# World Health Organization

## REGIONAL OFFICE FOR **Europe**

**By   Lourdes Ferrer**

# Engaging patients, carers and communities for the provision of coordinated/integrated health services: strategies and tools

## WORKING DOCUMENT

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# ABSTRACT

The paper illustrates strategies aimed at engaging patients, their families, and carers to be an active part of health disease management and treatment, guiding them to make informed choices. Furthermore, it outlines strategies aimed at empowering populations to adopt responsible health lifestyles and act as protagonists in influencing determinants of health in a human-rights based approach to health.

Exemplary tools for each type of strategies are proposed to support the realization of coordinated and integrated health services delivery.

## Keywords

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## LIST OF ABBREVIATIONS

CDC                Centre for Disease Control

CHANGE        Community Health Assessment and Group Evaluation Tool

CHI Navigator  Community Health Improvement Navigator

CIHSD           coordinated/integrated health services delivery

EBCD            Experience-based co-design toolkit

HRIA             Human rights impact assessment

IDeA              National Health Service Improvement and Development Agency

Medi-Cal       California Medical Assistance Programme

MINT            Motivational Interviewing Network of Trainers

NICE             National Institute for Health and Care Excellence

NPC              National Prescribing Centre

PAM              Patient Activation Measurement

QISMET         Quality institute for self-management education and training

RE-AIM         Reach Effectiveness Adoption Implementation Maintenance

WHO             World Health Organization

## ACKNOWLEDGMENTS

## PREFACE

In September 2012, the 53 Member States of the WHO European Region adopted the new European health policy framework *Health 2020.* Health system strengthening was recognised as one of four priority action areas in setting out a course of action for achieving the Region's greatest health potential by the year 2020[1].

The vision put forward by Health 2020 calls for people-centred health systems. In doing so, it extends the same principles as first set out in the health for all and primary healthcare agenda, reorienting health systems to give priority to areas such as disease prevention, continual quality improvement and integrated service delivery.

The global importance of health system strengthening is clearly defined in the WHO 12th General Programme of Work 2014-2019, with a priority technical cluster dedicated to the organisation of integrated service delivery as part of the interim global strategy for people-centred and integrated health services[2].

In line with these priorities, the strategic entry points for the period 2015-2020 have been identified with the following two priority areas: (1) transforming health services to meet the health challenges of the 21st century and (2) moving towards universal coverage for a Europe free of catastrophic out-of-pocket payments[3].

This document aims at expanding on the first of these priority areas and is set in the context of the overarching Regional Framework for Action for Coordinated/Integrated Health Service Delivery. Launched at the end of 2013[4], the Framework aims at supporting Member States in transforming health service delivery by adopting a results-focused, action-oriented approach relying on the identification of key entry points.

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[1] WHO Regional Office for Europe. (2012). Health 2020: A European policy framework and strategy for the 21st century. Copenhagen: WHO Regional Office for Europe.
[2] WHO. (2015). WHO global strategy on people-centred and integrated health services. Interim report. Geneva: World Health Organization.
[3] WHO Regional Office for Europe. (2015). Priorities for health system strengthening in the European Region 2015-2020: walking the talk on people centredness. Copenhagen: WHO Regional Office for Europe.
[4] WHO Regional Office for Europe. (2013). Strengthening people-centred health systems in the WHO European Region: a roadmap. Copenhagen: WHO Regional Office for Europe.

## Background

Transforming the provision of health services towards people-centred health systems requires actions by providers, managers of services and policy makers to support patients in being engaged in the management of their conditions and risks factors, in adhering to treatments and in participating to the clinical decisions.

It also involves the support for communities to be empowered with regards to their health and its determinants e.g. environmental, socio-economic and political, among others, to care for their health throughout the life course, to participate in the development and implementation of health policies, to exert their health rights and responsibilities, to choose options that better fit their needs while contributing to the development of healthy environments.

Actions targeting patients, their families and carers and communities are complementary and co-dependant, particularly, at the time of addressing inequalities in health.

Concepts like "empowerment", "engagement", "co-production", "participation", "involvement", and "activation" have been used interchangeably in different settings and refer to the different levels of capacity, activity and interest that patients, carers, families, individuals and communities have in relation to their health and its determinants. Working definitions of these concepts vary widely and are shaped both by the scope of the interventions and by the target groups involved.

*Empowerment,* for example*,* when referred to patients*,* most frequently means ensuring patient choice and respect, while when referred to communities - in the health context – it implies community action. The notion of *empowerment* relates to the intrinsic capability people have to control the factors and decisions that affect their health and the process of gaining power externally over those factors *(1)*. There are several suggestions as to what the dimensions of empowerment are. As an approach, it should entail people involvement in problem formulation, decision making and action. Empowerment can be conceptualised as a helping process, a partnership valuing self and others, mutual decision making, as well as freedom to make choices and accept responsibilities *(2)*. People need to be empowered in order to be able to engage and co-produce services and policies meaningfully.

*Engagement* refers to the degree of active involvement people have in taking care of their own health and in shaping their care systems. It focuses on the behaviour of individuals relative to their health care, rather than to the actions of professionals or policies and signifies that a person is involved in a process through which s/he harmonizes information and professional advice with her/his own needs *(3)*.

*Co-production* is a similar concept but implies the co-development of public services between professionals and the people using services, including their families, in the context of an equal and reciprocal relationship. Co-production needs the engagement of both sides - the "experts" and the people *(4)*.

*Patient activation* describes the knowledge, skills and confidence a person has in managing his/her own health and healthcare *(5)* and is therefore considered here within the more general concept of empowerment.

Adopting a perspective of health systems, this document seeks to illustrate those strategies and their common associated tools needed to engaging patients and empowering populations with the final aim of improving health outcomes and wellbeing. The document has been articulated in two main chapters that describe the evidence of strategies and their tools for supporting patients to self-manage chronicity, share decision making and provide/receive support to/from peers with section dedicated to patients' families and their carers. Other two chapters describe strategies and tools for empowering populations to protect their health and healthcare rights, foster share responsibilities, enable informed choices, strengthen health literacy and supports community development.

# STRATEGIES FOR ENGAGING PATIENTS

For the purpose of this document, patients include also their families, carers and extended support groups. These individuals bring complementary knowledge in their interactions with the health services. They have their own experience of health and ill-health, the knowhow in caring for themselves and their dependants, the knowledge of their interactions with the context and of how it affects them in their health, care choices and actions, the knowledge of their life and health goals, their values and preferences. These constitute inputs that shape the way care is delivered and the final health outcomes.

The term *patient* is used in this paper as a person entitled to holistic support to promoting health, preventing diseases, managing health conditions and improving health and wellbeing. However, it is acknowledged that the term is frequently used to define a person receiving or registered to receive medical treatment with a negative connotation due to its association with passive reception of care rather than with pro-active self-management. The word *patient* is vastly used by health providers, policy makers and patients' organisations.

Other related terms utilized are *user* or *client*. These terms highlight people's right to care but somehow disregard the intrinsic co-productive role of patients at the interface with services and the asymmetries of information. On the other hand, the term *citizen* refers to a legally recognised subject or national of a state, either native or naturalised. The concept is related to entitlements like the right to healthcare, to adequate emergency response to major public health threats and to the development of public health policies as in food regulation or tobacco control. The use of this term, however, excludes a high numbers of migrants that may suffer a heavy burden of health inequalities.

Four key strategies have been identified for engaging patients, their families and carers:

1. Self-managing health and health conditions. This involves support for developing knowledge, skills and confidence to manage one's own health (self-care), caring for a specific health condition and recovering from an episode of ill health.

2. Shared decision making that involves supports patients in taking decisions about their health, in considering options including the choice of taking no action, in pondering risks and benefits and in analysing how the available options suit their values and preferences.

3. Peer-to-peer actions support patients in providing and receiving help from others in similar conditions, based on mutual and shared understanding.

4. Support to families and carers. This seeks to develop knowledge, skills and actions to enabling people to care for themselves and for others.

## SUPPORTING PATIENT SELF-MANAGEMENT

Supporting self-management consists on helping people to develop knowledge, skills and confidence needed to manage their own health, to care for a specific condition or to recover from an episode of ill health. It helps people incorporate evidence-based health information into their everyday lives in order to become knowledgeable, confident, everyday problem-solvers and carers. It also helps them monitor their conditions and take appropriate action, for example contacting experts, when relevant.

In literature, *self-management* is used for patients with a long-term condition while *self-care* is used in general for all persons. Here both terms are used indistinctly and a specification is added when necessary.

The United Kingdom Department of Health defines self-management as "the actions that individuals and carers take for themselves, their children, their families and others to stay fit and maintain good physical and mental health, meet social and psychological needs, prevent illness or accidents, care for minor ailments and long-term conditions, and maintain health and wellbeing after an acute illness or discharge from hospital".

There are a wide range of initiatives to supporting self-management, including information leaflets, online peer support, one-to-one counselling, group education sessions, telephone coaching, technology to monitor symptoms, and psychological behaviour change interventions. These initiatives can be categorised along a continuum of interventions, with passive information provision about healthy behaviours and other 'technical' topics at one end of the scale, and initiatives that more actively seek to support behaviour change and increase self-efficacy at the other end of the continuum. There is growing evidence that strategies including active goal setting and behaviour change interventions which are co-created and co-led by service users and professionals more often result in positive outcomes.

Supporting self-management encourages patients to:
- find out more about their condition and access appropriate information and education;
- co-develop personalised health goals and plans with an outcome-focused approach and take shared decisions about their health and healthcare;
- work better and in partnership with health professionals, social workers, professional and informal carers;
- learn new skills and tools to help them manage their health;
- take charge of their health, become engaged and activated, take action.

Support on self-management is important at different points of the health continuum by individuals that seek to maintain good health and prevent illnesses and by patients living with long-term conditions.

Support to patient's self-management focusses not only on treating a condition but also on supporting people to improve their wellbeing when living with that condition. For example, in mental health the focus goes beyond the diagnosis or a particular illness or its medical management, into how to respond to the obstacles faced by the individual, whether these are viewed through a neurological, biochemical, psychological, social or spiritual lens *(9)*.

Interventions to support self-management vary considerably in aims, approaches, contents, durations and target groups. Different conditions or change in personal circumstances may require varying approaches in different moments. Best practice in supporting self-management include: involving people in decision making, emphasising problem solving, developing care plans as a partnership between service users and professionals, setting goals and following up over time, promoting healthy lifestyles and educating people on their condition and how to manage it, motivating people to self-management by using targeted approaches and structured information and support, helping people monitor their symptoms and in knowing when to take appropriate action, helping people manage the social, emotional and physical impact of their condition and proactively following it up, as well as providing opportunities to share experiences and learn from others *(6)*.

## IMPACT OF PATIENT SELF-MANAGEMENT

Patients themselves, their family and carers are most of the time their own main carers. Even when suffering from chronic conditions, they look after themselves and their dependants around 80 % of the time.

Evidence suggests that self-management improves people's motivation and confidence in their own ability, knowledge, experience and satisfaction. Supporting self-management also strengthens patient engagement in more healthy behaviours and encourages general behavioural change. Evidence suggests that supporting people to look after themselves can have benefits for people's attitudes and behaviours, quality of life, clinical symptoms and the use of health resources *(6)*. For example, patients have reported increases in physical functioning and benefits in terms of greater confidence and reduced anxiety *(7)*. Self-management programmes have shown to reduce unplanned hospital admissions for chronic obstructive pulmonary disease and asthma *(8)* and to improve adherence to treatments and medications *(7)*.

## PATIENT ACTIVATION

People who are more activated are significantly more likely to attend screenings, check-ups and immunisations, adopt positive behaviours, e.g. diet and exercise, and have clinical indicators in the normal range (body mass index, blood sugar levels, blood pressure and cholesterol). Patients who are less activated are significantly less likely to prepare questions for a medical visit, know about treatment guidelines or be persistent in clarifying advice. Patient activation scores and cost correlations show less-activated patients have costs approximately 8% higher than more-activated patients in the baseline year and 21% higher in the subsequent year *(5)*.

Studies of interventions to improve activation show that patients who start with the lowest activation scores tend to increase their scores the most, suggesting that effective interventions can help engage even the most disengaged *(5)*.

Patient activation as measured by the Patient Activation Measure provides a useful and robust assessment of a patient's ability to engage with his/her health, which in turn can be a reliable indicator for a number of health outcomes. More importantly, patient activation is changeable and targeted interventions have shown to increase it. Several programmes have demonstrated the ability to raise activation scores in patients. They typically focus on the patient gaining new skills and on encouraging a sense of ownership on their health, often using peer support, changes in the patient's social environment, health coaching and educational classes *(5)*.

## SUPPORTING PATIENTS' SHARED DECISION MAKING

Shared decision making is an interactive process in which patients, their families and carers, in collaboration with their health provider(s), choose the next action(s) in their care path following an informed analysis of possible options, their values and preferences.

Patients often find themselves at the crossroads when deciding on the next step in their care path, with an array of reasonable options in front of them and no certain outcomes. When patients are faced with such decisions, they should be supported in analysing each potential option, including the choice of taking no action, in light of evidence-based health information, weighing risks and benefits and evaluating how the options suit their values and preferences. The adequate consideration of patients' values and preferences, along with their beliefs, concerns, culture, personal and social circumstances provides a crucial input in reaching an effective decision. The decision making process and the rationality behind it should be then recorded and implemented.

In shared decision making, both sides, the health provider on one and the patient, family and carers on the other, have their specific expertise to contribute to the process. This collaboration should take place in a context of transparency, trust, understanding, empathy, and equality.

Shared decision making approaches and tools have been traditionally developed to be used during clinical consultations by patients and their doctors. Such approaches have recently moved to non-clinical settings in support to wider team actions including, for example, decisions in social care settings. When interactions are needed in different settings and timescales with the participation of several professionals, a trained professional can accompany the patient throughout the path and provide support as a "decision coach" *(11)*.

Shared decision making should be used whenever a decision needs to be taken by a patient about his/her care and more than one option is available. For example, when patients need to choose between undergoing screening or a diagnostic test, between different medical or surgical procedures, agree on self-management activities of a long-term condition, participate in a psychological intervention, change behaviour or lifestyle or take one or the other medication. Shared decision making is appropriate also when patient decision making capability is expected to be later impaired, for example in resuscitation plans. There are options for people in special circumstances, like people with mental problems or learning disabilities who cannot or do not wish to get involved or feel disempowered to get involved.

The Health Foundation in United Kingdom suggests that, to be effective, shared decision making requires patients empowered to play an active role, skilled health professionals and supportive organisational arrangement *(10)*.

There are two broad types of competencies that clinicians need for implementing shared decision making, relational competencies and risk communication competencies. Relational competencies include those necessary for creating a favourable environment for communication and appropriate interaction during the consultation, listening to patients and facilitating patient involvement as much as patients want. Risk communication competencies include discussing the concept of uncertainty in treatment outcomes with patients and effectively communicating information on the risks and benefits of different treatments or healthcare options *(30)*.

Many tools have been developed to support shared decision making in Europe, Canada and United States of America. A key tenet of the European health and consumer protection strategy lies in strengthening the involvement of patients in decision making *(39)*. They include patient training, access to decision aids, information on options and management of patient-held records; training and motivating professionals; development of policies embedding shared decision making in health systems and assessment of the quality of the shared decision making process.

IMPACT OF SHARED DECISION MAKING

An evidence review study from the Health Foundation in the United Kingdom concluded that shared decision making improves satisfaction with care but that little research is available on safety, timeliness or equity. Mixed results were found on clinical outcomes and resource use with some studies showing very favourable findings and others showing no difference from usual care. The study suggests that the mixed nature of the evidence base implies that shared decision making may be most effective when used as part of a broader ethos of care. As an example, a review found that patients who engaged in collaborative care, shared decision making with professionals and self-manage their conditions, have improved health outcomes. It is therefore suggested that shared decision making works better as part of a multicomponent intervention to improve health outcomes and may not have the same impact if used alone *(10)*.

## STRENGTHENING PATIENT PEER-TO-PEER SUPPORT

Peer support means "offering and receiving help, based on shared understanding, respect and mutual empowerment between people in similar situations" *(12)*. Providers and receivers of peer support consider themselves equals. They share knowledge and experience, while providing emotional, social or practical help. A wide range of activities are offered under the label of peer support. These may include listening to what people say, discussing ideas, mentoring, coaching, befriending, helping to gain access to specific services. Support focussing on activities such as exercise groups or book clubs, is common. Another type of peer support involves services delivered by (paid) peers such as dietary advice or education on how to manage health conditions *(13)*.

This support can occur spontaneously and remain informal or be based on formal arrangements. The numbers of people involved can vary from one-to-one to groups. The core principles of peer support strategies are mutuality, reciprocity, a non-directive approach, being recovery focused, strengths-based, inclusive, progressive and safe *(14)*.

### IMPACT OF PATIENT PEER-TO-PEER SUPPORT

Ample evidence indicates that peer support is a critical and effective strategy for ongoing healthcare needs and sustained behavioural change for people with chronic diseases and other conditions. Its benefits can be extended to the community as well as to the levels of organisations and the society. Studies show that peer support has positive effects on decreasing morbidity and mortality rates, increasing life expectancy, expanding the knowledge of a disease, improving self-efficacy, self-reported health status and self-care skills, including adherence to treatments and on reducing the use of emergency services. While those benefiting from peer support show increased self-esteem and confidence, improved problem solving skills, increased sense of empowerment, better access to work and education, higher number of friends, better relationships, greater feelings of being accepted and understood, reduced self-stigmatisation, greater hopefulness about their own potential and more positive feelings about their future *(15)*.

Additionally, providers of peer support report less depression, heightened self-esteem and self-efficacy, as well as improved quality of life. Givers can feel empowered in their own recovery journey *(16)*, have greater confidence and self-esteem *(17)*, suffer less self-stigmatisation and feel more valued *(18)*. Being employed as a peer worker is generally seen as a positive and safe way to re-enter the job market and thus resume a key social role *(19)*.

The introduction of peer workers is a powerful tool to drive forward a recovery-focused approach within a team. Just as peer workers provide hope and inspiration for others experiencing mental health problems, they challenge negative attitudes of staff and provide an inspiration for all members of the team. Peer workers also facilitate a better understanding between the people providing the service and those using it *(15)*. Peer workers can also use their personal experience to influence organisational policies, procedures and behaviours.

Additional ways in which peer support can enhance primary care is through outreach and engagement of high priority population groups. Peer supporters frequently come from communities served by primary care organisations and therefore provide a linkage between those communities and the primary care team. At the same time, research has shown that flexible, proactive peer support programmes can reach over 90% of "hard to reach" groups who all too often fail to get the clinical and health promotion services they need *(20)*.

## SUPPORTING PATIENTS' FAMILIES AND CARERS

Supporting patients' families and carers means to help unpaid carers and family members to develop knowledge, skills and actions to care for themselves and others. Carers are people who provide care for a member or members of their family, while some may support friends and neighbours. It is important to note that volunteers placed by voluntary groups or paid as a care worker and personal assistants are not included in the category of "carers".

Providing unpaid support to family members or friends is a major contributing activity to the health and welfare of society. Each caring relationship is unique to those individuals involved and needs to be taken into consideration when designing of care. It is possible to identify some key themes to personalise support for carers and some general principles on how to support and sustain the relationship between those involved.

### IMPORTANCE OF SUPPORTING PATIENTS' FAMILIES AND CARERS

Approximately 80% of people requiring long-term care will receive their care from spouses, relatives and friends. Quality of life for carers is generally poorer than for the society as a whole *(21)*.

Carers need support for many reasons. Becoming a carer could mean facing a life of poverty, isolation, frustration, ill health and depression. Often it also means to give up a regular income, future employment prospects and pension rights. Those who succeed in keeping a work outside their home juggle between their jobs with their responsibilities as carers, mostly struggling alone without help available. Access to information, financial support and breaks in caring are vital in helping carers to manage the impact of carrying on their own lives. At the end of their caring role, carers need support to rebuild a life of their own and to reconnect with education, work or social life *(21a)*.

The National Evaluation Study of the National Carers' Strategy Demonstrator Sites Programme in England found evidence that many types of carer support introduced had the potential to result in cost savings within the health and social care sector. Potential savings were identified in relation to preventing hospital or residential care admissions, earlier identification of physical and/or mental health issues and efficiency in clinical practices. Carer support improved the health and well-being of carers and helped them return to, or remain in, paid work. It also facilitated the establishment of informal support networks among carers *(22)*.

### DESCRIPTION OF SUPPORTING INITIATIVES FOR CARERS

Health checks may be offered to carers as physical health examinations and well-being checks, delivered either in combination or separately. Some sites experiment with delivering checks using non clinical staff and/or staff based in voluntary organisations. Support services offered in hospital and primary care settings include befriending and peer support activities, awareness training for staff, as well as improving information, documentation, referral arrangements and access to carers' assessments. Break provision for carers can include specialised short-term respite for carers of people with dementia and mental ill health, use of alternative care in the home and an extremely flexible approach to the delivery of personalised breaks.

Approaches to carers' support presented at the Carer's Evidence Summit in England include: improvement in communication and services, provision of services through the so-called Triangle of Care (service user, carer and professional), education and training for staff and carers, identification and recognition in primary as well as in acute care, continuity of support, end-of-life care and bereavement support as well as leadership support and carer's breaks *(23)*.

In England, Skills for Care in partnership with Skills for Health have developed the national common core principles for working with carers *(23a)*.

Making support accessible to carers was also the focus of a 2011 report by the Centre for International Research on Care, Labour and Equalities of the School of Sociology and Social Policy of the University of Leeds in the United Kingdom *(22)*.

**Table 1. Overview of key strategies and actions for engaging patients**

| Strategy | Possible actions |
|---|---|
| **Self-Management** | Raising Awareness.<br>Ex. www.myconditionmylife.org., self-care toolkit,<br><br>Providing information and support on healthy living using health literacy tools.<br>Ex. The European Directory of Health Apps (2012-2013), disease-specific management tools for diabetes, chronic pain, multiple sclerosis, arthritis.<br><br>Helping patients prepare for consultations.<br>Ex. Care and support planning guide for patients and carers.<br><br>Group-based education.<br>Ex. The Stanford Chronic Disease Self-Management Programme.<br><br>Training.<br>Ex. Practitioner Development Programme and The Patient Skills Training Programme, Emotion matters, facilitating and engaging intrinsic motivation.<br>Ex. Use of Information sheets for healthcare professionals, use of a guide with indicators of where people need support, share a range of written case studies and videos, equip and inspire champions of self-management.<br><br>Developing Personalised Care Plans.<br>Ex. The NHS Personalised care and support planning handbook "The journey to person-centred care"<br><br>Supporting care planning.<br>Ex. The Well-being Star™<br><br>Developing policy frameworks.<br>Ex. "Your health, your way", 'Gaun Yersel'-The Self-Management Strategy for Long-term Conditions in Scotland<br><br>Personal health budgets<br>Ex. Use of personal health budgets<br><br>Support networks.<br>Ex. Education for partnership<br><br>Shared good practices.<br>Ex. Year of Care Partnerships, Co-creating Health, USA Self-Management Alliance Website, Self-Management Network Scotland.<br><br>Monitoring and evaluation.<br>Ex. The quality institute for self-management education and training (QISMET), Assessing self-efficacy. |

**Table 1. Overview of key strategies and actions for engaging patients – Cont'd.**

| Strategy | Possible actions |
|---|---|
| **Shared Decision Making** | Use of analytical frameworks. Ex. Interprofessional Shared Decision Making (IP-SDM) Model, Ottawa Decision Support Framework (ODSF). <br><br> Raising awareness and training patients. Ex. Video "What You Need to Know about Shared Decision Making, 'Ask 3 questions' campaign. <br><br> Use of decision aids. Ex. The Ottawa Personal Decision Guide (OPDG) and Ottawa Personal Decision Guide for Two (OPDGx2). <br><br> Raising awareness and training providers. Ex. Ottawa Decision Support Tutorial (ODST), Training Modules in Decision Support as a Clinical Skill. <br><br> Support networks and exchange of good practices. Ex. Journal clubs for diabetes, cardiovascular disease, depression and osteoporosis; brief presentations, testimonials and links for scientific publications. The learning community of The Learning Collaborative of the Informed Medical Decisions Foundation. <br><br> Supporting implementation. Ex. Questionnaire that practices should complete before getting started, MAGIC, The Dartmouth-Hitchcock Centre for Shared Decision proposes a tool kit for implementing SDM in primary care and another one for specialty care (breast cancer and hip/knee osteoarthritis). AQuA strategy is to create a receptive culture or shared decision making. |
| **Peer Support** | Train peers. Ex. Peers for Progress Training Resources CDC Training Resources, Massachusetts Association of Community, Health Workers Training Resources, The Minnesota Community Health Worker curriculum. <br><br> Use of community health workers. Ex. The Minnesota Community Health Worker Alliance <br><br> Developing awareness-building strategies directed to key audiences including providers, policymakers and the public. <br><br> Tennessee Department of mental health and substance abuse: The Certified Peer Recovery Programme, Peer Recovery Call Centres, Peer Wellness Coaching, Peer Support Centres, Peer Support and Education (http://www.tn.gov/behavioral-health/topic/peer-recovery-services). <br><br> Support networks. Ex. The Global Network of Peer Support and the National Peer Support Collaborative Learning Network. |

**Table 1. Overview of key strategies and actions for engaging patients – Cont'd.**

| Strategy | Possible actions |
|---|---|
| **Support to families and carers** | Education and training for both staff and carers.<br>Ex. 'Caring with confidence', The Building Better Carers programme,<br><br>Developing policy frameworks.<br>Ex. Recognised, valued and supported: Next steps for the Carer's strategy. Carers and personalisation: improving outcomes.<br><br>Support networks.<br>Ex. Blended Learning Network, BLN |

# TOOLS FOR ENGAGING PATIENTS

## TOOLS FOR SUPPORTING PATIENT SELF-MANAGEMENT

### RESOURCES FOR PATIENTS

*Raising awareness:* Providing information and understanding on healthy living using health literacy tools or on people conditions and how to manage them are important components of supporting self-management. Information can be provided using leaflets, websites, emails, text messages, electronic forums, by telephone and in person, individually or in groups. For example, The European Directory of Health Apps (2012-2013) focusses on a range of health applications recommended by patient groups or empowered consumers. Disease-specific management tools for diabetes, chronic pain, multiple sclerosis, arthritis, etc. can also be found. NHS Choices website is a good example.

*Providing support:* Another type of self-management support involves helping people change their attitudes, for example through care planning, patient-held records, decision support tools or other support mechanisms. This is different from information provision because it aims at providing incentives for change or helping people learn new skills or practical coping strategies.

*Helping patients prepare for consultations:* Their involvement places demands on patients, who must be equipped to participate and make the best use of the limited consultation time. Tools such as option grids or brief decision aids are often involved. A United Kingdom charity, called The National Voices, has developed a Care and support planning guide for patients and carers designed for anyone who has health and care needs over time, or cares for someone. The guide helps them understand what care and planning is and help *(24)*.

*Behaviour change approaches* are promising tools to support self-management. These approaches include motivational interviewing by telephone or in person, group or individual education programmes with an active component, coaching with proactive goal setting and follow up and programmes based on psychological and emotional support that acknowledge people's stage of change. Individual and group education sessions are the most commonly evaluated interventions of this type. There is also an increasing focus on telephone coaching by nurses.

Group-based education is a very common intervention, although its duration and intensity varies. This model of support can be better suited to people with certain conditions than others. The Stanford Chronic Disease Self-Management Programme is a workshop organised in community settings such as senior centres, churches, libraries and hospitals attended by people with different chronic health problems. The topics developed include techniques to deal with frustration, fatigue, pain and isolation, appropriate exercise for maintaining and improving strength, flexibility and endurance; appropriate use of medications, communicating effectively with family, friends and health professionals; nutrition and healthy diet, decision making and evaluation of new treatments.

*Using Patient Activation Measurement (PAM):* PAM is a powerful and reliable measure of patient activation. Like patient-reported outcome measures (PROMs) and patient-reported experience measures (PREMs), PAM is a measure that patients complete themselves, although they can be supported in the process. PAM contains a series of thirteen statements designed to assess the extent of a patient's activation. These statements are about beliefs, confidence in the management of health-related tasks and self-assessed knowledge. Patients are asked to rate the degree to which they agree or disagree with each statement. The answers are combined to provide a single score of 0 to 100, representing the person's concept of themselves as active manager of their health and health care.

RESOURCES FOR PROVIDERS

Providers need to communicate effectively and to consider what level of self-management is appropriate for different patient. It is important that providers are aware of the value and scope of supporting self-management and that they are skilled to support this.

*Identifying and tailoring self-management support according to health literacy levels:* Several single-item questions, including use of a surrogate reader and confidence with medical forms have shown to be moderately effective for quickly identifying patients with limited literacy *(25)*.

The Practitioner Development Programme provides a set of practical skills and tools which clinicians, health coaches and others health professionals can use to support patients in self-managing. Available for downloading are the following tools: A Practical Guide on how workshops are structured which includes practical information on how to set them up; a Pre-training questionnaire to assess individuals own starting point and enables to track impact of the programme; a Pre-training delegate pack with a reading list of articles and information that delegates may find helpful to read beforehand; a Preparatory workshop slide presentation that outlines the challenges for today's health economy regarding long-term conditions, supports practitioners to explore their knowledge, beliefs and understanding of self-management and self-management support, and sets out the evidence base to support this approach; a Workshop 1 slide presentation that explores the skills contributing to successful collaborative agenda setting, and examines how team and services work and how such processes impact their ability to successfully support patients self-managing; a Workshop 2 slide presentation that explores the skills which help them understand the patient perspective (health beliefs and patient activation), explore patient importance, explore patient confidence, help patients at the beginning of the journey, explore ambivalence, support the patient to move forward with goal setting and action planning; a Workshop 3 slide presentation that helps participants explore the skills necessary to support collaborative goal setting and action planning, supports patients to review the progress, share success, consider problems and barriers, and how to move forward, solve problems, share information and expertise, identify the support needed to progress further; Workshop evaluation form; Handouts on self-management support and the enablers, Goal setting and action planning, Follow up, Skill descriptors; and Post training questionnaires (http://personcentredcare.health.org.uk/resources/practitioner-development-programme).

The Patient Skills Training Programme of The Health Foundation seeks to support anyone interested in developing a programme to enable patients and individuals to better manage their health. Their website contains overviews on self-management, patient skills programme, quality assurance as well as a guide on how to support participants after the programme ends. The programme is composed of three modules of activities containing a range of different components: goal setting, follow-up and problem solving, generic self-management skills and condition-specific self-management skills and topics. Their website also includes a series of instruments, like guides to programme lead and to facilitator training, skills and assessment, guides for facilitators and to quality assurance, facilitator manuals covering the activities of each module as well as participant workbooks and handouts.

Motivational interviewing is a coaching oriented technique that helps 'reframe' the consultation for one-to-one support or to promote behaviour change *(26)*. It works by facilitating and engaging intrinsic motivation with the client in order to change behaviour. Common techniques are open-ended questions, affirmations and reflective listening. Examples of strategies and techniques can be found at Motivational Interviewing Network of Trainers (MINT).

Information sheets for healthcare professionals in England have been created to help professionals support self-management in people with long-term conditions. Examples of the topics covered are: personalised care planning, needs assessment and risk management, goal setting and action planning, what motivates people to self-care, how information supports personalised care planning and self-care, and end-of-life care.

The Health and Social Care Alliance Scotland provides tools that help professionals support self-management, such as: a guide with indicators of where people need support. This includes key stages in the personal journey which people living with a long-term condition, highlighting the particular issues and potential impact of self-management in each stage of the journey, a framework to support self-

management that provides guidance on how to support self-management effectively, in relation to health and wellbeing, behavioural change, support networks, the promotion of independence and of work in partnership. Other tools provided by the Alliance include a range of written case studies and videos from health and social care professionals sharing their experiences, a self-management resource developed to equip and inspire champions of self-management, and a learning resource to help healthcare workers develop knowledge and understanding to support self-management.

Emotion matters is a resource for health and social professionals working with adults with long-term physical health issues. Managing emotions during consultations helps professionals develop more of an emotional language and a collaborative relationship with patients. This resource includes two tools: the *Ask Test Out Modify technique* to develop person-centred goals for patients with a long-term condition and applies this understanding to routine clinical practice, and the *SWIFT tool* to gain a more holistic perspective, identify how the long-term condition impacts on different areas of the person's life and then applies this understanding to routine clinical practice.

Education for partnership suggests changes to curricula, teaching, learning and assessment methods in medical education, to help clinicians willing to work with patients as healthcare partners recognise and actively support patient contribution.

*European services* have developed different information toolkits for care providers. In the United Kingdom, for example, the Self-Care Toolkit proposes instruments that help practitioners support self-care for people with long-term conditions. It includes tools and information for health professionals, information on programmes and services which professionals can refer patients to, information on rehabilitation and disease-specific education programmes which professionals can refer to, information on other supportive services including local governments and voluntary organisations, as well as information and resources for patients.

RESOURCES FOR POLICY

*Raising awareness and understanding of the importance of self-management:* The self-management awareness raising campaign of "My Condition My Terms My Life" under the leadership of the Health and Social Care Alliance Scotland, has developed courses and communities of practice on self-management. Their website contains introductory information on self-management, including available support, clear explanations of how self-management can benefit individuals and health professionals, as well as tips for effective self-management (http://www.myconditionmylife.org/).

*Developing personalised care plans that record the outcomes from care planning discussion, including any actions agreed upon:* Personalised care planning is about addressing an individual's full range of needs, taking into account their health, personal, family, social, economic, educational, mental health, ethnic and cultural background and circumstances. It recognises that, in addition to medical needs, there are other factors weighing in a person's health and well-being. Care planning discussions should include agreeing on the individual's goals, providing information, supporting individuals to self-care, agreeing on any treatments, medications, or other services such as access to support groups or structured education programmes. Personalised care plans can take the form of a written document, an electronic document or both. The patient owns the care plan and can freely share with carers and family members. A person may have one or several treatment/management plans that should converge into an overarching care plan. The NHS Personalised care and support planning handbook "The journey to person-centred care" contains links to practical guidance, case studies and theory on how to introduce personalised care and support planning. *Year of Care Partnerships* is a National Health Services in the United Kingdom organisation that is dedicated to driving improvement in long-term condition care using care planning to shape services. It focusses on culture change, care delivery and the development of care planning skills within the workforce, which in turn supports self-management and coordinated care. Resource materials developed for patients include sample letters, posters and leaflets, care planning result letters and care plans. Materials for healthcare professionals include DVDs incorporating awareness raising and consultation skills, IT Guidance for Key Systems (EMIS ,VISION, SystmOne), Reflective tools for Practitioners 'Mind Your Language' and Practice Pack. Materials for local steering

groups and coordinators include Evaluation Framework and Toolkit, Coordinator/Steering Group Guidance Document and sample LES/LIS.

National Voices, a United Kingdom coalition of health and social care charities. It works in collaboration with a range of partners and service users to develop a common understanding on what care and support planning is about. They have identified the main steps of the care and support planning process and a number of principles to help ensure that the process is truly person-centred *(24)*.

The Well-being Star™ is free tool that can support health professionals in their care planning discussions. The tool works by encouraging the person to consider a range of factors that impact on his/her quality of life and covers a broad range of issues including lifestyle, place of residence, family and friends, financial resources, work/volunteering and other activities, looking after themselves, managing symptoms and feeling positive.

The National Health Services Choices - "Your health, your way" is a guide to create a self-care competency framework for long-term conditions for staff. Key elements include developing a self-care competency framework for all staff, incorporating self-care in the knowledge and skills framework in job descriptions and annual appraisals, and working with professional bodies to embed self-care in core curricula.

'Gaun Yersel'' - The Self-Management Strategy for Long-term Conditions in Scotland was launched by the Health and Social Care Alliance and the Scottish Government in 2008. The main suggested approaches include improving patients' access to high quality information on their condition and its impact on their life, improving access to support including peer support, developing better working partnerships between the National Health Service, the voluntary sector and local authorities, increased provision of emotional and mental health support, and culture exchanges so that people -those receiving and those delivering services- have the confidence and capacity to work together as partners.

RESOURCES THAT SUPPORT IMPLEMENTATION

Lessons learned from implementation can be found at Co-creating Health, a demonstration programme of The Health Foundation that, working across eight sites between 2007 and 2012, aimed at embedding self-management support within health services across the United Kingdom. Each site focussed on one out of four clinical areas: chronic obstructive pulmonary disease, depression, diabetes and musculoskeletal pain. The programme focused on three areas: giving people with long-term conditions the skills, confidence and support to self-manage, helping clinicians develop the skills, knowledge and attitude to support and motivate people with long-term conditions to manage their health and changing health systems to facilitate self-management. The programme was divided in two phases: the first with testing the model, building skills and evidence and the second with sustaining and rolling-out the approach. The evaluation of the programme highlighted the benefits of training teams rather than individuals, the importance of support from senior leadership within the clinical community, the added value of integration with concurrent initiatives and the importance of providing support to both patients and clinicians after their initial self-management training.

In Canada, a report of the Health Council of Canada recommends that health system provides self-management support for patients with chronic conditions in a systematic way. The report recommends key areas for action: creating an integrated, system-wide approach to self-management support, enabling primary care providers to deliver self-management tools as routine component of care and treatment, broadening and deepening efforts to engage patients and informal carers as key stakeholders (http://healthcouncilcanada.ca/rpt_det.php?id=372).

The Self-Management Alliance Website is a United States of America working forum dedicated to making self-management an integral part of health care. It supports cross-sector dialogue, innovations and provides a library of tools and resources to help with this work.

The Self-Management Network Scotland supports members to share experiences, best practice and innovations through the publication of stories, resources, networking events, blog articles and e-mails.

*Assessing self-efficacy:* Self-efficacy refers to an individual's belief in his/her capacity to successfully learn and perform a specific behaviour. A strong sense of self-efficacy leads to a feeling of control and willingness to take on and persist with new and difficult tasks. When applied to health, this theory suggests that patients are empowered and motivated to manage their health problems when they feel confident in their ability to achieve this goal. Various psychometric instruments have been developed to assess self-efficacy for physical activities, like the Chronic Disease Self-Efficacy Scales (http://patienteducation.stanford.edu/research/secd32.html) and the Self-Efficacy Scales for physical activities, nutrition and weight control (http://userpage.fu-berlin.de/gesund/publicat/conner9.htm).

Annex 1 provides more examples of free accessible tools to evaluate patient education used by the Stanford Education Research Centre. The quality institute for self-management education and training (QISMET) supplies standards to audit organisations self-management programmes and interventions.


RELATED WEB LINKS FOR SUPPORTING PATIENT'S SELF-MANAGEMENT


- ✓ NHC Choices. (http://www.nhs.uk/conditions/Pages/BodyMap.aspx?Index=D)
- ✓ The Health Foundation. Person-centred care resource centre
- ✓ (http://personcentredcare.health.org.uk/resources/patient-skills-programme).
- ✓ NESTA's People Powered Health Programme
- ✓ The Self Care Forum
- ✓ http://www.yearofcare.co.uk/
- ✓ Self-management UK. The Expert Patients Programme
- ✓ www.talkinghealth.org
- ✓ The Stanford Patient Education Research Centre

## TOOLS FOR SUPPORTING PATIENT SHARED DECISION MAKING

### RESOURCES FOR PATIENTS

Patients should be given effective tools to accomplish the essential role in decision making, e.g. understanding options and the consequences of decisions including emotional support to express values and preferences and to be able to ask questions without censure from their clinicians *(27)*.

The Informed Medical Decisions Foundation in the USA, a division of Healthwise, has developed "What You Need to Know about Shared Decision Making" and other videos to help patients understand the importance of shared decision making and how it works. Their website (http://www.informedmedicaldecisions.org/patient-resources/) offers also a Patient Visit Guide designed to help patients work with their providers to make sure they have the information they need to make a fully informed decision.

The Newcastle upon Tyne Hospitals National Health Service Foundation Trust has made available a section in their website entitled: "Making decisions about your care and treatment". It includes explanations for patients on what decision making implies, why it is important for them to be involved, what is the patient role and where to find further information.

The Health Foundation proposes key strategies for building patient awareness on shared decision making. They include a video using shared decision making to improve mental health services for children and adolescents, as well as a video and materials supporting an 'Ask 3 questions' campaign (flyers, poster, case study, how to get information) (http://personcentredcare.health.org.uk/person-centred-care/shared-decision-making/implementing-shared-decision-making).

### DECISION AIDS

Decision aids are information resources especially designed to support the decision making process. They are intended to support patients in considering why one option is better than other and what is important for them about their decision. The patient decision aids are available online, in paper format, in a 'short form' version and via mobile apps. The National Health Service proposes that decision aids are articulated into five steps: introduction, compare options, my views, my trade-offs and my decision (http://sdm.rightcare.nhs.uk/).

Decision aids increased knowledge, resulted in a higher proportion of people with accurate risk perceptions, and of patients choosing an option congruent with their values. They also have been shown to lower decisional conflicts related to patients feeling uninformed and unclear about personal values, to reduce the proportions of people being passive in decision making and remaining undecided after the intervention and have a positive effect on patient-practitioner communication. Exposure to decision aids as compared to usual care has reduced the number of people choosing major elective invasive surgery in favour of more conservative options.

The Ottawa Personal Decision Guide and Ottawa Personal Decision Guide for Two are designed for any health-related or social decisions. They can help people to identify their decision making needs, plan the next steps, track their progress and share their views about their decision. Both decision guides can be accessed, together with a video example used to coach someone making a decision, at http://decisionaid.ohri.ca/decguide.html. Decision aids have also been developed for key decisions about medical tests, medicines, surgery and treatments (http://www.peacehealth.org/medical-topics/content/special/share.html). These aids usually cover the aspects related to evidence and facts, comparing options, personal feelings, personal decision and self-efficacy.

There are organisations that have developed patient decision aids for specific conditions. The Ottawa Hospital Research Institute has created an inventory of some of these organisations and the aids they have produced (http://decisionaid.ohri.ca/developers.html). In Canada, the Ottawa Patient Decision Aids Research Group, in the United Kingdom the Option Grid Collaborative; in the United States of

America, Healthwise with 172 decision aids, the Agency for Healthcare Research and Quality-AHRQ, and the Mayo Clinic.

In the United Kingdom, the Quality Improvement Productivity and Prevention –QIPP- Right Care Programme has developed 36 specific decision aids that can be accessed at http://sdm.rightcare.nhs.uk/about/about-the-nhs-shared-decision-making-programme/.

The available patient decision aids are of variable quality. Their quality can be evaluated using the International Patient Decision Aids Standards criteria, Checklist for Judging the Quality of Patient Decision Aids (http://ipdas.ohri.ca/resources.html).

The value of decision aids has repeatedly been demonstrated by Cochrane Systematic Reviews of Decision Aids (http://decisionaid.ohri.ca/cochsystem.html).


RESOURCES FOR SHARED DECISION MAKING UNDER SPECIAL CIRCUMSTANCES

Best interest decisions-making tools for people with learning difficulties and suffering from mental conditions are available on the website of the United Kingdom Social Care Institute for Excellence (http://www.scie.org.uk/mca-directory/bestinterestdecisions/decisionmakingtools.asp).

Tools for decisions in special cases such as bi-polar disorder, palliative care, end-of-life care or cardiovascular resuscitations are provided by the Advance Decisions to Refuse Treatment Programme of the Social Care Institute for Excellence in the United Kingdom (http://www.scie.org.uk/mca-directory/advanceplanninganddecisionmaking/advancedecisionstorefusetreatment.asp).


RESOURCES FOR PROVIDERS

Raising awareness. It is important to ease common provider prejudice on shared decision-making, like for example that it takes more time, patients do not want it or they are already doing it (28). Providers must become aware that there is enormous potential to be realised when patients are joint decision makers in their own treatment options. They are more likely to be satisfied with their healthcare experience and to adhere to their treatment, clinical outcomes and safety are improved. Shared decision making helps break down the barriers and the perceived hierarchical relationship between patients and their providers (http://www.england.nhs.uk/ourwork/pe/sdm/commitment/).

Education and training. The Cochrane "Review of interventions to increase adoption of shared decision making" found that when health professionals participate in education, they are more likely to use patient decision aids and share decision making with patients. Clinical and non-clinical professionals can be trained in decision coaching to offer support and develop patient confidence and skills in using the tools needed to consider their options (29).

The following are evidence- and theory-based educational programmes developed and evaluated by the Ottawa Hospital Research Institute: Ottawa Decision Support Tutorial (ODST), video example of the shared decision making process, Inter-Professional Shared Decision Making, Skill-Building Workshop, credit courses in decision making, tools for Integrating Patient Decision Support in Curriculum.

In the USA, training modules in Decision Support as a Clinical Skill suggest background reading and sets of slides (http://med.dartmouth-hitchcock.org/csdm_toolkits/clinical_skill_toolkit.html) for self-teaching or training workshops. The Advancing Quality Alliance (AQuA), a NHS health and care quality improvement organisation in the United Kingdom , working with the NHS Right Care Programme, has developed a free access session on the skills and tools required to develop shared decision making in clinical practice, with a list of the measures used to evaluate the effectiveness of the decision discussion, and an explanation on how one can apply the skills, tools and measures within one's clinical practice. Motivational interviewing promotes a collaborative approach between clinician and patient and seeks to provide a basis where patients can engage in the consultation in a productive way through empathy and non-verbal cues, thus developing the desire to engage in decision-making.

<u>Supporting networks</u>. The Shared Decision Making National Resource Centre of the Mayo Clinic in the USA proposes some resources to help share decision aids with colleagues and leaderships. (http://shareddecisions.mayoclinic.org/resources/sharing-with-others/). They include Journal Clubs for diabetes, cardiovascular diseases, depression and osteoporosis, brief presentations, testimonials and links to scientific publications. The website also provides updates on upcoming conferences on shared decision making.

RESOURCES FOR POLICY

Two analytical frameworks designed by the Ottawa Hospital Research have supported the development of shared decision making:

- ✓ The <u>Interprofessional Shared Decision Making Model</u> supports the process of decision making beyond a doctor-patient paradigm.

- ✓ The <u>Ottawa Decision Support Framework</u>  is an evidence-based, practical, mid-range theory developed to guide patients making health or social decisions. It uses a stepwise process to assess patient and practitioner determinants on decision making, to identify decision support needs, to provide decision support tailored to the patient's needs and to evaluate the decision making process and outcomes.

The United Kingdom's National Prescribing Centre (NPC) proposes a competency framework for shared decision making with patients which, if acquired and maintained, should help individuals and teams effectively engage patients in shared decisions on their medicines. The framework is best used as a starting point for discussion of competencies required by individuals or teams *(31)*.

National and regional policy makers can enable shared decision making to flourish by developing position papers and plans. The key messages for commissioners proposed by the National Health Service to engage them in implementing shared decision making are: shared decision making is a key priority, and is the cornerstone of current national healthcare policies; the delivery of shared decision making will require change across whole systems; commissioners have a range of contract management levers through which they can drive and support that change; patients who are informed and involved are more likely to be satisfied with their treatment options and to follow treatment plans; Implementing shared decision making can reduce variations in interventions; given informed choice, many patients choose less radical treatments, which may result in savings (http://www.england.nhs.uk/ourwork/pe/sdm/commitment/) .

In the United States of America, a report by the National Academy for State Health Policy of March 2012 suggests that the implementation of shared decision making should be supported by legislation, public-private partnerships and collaborations and incorporated into standards and expectations *(31a)*. The report suggests the following key steps: building shared decision making into current momentum to transform the healthcare delivery system; identifying procedures with significant variation in utilization rates according to state data or state-specific Dartmouth Atlas analysis; considering state legislation to promote pilot projects for these procedures, capitalising on state roles as purchasers, regulators, conveners, and educators; using a multi-faceted approach in collaboration with private partners; engaging providers as partners throughout the shared decision making process, providing adequate training and using provider expertise to integrate shared decision making into the care process; implementing shared decision making in an integrated system. The report highlights that the main challenges states face in implementing shared decision making are the lack of national certification of decision aids, the creation of an operating definition of shared decision making for their state or project, the resistance and engagement of providers, and the measurement of the implementation progress.

RESOURCES THAT SUPPORT IMPLEMENTATION

The Health Foundation in the United Kingdom proposes a <u>questionnaire that practices should complete before getting started</u> in developing share decision making. Key questions include: is your organisation

and clinical team ready to implement shared decision making? Have you identified a core team and other key roles? Have you worked out who needs to be involved and how you will engage with them? Have you got a clear plan? How will you build buy-in from the wider service, organisation or practice? Their resources for interested professionals include a stakeholder mapping tool, communication strategy template, engagement planning template, example of an agreement with clinicians to participate in shared decision making, example structure of a shared decision making programme. The Health Foundation suggests that the key elements involved in implementing shared decision making are building patient awareness, using decision support materials, practitioner development, improving systems and processes, measuring and evaluating the impact.

The Dartmouth-Hitchcock Centre for Shared Decision in the United States proposes a toolkit for implementing shared decision making in primary care and another one for specialty care (breast cancer and hip/knee osteoarthritis). The Centre proposes the following milestones for guiding implementation: identifying a clinical champion practicing in the clinical setting; defining goals and scope of project; completing project checklists; developing assessment; using decision support tools; educating and training; implementing and monitoring tools and linking to other resources (http://med.dartmouth-hitchcock.org/csdm_toolkits.html).

The Learning Collaborative of the Informed Medical Decisions Foundation supports research projects on shared decision making at both primary and specialty care demonstration sites across the United States. Demonstration sites are vitally important for learning how to overcome barriers to successful implementation of shared decision making in real world clinical settings. The Foundation also facilitate a learning community, provides patient surveys to help evaluate the decision aids and their impacts, provides access to a secure online data warehouse to capture patient survey data and performs data analyses on survey process measures (http://www.informedmedicaldecisions.org/shared-decision-making-in-practice/demonstration-sites/).

The Advancing Quality Alliance (AQuA) in the United Kingdom proposes to create a receptive culture for shared decision making. The tools they use include a one-day introductory skills session that explores the application of motivational interviewing to shared decision making and self-management support within a healthcare setting. The session includes lessons in communicating risk in ways that patients understand and tips on how to determine patients' goals and preferences.

http://www.aquanw.nhs.uk/improving-patient-experience/

The National Health Service Shared Decision Making Programme in the United Kingdom, part of the Quality Improvement Productivity and Prevention (QIPP) Right Care programme, is aiming at embedding the practice of shared decision making among patients, their families and carers and among health professionals and their educators. They propose three work streams: developing tools to support shared decision making and the provision of decision coaching, embedding shared decision making into the National Health Service and, lastly, creating a receptive culture for shared decision making.

The Health Foundation along with Cardiff and Newcastle Universities in the United Kingdom have been working on the implementation of shared decision making in primary and secondary care settings. Their training programme, MAGIC (making good decisions in collaboration), supports clinical teams to embed shared decision making with patients into their everyday and overcome the barriers to change. Lessons learned from the first phase of the project implementation in different sites are available in their first report. (http://health.org.uk/areas-of-work/programmes/shared-decision-making)

RESOURCES THAT SUPPORT MONITORING AND EVALUATION OF SHARED DECISION MAKING

There are a number of elements of the decision making process that can be measured as a means of evaluating shared decision making: outcome of decision, readiness, quality of the decision. Quality of the decision refers to the consistency of the individual's decision with his/her values and his/her satisfaction with the decision, participation in decision-making and patient–clinician communication *(32)*.

A review conducted by Scholl and colleagues organises existing and new measures into a framework separating measurement of feelings prior to the decision, decision process and decision outcomes *(33)*.


RELATED WEB LINKS FOR SUPPORTING SHARED DECISION MAKING


- ✓ The Ottawa Hospital Research Institute (OHRI), Patient Decision Aids
- ✓ Universite de l'Aval, Canada Research Chair on Implementation of Shared Decision Making in Primary Care
- ✓ The Informed Medical Decision Foundation and Healthwise
- ✓ The Health Foundation Person Centred Care Resource Centre
- ✓ The Radboud University Nijmegen Medical Centre, the Netherlands, Decision Aid Collection
- ✓ Mayo Clinic Shared Decision Making National Resource Centre.
- ✓ NHS Shared Decision Making
- ✓ Newcastle upon Tyne NHS Foundation Trust  (www.newcastle-hospitals.org.uk)
- ✓ www.healthwise.org
- ✓ http://www.rightcare.nhs.uk
- ✓ The Dartmouth-Hitchcock Centre for Shared Decision Making

## TOOLS FOR PATIENT PEER-TO-PEER SUPPORT

### RESOURCES FOR PEERS

Examples of resources for the training of peer workers include:

- ✓ Peers for Progress Training Resources.
- ✓ CDC Training Resources.
- ✓ Massachusetts Association of Community Health Workers Training Resources.
- ✓ The Minnesota Community Health Worker curriculum – Standardized curriculum available for purchase for schools outside the Minnesota State College and University System.
- ✓ Washington State Peer Support Training Resources.
- ✓ Training resources for people with intellectual disabilities. The Expert Patients Programme Community Interest Company in the United Kingdom offers support to people living with long-term conditions and disabilities. Self-management programmes are delivered by trained peer facilitators who are experienced at managing their own long-term condition. Peer-led programmes provide the optimal environment for patient engagement, as they are more responsive to learning from people with first-hand knowledge of the challenges they face.

### RESOURCES FOR PROVIDERS

Connecting patients with peer support programmes. *Peers for Progress*, a programme of the American Academy of Family Physicians, offers a wide range of training resources, general and condition specific. Providers are trained to assist patients to connect with peer support programmes and to involve their office support staff and care team members. They verify the availability of peer support programmes and services, learn about those programmes including referral procedures and actively encourage patients to join them. (http://peersforprogress.org/tools-training/primary-care/) *(33a).*

*Peers for Progress* also offers resources and examples to help practitioners develop peer support programmes within their practice (http://peersforprogress.org/take-action/start-a-program/) and tools to assess peer support. The assessment tool of peer support include indicators that measure benefits, advice on how to plan an assessment, how to evaluate changes in behaviours and health status or clinical outcomes, how to document peer support delivery, where to find example protocols and tools for programme evaluation and RE-AIM evaluation (http://peersforprogress.org/take-action/evaluate-peer-support/).

### RESOURCES FOR POLICY

The California Healthcare Foundation provides recommendations to health systems to make peer support interventions more successful on pages 35-37 of the report called "Building Peer Support Programs to Manage Chronic Disease: Seven Models for Success" *(33c).*

*Community Health Workers:* A 2010 World Health Organization report, Global Experience of Community Health Workers for Delivery of Health Related Millennium Development Goals: A systemic Review, Country Case Studies, and Recommendations for Integration into National Health Systems 2010 illustrates the roles and impact of community health workers in various contexts e.g. diseases, regions and provides policy recommendations. The executive summary and typology tables can be helpful in promoting peer support provided by community health workers.

RESOURCES THAT SUPPORT IMPLEMENTATION

*Learning from successful stories:* best practice programmes provide elements to be considered for success: focus on recovery and empowerment, opportunities for patients members of the peer support group to tell their stories to other peers and to wider audiences, a conviction that recovery is possible and that the support of peers who believe in recovery is needed. Examples of these stories from the USA include:

- ✓ The Veterans Administration has widely employed peer specialists who facilitate support groups, advocate for veteran consumers, provide crisis support, act as liaisons between staff and veterans, work on a variety of clinical teams, provide outreach and educate.
- ✓ In Tennessee, peer specialists operate in peer support centres leading evidence based classes (Wellness Recovery Action Plan), health and wellness classes, and support groups.
- ✓ Vermont's Blueprint for Health is a model for integrating behavioural health and chronic disease management through the employment of peer supporters. It utilises community based, interdisciplinary teams including peer supporters that provide integrated chronic disease management and mental health services to patients.
- ✓ Amigas Latinas Motivando el Alma (ALMA) is a community partnered research project. ALMA is a lay health advisor intervention whose primary focus is to prevent depression and anxiety among Latinos in three counties of central North Carolina.

*Supporting Networks:* The Global Network of Peer Support and the National Peer Support Collaborative Learning Network focus on developing and sharing evidence of benefits of peer support programmes, best practices, effective evaluation methods, models of peer support organisation within health systems as well as effective models of advocacy.

RELATED WEB LINKS FOR PEER SUPPORT

- ✓ http://peersforprogress.org/
- ✓ InterNational Association of Peer Supporters
- ✓ Minnesota Community Health Worker Alliance

## TOOLS FOR SUPPORTING PATIENTS' FAMILIES AND CARERS

### RESOURCES FOR CARERS

*Training programmes:* In the United Kingdom, the National Health Service Choices offers a free online training programme for carers called 'Caring with confidence'. The Carers Trust, formerly the Princess Royal Trust for Carers and Crossroads Care, runs services for carers across the country, including carers' centres that offer support, information and advice. The Carers Trust website lists all the services provided, including carers groups. In the United States, the Building Better Caregivers programme was developed and piloted by the Department of Veteran Affairs in California, Southern Nevada and Hawaii for family members and carers who are either veterans or take care of veterans with traumatic brain injury, post-traumatic stress disorder, dementia or diagnosed memory impairment.

*Respite care:* There are a number of ways for carers to take a break from their caring role. There are residential respites that provide care for patients for short periods during which the family members and carers can take distance. Examples are residential, nursing and domiciliary care but also activities such as excursions, school and day care centres among others.

*Access to communities of practice:* In the United States, the Blended Learning Network is a community of practice in which people with various backgrounds and different experiences share a common interest and work together to achieve a common goal.

Other resources include network partners providing respite care, vouchers and holidays, as well as direct payments and personalised budgets.

### RESOURCES FOR PROVIDERS

The National Institute for Health and Care Excellence -NICE in the United Kingdom recommends in 2014, for the first time, that mental health professionals support family members and carers in the guidelines on psychosis and schizophrenia (https://www.nice.org.uk/Guidance/CG178).

In the United Kingdom, the Royal College of General Practitioners offers advice and resources to general practitioners on how to organise work in their practice so as to provide support to carers and improve work with patients with multiple chronic conditions http://www.rcgp.org.uk/clinical-and-research/clinical-resources/carers-support.aspx).

### RESOURCES FOR POLICY

Recognised, Valued and Supported: next steps for the carers strategy is a policy paper published in 2010 by the United Kingdom Government which proposes to help those with caring responsibilities at an early stage, recognising the value of their contribution and involving them from the outset in designing local care provision and planning individual care packages. It recommends that those with caring responsibilities be allowed to fulfil their educational and employment potential and to have a family and community life, by personalising the support for both carers and those they support, thus helping carers remain mentally and physically well (https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/213804/dh_122393.pdf)

Carers and personalisation: improving outcomes is another policy paper issued in 2010 by the Department of Health of the United Kingdom Government. The report suggests key actions: recognising the expertise of carers, working in genuine partnership with carers at all levels of service design and delivery, enabling carers to design and direct their own support, having access to direct payments, engaging carers in the support plan of the patients. The report recommends to establish a whole-of-family approach that ensure integrated support planning that benefits everyone involved, recognition of the social and emotional impacts of providing support to a patient not accounting for the number of hours or the tasks undertaken but rather by developing a full range of options and opportunities

matching the diverse needs of carers - including those who do not choose to identify themselves as carers - and the outcomes they wish to achieve in their lives.
https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/213806/dh_122383.pdf

Carers' stories can be used to sensitise people to their carer's needs for support. Some examples of these stories are accessible at http://www.carers.org/carers-stories.

Carers' Evidence Summits are held in United Kingdom on a regional basis and organised by the National Health Service and the Royal College of General Practitioners. These summits seek to identify and share local and regional examples of what works well and what makes a positive difference to carers' health and wellbeing. Case studies are used to create principles of good practice for the commissioning of services and are then published. Carers' Evidence Summits also use social media to gather interest and theatre skills to engage participants at a different level.

## TOOLS FOR MONITORING AND EVALUATION

Carers' assessments offer an opportunity to carers to discuss with their local council what support or services they need. The assessment will look at how caring affects their life, including physical, mental and emotional needs and whether they are able or willing to carry on this roles.

The Royal College of General Practitioners in United Kingdom in 2014 emphasised the need to develop national metrics which recognise the role of partnerships or benefits of integration in supporting carers.

## RELATED WEB LINKS FOR FAMILIES AND CARER'S SUPPORT

- ✓ Rehabilitation Research and Training Centre on Family Support (will be opened soon)
- ✓ Website 6th International Carers Conference
- ✓ http://www.eurocarers.org/
- ✓ The Swedish Family Care Competence Centre, SFCCC
- ✓ International Alliance of Carers Organization
- ✓ http://www.skillsforcare.org.uk/
- ✓ http://www.carersuk.org/
- ✓ Carers' Evidence Summits https://www.networks.nhs.uk/news/evidence_summits

# STRATEGIES FOR EMPOWERING POPULATIONS

In this document, the term *populations* refers to individuals, communities and the public in general. The term *populations* is commonly used to refer to all the inhabitants of a particular place whether or not they share a common identity. Population health is a term used in public health to refer to the health outcomes of a group of individuals, including the distribution of such outcomes within the group. In the context of this document the term *population* incorporates all individuals. An *individual* is a person and the term specifically refers to that individual being a person separate from the other persons and who possesses his/her own health needs.

The term *public* includes people in general while the term *communities* encompasses not just geographical communities, but also people sharing a common identity by reasons of their faith, ethnic origin, occupation or organisational affiliation.

Four key strategies have been identified for empowering populations:

1. Protecting rights and fostering shared responsibilities by creating transparent, respectful and accountable relationships between populations, providers and policy makers, protecting entitlements and fostering patients' responsibilities for their health and utilisation of health services. This strategy includes the verification of the application of human rights to the context of patient care, supporting the conditions necessary for everyone to develop their own full potential supporting individuals to take responsibility over behaviours, lifestyle choices and health determinants.

2. Enabling informed choice, which includes supporting people to have control over the choices that affect their health and care. This includes, among others, choices on health providers, care pathways and lifestyles.

3. Enhancing health literacy to develop people's knowledge and social skills that determine their motivation and ability to gain access to, understand and use information in ways which promote and maintain good health and wellbeing. This includes:

   • Functional literacy which develops skills needed to function in everyday situation.

   • Interactive literacy which develops skills needed to actively participate in everyday life and to apply new information to changing circumstances.

   • Critical literacy which develops skills needed to analyse information and to use it to exert greater control over life events and critical circumstances.

4. Supporting the development of community health including supporting the activation and engagement of people to organise themselves and work together to identify their own health needs and aspirations, taking action to exert influence over the decisions which affect their lives, improving the quality of their own lives and that of the communities of which they are part of.

## PROTECTING PEOPLE'S RIGHTS AND FOSTERING SHARED RESPONSIBILITIES

Protecting people's rights and fostering shared responsibilities is essential to supporting populations' engagement in health, healthcare, behavioural changes and healthy lifestyles. Clearly defined rights and responsibilities are in practice co-dependant and synergetic approaches and allow societies, health systems, providers, patients and populations to work together through transparent, respectful and accountable relations.

The theory and practice of health rights have evolved within two interrelated perspectives. A first one seeks to protect everyone's right to health and the other focusses on protecting the rights of individuals to healthcare.

The right to health is the right to the highest attainable standard of physical and mental health and wellbeing. A right-based approach to health converts passive beneficiaries into claim-holders and identifies states and other actors as duty-bearers held responsible for their discharge of legal and not merely moral obligations *(34)*. The right to health goes beyond the right to healthcare to the right of enjoyment of environments and opportunities that help people live healthy and fulfil their lives. Societies are therefore accountable to generate conditions in which everyone can be as healthy as possible. Such conditions range from ensuring the availability of health services, healthy and safe working conditions, adequate housing and nutritious food, water and sanitation. The right to health contains four elements: availability, accessibility, acceptability and quality. Approaches on Consumer's rights and citizens' rights in the context of health tend to fall under this perspective.

Right to healthcare (patients' rights) refer to those rights that people are entitled to when they use healthcare services e.g. all patients have the right to take part in decisions on their health and wellbeing and to be provided with the information and support to do so. A related and interwoven concept, "Human Rights in Patient Care" refers to the application of human rights in the context of patient care, focussing on systemic issues and state responsibility, particularly in the interaction between patients and providers. Human rights in patient care recognise health providers as important actors whose rights must be respected both as a matter of principle and for the benefit of the patient.

Fostering shared responsibilities is about supporting societies, providers and individuals to be mutually accountable for actions and attitudes. There are three perspectives that fall into this component: fostering the responsibilities of patients when interacting with health services, fostering the responsibilities of individuals in taking healthy decisions and caring about themselves and their dependants, and fostering social responsibility in coproducing healthy societies. The responsibilities of patients when accessing health services help these to function effectively and to ensure that resources are used responsibly. Some examples of patients' responsibilities include treating health staff as well as other patients, their carers and family members, with dignity and respect, helping to prevent the spread of infections in places where patients receive care or individuals visit patients.

Individual responsibility is about holding individuals accountable for their choices in the context of health care. This approach is however controversial. It can be unfair to hold individuals entirely responsible for their own health since their choices are determined by factors outside their control. For example, the complex interplay of genetic and environmental factors in determining the expression of some cancers is yet to be understood. Although individuals should play an important role in maintaining their own health, they should not be held entirely responsible for it. Certain strategies that create incentives or disincentives towards some choices can affect behaviours and modify future conducts. Levying taxes on certain behaviours, like smoking and drinking, can affect behaviours and future conducts while raising income from the sales of tobacco and alcohol that can be redirected to support health systems for the management of chronic conditions *(35)*.

Assuming that responsibility for health rests either with individuals or with society, it follows that society should also help to promote health and prevent disease *(36)*. Most of the discussion concerning social responsibility for health has focussed on the obligation of society to provide access to healthcare. However, while recognizing that access to healthcare remains an important social responsibility, societies can promote health through sanitation, pollution control, food and drug safety, health

education, disease surveillance, urban planning and occupational health. Greater attention should be paid to strategies for health promotion other than access to health care, such as environmental and public health and health research.

### HUMAN RIGHTS BASED APPROACH TO HEALTH

Currently, health systems and knowledge about health and healthcare places complex demands on patients and populations and asks them to take on new roles in seeking information, understanding their rights and responsibilities and making health decisions for themselves and others.

The available information on rights and responsibilities allows patients, consumers, families, carers and health professionals to share an understanding of the entitlements and duties of all actors involved. However, there remain discrimination and social exclusion against certain groups, such as people living with HIV, ethnic minorities, sexual and gender minorities, drug users, and people with disabilities usually exacerbated by the power imbalance between health professionals and patients. Specifying and enforcing human rights in patient care approach calls for a focus on the most marginalised and vulnerable at the moment of formulating health laws and policies, guidelines and training for health providers, as well as advocacy and litigation to address violations *(37)*.

Providers are unable to deliver high-quality care unless their rights are also respected and they can work in decent conditions with adequate systems and team support. Violations to the rights of health providers thrive on a culture of disrespect and abuse that has the potential to harm everyone who comes into contact with the health services. The application of human rights in patient care approach does not put patients against providers but rather creates the conditions for a joint advocacy to address systemic issues *(37)*.

Government roles and responsibilities are increasingly delegated to non-state actors (e.g. health insurance companies, health management organisations, pharmaceutical industry, biomedical research institutions) with poorly defined accountability arrangements and inadequately monitored.

The application of human rights to health implies the use of internationally accepted and nationally agreed norms, standards and accountability mechanisms within health systems. Legal mechanisms can sometimes also provide channels of redress for individuals whose rights have been violated in the context of public health interventions *(38)*. The core components of such rights-based approach to health include the examination of laws and policies and the systematic integration of core human rights principles such as participation, non-discrimination, transparency and accountability into policy and programme responses, and the emphasis on key elements of the right to health (availability, accessibility, acceptability, and quality) when defining standards for the provision of services *(38)*.

## ENABLING POPULATIONS' INFORMED CHOICE

Enabling informed choice is to support people to have power over the choices that affect their health and healthcare. Populations' choices relate not only to the free selection of health providers or care paths. It also implies providing tools to make informed choices about how lifestyles and behaviours impact long-term health needs. Providers, treatment, behavioural and lifestyle choices are determined by values and preferences and shaped by populations' social determinants.

An informed choice implies that people have the information and support to think the choice through and to understand what the reasonably expected consequences may be of making that choice. At the moment of providing information or designing strategies, it is important to highlight that too much information can be oppressive and that people have different capacities and needs in terms of health information.

Enabling informed choice to improve the health of populations finds root on values and analytical constructs. Rational decision theory argues that if individuals are adequately informed, they will make choices that maximise their own interests. In order to make appropriate those health decisions and act upon them, people retrieve and process health information, assess its credibility and quality and analyse risks and benefits. Though, when faced with complex decisions, people tend to abandon logic and to rely on intuition to guide their decisions *(40)* and the assumptions based on everybody's knowledge and skills to gather and process information seem contradicting with the reality. To enable informed choice is to support people to developing the knowledge and skills needed to choose their lifestyle, their care providers, their treatments and the health systems and policies. People should also be supported in analysing different options and repercussions in the light of their personal values and preferences. In fact, consumers' capacity for judging healthcare quality tends to be poor *(45)*. In the United States, for example, patients did not to use information on quality of care to switch from hospitals with poor quality to those with high quality *(46)*.

Arguments that support enabling choice in the light of its efficiency gain through market competition are more contested. In line with this argument is the belief that the empowerment of potential choices rewards provider performance which translate in a more efficient allocation of resources and improved quality *(41)*. There is evidence of micro-efficiency resulting from provider choice and scant evidence that choice alone contains costs resulting from an injection of 'market-like' incentives into the health system *(42)*.

Some authors believe that the increased reliance on 'provider choice' has led to the progression of 'consumerism' governing the relation between patients and the health service, for example in the United Kingdom *(43)*.

The main strategies to enabling informed choice consist on making available relevant information, supporting self-directed care (personal health budgets), supporting people in decision making as well as through advocacy. Advocacy services are crucial when people are more vulnerable, if for example they have learning difficulties or are being treated for a mental health condition.

Personal health budgets are implemented differently in various countries and consist on people given the possibility to manage their own care within a given budget. Sometimes people are given cash, others organisations make payments on their behalf. There is some evidence that personal health budgets help people feel more confident and empowered because they are in control of decisions over their care but the impact on health outcomes and service use is mixed. There is limited evidence on value for money of personal health budgets largely because there are few rigorous studies and the costs of traditional care and personal budgets tend to be underestimated. Most of international studies related to personal health budgets are from the United States of America, Germany, the Netherlands and the United Kingdom *(47)*.

## STRENGTHENING HEALTH LITERACY

Strengthening health literacy consist on supporting people to develop key knowledge and social skills that determine their motivation and ability to gain access to, understand and use information in ways that promote and maintain good health and wellbeing. Good health literacy implies the achievement of a certain level of knowledge, personal skills and confidence to take action to improve personal and community health by changing personal lifestyles and living conditions. It enables people to make important healthcare decisions and to communicate, assert and enact these decisions *(48)*. Strengthening health literacy seeks to improve the ability of individuals and populations to engage with health information, services and policies, so as to be able to act upon their individual behaviour and their healthcare, social and political environment.

Health literacy is different from general literacy. Literacy is a necessary foundation for health literacy, but lower levels of health literacy can co-exist with high levels of literacy. Health literacy is the result of an interactive set of skills, not all included in general literacy, such as the ability to find, understand, evaluate and communicate health-related information *(49)*.

Many conceptual approaches to health literacy have been developed during the past decade. The conceptual model developed by the European Health Literacy Consortium for the European Health Literacy Survey identifies twelve sub-dimensions of health literacy related to competencies of accessing, understanding, appraising and applying health-related information within health care, disease prevention and health promotion settings.

Three types of health literacy have been described. Functional literacy relates to the skills needed to function in everyday situation. Interactive literacy refers to the skills needed to actively participate in everyday life and to apply new information to changing circumstances. Critical literacy refers to the skills needed to critically analyse information and to use this information to exert greater control over life events and situations.

In clinical settings, low levels of health literacy are often associated at higher clinical risk determined by the individual functional skills, the communicative interactive relationships and the context of its healthcare provider. Three are health literacy key actions that supports patients, carers and family empowerment on clinical settings: *access* to health care, *communication* between patients and health providers and *self-management support*. In public health and health promotion, health literacy is seen as an asset that can be built through education and communication and that enables individuals and communities to exert greater control over their health and personal, social and environmental determinants of health *(50)*.

Health literacy responsiveness describes the way in which services, environments and products make health information available and accessible to people tailoring it to their features *(48)*. Health literacy responsiveness also characterizes the friendliness of the various settings in which people live, play and work *(51)*.

### RATIONALE FOR INTERVENTIONS IN HEALTH LITERACY

Strengthened health literacy improves health outcomes, effective use of health services and reduces health inequalities *(56)*. On the contrary, poor levels of health literacy are extremely common and affect everyone, not only the poorer. A recent European Health Literacy Survey found that nearly half of all adults in the eight European countries tested have inadequate or problematic health literacy skills that adversely affect their health literacy *(52, 53)*. People with lower health literacy are associated to unhealthy choices and lifestyle, riskier behaviour *(53)*. People with lower levels of health literacy are also 1.5 to 3 times more likely to record poorer health outcomes and self-reported health, wait longer before seeking care, find harder to access services appropriate to their needs and to understand labelling of medications *(53a, 53b)*.

They are also less able to communicate with health professionals and take part in decisions, less likely to engage in health promotional activities, such as influenza vaccination and breast screening and more at risk of developing multiple health problems *(53a, 53c)*. They have higher rates of emergency admissions, higher risks of hospitalisation and longer in-patient stays, difficulties in managing their own health, that of their children and anyone else they care for, and have greater difficulties in looking after themselves with a long-term condition. (The Health Foundation, United Kingdom) (http://personcentredcare.health.org.uk/person-centred-care/health-literacy/why-does-health-literacy-matter).

Low health literacy is often associated to greater health inequalities. Low health literacy is more common in low income and minority ethnic groups, immigrants, people without full citizenship, in those with fewer years of education and in older people *(54)*.

Limited health literacy increases the gap between knowledge and practice and has negative impact on health outcomes and system costs. David A. Kindig in the United States National Plan to Improve Health Literacy, calls this the *"silent epidemic" (where) the lack of understanding by most professionals and policy makers of its extent and effect, and the individual shame associated with it, keeps it even more silent and hidden" (55)*.

### FEATURES OF INTERVENTIONS TO STRENGTHENED HEALTH LITERACY

Health literacy interventions aim at providing information and education, encouraging appropriate and effective use of health resources and tackling health inequalities. Overall, these interventions are important for assisting organisations to make health services more accessible.

The different forms of interventions undertaken (e.g. computer-based participatory processes, in-person Saturday school classes, and plain-language pictogram-based medication sheets) have demonstrated that limited health literacy can be successfully addressed. Written health information tailored to individual needs can be helpful in reinforcing professionals' explanations of health problems. Computer-based information may be more effective than paper-based information, as it can be more easily tailored to needs. Interactive television, audio tapes and web-based interventions have mixed results for improving knowledge but can have beneficial effects on patients' confidence and ability to get involved in decisions. They may also improve clinical outcomes and health behaviour.

Well-designed education programmes can make a difference, and some evidence shows that people from disadvantaged groups benefit more from computer-based support than do people from affluent groups if access barriers can be overcome.

Evidence-based strategies to address health literacy are emerging from the fields of communication, healthcare, public health and adult education. Much of the evidence on interventions comes from simplifying and improving written materials, using video or other targeted approaches to patient education and improving patient–provider communication.

Health literacy interventions take a number of forms that have different merits. The Health Literacy Place in the United Kingdom proposes the following interventions, considered suitable to promote the required changes in practice and culture: raising the awareness and capabilities of professionals to address health literacy, promoting the development and spread of existing and new health literacy tools, innovations and technologies and improving access to useful health literacy tools and resources. More details on these interventions can be found at www.healthliteracyplace.org.uk.

Addressing low levels of health literacy in populations implies improving access to health education in primary school and reaching adults who missed it out. Effective responses to health literacy issues can improve health outcomes and reduce health inequities. Policies and practices must promote the identification of health literacy issues and the implementation of targeted responses.

## SUPPORTING COMMUNITY DEVELOPMENT

"Communities" is defined as groups of people who share common interests, concerns or identities. They may or may not be spatially connected.

Community development enables people to come together, to organise themselves and to work for identifying their own needs and aspirations, to take action to exert influence on the decisions which affect their lives, to improve the quality of their own lives and the one of the communities in which they live and of the societies of which they are part. Community development is often conceptualised as a long- term value-based process which aims at addressing imbalances in power and bringing changes based on social justice equality and inclusion *(61)*.

Community engagement usually refers to the process of getting communities involved in decisions that affect them. This includes the planning, development and management of services as well as activities aimed at improving health or reducing health inequalities.

Community empowerment refers to the process of enabling communities to increase control over their lives while community involvement in health refers to communities taking responsibility for their own health through the adoption of strategies such as behaviours to prevent and treat diseases, the effective participation in disease control activities, the contribution to the design, implementation and monitoring of health programmes and the provision of resources for health *(62)*.

Communities need to be engaged to determine local needs and aspirations, to promote health and reduce inequalities, to improve service design and quality of care and to strengthen local accountability *(63)*. For communities to be able to fulfil these tasks, they need some degree of community development.

Supporting community development is reported to produce benefits, such as reduction in isolation and alienation, increase in cooperation and social capital, better identification of community needs and priorities, improvement in knowledge on priority setting, more transparency and accountability, more effective community participation and activity, raised trust between health systems and communities, as well as a perceived improvement of the accessibility and quality of health services (Dept for Communities and Local Govt (2006) Community Development Challenge.).

Community representatives often feel constrained to act on their own due to lack of incentives to support joint work, limited time for deliberations, short notice for meetings and lack of feedback. External facilitation and support are crucial to enable health professionals and community representatives to arrive at effective working arrangements.

Community engagement and development can help governments and organizations meet their legal obligations, improve health and tackle health inequalities, realise the potential of individuals and communities, change people's health-related behaviour and meet public health and adult social care responsibilities *(64)*.

There is also evidence that as communities work together to solve problems affecting them, leaders emerge, social capital improves and health benefits are substantial *(65)*. Although the impact on health may be indirect, evidence correlates good health with strong social relationships encouraged through community development.

A recent study of 30 OECD countries examined the association of five different health indicators with expenditures on both health and social care including housing. Higher per capita expenditures on both health services and social services were related to longer life expectancy. However, the greater the ratio of spending on social services relative to health services, the better the country's health outcome, regardless of the level of health expenditures. Given the comparatively greater contribution to health of behavioural and social conditions than of health care, it is not surprising that expenditures on social programmes appear to yield better health returns than do equivalent expenditures on healthcare *(66)*.

Approaches to community development are broadly grouped into information provision and exchange, consultation, co-production, delegation of power and community control *(68)*. The tools used include building awareness, providing information and facilitating its dissemination and exchange, using community assets and resources, training in community work with participatory methods, training and employing community development workers, engaging volunteers, developing coalitions and community coalition-driven interventions, supporting community networks, and showing the results achieved. Community development impact should be assessed against changes in values such as equality and anti-discrimination, social justice, collective action, community empowerment and working and learning together *(67)*.

**Table 2. Overview of key strategies and actions for empowering populations**

| Strategy | Possible actions |
|---|---|
| **Rights and responsibilities** | Applying human rights to health, using internationally accepted and nationally agreed norms, standards and accountability mechanisms within health-care systems. Ex. Health on the Net (HON) code of conduct for medical and health web sites. Developing and making available explicit compacts on the rights and responsibilities of a healthcare setting. Use of Patient's Bill of Rights. Ex. Health Consumer Alliance in California, The Charter of Patient Rights and Responsibilities, Scotland, The European Charter of Patients' Rights, The NHS Constitution "Your rights and responsibilities". Encouraging and building capacity for people participation: citizens' panels, citizens' juries, citizens' assemblies, and local involvement networks. Use of evidence based co-design. Ex. Informed Consent, Talking With Your Doctor, Speak Up™ programme, the McMaster Health Forum. Supporting co-production of health services and policies. Ex. Experience-based co-design toolkit, Participation Compass. Training providers in the right to health. Ex. The Right to Health: A toolkit for health professionals. Developing health promotion activities. Ex. Health Strategic Health Promotion Framework Supporting networks. Ex. Local Involvement Networks (LINks). Monitoring and evaluation. Ex. Health related human rights impact assessment (HRIA). |
| **Informed Choice** | Making available relevant information. Ex. Consumer's health choices, 2014 to 2015 NHS Choice framework, Supporting patient when visiting services. Ex. List of issues to consider when choosing a doctor or a hospital. Training providers. Ex. Informed risks, Consumer's health choices, Supporting choice in health and social care practice. Ex Choice at the end of life   Choice and control. Use of policy frameworks. Ex. Supporting choice and control Use of patient dashboards. Ex. Patient Insight Dashboard Supporting self-directed care (personal health budgets). Ex. Personal Health Budgets online toolkit Monitoring and evaluation. Ex. POET © - Personal Outcomes Evaluation Tool. |

**Table 2. Overview of key strategies and actions for empowering populations**

| Strategy | Possible actions |
|---|---|
| **Health Literacy** | Improving access to Health Education in primary school and reaching adults who missed it out. Ex. Skilled for Health, Skills for Life Network.<br><br>Training providers and improving patient–provider communication. Ex. Teach-back.<br><br>Simplifying and improving written materials, using video or other targeted approaches to patient education. Ex. Adult Community Learning (ACL).<br><br>Raising awareness and developing targeted campaigns and programmes. Ex.www.nala.ie/projects/. http://www.health.gov/communication/literacy/TownHall/ca.htm.<br><br>Use of interactive programmes. Ex. NHS Widening Digital Participation Programme.<br><br>Using implementation framework, toolkits and strategies. Ex. The WHO Health literacy toolkit for low- and middle-income countries, Making it Easy, The European Health Literacy Project (HLS-EU).<br><br>Support networks. Ex. The network Health Literacy Europe.<br><br>Researching, measuring and evaluating. Ex. Intervention Research on Health Literacy among Ageing Population (IROHLA), Information and Support for Health Actions Questionnaire (ISHA-Q), Health Literacy Questionnaire (HLQ), The Health Literacy INDEX, Health Literacy Survey Questionnaire (HLS-EU-Q), Patient Activation Measurement. |
| **Community Health Development** | Raising awareness. Ex. Community development – improving population health - Part of the Smart Guides to Engagement series<br><br>Providing and exchanging Information. Ex. The Community Tool Box - section "Help take Action". Reaching out – community engagement and health.<br><br>Consulting the community opinion. Ex. Community Appraisals<br><br>Using community assets and resources. Ex. Asset-based Community Development Institute; Appreciating assets.<br><br>Supporting co-production. Ex. Community planning.<br><br>Training in community work. Ex: Community Tool Box training curriculum. Participatory community learning of students and providers. Ex. participatory theatre.<br><br>Training and Employing Community Development Workers (CDH). Ex. Community Development National Occupational Standards (NOS).<br><br>Engaging volunteers. Ex. The United Kingdom Cities of Service.<br><br>Sharing good practices. Ex. Tailor Made: how community groups improve people's lives, Reflective case stories.<br><br>Developing Coalition and Community Coalition-driven Interventions. Ex. community toolbox website.<br><br>Supporting networks. Ex. Knowledge Hub.<br><br>Supporting community implementation programmes and assessment. Ex. Community Health Assessment and Group Evaluation Tool (CHANGE). |

# TOOLS FOR EMPOWERING POPULATIONS

## TOOLS FOR PROTECTING PEOPLE'S RIGHTS AND FOSTERING SHARED RESPONSIBILITIES

### RESOURCES FOR POPULATIONS

Resources must be developed and made available on the rights and responsibilities of people within a healthcare setting. Health consumer brochures can help people get the care they need; e.g. Health Consumer Alliance in California.

The Charter of Patient Rights and Responsibilities developed by the Scottish Government suggests the following components for action: access, communication and participation, confidentiality, respect, safety, comments and complains.

The European Charter of Patients' Rights, Rome 2002, establishes 14 rights for patients. They are the right to preventive measures, access, information, consent, free choice, privacy and confidentiality, respect of patients' time, observance of quality standards, right to safety, innovation, avoidance of unnecessary suffering and pain, personalised treatment, complaint, and right to compensation. There are also three rights related to "active citizenship", that is the rights to: perform general interest activities, perform advocacy activities, and participate in policy-making in the area of health. The document does not highlight responsibilities. The National Health Service Constitution "Your rights and responsibilities" proposes 6 targets: access to health services, quality of care, nationally approved treatments, medicines and programmes, informed choice, complaint and redress.

Encouraging and building capacity for participation

People need support in understanding and applying informed consent and to prepare before the consultation with their doctor. A number of resources are available on line under the heading "Talking With Your Doctor".

The Speak Up™ programme is a national patient safety campaign developed in the United State of America by The Joint Commission and the Centres for Medicare & Medicaid Services. It urges patients to take an active role in preventing healthcare errors by becoming involved and informed participants on their healthcare team. Their website offers free downloadable infographics, brochures, posters, animated videos and podcasts.

Active Citizenship Network and Local Involvement Networks (LINks) are networks of local people, organisations and groups that want to improve healthcare services. They publish evidence of what 'patient and public voice' activity has been conducted, its impact and the difference it has made.

### RESOURCES FOR PROVIDERS

Health professionals have a role to play in the reduction and prevention of human rights violations and in ensuring that health policies and practices promote human rights. This needs joint efforts in terms of advocacy, application of legal standards and public health programming through the schools of medicine, schools of public health and nursing schools but also professional associations and colleges to widely educate and train health workforce how to operationalize the principles of human rights into their work.

The Right to Health: A toolkit for health professionals is a resource developed by the British Medical Association, the International Federation of Health and Human Rights Organisations and the Commonwealth Medical Trust. It highlights providers' skills in daily work: honesty, politeness, respect for all patients without discrimination, respect for the autonomy and dignity of patients and their right to self-determination, provision of up-to-date and relevant information without discrimination to support patients' decision-making, respect for patients' confidentiality and treatment of patients to the highest ethical standards. The tool also suggests key actions to promote human rights education, like examine

the curricula of medical and other health professional training schools to identify whether they include appropriate instructions in medical ethics and human rights, advocate the adoption of an ethical and human rights approach to health in the training of health professionals at all levels, and include within the curricula of medical schools a component on the legislative framework of the right to health.

## RESOURCES FOR SERVICES

The Experience-based co-design toolkit (EBCD) originates from the Patient-Centred Care Project at King's College and King's College Hospital Foundation. The tool provides a step-by-step guide to improving patient experience of health services using a technique called experience-based co-design. A revised version was launched in 2013, adding new learning gathered from more than 60 EBCD projects, as well as responding to the requests of users for the tool kit. A 2013 global survey had found out that EBCD projects had either been implemented or planned in more than 60 healthcare organisations in at least seven countries, including Australia, Canada, the United Kingdom, the Netherlands, New Zealand, Sweden, and the United States of America. EBCD involves gathering experiences from patients and staff through in-depth interviewing, observations and group discussions, identifying key 'touch points' (emotionally significant points) and assigning positive or negative feelings. EBCD focusses on patient and staff experience emotions rather than attitudes or opinions. The approach uses storytelling to identify opportunities for improvement, focusses on the usability of the service for patients and staff and empowers staff and patients to make changes. The toolkit includes the evidence gathered so far and suggestions on how to adapt the approach to different context.

*Patient's Bill of Rights.* In the early '70s the American Hospital Association drafted a Bill of Rights to inform patients on what they could expect while in hospital. Various groups have since developed a number of different declarations, so that now there is more than one version of the Patient's Bill of Rights. For example, at Johns Hopkins Hospital the bill focusses on patients' rights to speak openly with their health team, take part in their treatment choices and promote their own safety by being well informed and involved in their care. As healthcare has changed, newer bills of rights evolve and tend to discuss patients' rights in dealing with insurance companies and other specific situations. Medicare and Medicaid Bill of Rights addresses eight key areas such as information for patients, choice of providers and plans, access to emergency services, participation in treatment decisions, respect and non-discrimination, confidentiality of health information, complaints and appeals, and consumer responsibilities. There are also Bills of Rights for different conditions, like mental health.

## RESOURCES FOR POLICY AND SYSTEMS

The key principles of public participation contributing to health equity are the following: it reaches communities and groups with distinct health needs including those who experience poor health outcomes, it takes into consideration how to reach people experiencing difficulties in accessing health services or having health problems caused or affected by their socio-economic circumstances and it ensures the specific protection and empowerment of people lacking certain abilities. The Participation Compass is a toolkit that provides practical information for those working to involve people. It contains information on different methods of participation, case studies of participation in action, written resources and guides on participation, the organisations that provide expertise on participation and news on participation.

A Citizens' Panel is a large, demographically representative group of citizens, used to assess public preferences and opinions. Participants are recruited through random sampling of the electoral roll or postcode address files. Citizens' panels can range in size from a few hundred to several thousand people and can be used in all different types of setting. The McMaster Health Forum of the McMaster University in Canada uses citizens' panels to uncover unique understanding of key issues and spark insights into viable solutions in line with citizens' values and experiences. The United Kingdom National Institute for Health and Care Excellence (NICE) uses a Citizen Council to receive the public perspective on overarching moral and ethical issues to be taken into account when producing guidance.

The use of citizens' juries in health policy decision-making is a method of deliberation developed where a small group of people (12 to 24), representative of the demographics of a given area, come together to deliberate on a certain clearly defined issue over a period of 2 to 7 days. However, the process precludes the use of the 'ideal' citizens' jury with potential loss of an effective method for informed community engagement. Adapted citizens' jury models provide an alternative, and special attention must be paid to recruitment, independent oversight, duration and moderation *(70)*.

Other approaches to supporting participation in health include: the establishment of National Citizens' Assemblies for adults and young people, the launch of 'Excellence in Participation Awards' scheme that provides status and profile to patient and public participation to promote best practice, the set-up of a Participation Academy, a programme of learning and development for people who want to explore roles as patient and community leaders in health care, and the creation of a 'People Bank' where citizens and organisations can register their interest in participation opportunities.

Supporting the Right to Health. Legal instruments that support policy making with a health and human rights approach are international treaties and conventions, international declarations, norms and standards, international conference documents and their follow up.

The Health on the Net Foundation in Switzerland promotes and guides the deployment of useful and reliable online health information and its appropriate and efficient use. Their code of conduct for medical and health web-sites is an ethical standard for websites aiming at offering quality health information and wanting to publish transparent information. It is expected that the transparency of a website will improve the usefulness and objectivity of the information and ensure that correct data are published *(71)*.

Key features of a health system that supports health rights include transparency, participation, equity and equality, a comprehensive national health plan, a minimum basket of health services and facilities, disaggregated data, monitoring and accountability, leadership and governance. A rights approach should be consistently and systematically applied across the building blocks that together constitute a functioning health system *(69)*.

The François-Xavier Bagnoud Centre for Health and Human Rights at the Harvard School of Public Health has developed a Health and Human Rights Resource Guide as a user-friendly, multi-purpose tool in advocating for health and human rights with a wide array of users, including health workers, trainers, programme designers, litigators and policymakers. The introduction provides a primer on the application of human rights in health. Each of the nine chapters focusses on a specific health issue or a vulnerable population.

Health-related human rights impact assessment (HRIA) is used to assess health related implications of public policies. The application of health related HRIA leads to improved decision-making processes, healthier policies and greater human rights respect *(72)*.

RELATED WEB LINKS FOR EMPOWERING POPULATIONS

- ✓ http://www.activecitizenship.net/
- ✓ http://fxb.harvard.edu/
- ✓ http://www.healthwatch.co.uk/rights-and-responsibilities
- ✓ http://www.consumersinternational.org/who-we-are/consumer-rights/
- ✓ International Federation of Health and Human Rights Organisations
- ✓ World Health Organization: Human Rights
- ✓ World Medical Association: Health and Human Rights
- ✓ Health Rights: Human Rights in Patient Care
- ✓ http://participationcompass.org/pages/index/about
- ✓ Health and Human Rights Resource Guide

## TOOLS FOR ENABLING INFORMED CHOICE BY POPULATIONS

### RESOURCES FOR POPULATIONS

Consumer Health Choices has developed free consumer reports that support consumers in identifying and choosing high-quality, high-value products and services thus optimizing their health and wellness. Examples of these reports include advice for carers, treatments and tests for seniors, 10 things to reject in the delivery room and heart tests before surgery.

In the United Kingdom, the National Health Service Choices is a website that aims at supporting people in making important health decisions, including how to choose a general practitioner surgery, how to choose a hospital, how to exercise and how to eat healthily as a family. The 2014-2015 National Health Service Choice Framework brings together information on patients' rights of choice to their health care, where to get the best information to make a choice, and how to complain if they are not offered a choice. The Framework covers topics such as General Practitioners and General Practitioners' practices, maternity services, where to go to for a first appointment as an outpatient for physical or mental health conditions, how to change hospital if one has to wait longer than the maximum waiting time (18 weeks, or 2 weeks for a cancer specialist), which services are provided in the community, who carries out a specialist test if a person needs one, how to take part in a health research, how to have a personal health budget, and how to travel to another European country for treatment.

Disease ad-hoc associations often produce guidelines for their members on how to choose a doctor or a hospital. As an example the American Cancer Society proposes a list of issues to consider when choosing a doctor or a hospital.

### RESOURCES FOR SERVICES

Skills for Care in the United Kingdom supports people who need care and support to take informed risks, which is an essential element of personalisation and encouraging "choice and control". They have developed resources which support the learning and development of staff to help them balance risk enablement with their professional duty of care, while taking a person-centred approach. Providing real choice and control for people using care means enabling them to take the risks they choose.

The Social Care Institute for Excellence recommends actions to support people to have control over their healthcare choices. As an example, the full documentation of a person's previous history, preferences and habits can be used by staff to support choices consistent with the person's character *(73)*.

The Marie Curie Delivering Choice Programme of the Marie Curie Cancer Care in the United Kingdom is a programme dedicated to design and deliver innovative patient-centred end of life care.

### RESOURCES FOR POLICY

*Policy frameworks:* Supporting choice and control by In-Control in the United Kingdom is a template policy framework for delivering person-centred outcomes by a positive approach to risk *(74)*.

*Patient Dashboards:* The National Health Service England has developed a Patient Insight Dashboard to display patient experience data, to be published and made available to the public. The most useful data and insights are presented in a format that can be understood by patients, the public and local supervisors.

*Culturally adapted guidebooks:* Based on the principle that understandable health information improves access to care, the California Medical Assistance Programme (Medi-Cal) recently partnered with the University of California–Berkeley School of Public Health to help seniors and people with disabilities understand their Medi-Cal healthcare choices. The School of Public Health used participatory design to create a guidebook in English, Spanish, and Chinese that explains enrolment options and benefits. The

guidebook is easy to understand and includes accurate cultural adaptations. An evaluation showed that the guidebook has increased understanding of enrolment options and the capacity to make choices. More on this strategy at http://www.health.gov/communication/literacy/TownHall/ca.htm

*Use of personal budgets:* The Third National Personal Budget Survey in United Kingdom, October 2014 showed that for more than 80% of people surveyed a personal budget had made things better or a lot better in terms of support and quality of life. At least two thirds also reported that having their personal budget had made things better or a lot better in terms of independence, arranging support, mental health, control over their life, feeling safe, relationships with family and people paid to support them, friendships and self-esteem. More than two thirds of carers also reported things getting better or a lot better thanks to the personal budget of the person they care for in terms of quality of life, their own and that of the person they care for. In April 2014 in the United Kingdom, people eligible for continuing healthcare, were given the right to ask for a personal health budget. The "In-Control" website offers webinars that explain what a personal health budget is, its purpose, how it differs from a social care personal budget, the Department of Health pilot programme and roll out in continuing healthcare, the basic steps in the implementation process and examples of how personal health budgets are being used. The Personal Health Budgets online toolkit brings together learning from this pilot programme and shows how personal health budgets can be implemented.

## MONITORING AND EVALUATION

The POET© - Personal Outcomes Evaluation Tool was developed by In-Control and Lancaster University over the past 10 years as a way to measure what is working and what is not when it comes to personal budgets and personalised care and support. It was originally conceived for use in adult social care, but has now been developed for use in health, children's services and education. A version for providers is also in development.

## RELATED WEB LINKS FOR INFORMED CHOICE BY POPULATIONS

- ✓ Competition and choice resources at the Kings fund
- ✓ NHS Choices
- ✓ http://healthtalk.org/about/overview
- ✓ Consumer health choices,
- ✓ In Control
- ✓ Society for Public Health Education (SOPHE)

## TOOLS FOR STRENGTHENING HEALTH LITERACY

Suitable tools for strengthening health literacy focus on raising awareness, developing skills for health, encouraging general literacy activities, supporting patients asking the right questions, reaching vulnerable populations, embedding teaching and learning materials in a number of settings, training providers, applying proven health literacy design principles and standards to health information and services, using a universal precautions approach to health communication, using tailored programmes and communication, enhancing health literacy at transitions of care, developing health literate organisations, using improvement framework, strategies and toolkits, developing partnerships, measuring and evaluating.

Effective responses to health literacy needs are those tailored to address each individual and community. These responses will usually be a mix of interventions that target:

- the individual's skills, knowledge, beliefs, motivation and confidence,
- the individual's personal resources and supports,
- the information and care available to people in the community and its accessibility to those with varying health literacy needs and strengths,
- the capacity of health services and providers to respond to changes in the needs of people they serve, and,
- policies that promote assessment of health-literacy needs and focus efforts on targeted responses to identified needs *(81)*.

### RESOURCES FOR PEOPLE

*Raising awareness*: Health and community organisations, associations, centres and providers should seek to understand the issue of health literacy through the following questions: What is health literacy? What are the levels of health literacy in your community or practice area? Who is most at risk? The health-literacy map of the Canadian Council of Learning is one tool that can help health-care providers understand needs within their community *(75)*.

*Developing skills for health*: Health literacy skills can be categorised in (1) basic health competencies and the application of health promoting, health protecting and disease preventing behaviours, as well as self-care; (2) patient competencies to navigate the health system and act as an active partner to professionals; (3) consumer competencies to make health decisions in the selection and use of goods and services and to act upon consumer rights if necessary; and (4) citizen competencies, through informed voting behaviours, knowledge of health rights, advocacy for health issues and membership of patient and health organisations *(76)*.

Skilled for Health in the United Kingdom is the national programme that embeds Skills for Life learning into health improvement topics. It aims to address both the skills and health inequalities prevalent within traditionally disadvantaged communities and to identify general health topics relevant to a wide range of learners and use them as leverage for the development of literacy, language and numeracy skills. The material used covers issues related to health and healthy living rather than specific health conditions. Skilled for Health presents two sets of resources: Making the Case which promotes the strategic goals and Teacher and Learner which supports practical implementation with two sets of materials – health and wellbeing and services and self-care. They include topics like healthy food and drinks, physical activity and fitness, substances, mental well-being, keeping safe, and first aid.

*Regular literacy activities*: Research in Canada suggests that the strongest determinant of health literacy is the regular practice of a broad range of literacy activities: daily reading of newspapers, books, e-media and magazines can help keep your brain healthy and active as well as maintain your literacy skills. Reading each day could keep the doctor away *(77)*.

*Helping patients ask the right questions:* It is important that all patients ask the right questions about their health and care and that they receive information and instructions in a way that they can

understand. For example, the Manitoba Institute for Patient Safety encourages patients to ask their care providers three simple questions: - What is my health problem? - What do I need to do? - Why do I need to do this? Additional information about the "It's Safe to Ask" initiative, as well as information in a variety of languages, is available on the website of the Manitoba Institute for Patient Safety *(78)*.

*Reaching migrants:* Pharos, the Dutch centre of expertise on health disparities, in coordination with other stakeholders, has developed tools specific for the care of migrant groups, such as a website for General Practitioners with questions on the care for immigrant patients, a school teaching toolkit for education in the prevention of girls' circumcision, parental support guidance for Somali parents, a programme for refugee children 10-12 years old, that aims to strengthen the competence of refugee children in aspects like self-esteem, coping skills, social skills and adjusted behaviour, by creating opportunities allowing them to express themselves in a safe and familiar environment *(79)*.

*Embedding teaching and learning materials in a number of settings which will be of use in community-based programmes:* The Excellence Gateway, supported by the United Kingdom Education and Training Foundation, provides embedded teaching and learning materials in a number of settings, which can be used in community-based programmes. They provide an important example of how literacy, language and numeracy learning can be integrated into adult and community learning settings. Modules are available on subjects such as education in family health, family life, how to get on in the community, sports leadership, first aid, and the Skilled for Health materials.

http://rwp.excellencegateway.org.uk/Embedded%20Learning/Community/

RESOURCES FOR SERVICES

*Training providers:* Health staff should be empowered to recognise people's health literacy needs, be aware of appropriate resources and employ a range of communication tools. Health professionals often underestimate people health literacy needs. This happens because such needs often remain hidden and some people actively hide them *(80)*. The Scottish Health Literacy Action Plan aims at establishing a healthy organisational culture, effective leadership and management and most particularly at having a capable workforce. This action plan recommends the following techniques for staff to use: 'Teach-back' type techniques, checking that they have explained things in ways people understand, by asking them to explain in their own words the information they were given; the "Chunk and check" technique by breaking the information they need to convey into small chunks, and checking that they were understood by using teach-back before continuing; the use of images through drawings and pictures to help convey a complex concept or body part; the use of simple language by avoiding jargon, and using a language that is easy for the person in front of them to understand, in both written and/or verbal information; checking literacy awareness by routinely asking people if they would like help in filling out forms *(80)*.

In order to strengthen health literacy, service leaders and managers should take the following actions: raise awareness, ensure staff is aware of health literacy tools and has access to them, address staff capability to support people's health literacy needs, and develop an organisational culture that promotes health literacy *(80)*.

*Developing health literate organisations:* A health literate health organisation enables people to better navigate, understand and use information and services they need to take care of their health. The institute of Medicine in the United States of America presents the attributes that health organisations should strive for to become health literate *(98)*.

RESOURCES FOR POLICY

The Ophelia (OPtimising HEalth LIterAcy) Health Literacy Response Framework is a model that outlines the sorts of strategies required, across the different levels of the health system, to optimise the health literacy of individuals and communities and to respond to individuals with varying health literacy strengths and limitations.

The WHO Health literacy toolkit for low- and middle-income countries includes a series of information sheets introducing health literacy, its relevance to public policy, and the ways it can be used to disseminate the promotion of good health, the prevention and management of communicable and non-communicable diseases, and the reduction of health inequities. It provides information and links to further resources to assist organisations and governments to incorporate health literacy responses into practice, service delivery systems, and policy *(82)*.

*Use strategies to improve information on food, medicines and medical devices:* Individuals with limited health literacy skills are at particular risk of misunderstanding medical information on product labels, manuals, package inserts, and nutrition labels.

*Develop partnerships:* The European Union Health Policy Forum (EUHPF) has created a collaborative network called Health Literacy Europe for all those involved in European public health issues, which will help achieve more active coordination across member states *(83)*.

*Organise national campaigns:* The Public Health Association of British Columbia has proposed an inter-sectoral approach to improving health literacy for Canadians using a logic model that suggests a cadre of individual and collective actions that can be taken by key sectors to positively influence health literacy and health determinants. A number of fundamental components were identified to improve health literacy in the population: developing knowledge, raising awareness, capacity building, building of infrastructure and partnerships *(84)*.

*Organise targeted campaigns for specific groups:* Radio Bilingue is the only Latino radio network in the United States, reaching out to listeners in nearly 80 communities across the country. The network features La Cultura Cura, a radio campaign that promotes health and wellness for Spanish, Mixtec, and Triqui speaking farm workers and their families. Language and cultural barriers often keep this population from accessing healthcare and navigating the medical system. La Cultura Cura includes talk shows, feature news reports, educational messages, and mini radio dramas, all designed to create health behaviour changes, community action, and public policy changes. An evaluation of a recent campaign found that 66% of listeners had discussed the health programming with others. Moreover, the new reports have prompted new pesticide drift regulations and prompted regulations that address health-related illness and death in fields in California. More information on this strategy is available at http://www.health.gov/communication/literacy/TownHall/ca.htm.

*Use interactive programmes:* As the shift towards the use of more digital based services becomes more widespread throughout health services, there is the danger that the inequalities in health already felt by digital illiterate groups become even more pronounced. The National Health Service Widening Digital Participation programme, developed in association with the Tinder Foundation, aims at improving through local community networks the digital skills and digital health literacy skills of groups most likely to experience health inequalities like older or disabled people and those on low income.

Making it Easy, a Health Literacy Action Plan for Scotland suggests actions that seek to help health and social care workers cater for the health literacy needs of those they are trying to support. They were chosen because they promote change in practice and culture by raising awareness and the capabilities of professionals to address health literacy, promoting the development and spread of existing and new health literacy tools, innovations and technologies, improving access to useful health literacy tools and resources and enhancing health literacy at transitions of care, which are key learning and patient safety points in health and social care.

The European Health Literacy Project Consortium recommends that the gap in health literacy be challenged by professionals and policy-makers in terms of allocation of resources and means; health systems and other relevant sectors recognise the importance of health literacy in terms of their readability and accessibility of services; health literacy be strengthened at personal level through focus on enhancing life competencies at school, at work, at the market place and in the political arena; learning for well-being and health literacy be prioritised to enhance quality of life and linked to the social determinants of health; and relevant stakeholders such as governments, the private sector, and civil society make collaborative efforts to advance health literacy in Europe. The consortium supported the launch of the network Health Literacy Europe which is now a platform for health literacy in Europe.

The EU-funded research project Intervention Research on Health Literacy among Ageing Population focusses on improving health literacy for the elderly in Europe. The project is preparing evidence-based guidelines for policy and practice for local, regional and national government authorities to start action in health literacy, to be launched at the 3rd European Health Literacy Conference in November 2015.

MONITORING AND EVALUATION

Haun and colleagues provide a descriptive review of the psychometric properties and conceptual dimensions of published health literacy measurement tools. For each tool, the conceptual dimensions assessed, test parameters, and psychometric properties are evaluated. Of the 51 identified, 26 tools measure general health literacy, 15 are disease or content specific and 10 aimed at specific populations. Most tools were found to be performance based, to require in-person administration and to be exclusively available in a pencil and paper testing mode *(85)*.

The Health Literacy Index is a comprehensive tool with evidence for reliability and validity that can be used to evaluate the health literacy demands of health information materials. It is comprised of 63 indicators organised into ten criteria: plain language, clear purpose, supporting graphics, user involvement, skill-based learning, audience appropriateness, user instruction, development details, evaluation methods, and strength of evidence *(86)*.

The European Health Literacy Survey Questionnaire (HLS-EU-Q) includes two sections, a core health literacy section and a section on determinants and outcomes associated to health literacy. The health literacy section includes forty-seven items addressing self-reported difficulties in accessing, understanding, appraising and applying information in tasks concerning decisions making in healthcare, disease prevention, and health promotion. The second section includes items related to health behaviour, health status, health service use, community participation, socio-demographic and socio-economic factors *(87)*.

*Assessing Health Literacy Needs:* The Information and Support for Health Actions Questionnaire and the Health Literacy Questionnaire are used to better understand the health literacy strengths and difficulties of people from a range of socioeconomic and ethnic backgrounds, and of people living with disabilities or long-term health conditions. The Information and Support for Health Actions Questionnaire is designed for cultures in which decision-making on health is often a communal activity. The Health Literacy Questionnaire is a comprehensive measure of health literacy. It captures fine details on an individual's health literacy and provides full information on what needs to be done to improve systems and services. It is patient-centred and is derived from extensive consultations with patients, practitioners and policymakers *(81)*.

*Assessing health literate organisations:* Tools for this purpose are: The Enliven Organisational Health Literacy Self-Assessment Resource; The Health Literacy Universal Precautions Toolkit; Communication Climate Assessment Toolkit; Health Literacy Environment of Hospitals and Health Centres; Advancing Effective Communication, Cultural Competence, and Patient and Family-centred Care: A Roadmap for Hospitals; Pharmacy Health Literacy Assessment Tool; Health Plan Organisational Assessment of Health Literacy Activities; Consumer Assessment of Healthcare Providers and Systems; Literacy Audit for Health Literacy Settings *(88)*.

In the United States the Institute of Medicine issued a landmark study on Health Literacy entitled 'Health Literacy: The End of Confusion' in 2003 and has since led the only economic evaluation of health literacy *(89)*.

## RELATED WEB LINKS FOR STRENGTHENING HEALTH LITERACY

- ✓ http://www.healthliteracy.org.uk/
- ✓ Health Literacy Canada
- ✓ The Health Literacy Place
- ✓ Community Health and Learning Foundation
- ✓ ROHLA - "Intervention Research on Health Literacy among Ageing Population"
- ✓ Making it Easy: A Health Literacy Plan for Scotland
- ✓ The Knowledge Network (Scotland)
- ✓ National Adult Literacy Agency (Ireland)
- ✓ Intervention Research on Health Literacy among Ageing Population (EU)
- ✓ Health Literacy Projects/: Healthy Cities: Stoke-on-Trent ; https://www.ophelia.net.au/
- ✓ Health Literacy and Learning: The Community Health Learning Foundation (United Kingdom )
- ✓ Health Literacy Conferences/ Meetings: 2015 Health Promotion Conference. Health Literacy: Research, Policy and Practice (Ireland)
- ✓ https://www.skillsforhealth.org.uk
- ✓ https://ophelia.net.au/about-health-literacy

## TOOLS FOR SUPPORTING COMMUNITY DEVELOPMENT

### RESOURCES FOR COMMUNITIES

The "Help Taking Action" section of the Community Tool Box offers guidance and support to people working with communities. It offers tools such as a troubleshooting guide that provides guidance in solving common problems and dilemmas in community work, a model for getting started, supports for implementation that include twelve Best Change Processes for promoting community change and improvement, a database of best practices, free online courses, advisory support.

### RESOURCES FOR PROVIDERS

Community Appraisals are surveys of local needs and opinions on issues such as local housing, schooling, training, employment, culture, health, social welfare and community facilities.

*Assessing needs and resources:* The Asset-Based Community Development Institute is at the centre of a large and growing movement that considers local assets as the primary building blocks of sustainable community development. It offers toolkits to support community development arranged into three general categories: talking points, asset mapping and facilitating tools. The Appreciating Assets report explains what asset-based community development means in practice. It was produced by the International Association for Community Development and the Carnegie United Kingdom Trust.

### RESOURCES FOR TRAINING AND EDUCATION

Participatory community learning equips students with public health skills, knowledge, and enhanced understanding of communities. It offers a way to effectively teach public health, while emphasising the extended role and societal responsibilities of doctors. Students acquire public health skills, including conducting a needs assessment, searching for research evidence and designing an evaluation framework *(90)*. Participatory theatre, for example, has been used in the professional development of youth and community practitioners.

The Community Tool Box team has developed a training curriculum designed for use in workshops, classes, and webinars to support core skills in community work. The available tools include: Participant's Guide, Facilitator's Outline, PowerPoint, Interactive Activities, and Supplemental Online Readings. The workbook The Role of Community Culture in Efforts to Create Healthier, Safer and More Equitable Places draws on the experiences and lessons of numerous communities working to advance place-based prevention efforts. It is designed to guide community health practitioners who want to learn more about the role of community culture in environmental change efforts.

The Community Development National Occupational Standards aim at defining the skills, knowledge and understanding required to undertake the functions carried out by community development practitioners. Pathways to Health training is delivered at three levels to match varying needs within the sector. Level 1 aims to increase individual knowledge of community development and health inequalities, level 2 explores how community development can be better embedded in organisational practice and level 3 challenges those who work at a more strategic level to increase the profile of community development within the policy and governmental arena as a way to address health inequalities.

RESOURCES FOR SYSTEMS

*Commissioning for community development:* Community development – improving population health is part of the Smart Guides to Engagement series. This guide helps clinical commissioning groups understand and invest in community development to improve the health of their population.

The CDC Community Health Improvement Navigator (CHI Navigator) is a website for people who lead or participate in CHI work within hospitals and health systems, public health agencies, and other community organisations. It offers community stakeholders expert-vetted tools and resources for: Depicting visually the who, what, where, and how of improving community health; Making the case for collaborative approaches to community health improvement; Establishing and maintaining effective collaborations; and Finding interventions that work for the greatest impact on health and well-being for all. Several hospitals initiated these activities as a result of findings from their community health needs assessments. Many undertook community-based initiatives to address the needs of patients who are often clustered geographically and frequently interact with the health system (super users). The tools include: Assess Needs and Resources; Focus on What is Important; Choose Effective Policies and Programmes; Act on What is Important; and Evaluate Actions.

Reaching out – community engagement and health, by the National Health Service Improvement and Development Agency (IDeA), raises issues and provides practical examples of joint working to improve health.

*Engaging volunteers:* Volunteering is sometimes referred to as social action or simply people helping people. The United Kingdom Cities of Service seeks to organise hundreds of volunteers within their cities to tackle local problems replicating the highly successful US model initiated by the former mayor of New York City, Michael Bloomberg. Mayors and citizen volunteers play key roles in connecting residents to the resources and information necessary to lead healthy lives, from increasing the number of community gardens providing fresh fruits and vegetables in neighbourhoods that lack fresh produce markets to helping people exercise to combat obesity. Resources and advice are available in their website.

Nesta, an innovation charity in the United Kingdom, supports the development of hospital volunteering service to improve patient experiences. The vast majority of managers agreed or strongly agreed to the "added value" of volunteers' work in different domains, from improving the experience of patients and carers, to increase in services, and community involvement *(91)*. Volunteers play an important role in improving people's experience of care, building stronger relationships between services and communities, supporting integrated care, improving public health and reducing health inequalities. Chris Naylor and colleagues at the King's Fund propose a number of specific actions that will help volunteering fulfil its potential *(92)*. Nesta suggests a number of techniques to increase the impact of volunteers' work, such as asking nurses what jobs they wish they had time to do that volunteers could help with (usually things like holding a patient's hand to reassure them before surgery), training volunteers in specialist skills (like reminiscence games for patients on dementia wards), and developing hospital-to-home services to support patients to settle successfully at home.

RESOURCES FOR POLICY

Community planning is a process led by councils in conjunction with partners and communities to develop and implement a shared vision for their area, a long term vision which relates to all aspects of community life and which also involves working together to plan and deliver better services which make a real difference to people's lives *(93)*.

*Sharing good practices:* 'Tailor Made: how community groups improve people's lives' is a micro site based on a research project which shows the vital contribution small community groups are making to society and how funders can best support them.

Community Health Champions help others enjoy healthier lives by raising awareness of health and healthier choices, sharing health messages, removing barriers and creating supportive networks and environments *(94)*.

The Building Community Pharmacy Project works with pharmacists and local communities to identify and address local needs using a community development approach.

Healthy Cities/Healthy Communities is a theoretical framework for a participatory process by which citizens can create healthy communities. There are no step-by-step instructions for employing it. It is meant to be adapted to the different needs of different communities. There are, however, necessary components of any healthy city/healthy community initiative such as creating a compelling vision based on shared values, embracing a broad definition of health and wellbeing, addressing quality of life for everyone, engaging diverse citizen participation and being citizen-driven, acknowledging the social determinants of health and the interrelationship of health with other issues, addressing issues through collaborative problem-solving, focussing on system change, building capacities using local assets and resources, measuring and benchmarking progress and outcomes.

### RESOURCES FOR IMPLEMENTATION

Four principles are proposed as the basis for community empowerment in the health sector: adopting a community development approach, providing committed leadership, working in partnership, and capacity building *(95)*. Here below are two tools that support building partnerships.

*Networking and supporting networks:* "Development of community is about strengthening and extending networking between individuals, between groups, between organisations and just as importantly between different sectors and agencies" *(96)*. The Knowledge Hub offers a platform that supports professional social networking, collaboration and information sharing in the public sector.

*Coalition building and community coalition-driven interventions:* A coalition is a group of individuals and/or organisations with a common interest who agree to work together towards a common goal. The community toolbox website offers a toolkit to start and maintain a coalition. Recent evidence shows that interventions led by community coalitions to reduce health disparities among racial and ethnic minority populations have the capacity to connect health and human service providers with ethnic and racial minority communities in ways that benefit not only individual health outcomes and behaviours, but also healthcare delivery systems *(97)*.

The Community Health Assessment and Group Evaluation Tool (CHANGE) is a data collection tool and planning resource for community members who want to make their community healthier. Its action guide provides step-by-step instructions for successfully completing the CHANGE tool. CHANGE can be used to gain a picture of the policy, systems, and environmental change strategies currently in place throughout the community, to develop a community action plan for improving policies, systems, and the environment, to support healthy lifestyles, and to assist with prioritising community needs and allocating available resources.

### RELATED WEB LINKS FOR SUPPORTING COMMUNITY DEVELOPMENT

- ✓ Community Toolbox box
- ✓ CDC Community Health Improvement Navigator
- ✓ Community Development and Health Network
- ✓ The Community Development Challenge (DCLG, 2006)
- ✓ Federation of Community Development Learning
- ✓ Leadership for Healthy Communities
- ✓ Community Development Foundation
- ✓ http://www.justact.org.uk/
- ✓ http://www.nesta.org.uk/

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## ANNEX RESEARCH INSTRUMENTS-STANFORD PATIENT EDUCATION RESEARCH CENTRE

**Any of these scales may be used at no cost without permission.**
The individual scale documents have the items, their properties (if available), and coding and scoring instructions.

Example questionnaires are also provided.
- CDSMP Outcomes Review from CDC and NCOA
- Primer for Evaluating Outcomes
- Sample Chronic Disease Questionnaire (English)
- CDSMP Questionnaire Code Book
- Sample Diabetes Questionnaire (English)

**Self-Management Behaviours**
- Exercise
- Cognitive Symptom Management
- Mental Stress Management/Relaxation
- Communication with Physicians

**Self-Efficacy**
- Original Chronic Disease Self-Efficacy
- 6-Item Chronic Disease Self-Efficacy
- Diabetes Self-Efficacy
- Arthritis Self-Efficacy

**Health Status**
- Self-Rated Health
- Illness Intrusiveness Rating
- Fatigue Visual Numeric
- Energy/Fatigue
- Pain Visual Numeric
- Pain Severity/Interference
- Shortness of Breath Visual Numeric
- 20-Item HAQ-Disability
- 8-Item HAQ-Disability
- Health Distress
- PHQ-9 (Depression)
- Social/Role Activities Limitations
- Hyperglycaemia
- Hypoglycaemia

**Healthcare Utilization**
- Visits to Providers
- Visits to Providers (Diabetes)

**Education**
- Years of Education

**Diabetes-Specific Scales**
- Eating Breakfast with Protein
- Glucose Testing
- Diabetes Self-Efficacy
- Hyperglycaemia
- Hypoglycaemia

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