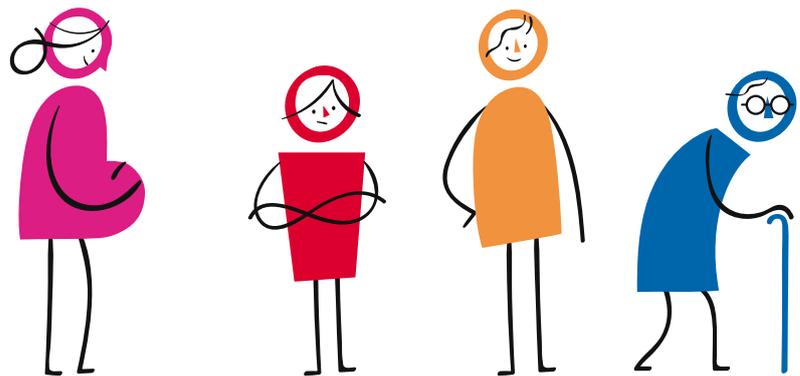


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My healthy future

discussion notes on
person centred healthcare



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Roundtable on person centred healthcare

Person centred healthcare (PCH) seeks to promote individualism within healthcare, considering patients as co-producers of health.

The *My healthy future* roundtable on person centred healthcare brought together experts from the health service, commercial, policy and research sectors. Participants considered what they deemed the significant opportunities and challenges of PCH in a technologically driven system including for personalised prevention.

The roundtable was held at King's College, Cambridge on 18 October 2018.

This document presents a summary of the discussion, along with further analysis and reflection, which has fed into the *My healthy future* project and final report.

The views expressed are not necessarily those of the PHG Foundation.

A vision for personalised health using new technologies for prevention

My healthy future envisages that twenty years from now:

- Technologies will be available to provide much more personalised information about risk and early disease to individuals. For those with chronic disease, this will provide many opportunities for individuals to understand and manage their own conditions to maintain the best overall health
- There will be emphasis on shared responsibility for health, with individuals taking personal responsibility where they have the resources and capabilities to do so, and community and health system support available to those who are less able to
- This enables greater potential for personalised prevention

Health in the positive sense can also be present in the face of disease; coping well with chronic disease. This is particularly notable in the context of ageing, where 'healthy ageing' does not require that the individual maintains perfect health, but acknowledges that resilience can help individuals maintain overall wellbeing despite the onset of morbidity/multi-morbidity. Thus, in public health terms – primary, secondary and tertiary prevention are all relevant to the notions of personalised prevention. Individuals could take complete responsibility for optimising their own health: understanding their own risk and using preventive strategies and accessing 'technical' assistance as and when they deem necessary. This could be thought of as a market based 'free-for-all'. However, experts thought that this was an unlikely scenario and one that should not be encouraged within a society that deems health to be important and provides substantial resources and services to provide it (health care, public health, social services etc.).

Reasons for this included:

- The serious effects on individuals and society of 'getting it wrong' and the great advantages of 'getting it right'
- The complexities involved and the abilities/capacities/resources of individuals to deal with these
- The generalised belief that the health of all citizens is important and a concern about health inequalities

This is particularly the case within the UK NHS system, in which most individuals are entitled to access primary healthcare by registering with a general practitioner who then acts as a gatekeeper for accessing more costly secondary and tertiary care.

It follows that health optimisation of individuals using preventive strategies will require some form of interaction with the health system.

Experts thought that this should have the following features:

- It should recognise and be based around a positive/holistic view of health
- It should occur against a solid backdrop of public health (population based) interventions
- It should be 'personalised', making the best use of technology to assess an individual's needs, to understand the best ways to help them (intervention), and to provide those interventions effectively
- Medical/biological assessments and interventions should be undertaken on the basis of high quality technological/research based understanding (using 'precision medicine')
- It should be person centred

Experts suggested that this interaction with the health system, which potentially includes providers outside the statutory sector, could be termed 'personalised health'.

Characteristics of personalised health

Holistic

From the person centred healthcare background research and roundtable we noted the importance of health in the positive sense, which includes:

- Mental/emotional/psychological health and wellbeing
- Social health and wellbeing
- Biological (medical) health and wellbeing

Personalised health should be orientated towards the holistic needs of individuals. We set out these needs in three main dimensions: emotional/psychological; social; and physical/medical/biological (i.e. precision medicine).

Mental/emotional/psychological health

Mental wellbeing is not merely the absence of a mental condition. Good mental health enables individuals to regulate their emotional states, pursue actions that lead to positive wellbeing and fulfilment, adapt and manage in times of change and uncertainty, and enact and maintain healthy behaviours. Mental wellbeing is dynamic, and can fluctuate day to day, year to year.

Individuals gain value from having others care for them. The nature and quality of relationships (including the physician/patient relationship) can therefore heavily influence emotional and mental health.

Social health

Social health and wellbeing refers to a person's level of support from the people and institutions around them. There is growing evidence to suggest that health assets exist at a community level. Often taking the form of networks, these are essential for health: to help build resilience, reduce loneliness and encourage health-seeking behaviours. Being connected to people through family, work and the community provides a support system that can help empower individuals to better take control of their health. The role of this aspect is crucial as most people spend their whole lives living in communities but only a fraction using health services.

Biological (medical) health

Medical health refers to the prevention or good management of disease or infirmity. It uses the best available research knowledge and technologies to understand individual health risk, detect early disease, diagnose and treat disease. Interventions offered are tailored to a precise diagnosis and to the best understanding of an individual's physiology – for example, genetic determinants of their likely response to different drugs.

Although each individual has needs in each of these dimensions, the nature and level will vary depending on internal factors relevant to potential disease experience, such as genetic risk, exposures and lifestyle, personality and circumstances.

Meeting holistic needs

The ways in which needs in these various dimensions can be met will also vary for each individual. In particular, individuals can draw on internal resources and from family, wider relationships, community and work. But for many, there will be a support gap. This may be in any of the dimensions and should be filled by other services which may include, health, social services, education, voluntary organisations, commercial sector and others. We envisage this internal and external support related to need as three pillars on which an individual's wellbeing depends.

Providing personalised health

The provision of personalised health includes the processes of assessing need and providing the necessary components along these three dimensions. It includes precision medicine as one of its pillars to provide the best available in biological assessment and management for that individual, and it also includes the other two pillars directed towards the social and mental/psychological/emotional dimensions. Combining the medical, emotional and social needs of the individual and situating their health within the broader context of their lives enables a more holistic approach to health and wellbeing and a more rounded and tailored set of interventions.

Person centred healthcare

Person centred healthcare (person centredness) is a quality of the relationship between the individual and the health system through which personalised health is provided. It includes an individual assessment of need in the three dimensions, an assessment of the support gaps and consideration of the various provisions required to fill these gaps. Clinicians must be experts in biological medicine, but should also be equipped to constantly assess the whole picture of health and wellbeing. Experts discussed principles and characteristics in the context of prevention.

Principles of the new person centred healthcare

- Individuals need a lifelong relationship with 'personalised health', spanning pre-birth to old age
- They will need some level of 'person centred' health advice and support throughout this time – we call this 'person centred healthcare'
- The input that they need will vary throughout their lifecourse and will need to be personalised according to social/emotional/biological circumstances. Even for those with similar circumstances, what is important to one person in their healthcare will differ from another
- All individuals require input and support in the three domains – but the external input they require will differ according to their own personal capabilities, resources and the nature of their problems, which include the impact of particular diseases and conditions
- With respect to their interaction with health and health interventions, individuals will also differ according to their own level of 'activation' (see section 5.2), which can change over time. This may be particularly the case in disease prevention and health promotion

What are the characteristics of person centred healthcare?

Person centred healthcare encompasses a range of characteristics and principles, including but not limited to:

- Considering patients as co-producers of health, autonomous partners in preventing, treating and managing disease
- Promoting individualisation, respect, compassion, dignity and choice in relation to a person's circumstances and relationships in healthcare
- Ensuring that interactions with healthcare professionals are informative, empathetic, and empowering and that patients' values and preferences are taken into account
- Recognising the needs of clinicians (doctors/nurses) to provide a high quality service within a valued professional relationship

Providing person centred healthcare in the context of wellness and prevention

Providing person centred healthcare within the context of wellness and prevention requires that opportunities are found to engage with individuals. Whilst systematic opportunities are limited (for example 'NHS Health Check' or formal screening programmes), it will be important to capitalise on other encounters, particularly clinical encounters that are (or could increasingly be) orientated around wellbeing. Much of this could be in the context of primary care.

Life events and stages such as pregnancy, neonatal and early childhood, teenage years or ageing all offer an opportunity for consideration of holistic needs and wellbeing and for offering preventive options. For example, for some women, consultations over contraception may be a useful time to introduce discussion about future plans for having children and associated hopes or concerns regarding pregnancy, to talk about optimising health around conception and some of the pros and cons of the various interventions during pregnancy that may ensure maternal wellbeing and the birth of a healthy child. For other women, especially younger women, these topics may be wholly inappropriate. Thus the context, as well as cues from the patient will guide what is discussed.

The clinical consultation also provides a useful entry point for personalised prevention. Most directly, individuals may present with direct concerns about their own risk. This might be prompted by family history of disease (for example, a close relative having been diagnosed with breast cancer) which prompts the individual to become concerned about their own genetic risk. There are also increasing opportunities to obtain personal health information by accessing commercial testing, using wearable or environmental sensors or through publicly accessible risk assessment tools such as online questionnaires.

Clinical consultations over health events also provide opportunities for prevention, which may either relate to the condition in question or to wider disease risk. All consultations present the clinician with an opportunity to provide general health promotion or prevention advice, but also to tailor this to the individual. For example, this may be by identifying obesity, or lifestyle problems such as alcoholism, lack of exercise, stress, smoking or poor diet.

In the context of the investigation of presenting clinical symptoms, there may be opportunities to test for other possible risks or conditions (secondary findings) through imaging (for example a CT scan) or in genetic testing where genome wide panels or whole genome testing is offered. For example, the symptomatic patient being tested for a genetic diagnosis underlying cardiac arrhythmia may be offered (as part of the overall test) testing for variants such as BRCA1/2 which are associated with increased risk of breast cancer (and for which preventive options are currently available).

Finally, individuals could be identified for personalised preventive healthcare through the wider community – for example, through the workplace, school, locality/local authority or voluntary sector settings.

Moving forward on person centred healthcare

Societal advances and developments provide opportunities to move forward with person centred healthcare in the context of prevention. Whilst it is possible to identify and address the main opportunities and barriers, it is, however, crucial to keep at the heart of any strategy the knowledge that individuals need an individual approach: what is the right approach for one person may not suit another. This is the very essence of person centred healthcare.

In general terms, there are a number of societal enablers, including a shift of power towards consumers, the rise of consumer expectations about health and an expansion in the tools available to consumers to maintain and increase health. The development of new technologies and their wide availability from diverse providers is one key enabler. As many of these technologies depend on digital literacy (whether to access them or to use them) – the rise in digital literacy is also a marked enabler.

Professional roles

The need to 'rethink' professional roles, behaviours and practice was raised at the roundtable. This will require changes in education and training, changes in attitude and the culture surrounding health professionals and a generally supportive health system environment.

Whilst education and training should continue to ensure technical efficiency, this will need to be further developed to enable clinicians to combine scientific and clinical knowledge with social science, psychology as well as input and perspective from the patient. Practical wisdom should be fostered and an ability to navigate the various tensions that will arise.

It is envisaged that the role of the clinician will have to change to become more interpretative. This will especially be the case as artificial intelligence will supplement the knowledge of the clinician with knowledge derived from big data and the best evidence available from research.

The attitudes and approach of healthcare professionals will undergo change. An emphasis on shared decision making will require clinicians to shift the balance of power towards patients – a change which in some instances may require some adaptation. Overall the narrative should become one of compassion. Clinicians will need to favour finding the best solution for the patient, rather than championing the best evidence based option. They must learn to be less anxious about 'getting it wrong,' recognising that following a person centred approach may be more important than the technically best option. As they weigh up medical versus other approaches to management, they may need to recognise and manage their tendency to overestimate the benefits of these medical approaches and to underestimate the harms.

Changes will also be required in the systems and culture that surrounds and supports clinicians to enable them to practise in a person centred way. Teams will need a shared agreement about what person centred healthcare is and a set of principles towards which they agree to work. Health professionals will need to be trained and incentivised to be person centred and means of measuring this as a quality of care should be developed. They must have the time and resources to operate in this way – it is possible that the technologies themselves could be used to free up professional time. As person centred healthcare is developed and implemented, adaptations in professional relationships and power must be facilitated – and vested interests recognised and addressed.

Patient health activation

Person centred healthcare must recognise and adapt to an individual's level of activation. Whilst this has mainly been described in the context of managing long term conditions, it is also relevant in the area of prevention. 'Patient activation' describes the 'knowledge, skills and confidence a person has in managing their own health and care'.¹ Evidence shows that an activated patient benefits from better clinical outcomes and reduced demand for avoidable healthcare services.² The level of a patient's activation can be measured by tools such as the Patient Activation Measure (PAM) - a validated instrument which has been used on license by several NHS sites. The level of activation of an individual is not static, but can be increased in an individual by focused programmes. Whilst there is some association between low patient activation scores and personal characteristics such as lower socioeconomic group or lower levels of education, this is not necessarily the case - with some well resourced individuals having low levels of activation and vice versa.

Overall, the amount of personal responsibility that an individual is able to take for his or her health will depend on their level of activation - i.e. explicitly on their level of knowledge, skills and confidence in acting on health information. In the area of prevention, this may be varied and highly complex and uncertain. In particular, we should be cautious about pushing digital tools onto patients. Only those who are very activated and engaged will be happy to use them, whereas others may think that they are being 'fobbed off' or that the interaction has been 'dumbed down'. For these people, trust needs to be built over several appointments before digital tools can be introduced.

Stratifying individuals on the basis of their level of health activation and tailoring care pathways accordingly might enable the health system to offer a more holistic, personalised approach for people who feel less confident, skilful or knowledgeable about taking responsibility for their health. An example of this is Dr Oliver Hart's Quadrant Model³ - a pilot of a person-centred approach to how primary care can support people living with diabetes. Patients are assessed using PAM, then segmented into four quadrants based on their PAM score and the level of medical complexity of their condition. This helps avoid a 'medicalised' approach for those who don't need it at that time, whilst directing resources towards those who do. It should be noted, however, that this must be done sensitively as patients may in some instances feel that they are being assessed, and labelled in either a positive or negative way.

Alternatively, those with lower levels of health activation may be more receptive to having an initial conversation with a trained 'non-medical healthcare professional'; or 'health trainer'. The potential benefits of this approach have been highlighted in the 2015 King's Fund report on the Nuka system of healthcare⁴ where intentional whole system redesign encourages staff to work in multidisciplinary teams that include doctors, nurses, pharmacists and behavioural health consultants to offer co-ordinated, whole-person care. This has been proven to increase levels of trust in patient/doctor relationships and encourage people to become more involved in their own healthcare.

Overcoming system wide barriers

Despite much political and professional support for person centred healthcare and prevention in general, it is often perceived as challenging currently accepted models of care. These barriers will have to be overcome in order to implement person centred healthcare at scale.

In prevention, person centred, or personalised prevention is frequently viewed as challenging the well accepted programmes of population based prevention. The latter, for example, focuses on social determinants of health, or on changing harmful lifestyles such as poor diet or smoking through structural approaches aimed at the entire population (examples include the smoking ban or improvements to food labelling). Personalised or individual based interventions are often seen as a diversion, likely to be of very small effect and, more importantly, placing responsibility on the individual rather than reinforcing the role of the state in addressing social inequalities.

The consensus from the roundtable was that the two forms of prevention (population and individual based) should be seen as complementary and that the limitations of personalised prevention are recognised, especially in relation to individuals who have lower levels of health activation, or fewer resources on which to draw. It is likely that the standard population based and public health measures will overall have the greatest effect on health. Personalised prevention may have more to offer where the risks are larger (for example inherited cancer syndromes) and fewer people are affected.

Person centred healthcare is, paradoxically, often thought of as being at odds with personalised medicine. This arises as personalised medicine relies on precise diagnosis, informed by biomolecular characterisation of the disease and treatment tailored to the individual's underlying genetic and biological makeup. Personalised medicine, thus seems to provide a definitive 'best option' for the patient which, some commentators argue, leaves very little room for varying decision making based on individual preferences or a different set of values.

The lack of clear evidence surrounding the effectiveness of person centred healthcare focused on prevention creates additional challenges. There are methodological difficulties in developing evidence in prevention because of the long timescales required to show differences in effect, and the limitations of current gold standard methods such as randomised controlled trials which usually specify eligibility criteria (not accounting for individual patient differences) and pre-set intervention options.

In the practical sense there will also be difficulties in implementation. Overall there is a lack of understanding of what person centred healthcare is and how to enact it. Very little work has hitherto been undertaken in the area of prevention. For progress to be made the whole system will need to become a 'learning system'.

Because each person is an individual- with different needs and requiring different interventions, implementation must be diverse and detailed. It will require the creation of a model of care, a set of tools that may help in the assessment of individuals and a variety of options or interventions that may be offered. These may need to reach far beyond the boundary of healthcare, certainly to involve other statutory and voluntary services – but sometimes to link to resources beyond health – for example information resources or commercially available apps. Indeed, many of the solutions to person centred prevention may lie outside the health system. At a time when the overriding priority is for cost containment, these approaches, which seem to prioritise quality over quantity may be hard to sustain.

Finally, although there is much apparent political pressure for personalised prevention, (for example the latest Government report *Prevention is Better than Cure*⁵), the complexities and difficulties of providing this at scale to individuals in a population have not been recognised. There is a major push for individuals to 'take responsibility for their own health'. However, the amount of personal responsibility that an individual is able to take for his or her health will depend on their level of activation. This could be addressed through the health and social care system by encouraging greater community support, social prescribing, and multidisciplinary primary care teams providing integrated health and care services.

Conclusion

This roundtable represented, to our knowledge, the first time that experts in person centred healthcare had met to discuss the concept and practical challenges in the context of new technologies that would enable personalised prevention.

Following background preparation on concepts of person centred healthcare and an introduction to the new technologies, including biomedical, genomic and digital technologies that would enable personalised prevention, the experts concluded that, although new technologies for personalised prevention could be accessed and used directly by the individual, it was likely that optimal use and implementation for society would require interaction with the health system and integration with population facing health promotion and disease prevention.

The interaction of individuals with the health system should be person centred – and the group went on to consider principles, practice and implementation of such person centred prevention. Overall it should recognise and respond to the holistic nature of health. There would need to be changes and developments in professional roles and consideration would need to be given to assessing and responding to different levels of patient activation.

Two interfaces were noted as being important.

- Person centred healthcare in the context of prevention must be carefully integrated with wider population (public health) approaches and seen as complementary rather than antagonistic.
- Person centred approaches should be employed alongside precision medicine in order to deliver truly personalised healthcare recognising that health goes beyond biological or medical needs, to encompass the domains of emotional/psychological and social needs.

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Delegates

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