financial modeling for the impact of self-management for chronic conditions across London.

²² http://si.easp.es/derechosciudadania/wp-content/uploads/2009/10/4.Informe-Wanless.pdf

²³ http://www.nesta.org.uk/publications/people-helping-people-peer-support-changes-lives

²⁴ London Health Commission, 2014, based on systematic review of relevant research evidence

²⁵ http://www.nesta.org.uk/publications/business-case-people-powered-health

²⁶ https://www.ncbi.nlm.nih.gov/pubmed/10413387

 $^{27\ \} https://www.nesta.org.uk/sites/default/files/at_the_heart_of_health_-realising_the_value_of_people_and_communities.pdf$

A resource for local commissioners

The development of community based resources and systems for self-care may take time. Most CCGs will currently commission Expert Patient Programmes. Commissioners may therefore achieve returns on any NHS investment more quickly from these programmes. Thus, whilst developing community based resources and systems to support self-care, commissioners could expand existing Expert Patient Programmes, with a review to ensure they are operating according to best evidence and practice, and effectively measuring the health, service, social and financial outcomes.

How much investment is needed to achieve these benefits?

There are large variations in investment, due to the range of potential models with differing levels of involvement from the VCS and volunteers. Nesta (Nesta 2013b)²⁷ concludes that interventions which were part of their 'People Powered Health' programme required an annual investment of between £100 and £400 per person per annum.

As part of the Realising the Value workstream Nesta have released an economic modelling tool²⁸ which is a pivot table allowing customisation to local CCGs to estimate potential returns on investment from approaches which were examined as part of this work (group activities, peer support, health coaching, and self-management). It includes estimates of costs for approaches as well as benefits.

²⁷ http://www.nesta.org.uk/publications/business-case-people-powered-health

²⁸ http://www.nesta.org.uk/publications/impact-and-cost-economic-modelling-tool-commissioners

3. Digital support and engagement

The National Information Board's Personalised Health and Care 2020: A framework for action (National Information Board 2014)²⁹, sets out the role of digital technology in transforming outcomes for citizens and communities. Data and technology can lead to improved customer experience, convenience and choice; improved citizen-professional communications and shared decision-making; and realise efficiency savings.

The ONS estimate that 82% of adults in Great Britain access the internet almost every day (ONS 2016)³⁰. 81% of the UK population have a smart phone (Deloitte 2016)³¹. However there are also groups who are currently digitally excluded. Commissioners need to be conscious of this group too so that any development of digital services does not contribute to increasing inequalities.

Increased levels of digital access present opportunities to digitally enable frontline professionals and digitally empower patients, and create new ways to connect people and organisations involved in self-care (through online directories for example). Digitally enabled support is not for everyone, but there is strong evidence that the majority of the population want choice provided through multiple means of access and personalisation through an online account (NHS England 2015b). The three-year Widening Digital Participation programme targeted and trained 221,941 people nationwide who fell into at least one category of social exclusion. A recent evaluation of the programme published by the Tinder Foundation and NHS England (Tinder Foundation 2016)³² provides new evidence that socially excluded people can benefit from digital skills and enable them to take charge of their own health (see table two). This complements NHS England's conjoint research that presents compelling evidence that the vast majority of people want self-service and access to health services in a variety of ways including digitally. There may also be opportunities to align future pan-London work in this area with the GLA's strategy for digital inclusion (Mayor of London 2015b)³³.

Health & Digital: Reducing Inequalities, Improving Society An evaluation of the Widening Digital Participation programme (Tinder Foundation 2016)

- 41% of those surveyed say they have learned to access health information online for the first time (a further 32% have learned to do this more effectively).
- After learning about using the internet to manage their health:
 - i. 56% of learners went on to find information on the internet about health conditions, symptoms or tips for staying healthy.
 - ii. 54% of learners in need of non-urgent medical advice said they would now go to the internet before consulting their GP, to look at sites such as NHS Choices.
 - iii. 51% of learners have used the internet to explore ways to improve mental health and wellbeing.

²⁹ https://www.gov.uk/government/publications/personalised-health-and-care-2020

 $^{30\} https://www.ons.gov.uk/businessindustryandtrade/itandinternetindustry/bulletins/internetusers/2016$

³¹ https://www.deloitte.co.uk/mobileuk/

³² http://nhs.tinderfoundation.org/wp-content/uploads/2016/07/Improving_Digital_Health_Skills_Report_2016.pdf

³³ https://www.london.gov.uk/sites/default/files/a_digital_inclusion_strategy_for_london.pdf

A resource for local commissioners

• 65% of respondents feel more informed about their health.	• 21% of learners made fewer calls or visits to their GP, with 54% of those saving at least three calls in the three months before being surveyed and 40% saving at least three visits over this period.
59% of respondents feel more confident using online tools to manage their health.	10% of learners made fewer calls to NHS 111, with 42% of those saving at least three calls in the three months before being surveyed.
• 52% of respondents feel less lonely or isolated and 62% feel happier as a result of more social contact.	6% of learners made fewer visits to A&E, with 30% of these saving a minimum of three visits in the three months before being surveyed.

Table Two: Impact of digital training for socially excluded groups (Tinder Foundation 2016)

The potential benefits of this include:

- Sharing of information about care plans, collaborative approach to decision-making, improved
 professional understanding of what matters to people and ability to review and monitor personal
 goal-attainment
- Improved public and professional awareness of wider care and support options through online directories
- Efficiencies realised through online transactions (e.g. e-referrals and online bookings)
- Easier access to evidence based interventions and support

Sharing information

Personal care and support plans

Care planning will usually be face to face, but GP systems and the internet have guidelines for collaboratively developing the care plan and templates to record it. Apps or internet services can enable people to see their plan, to communicate with specific clinicians who are coordinating any care and to arrange for repeat prescriptions and to schedule appointments. They can be used to record therapeutic activity and include positive feedback on completion of such tasks, encouraging repetition and increasing confidence in a person's ability to manage their own health (activation). Such functionality would be core to any Online Account or Passport, and should be available to support self-care.

Access to information

Concerns have been expressed about information from the internet. Much of it is not professionally assured, and can be produced from particular standpoints. However, Cole et al (Cole J et al 2016)³⁴ concluded that internet forums may be a source of quality information about health. More research is needed to further evaluate the helpfulness of such forums.

A resource for local commissioners

Information about how health and care services work, and how to get the best from GP appointments and other advice can be found at:

- NHS Choices (http://www.nhs.uk/pages/home.aspx and http://www.nhs.uk/Conditions/social-care-and-support-guide/Pages/what-social-care-services-are-available.aspx)
- Healthy London Partnership (https://www.myhealth.london.nhs.uk/your-health/general-practice/getting-most-your-gp-appointment)

Online directories of services

Much of the debate surrounding choice centres on how to equip individuals, families, carers, community organisations and professionals with reliable and up-to-date information about the myriad of 'hyper-local' care and support options available within our neighbourhoods. In a self-care context, online directories have an important role in promoting local support, networks and volunteering opportunities to combat isolation, loneliness and alleviate social problems. Online directories should not replace health and care workers but can provide invaluable assistance in planning and agreeing care plans around individual's goals. Across London, mirroring the national picture, many local authorities have invested in local online directories as a means of improving public awareness and access to a range of local services.

Healthy London Partnership carried out a rapid review of online directories that revealed considerable variation in terms of investment, public utilisation and local provider buy-in to directories available across London. Existing directories range from CarePlace provided across 19 London Boroughs and Shop4Support that provides services across the country, to more bespoke local community directories (e.g. Hillingdon) and formal local emarketplaces (e.g. Enfield). In Harrow, My Community E-Purse utilises the CarePlace platform to support people to manage their own personal care budgets and to make direct payments. Harrow Council introduced My Community E-Purse as a means of increasing the number of local personal care budget holders, stimulate new entrants to the market and to realise back-office efficiency savings. Over a four year period, My Community E-Purse has seen take-up of Personal Budgets rise to around 750 local residents. The application is also linked to developing a vibrant local marketplace, through CarePlace, which over a 4 year period has seen Harrow move from two block contracts and eight niche providers to 900 plus care and support options available to local people. Harrow has also made significant savings on the processing and management of their personal budgets. These savings have been realised by replacing manual activities with automated processes. This has resulted in the streamlining of the process, reduced back-office administration costs and reduction in service provider charges.

The Healthy London Partnership's rapid review reached the following conclusions:

- Online directories are widely available across London and have an important role in signposting
 the public and appropriate professionals to information on wider care and support options
 available in their communities
- Online directories are underused community assets. More could be done to promote through online directories public information and access to a wider range of 'hyper-local' care and support provided by non-statutory voluntary and community sector organisations 'up my street'

A resource for local commissioners

- A modest amount of investment is required in some areas to make improvements so online directories become more customer friendly and better meet the needs of the public (e.g. predictive key word search, increased utilisation by voluntary and community sector organisations)
- Further work needs to be carried out to understand how London's existing online directories can operate in a way to aggregate information, possibly through a meta-database. This could enable the development of a new model that allows GP practices to refer, navigators to signpost and the public to access a wider array of support through a holistic and scalable model that provides channel choice but does not replace the option to have face-to-face with a link worker. The rollout of Patients Online (see below) and the emergence of Babylon Health³⁵ and Dr Now³⁶ are examples of online GP services. As public demand for virtual general practice grows then so will the need to develop online methods for carrying out consultations, tailored health advice and referring to community resources in addition to medical prescriptions.

Efficiencies

Online transactions

There is the potential to increase productivity through the use of shared electronic health records, alternative channels for consultations with GPs, and the use of apps and digital tools etc (Ventola CL 2014)³⁷. For example Patients Online³⁸ is an NHS England programme which can be promoted to people and supports them to book and cancel GP appointments, order repeat prescriptions, and access their GP medical records online. The time freed up for the whole practice team through using these tools can be used in other ways to promote and support self-care. Receptionists for example could undertake a more active role signposting people to other resources.

Self-Monitoring and Diagnostic Information

Self-monitoring can be a powerful tool in raising awareness of issues – e.g. levels of activity or alcohol use – which can help to identify problems and increase motivation to address them. There are a number of apps available for this. For example the Florence system³⁹ being used in South East London uses text messaging to remind and enable patients to submit health monitoring information to a central point from where it is relayed to their clinician. There is also a system to ensure clinician alerts if certain parameters are passed.

Wearable and other technology now allows for the collection of data which can help with diagnosis e.g. heart and BP monitoring. Systems need to be set up to enable the collection and submission of this data, with subsequent sharing of it and what it means with the person. Examples include the ADAMM system⁴⁰ which helps people to monitor asthma symptoms, reminds them to take medication and can submit data to a healthcare practitioner. Vitaliti⁴¹ is another remote diagnostic and information system. iTriage⁴² is an app providing online triage and health information and a function to find a doctor or facility.

- 35 http://www.babylonhealth.com/
- 36 http://www.drnow.com/
- 37 https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4029126/
- 38 https://www.england.nhs.uk/ourwork/pe/patient-online/
- 39 https://www.getflorence.co.uk/
- 40 http://healthcareoriginals.com/
- 41 http://www.clouddx.com/vitaliti.html
- 42 https://www.itriagehealth.com/

A resource for local commissioners

Access to Interventions

Interventions can be provided online enabling access and providing flexibility – many are available 24/7 and can be accessed using smartphone, tablet or computer. This could be a full course of an evidence based intervention or a range of interventions to support an individual as part of a self-care package. Online interventions can be more convenient for those who may have mobility issues, and the clinician, as they can reduce travelling time. It is also a discreet route to help for issues associated with stigma such as mental health conditions.

Examples are given below, but these are not recommendations:

- Self-management UK provides Expert Patient Programmes, generic and tailored to conditions and demographic groups including online services (http://selfmanagementuk.org/)
- The IBS Network (https://www.theibsnetwork.org/the-self-care-plan/) provides online access to resources to self manage Irritable Bowel Syndrome
- Living Life to the Full (http://llttf.com/index.php) is a free access full programme of Cognitive Behavioural Therapy (CBT, a NICE recommended psychological intervention for people with common mental health and long term physical conditions)
- Know your own health, (http://kyoh.org/) provide online support and coaching to help people self-manage
- Silver Cloud (http://www.silvercloudhealth.com/what-we-do/programmes/chronic-illness) is developing CBT based modules specifically to help people with psychological aspects of a long term health condition and mixes online and digital aspects of the service with access to a therapist by telephone
- Tunstall (http://www.tunstall.co.uk/) provide a range of online services to support people

Access to support tools

Over 150,000 apps are now available to support health and wellbeing, with billions of downloads expected by 2017⁴³. Some are to monitor specific aspects of health, others are an intervention or support an intervention. Knowing which ones to use (if any) can be hard. The NHS Choices site includes a wide range of apps⁴⁴. ORCHA is an independent organisation which provides ratings based on value and risk for each app there⁴⁵.

National requirement and standards for data

Governance arrangements will need to be relevant to the local model used for data sharing. The specific legal frameworks that govern the use of personal confidential data in healthcare are as follows:

- NHS Act 2006
- Health and Social Care Act 2012
- The Data Protection Act 1998
- The Human Rights Act 1998

⁴³ http://www.economist.com/news/business/21694523-mobile-health-apps-are-becoming-more-capable-and-potentially-rather-useful-things-are-looking 44 http://www.nhs.uk/tools/pages/toolslibrary.aspx

⁴⁵ https://www.orcha.co.uk/

A resource for local commissioners

In July 2016, the government commissioned two independent reviews which make recommendations about data security and consent in the health and care system in England. Their recommendations include:

1) Trust and data sharing

National Data Guardian for Health and Care⁴⁶ highlighted in 2016 that the public does trust the NHS with confidential data. It is important to maintain the trust by optimising the benefit that comes from sharing information safely and consistently across the health and care system where there is a legitimate reason for doing so. The dallas⁴⁷ interoperability profile⁴⁸ provided information and a framework about identity and consent for self-care systems. The experience of a range of users led the design process for this framework.

2) Data protection

The public need assurance that they will not be identified and that personal data will be effectively protected. In the case of self-care, more stakeholders are involved with more people (potentially lay and professional) needing to access information on a range of platforms increasing the risk and complexity of data protection.

3) Data security

Having up to date IT systems will ensure they are safe to use and store data. Interoperability between systems is an important part of digital self-care and will enable sharing of information, but does increase security risks. The dallas interoperability profile⁴⁹ provided some information about essential stakeholder requirements and guidance on the connection of Personal Health Records (PHR) with Statutory Systems.

Further details can be found in:

- Safe data, safe care (CQC 2016)⁵⁰
- Review of data security, consent and opt-outs (National Data Guardian for Health and Care 2016)⁵¹ documents.

Risks and governance for digital self-care systems

Digital self-care data sharing projects are in the early stages of development in London. Governance and risk issues will be identified and resolved as the projects develop. Governance and risk issues already identified for digital self-care are summarised below.

Patients choosing to opt out of data sharing. Digital health systems should avoid this as it may reduce the achievement of potential system benefits. Commissioners and providers need a robust communication and engagement plan to ensure public confidence is established and maintained. An example is provided by the North West London Integrated Care team which has highlighted the following in their Information Governance Agreement:52

⁴⁶ https://www.gov.uk/government/organisations/national-data-guardian

⁴⁷ The dallas (delivering assisted living lifestyles at scale) programme was developed by Innovate UK and jointly funded by the National Institute for Health Research and the Scottish Government. It thinks beyond traditional health and social care to consider how new ideas and technology can be used to improve the way people live. https://connect.innovateuk.org/web/dallas/i-focus1

⁴⁸ https://connect.innovateuk.org/documents/3217986/0/dallas+interoperability+profile+Requirements+for+Profile+ID+and+Consent/1c96859a-f7d0-47b1-9cce-254c93672fad

⁴⁹ https://connect.innovateuk.org/documents/3217986/0/dallas+Interoperability+Profile+Guidance+on+the+Connection+of+PHRs+with+Statutory+Systems/517 89e64-3fad-4584-936a-10cde6521668

⁵⁰ http://www.cgc.org.uk/content/safe-data-safe-care

⁵¹ https://www.gov.uk/government/publications/review-of-data-security-consent-and-opt-outs

 $^{52\} http://integration.healthiernorthwestlondon.nhs.uk/Images/upload/NWL\%20DIGITAL\%20Information\%20Sharing\%20Agreement.pdf$

A resource for local commissioners

- o effectively inform patients about what shall be shared, who it may be shared with, and how the information they have provided may be used
- o effectively inform patients they have the right to opt out of sharing their information or select/ restrict which elements of their information may or may not be shared and that any consent can be changed in the future
- o in accordance with the NHS Constitution, where a patient wishes something that cannot be followed, to effectively inform the patient of the reasons why
- o effectively inform patients of the implications for the provision of care or treatment (such as the potential risks involved), if their full Individual Integrated Care Record is not made available to health professionals involved in their direct care
- Legacy records. Where organisational changes result in legacy records, guidelines should be developed to clarify ownership of and how legacy data can be accessed.
- Patients feel pressure to share data. Patients, especially those who are vulnerable, may feel
 under pressure to share data or have data shared. They should be provided with accessible
 information and have the opportunity to ask any questions and seek assistance in the discussion
 if they so wish. Commissioners should ensure that information standards are co-produced with
 professionals and patient groups to protect vulnerable individuals.
- Data entry errors. Information that has not been agreed with the patient is put on the system in error. Data entry standards need to be developed by professionals and patient groups.
- Interoperability or integration of systems. This should be decided locally, regionally and nationally.

4. Implementation

i. Identifying the target population

Increasing self-care is an objective for the whole population. However, commissioners may wish to target particular populations to support to care more for themselves in the first instance according to local needs. Given the evidence for the benefits of self-care, those with long term health conditions would be a suitable group to begin with. Local areas could use existing knowledge to determine specifically the candidate populations to target through their Joint Strategic Needs Assessment, STPs, or other planning processes such as risk stratification.

Criteria might include:

- People living with long term conditions or disability
- People newly diagnosed with long term conditions or disability
- People who:
 - o Do not feel supported to manage their long term conditions (GP Patient Survey⁵³ item 33) or
 - o Do not feel confident to manage their health and wellbeing (GP Patient Survey item 34) or
 - o Are at an agreed level on the Patient Activation Measure
- People who use an agreed level of health and care services

It is hard to identify people's use of primary care or prescriptions without working directly with a practice. Commissioners may therefore seek to set thresholds relating to secondary care use (using for example Hospital Episode Statistics), which practices themselves could then follow up to identify potential beneficiaries using data and the personal knowledge they hold themselves. In addition, risk stratification tools can be used to identify people at risk of developing long term conditions⁵⁴. Public health teams are likely to be able to help with this.

ii. Operating model and funding sources to support self-care

Operating model

- Commissioners could use a new operating model and commission a service specification to improve support from primary care to self-care (see figure 4 for a potential model).
- Based on agreed criteria, practices could identify people who meet those criteria and invite them in for a review appointment (which would be a double appointment to allow extra time).
- The conversation should be based on the personal care and support plan principles with the objective of agreeing personal goals and agreeing on the next steps.
- This might involve the person using a range of services e.g. an Expert Patient Programme, but also possibly seeing a social prescribing link worker who can have a further and longer conversation and support them to use an appropriate range of community based resources, which can help with social issues where they exist (see separate social prescribing resource).

⁵⁴ https://www.england.nhs.uk/resources/resources-for-ccgs/out-frwrk/dom-2/ltc-care/

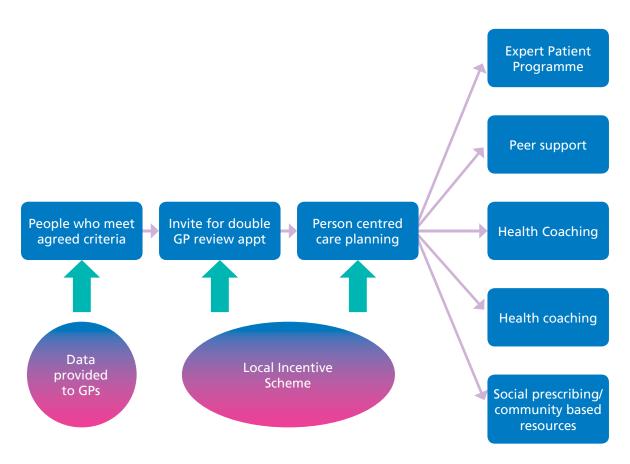


Figure Four: Potential operating model to promote self-care

Funding sources

There are a lot of different ways that self-care developments could be funded or influence new funding. Some are described below.

Best Practice Tariffs

• Designed to encourage delivery of best practice⁵⁵. They are currently being developed and not likely to be ready till 2018-19 commissioning round. Subject to development they may be a good vehicle for supporting implementation of self-care.

CQUINs

- The planning guidance for 2017-19⁵⁶ includes a CQUIN (no 11) to incentivise secondary care providers to use the PAM and train their staff in the use of personal care planning.
- A CQUIN template for promoting self-care for long term conditions is available at the self-care forum website⁵⁷.

QOF/Local Incentive Scheme

 Outcomes relating to self-care might be included, but QOF is under review and may come to an end (replaced by New Care Models contracts). A more likely option to influence primary care activity is to include it in the core contract or any locally agreed incentive schemes with federations/care networks (as in figure four).

⁵⁵ https://improvement.nhs.uk/uploads/documents/BPT_Additional_Information_-_FINAL_WITH_IRB.pdf

⁵⁶ https://www.england.nhs.uk/ourwork/futurenhs/deliver-forward-view/

⁵⁷ http://www.selfcareforum.org/resources/

A resource for local commissioners

Personal Health & Care Budgets

Where individuals have agreement for a personal budget (for health and/or social care – see above), they could use that budget to purchase support to care for themselves. This would be independent of commissioners.

Local commissioners could negotiate with providers for a proportion of block funding from all out of hospital contracts to be used for personal health budgets which will be promoted through local social prescribing schemes and expert patient programmes. Block contracts present barriers to offering people choice and control. In order to release funds for personal health budgets, CCG commissioners need provider's time and input to review current funding and contracts and how they can be used to increase the uptake of PHBs. Provider's concerns about the potential destabilising effect of this on local provision are understood. Commissioners are therefore encouraged to work with all providers of out of hospital services to explore:

- i. A local risk-share agreement releasing portions of block contracts
- **ii.** Extending an existing CQUIN or developing a new scheme which will incentivise providers to free up a percentage of the block contract to be prioritised for the wider uptake of PHBs and enable the supported transition to a more diverse local supplier marketplace.

A range of resources are available at the NHS England website⁵⁸.

Capitated Budgets

- Capitated budgets allocate funds according to population numbers fitting certain criteria. They focus care on the individual, not on budget lines, and on outcomes rather than activity.
- Using capitated budgets to fund more integrated care (including self-care) in Valencia in Spain found (Oldham J et al 2012)⁵⁹:
 - o Reduction in costs by up to 26%
 - o Increase in hospital productivity of 76%
 - o Patient satisfaction rates of 91%
- Useful information about this commissioning model is available from the NW London Integrated Care programme website⁶⁰.

In addition commissioners could consider a funding model which incentivises providers through agreed proportional splits between commissioner and provider of any savings accrued through increasing self-care. This may work particularly well with the capitated budget model.

⁵⁸ https://www.england.nhs.uk/healthbudgets/

 $^{59\} https://www.imperial.ac.uk/media/imperial-college/institute-of-global-health-innovation/public/Primary-care.pdf$

 $^{60\} http://integration.healthiernorthwestlondon.nhs.uk/section/why-is-capitation-often-used-in-integrated-care-systems-part of the control of the control$

5. Monitoring, evaluating, and demonstrating value

Monitoring of activity and outcomes needs to be tailored to reflect the aims and priorities of local stakeholders. The framework successfully used in Improving Access to Psychological Therapies⁶¹ can help to structure this monitoring. Outcomes can be structured into personal, health and wellbeing, service activity (including return on investment) and quality of life outcomes to enable balanced evaluation (see Figure five).



Figure Five: Framework for evaluating value, benefits & outcomes

Using this framework, outcomes could include:

Personal:

- Severity of personally defined problems
- Progress towards achievement of personal goals
- Subjective experience of using services evaluated through interviews. Some schemes also use focus groups and other participatory approaches to gather views
- Self-efficacy/patient activation
- Improved self-confidence & self-esteem
- Improved resilience & motivation

A resource for local commissioners

Health & Wellbeing:

• Outcome measures relating to particular health conditions. Schemes can usefully monitor the severity of specific conditions using a variety of validated measures. A good range are available at http://patienteducation.stanford.edu/research/

Service Use & Activity - including Return on Investment (ROI):

- Service use before and after an intervention. The types of activity data whose pre post comparison is relevant to demonstrating changes are:
 - o General Practice attendance (ideally with information about type of practitioner seen, to assist with ROI calculations)
 - o Prescriptions
 - o Hospital Episode Statistics for outpatient appointments, Accident and Emergency attendances, and in-patient episodes.
- Return on investment; schemes can use the above information, health status measures, and other subjective or social outcomes. Costs and savings need to make use of existing information (such as staff costs, prescription expenditure, and cost data for different types of patient episode or interventions) or financial proxies and economic modelling where these are not readily available. Local commissioners may wish to refer to Return on Investment work undertaken for other schemes.
- Opportunity costs; in the general practice, any reduction in attendances frees up GP time, but may not release any money directly. This can be of high value to practice staff however.

Quality of Life:

- Services need to measure the impact of a problem on someone's quality of life such as their ability to work, living arrangements (e.g. living alone or with others), social connectedness, and areas of concern such as debt.
- Measures of functioning are available e.g. the Wellbeing Star and Work and Social Adjustment scale (see below). The evaluation of the Rotherham Social Prescribing pilot included a Wellbeing Impact Tool to demonstrate wider social impact.

Commissioners may choose to focus on certain measures for their evaluation which they deem most significant e.g. health service usage and satisfaction. Academics may find a different set of measures most significant, as may a person who is using the service.

Example measures of outcomes and recording of feedback:

- EQ5D (http://www.euroqol.org/home.html)
- Patient Activation Measure (http://www.insigniahealth.com/products/pam-survey)
- Wellbeing Star (http://www.outcomesstar.org.uk/well-being-star/)
- Wellbeing Impact tool (http://www4.shu.ac.uk/research/cresr/sites/shu.ac.uk/files/rotherham-social-prescribing-summary-report-2016_7_0.pdf)
- Work and Social Adjustment Scale (http://bjp.rcpsych.org/content/180/5/461)
- National Brokerage Network (http://www.nationalbrokeragenetwork.org.uk/essential-information/)
- A range of free to use rating scales for chronic disease self-management is available at http://patienteducation.stanford.edu/research/

6. Enablers

i. Health self-efficacy & patient activation

The concepts of health self-efficacy and patient activation are related. Self-efficacy is "the extent to which people believe they are capable of performing specific behaviours in order to attain certain goals"⁶². Patient activation is defined as "an individual's knowledge, skill, and confidence for managing their health and health care"⁶³. The Patient Activation Measure (PAM) has been developed by Insignia Health specifically to assess this⁶⁴. A licence is required to use it.

- There is good evidence that a person's level of activation as measured by PAM predicts health service use, and that their activation level can be changed, leading to better health self-management⁶⁵.
- PAM can identify a group of people who can be helped to increase their levels of activation, to improve self-management, reduce service use and so save money for the NHS and others.
- If PAM licenses are not available, measures of health self-efficacy can help to indicate levels of activation. Those from Stanford University are freely available⁶⁶.

If GPs and other clinicians have access to PAM levels/information about health self-efficacy, they can use it to influence their assessments and promote greater collaboration when discussing and agreeing care plans. It can also help with motivational interviewing. It might be presented electronically, so that the information appears on the clinician's computer desk top when referring to someone's health record.

ii. Health Literacy

Health literacy is 'the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions' 67.

- A range of health literacy information and resources can be found at http://www.healthliteracy. org.uk/
- Access to health related information, glossaries, and dictionaries of medical terms and phrases are at http://www.chlfoundation.org.uk/resources.htm

iii. Workforce development

Moving to more self-care will require changes in culture, attitude and behaviour by clinicians. This is particularly true of primary care which is the front line for meeting demand and the gatekeeper to other NHS services. If GP behaviour does not promote self-care, potential benefits will not be realised. All health professionals need to respect people's own expertise and to work with them more collaboratively. 'A commitment by both clinician and patient to shared decision making is considered essential for personalised care planning. The process is unlikely to succeed if either party is reluctant to participate' (Coulter et al 2015)⁶⁸. Information about personalised care and support planning can be found at https://www.england.nhs.uk/wp-content/uploads/2016/04/core-info-care-support-planning-1.pdf.

- 62 https://chirr.nlm.nih.gov/self-efficacy.php
- 63 https://www.kingsfund.org.uk/sites/files/kf/field/field_publication_file/supporting-people-manage-health-patient-activation-may14.pdf
- 64 http://www.insigniahealth.com/products/pam-survey
- $65\ http://www.kingsfund.org.uk/publications/articles/activate-next-level-patient-engagement$
- 66 http://patienteducation.stanford.edu/research/
- $67\ https://health.gov/communication/literacy/quickguide/factsbasic.htm$
- 68 http://onlinelibrary.wiley.com/doi/10.1002/14651858.CD010523.pub2/abstract

A resource for local commissioners

Skills for Care list seven principles to support self-care⁶⁹ stating that anyone promoting self-care:

- Engages, supports, encourages and helps individuals to make decisions that are right for them
- Communicates effectively to assess their needs, and develop and gain the confidence to self-care
- Enables access to appropriate information and the range of options
- Enables access to a range of learning and development opportunities
- Uses new technology
- Enables access to support networks.

Skills for Care have produced supporting materials for training in self-care⁷⁰.

Clinicians will need to understand the concept of patient activation and its impact on self-management (see above for sources of information). Motivational interviewing can be used to help start people on the road to change and then to keep on with it⁷¹. They will also need to be able to access information about the range of resources which can help people (as will people themselves).

GPs and general practice teams need to offer people, families and carers genuine alternative options for support and access to help with their health and social problems. Nurse specialists, health trainers and health champions currently working in the community have a potential role in promoting and supporting self-care. They also need to be able to access training. Altogether Better have brought practice teams together with volunteers from their practice lists who become health champions and all work to improve health and wellbeing in their area⁷². They are currently delivering such a service in Barnet.

Where social prescribing is available, people will be working with a whole range of others to help them to self-manage and make improvements in their own health and wellbeing. The majority of this workforce will be in the voluntary sector, and not under the direct influence of the NHS. Commissioners need to ensure that contracts identify the provider's responsibilities for ensuring they have a workforce which has the appropriate knowledge, skills and attitudes (including basics such as risk management, information governance & safeguarding - please see separate resource for social prescribing for more information).

There are many providers of training. They include:

- Self Help UK http://www.selfhelp.org.uk/selfcare/#Fundamentals
- e-learning for Health Care; http://www.e-lfh.org.uk/programmes/supporting-self-care/
- Virtual College; http://www.virtual-college.co.uk/products/self-care.aspx
- NHS Scotland; Supporting Self Management online training resource http://www.nes.scot. nhs.uk/education-and-training/by-theme-initiative/self-management/supporting-self-management.aspx
- Education for Health https://www.educationforhealth.org/ have more courses for staff
- http://www.nsahealth.org.uk/e-learning/courses-we-offer/57-personalised-care-planning
- National Brokerage Network provide training to support disabled people having more control and care more for themselves http://www.nationalbrokeragenetwork.org.uk/training/)
- Local trainers and services may also be able to provide training

 $^{69\} http://www.skillsforcare.org.uk/document-library/skills/self-care/commoncoreprinciples.pdf$

⁷⁰ http://www.skillsforcare.org.uk/Topics/Self-Care/Self-care.aspx

⁷¹ http://www.motivationalinterviewing.org/

⁷² http://www.altogetherbetter.org.uk/about-us

A resource for local commissioners

A meta-analysis of disease management interventions for people with chronic illness (Weingarten et al 2002)⁷³ demonstrated the importance of not only educating healthcare providers but also providing them with feedback about the care they provide and outcomes. This was associated with 'significant improvements' in both provider adherence to clinical guidelines and disease control.

Expert patient programmes (see above) are a well-established way to train people to manage their health and wellbeing better.

7. Useful Websites

Networks

The Self-Care Forum

Supports people and practitioners to promote more self-caring for illness. Their site includes self-help information and learning resources.

http://www.selfcareforum.org/

The People Hub

An extensive range of information, advice and support aimed at the public and professionals relating to personal health budgets.

http://www.peoplehub.org.uk/

Patient Information Forum

A membership organisation. Their website has a wide range of information and resources to help with potentially thorny questions over patient information.

http://www.pifonline.org.uk/

Social Prescribing Network

A network of all interested in social prescribing, including patients, academics, commissioners and statutory and voluntary sector providers.

https://www.westminster.ac.uk/patient-outcomes-in-health-research-group/projects/social-prescribing-network

London Voluntary Service Council/Regional Voices for Better Health

The LVSC/Regional Voices has produced a Social Prescribing Map for London which has information about social prescribing projects and services across the capital.

http://www.lvsc.org.uk/advice-support/london-social-prescribing-map.aspx

International Models

Buurtzorg, the Netherlands

A model of autonomous district nurses which has been very successful in improving the quality and outcomes of community based care and reducing demands on secondary care.

https://www.rcn.org.uk/about-us/policy-briefings/br-0215

Information about other European models of care & services can be found at:

http://www.nhsconfed.org/regions-and-eu/nhs-european-office/eu-knowledge-sharing

A resource for local commissioners

Reports and resources

NESTA

An innovation charity which seeks to bring ideas to life had a "People Powered Health" workstream which brought together a range of evidence and examples of self-care. It has followed this with "Realising the Value". Evidence to support business cases (including a new financial modelling tool) can be found here.

http://www.nesta.org.uk/project/people-powered-health

http://www.nesta.org.uk/project/realising-value

The LINKS scheme in Scotland

A very useful website with lots of resources reporting on and sharing the benefits of their experience. http://links.alliance-scotland.org.uk/

The Year of Care pilot

A range of information about the year of care model and how to support its implementation, including training.

http://www.yearofcare.co.uk/ & http://www.yearofcare.co.uk/year-care-solution

Think Local Act Personal

A website that takes you through steps of personal care and support.

http://www.thinklocalactpersonal.org.uk/personalised-care-and-support-planning-tool/

Working Together for Change

Provides guidance on how to work effectively with communities to commission and develop services. http://www.helensandersonassociates.co.uk/person-centred-practice/working-together-change/

Integrated Care

North West London's Whole Systems Integrated Care programme has a website which has a range of useful information to support the development and operationalisation of integrated care.

http://integration.healthiernorthwestlondon.nhs.uk/

There is a national site with further examples and resources for integrated care.

https://www.england.nhs.uk/pioneers/

Collaborative Care

The Coalition for Collaborative Care champion person centred care for people with long term health conditions.

http://coalitionforcollaborativecare.org.uk/

National Brokerage Network

Provides information and training to support increased independence, control and choice for disabled people.

http://www.nationalbrokeragenetwork.org.uk/

8. References

Behavioural Insights Team (2015); EAST: Four simple ways to apply behavioural insights.

Bodenheimer T, Lorig K, Holman H and Grumbach K (2002) Patient self-management of chronic disease in primary care . JAMA 288(19): pp2469-2475

Campos FAL, Pinto de Sousa AR, Costa Rodrigues VP, Silva Marques AJP, Rocha Dores AAM, Queiros CML (2014) Peer support for people with mental illness. Rev Psiq Clín. 2014;41(2):49-55

Care Quality Commission (2016) Safe data, safe care: report into how data is safely and securely managed in the NHS

Cole J, Watkins C, Kleine D (2016) Health advice from internet discussion forums: how bad is dangerous? JMIR Vol 18 (1)

Coulter A, Entwistle VA, Eccles A, Ryan S, Shepperd S, Perera R (2015) Personalised care planning for adults with chronic or long-term health conditions. Cochrane Database Syst Rev 3(3)

Dac Beachcroft LLP (2015) North West London Integrated Care: Digital Information Governance Agreement

Dallas (2012) Framework for identity and consent: stakeholders requirement. I-focus

Dallas (2012) Guidance on the connection of PHRs with statutory systems

Deloitte (2016) There's no place like phone: Consumer usage patterns in the era of peak smartphone

Health Service Journal (2014) Activate the next level of patient engagement

Healthy London Partnership (2016) Personalisation and Self-Care: Case for Change.

Humphries R & Curry N (2011) Integrating Health & Social Care: Where next? Kings Fund.

King's Fund (2016) Supporting people to manage their health: An introduction to patient activation

Lee Ventola CL (2014) Mobile devices and apps for health care professionals: uses and benefits. Pharmacy and Therapeutics. Vol 39 (5)

London Health Commission (2014) Better Health for London - Financial Impact Assessment. Greater London Authority

Lorig KR, Sobel DS, Stewart AL, Brown BW Jr, Banura A, Ritter P, Gonzalez VM, Laurent DD, Holman HR (1999) Evidence suggesting that a chronic disease self-management program can improve health status while reducing hospitalization: a randomized trial. Med Care 27 (1):5-14

Mayor of London (2015) Better Health for London: One year on. Greater London Authority

A resource for local commissioners

Mayor of London (2015b) A digital inclusion strategy for London. Greater London Authority

National Information Board (2014) Personalised health and care 2020: a framework for action

National Data Guardian for Health and Care (2016) Review of data security, consent and opt-out

National Voices (2014) Person centred care 2020: Calls and contributions from health and social care charities

Nesta (2013a) People helping people: peer support that changes lives

Nesta (2013b) The business case for people powered health

Nesta (2016) Impact and cost: Economic modelling tool for commissioners

NHS England (2014) Five year forward view

NHS England (2015) Using case finding and risk stratification: A key service component for personalised care and support planning

NHS England (2015b): Conjoint Research: Patients and Information. YouGov

NHS England (2016) At the heart of health: Realising the value of people and communities. Realising the value.

NHS England (2016) NHS England personalised care and support planning handbook – core information. Coalition for Collaborative Care

NHS England (2016) NHS operational planning and contracting guidance 2017-2019

Office for National Statistics (2016) Internet access – households and individuals

Oldham J et al (2012); Primary Care - the Central Function and Main Focus. Report of the Primary Care Working Group. Global Health Policy Summit

Patient Information Forum (2013); Making the case for information.

Realising the Value (2016); At the heart of health – realising the value of people and communities.

Realising the Value (2016b); Spreading change. A guide to enabling the spread of person- and community-centred approaches for health and wellbeing.

Royal College of Nursing (2015) The Buurtzorg Nederland (home care provider) model: observations for the United Kingdom

Sanderson H. Lewis J. (2012) A Practical Guide to Delivering Personalisation; Person-Centred Practice in Health and Social Care. London; Jessica Kingsley

Skills for Care and Skills for Health (2015) Common core principles to support self-care

A resource for local commissioners

Tinder Foundation (2016): Health & digital: Reducing inequalities, improving society. An evaluation of the Widening Digital Participation programme

Ventola CL. (2014); Mobile Devices and Apps for Health Care Professionals: Uses and Benefits. Pharmacy and Therapeutics.39(5):356-364.

Wanless (2002) Securing our Future Health: Taking a Long-Term View. The Public Enquiry Unit, HM Treasury

Weingarten SR, Henning JM, Badamgarav E, et al. (2002); Interventions used in disease management programmes for patients with chronic illness—which ones work? Meta-analysis of published reports. BMJ: British Medical Journal.;325(7370):925.

Appendix A: Using the EAST framework for implementation

The EAST framework was developed by the Behavioural Insights Team (Behavioural Insights Team 2015)⁷⁴ and recommended by Realising the Value when seeking to increase self-care (Realising the Value 2016)⁷⁵. It suggests that behaviour change should be easy, attractive, social and timely.

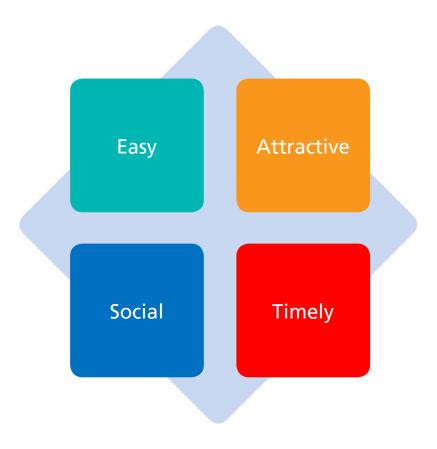


Figure Six: EAST Framework (Behavioural Insights Team 2015)

The principles from EAST are:

1. Easy

- Harness the power of defaults. People tend to choose the default or pre-set option, as it is easier.
 Making the default option the one you wish people to choose makes it more likely that they will choose it.
- Reduce the 'hassle factor' of taking up a service. People are less likely to do something which requires extra effort. Therefore reducing the effort required increases the likelihood of people doing it.
- Simplify messages. The clearer the message, the more likely it is to get through. If a message is complex, break it down.

⁷⁴ http://38r8om2xjhhl25mw24492dir.wpengine.netdna-cdn.com/wp-content/uploads/2015/07/BIT-Publication-EAST_FA_WEB.pdf75 http://www.yearofcare.

⁷⁵ http://www.nesta.org.uk/sites/default/files/rtv-spreading-change.pdf

A resource for local commissioners

2. Attractive

- Attract attention. Attractive presentation (colours, images etc) draws peoples' attention, and makes them more likely to do something.
- Design rewards and sanctions for maximum effect. Rewards and sanctions need to be meaningful to the target group. Money can motivate people but so can other incentives, which may be cheaper and appeal to peoples' altruism such as contributions to a good cause or time off.

3. Social

- Show that most people perform the desired behaviour. If you think that most people do something you are more likely to do the same thing.
- Use the power of networks. People are more likely to trust their peers or close social contacts. Communicating messages through these networks is more likely to be effective.
- Encourage people to make a commitment to others. People are more likely to do something to which they are committed. Providing a forum for making commitments can therefore increase the likelihood of change. Commitment to others enhances this.

4. Timely

- Prompt people when they are likely to be most receptive. People are more likely to change if their current habits have already been disturbed for some reason. Striking at this time increases the likelihood of successful change.
- Consider the immediate costs and benefits. The closer the consequences of a behavior, the more likely those consequences are to influence whether that behaviour is repeated/done less.
- Help people plan their response to events. Planning to change and actually changing do not necessarily follow. Help people to prepare for what might hinder their changing so they can prepare for and deal with any barriers.

The following is intended to be an example of how to use this framework as part of local developments, through examples of making it easy.

For healthcare providers:

Barrier: GPs cannot retain knowledge of local community-based support so will not refer to those services, and will not fill out new forms or referrals on top of their current workload.

Make it Easy: Being Well Salford uses social prescription pads for GPs to write paper 'prescriptions' to be collected by a community organisation, who gets in touch with people directly to discuss support and to be linked up with suitable community-based resources. This approach removes hassle factors for the GP and is a familiar behaviour. Mid Sussex District Council use pre-populated forms embedded into GP computer systems to boost uptake for the same reasons.

For individuals:

Barrier: Complex eligibility criteria and the need to see a GP to be referred, as well as complicated healthcare plans and inconvenient locations prevent individuals from changing behaviour.

Make it Easy: Being Well Salford have a self-referral scheme, use minimal eligibility criteria and create simple SMART goals and action plans e.g. 'Make a gym induction for Monday 16th March', as opposed to 'Increase daily exercise'.

Appendix B: Interventions relating to the self-care continuum

The self-care continuum

	Lifestyle Choice	Self-managed ailments	Minor ailments	Long Term conditions	Acute episodes/ Major trauma
Examples*	Weight loss/ smoking	Migraine/ flu	Minor burns/ broken bones	Diabetes/ depression	Stroke/ psychotic episode
Health coaching	~	*	*	~	×
Social prescribing	✓	✓	×	~	×
Peer support	✓	✓	*	~	×
Personal Budget	*	*	*	~	*
Expert patient programme	×	×	×	~	×

^{*}All conditions can be either physical or psychological

Healthy London Partnership 15 Marylebone Road, London, NW1 5JD

www.healthylondon.org Follow us on Twitter @HealthyLDN