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# My healthy future

person centred  
healthcare



UNIVERSITY OF  
CAMBRIDGE

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## 1 Introduction

The PHG Foundation programme, *My healthy future* imagines a future health system where new technologies enable individuals to acquire and act on a wide range of information about themselves, their health and their risk of disease; and when ill, to understand more precisely the nature of their disease, its physical, psychological and social impact and the best means of treatment, management or mitigation.

Such a future is built on the biological and technological developments that enable more effective and targeted personalised medicine (sometimes called precision, stratified or P4 medicine). But individuals will still interact with health systems – for advice and support, disease prevention, diagnostics and wider assessments, treatment and supportive care, and it is in these interactions that person centred healthcare (PCH), as a holistic approach to the delivery of individualised care, will continue to be important.

Although some consider that PCH is the antithesis of personalised medicine (because the latter seems to reduce choice, potentially to a single evidence based option), the alternative view is that, by providing the individual with more information and setting that in the context of their wider wellbeing, circumstances, values and preferences, there is an opportunity to provide meaningful person centred healthcare.

In *My healthy future* we have taken the position, in line with policymakers and health leaders in the UK and wider, that person centred healthcare is an important quality to which health systems should aspire. We aim to set out our vision for person centred healthcare, developed firstly through four life stages examined in our *My healthy future* workshops. In the person centred healthcare roundtable we will ask the question – what would person centred healthcare look like in a future where new biological and digital technologies are widely used by citizens in the context of their own health and in conjunction with health systems, commercial and other sectors?

In this background document we introduce some of the main concepts of person centred healthcare, setting it within a wider policy background and look forward to consider its relevance and possible barriers to introduction in the context of disease prevention, particularly that enabled by new biomedical and digital technologies.

By focusing on prevention we are also supporting current policy debates, such as that presented in the priority areas included in the outline NHS 10 year plan for which NHS providers are currently (Autumn 2018) developing detailed proposals.

## 2 Concepts

Person centred healthcare seeks to ensure that care delivery is responsive to a patient's physical, emotional and social needs, that interactions with staff are informative, empathetic, and empowering and that patients' values and preferences are taken into account. It seeks to be transparent and promotes individualisation, respect, compassion, dignity and choice in relation to a person's circumstances and relationships in healthcare.

Essentially PCH moves away from a paternalistic way of thinking about the patient's role, towards considering patients as co-producers of health, autonomous partners in treating, managing and preventing disease. In provision of care it seeks to be coordinated and supporting. As an evolving concept, there is no single agreed definition of person centred healthcare, but instead it is usually thought of as an amalgamation of principles that should be kept at the centre of healthcare practice. One example is presented in the Health Foundation report *Person-centred care made simple* (see Box 1)<sup>1</sup>.

### **Box 1. The Health Foundation – *Person-centred care made simple***

The term person-centred care is used to refer to many different principles and activities, and there is no single agreed definition of the concept. This is partly because person-centred care is still an emerging and evolving area. It is also because, if care is to be person-centred, then what it looks like will depend on the needs, circumstances and preferences of the individual receiving care. What is important to one person in their health care may be unnecessary, or even undesirable, to another. It may also change over time, as the individual's needs change.

Instead of offering a concise but inevitably limited definition, the Health Foundation has identified a framework that comprises four principles of person-centred care:

- Affording people dignity, compassion and respect
- Offering coordinated care, support or treatment
- Offering personalised care, support or treatment
- Supporting people to recognise and develop their own strengths and abilities to enable them to live an independent and fulfilling life.

### 3 Policies

Person centred healthcare has been an explicit policy goal in the UK for at least the last 20 years <sup>2</sup>; both PHE and NHSE have long professed a commitment to putting patients at the heart of all they do. The concept of PCH is consistent with a set of developments that encourage a greater role for individuals in their own health, such as those concerned with consumerism, patient empowerment, the retreat of traditional conservatism and paternalism, the use of patient advocates and the emergence of stronger and more assertive health charities and rights campaigners.

The policy justifications for this raft of measures comprise improvement in health and wellbeing, improvement in quality of care, increased financial sustainability and the efficient allocation of resources. However, although a recurrent theme within many areas of UK health policy, person centred healthcare has hitherto not been a focus in its own right, which has meant that the multiple and complex steps required to integrate it as a central feature of the health system have not been realised.

Partly in response to the poor standards and patient suffering exposed through the Winterbourne View review and the Francis report, an NHSE strategy in 2014 (Putting Patients First <sup>3</sup>) set out to rectify these shortcomings, and improve quality of care by making patients 'the first and foremost consideration of the system and everyone who works in it' <sup>4</sup>. It noted lack of systematic progress on patient involvement, which, it was suggested, had arisen from lack of clarity and confusion about how to do it, the challenges that this posed for current practices and vested interests, and the difficulty of changing the way in which the public thinks. The failure to operationalise patient involvement was compounded by persistent lack of prioritisation of PCH by health systems.

There have, however, been a number of initiatives that have attempted to develop person centred healthcare.

Through policy documents, successive governments have taken practical steps to empower patients and put them at the centre of their health and care. Most recently this was included in statutory guidance issued to CCGs and NHSE (2016 <sup>5</sup>), which provided a set of values and principles:

- Supporting people to manage their own health and wellbeing on a daily basis
- Supporting individuals to become involved as much as they want, or are able, in decisions about their care
- Giving people choice and control over the NHS services they receive
- Focusing on what matters to the individual within the context of their lives
- Commissioning services that routinely provide individuals with the information, care and support to determine and achieve the outcomes that matter to them

The changes that health services are expected to make have included promoting and publicising the choices that are available to people, personal budgets, monitoring and assuring provider and commissioning processes to check for involvement of people, and implementing workforce strategies that emphasise and equip professionals to provide person centred healthcare.

Involvement of patients in their own care has been accompanied by guidance about patient and public involvement in development and commissioning of health services, in particular by being involved in governance, planning, proposals for change and operational decisions<sup>3</sup>. It was thought that increasing involvement in the wider provision of healthcare would also increase individuals' knowledge of services and 'how to use them appropriately, supporting them to be in control of their own health and care'.

In a further policy initiative on development and access to innovations, the Accelerated Access Review noted the importance that patients attach to the NHS providing access to emerging, transformational innovations as early as possible<sup>6</sup>. Accordingly they recommend that patients should be involved in horizon scanning and prioritisation of potential developments and that their involvement should continue along the entire innovation pathway. Such an initiative highlights the importance of including patients in choices that will shape the future of care and care for other patients rather than just for themselves.

Whilst government policy has articulated the primacy of patient involvement in the form of rights, a complementary element has emerged. Alongside rights, through the NHS Constitution in 2009 the government has also introduced an associated set of duties placed on patients and individuals to take responsibility for their own health accompanied by a commitment that the NHS would support individuals to do so<sup>7</sup>.

## 4 Justification

Academics, commentators and policy leaders characteristically justify person centred care on the basis of a number of considerations, including ethics, efficacy and safety of treatment, and economics. Some of these will be explored in brief below.

### 4.1 Ethics

Professional practice in healthcare is often judged on the basis of whether it is consonant with prevailing ethical principles. In the case of PCH, commentators have sought to justify their practice in terms of compatibility with three dominant moral theories: deontology, virtue ethics and consequentialism<sup>8</sup>.

- **Deontology** – argues that actions and attitudes are considered morally good in and of themselves because they possess some intrinsic property of rightness that ought to be pursued as a matter of duty. An example of this within healthcare might be codes of medical ethics which outline duties, ideals and standards of conduct that should be upheld as they are regarded as inherently right.
- **Virtue ethics** – this theory appeals to the idea that attitudes and actions exist in equilibrium. Fostering the right kinds of character traits in healthcare professionals will lead to more authentic medical practice. Therefore, although one can *act* in a person centred way, if one lacks the attitudes and beliefs underlying person centredness, these actions will not really *be* person centred.
- **Consequentialism** – consequentialist approaches focus on outcomes and argue that an action is morally justified if it leads to good consequences (such as improved patient outcomes, decreased cost etc.) Research has shown that PCH can lead to a broad range of patient safety and clinical effectiveness outcomes (see section 4.2).

Although each of these theories can be employed to ground the belief that PCH is morally desirable, at the core of PCH lies a collection of inherently moral values which are important regardless of attitudes or outcomes, resonating with a deontological approach. These values appear to be consistent across definitions (of PCH), and collectively, arguably provide the most convincing ethical grounding for person centred healthcare. These values include:

- **Engaging with the patient as a whole person** – This involves appreciating the uniqueness of the individual. A physician should recognise that the ‘life story’ of one patient may be completely different to another with the same condition. It is crucial to recognise the relational and social context surrounding how patients make important decisions about their care.

Treating patients in this way is not merely good clinical practice - it is also a good moral practice. Indeed some ethicists emphasise the use of narratives to fully inform moral decision-making<sup>9</sup>, on the presumption that having all information about a given situation is important for determining the right way to act.

- **Respect for persons** – This involves recognising the individual as an end in themselves irrespective of their individual capacities and accomplishments. Guided by the categorical imperative, Kant’s description of each individual, as a rational agent, having ‘unconditional and incomparable moral worth’<sup>10</sup> is consistent with one of the first definitions of PCH: ‘understanding each person as a unique human being’<sup>11</sup>.

- **Shared decision-making** – Here the physician encourages the patient to become an active participant in their own care. This can be grounded in the ethical principle of respect for **autonomy** as it acknowledges the importance of the beliefs, values, preferences and choices of the individual patient. It is for this reason that some argue PCH has a ‘powerful ethical resonance’<sup>12</sup>.

Other commentators argue that PCH is ethically justified not from any inherent moral value but because of its opposing relationship to other models of care. For example because of how it differs from disease or illness-focused care, or how PCH is in contrast to traditional paternalistic professional/patient relationships. (See section 4.4)

### 4.2 Effectiveness, efficiency, quality and safety

It is believed that PCH may lead to safer, cost-effective healthcare, which in turn reduces health service utilisation rates and improves health outcomes.

People with high levels of health activation (that is, who have the knowledge, skills, and confidence to manage their health) are more likely to adopt healthy behaviour, to have better clinical outcomes and lower rates of hospitalisation (and therefore lower overall healthcare costs), and to report higher levels of satisfaction with services<sup>13</sup>. This may be related to greater self-confidence, better treatment adherence, better relationships with health professionals and less use of emergency services. Although there was an initial expectation that person centred healthcare may mainly benefit those in higher socioeconomic groups (who may be more assertive and able to engage with the health system), in practice the findings have been that the benefits can be achieved across the full socioeconomic range;<sup>14</sup> ‘people from low literacy groups can benefit more than most when appropriate efforts are made to inform and empower them’<sup>15</sup>. Rather than exacerbating inequalities, a person centred approach to care can help tackle inequalities at an individual level. Some person centred approaches are underpinned by statutory obligations. For example, the Mental Capacity Act 2005 creates a statutory requirement to take ‘all practicable steps’ to help an individual have sufficient competence to make a decision<sup>16</sup>. Therefore, person centred healthcare can act as an important tool for clinicians to inform and empower patients with lower levels of capacity, rebalancing health inequalities.

### 4.3 Economics

Globally, governments are attempting to ensure that diminishing financial resources are employed to maximum effect. As health systems move to a value based pursuit of cost effectiveness – achieving the best clinical outcomes at the lowest financial cost - person centred healthcare warrants attention. The economic impact of long term chronic conditions poses a threat to sustainable health services and there is a potential for PCH to mediate ‘significant changes in patient behaviour’ and the nature of service use. In particular, PCH could underpin a transformation of care for those with chronic illness by moving provision in the acute sector to care in the patient’s own home thus enhancing ‘patient autonomy, dignity and sheer convenience at the same time as reducing costs’<sup>17</sup>.

PCH has also been associated with reduced diagnostic testing costs in primary care settings<sup>18</sup>.

### 4.4 As an essential corrective to the problem of continuing depersonalisation within healthcare

Person centred healthcare recognises the extra dimensions of long term, co- and multi-morbid, socially complex illnesses that have become much more prominent in ageing societies and present major challenges to health systems. The European Society for Person Centered Healthcare notes the need to focus on the whole person rather than individual organs and underlying molecular abnormalities, commenting that the latter has led to 'super-specialisation and silo-isation of care that has greatly fragmented clinical services rendering them unable to serve patients well'<sup>17</sup>.

## 5 Scope of person centred healthcare in current policy and practice

Initially developed for palliative care, until recently, PCH has been applied mainly to chronic illnesses and long-term conditions. This may be because people with long term conditions often require regular monitoring and continuous treatment; they may be in contact with multiple different specialists (also a particular feature for those with genetic disorders); and throughout life need to make adjustments in work, social and personal life in order to best live with their condition. The challenges they face vary widely depending on their personal circumstances; the number, nature, and stages of their conditions; the need for lifestyle, specialist, and technical interventions; and their capacity to self-manage effectively. Individual priorities and goals also differ and may often extend beyond a specific condition or health focus. It is, therefore, even more important that people receive care that takes account of these considerations. Person centred healthcare has been developed in many settings including terminal care, dementia and Alzheimer's disease, diabetes, learning disability and care of older people <sup>19</sup>. 'Woman centred care' is also referred to in guidance and policy documents on maternity services <sup>20</sup>.

At the same time, prevention has increasingly been recognised as an important way to avoid chronic disease, and better manage its progression. Emphasis has been placed on holistic models of health and wellbeing, which recognise the importance of everyday lifestyle choices whilst continuing to place emphasis on the social context in which choices are made, including access to resources. Availability of digital technology to support choices has led to the expectation that health and care will increasingly be personalised and respond to people's needs in the moment. Such expectations have been reinforced by consumer expectations from other sectors and from new entrants to health and healthcare that place emphasis on choice, convenience and personalisation.

In acute care, episodes may arise as an exacerbation of chronic disease or as standalone events which may arise from disease or trauma. There is a general feeling that it is harder to provide care that is person centred in a crisis oriented acute care setting which lacks the time to develop physician-patient relationships and the resources for continuity of care. However, although more challenging, this should still be possible, and could be better enabled by technological advances. Online healthcare records, for example, could enable healthcare professionals to access a full picture of their patient quickly, including medical history and wider social circumstances or preferences (such as may have been documented for management of a chronic disease) and help facilitate person centred healthcare.

## 6 The practice of person centred healthcare

Whilst there is considerable rhetoric about the desirability of person centred healthcare, much less detail exists on the essential elements and how it should be put into practice. At the heart of PCH is a commitment to understanding the patient holistically and a process of shared decision-making which is informed, shows respect for the patient, takes into account values and preferences and enhances autonomy, empowerment and support for self-management. Compassionate care for the patient is also an essential element.

However, whilst these top level principles are generally agreed, the tools by which they are enacted and monitored do not yet exist in a comprehensive form. For example, Miles *et al* comment that 'there is an urgent need to utilise or develop de novo a range of additional tools with which to elicit the patient's narratives, values and preferences, means to understand their psychological, emotional, existential and cultural needs, methods to assess their relational and social functioning and methods to explore and respond to patients' overall goals and life plans'<sup>17</sup>. Guidelines on person centred healthcare in the context of multi-morbidity (NICE guidance NG56) are 'heavy on principles and exhortation but light in terms of actionable methodology'<sup>21</sup>. They also note a relative absence in clinicians of the necessary skills to change their practice towards PCH. The European Society for Person Centered Healthcare has plans to develop the generalities of PCH as expressed in the NICE guidance into a set of multiple components that are particularised to the management of specific clinical conditions.

## 7 Perceived challenges in providing person centred healthcare

A number of obstacles or barriers to providing PCH are commonly described. Whilst these are important factors to consider, a number of responses have also been rehearsed in the literature, discussion forums and the PHG Foundation *My healthy future* workshops. We summarise some of these in Table 1 below, including some of our own comments on the relevance of these barriers in the context of personalised prevention.

Table 1. Perceived challenges to person centred healthcare and emerging responses

Challenges	Responses
<b>Time and resources</b> - short consultation times may seem to prohibit the wider exploration of a patient's needs and the discussion and negotiation involved in enabling patient centred decision-making.	Longer consultations may help doctors to avoid prescribing medication or interventions that the person finds difficult to fit around their routine - resulting in non-adherence, worsening symptoms and further consultations down the line.
<b>Increased cost</b> – there is a general expectation that person centred healthcare will be more expensive to provide	Sometimes patients will decide in favour of less invasive or intensive options which may also be less expensive for the health system <sup>1,22</sup> . Examples of this could include a diabetic patient going to a cookery class to learn what to eat to control their glucose levels rather than relying on expensive medications, or responding to DCIS (an early form of breast cancer) with increased monitoring and regular scans rather than a surgery.
<b>Lack of a precise definition</b> – different groups (professional or lay) focus on different aspects of PCH	There are many definitions but they share the same elements. It is important to get beyond this argument by taking the principles and translating them into practice. Moving forward the question will be how the various aspects of the definition should be put into operation.
<b>Technical nature of medicine</b> – genomic/ precision medicine may mean that there is a need for more expert mediated decision-making. It may also require integration of multiple data types that could be done using AI. Increasingly 'answers' may be provided by computers using algorithms that develop recommendations based on an individual's data and preferences.	<p>Precision medicine reduces uncertainty surrounding medical outcomes and should lead to more understanding and a better technical quality of medicine. It may be perceived that precision medicine makes it more difficult for patients to refuse a proposed intervention.</p> <p>However, individual choice remains crucial; patients can refuse treatment even though it is better targeted, and should they choose to proceed they are able to do so with consideration for their own circumstances, and what particular treatment pathways or outcomes mean for them. Given appropriate information, only they can judge the potential impact of disease on job, activities, independence or family and take a decision on a treatment option that best meets immediate and long term needs.</p> <p>Increasingly patient decision-making may also be assisted by computers using algorithms that develop recommendations based on an individual's personal and social as well as clinical data and preferences.</p>
<b>Confidentiality and patient integrity</b> – patient narrative may include embarrassing or otherwise sensitive details about personal feelings and history, social relationships, and related aspects. This is compounded by requirement for the multidisciplinary nature of care and the need for continuity of care which requires documentation, storage and sharing of patient details	The disadvantage of personalising things is that it is personal. We need to consider the social contract – are we demanding things from patients that they don't want to be open about?

### Challenges

### Responses

**Equity** – allowing patients to adapt treatment and care according to preferences and circumstances would risk benefiting patients with more sophisticated preferences and life-styles at the cost of patients with lower expectations.

If clinicians know that particular groups are less likely to make demands they can adapt their conversation in order to address this.  
Decision-making should incorporate social, gender and other relevant factors such as ethnicity.  
We can do more to tackle inequalities if we understand what the barriers to particular groups are, and what interventions work.  
Stratification, not just by disease but by beliefs/values and social characteristics would also help to promote equity.

**Responsibility** – person centred healthcare might unfairly inflate patient's responsibilities for their health.

People already take responsibility for medical decisions to a large extent. We need to recognise that increasing autonomy will be something that some people are fine with and others find very scary. 'There is a danger of catastrophising risk!'

Concerns that patients may make the '**wrong**' decision – this presumes that there *is* a right decision and conversely that some decisions would be 'wrong' and go against advice based on medical evidence.

Most would agree that individuals have an intrinsic interest in their own well-being and so are in a unique position to make the 'right' decision for themselves. Important factors in this consideration include that:

- Decisions rarely stand on their own but are often one in a long line of choices that accumulate to shape an individual's life.
- 'Regret aversion' is extremely powerful, ('what would I feel if..') but does not necessarily lead to the best decision.
- The law provides some limits for certain types of decision-making that are limited on grounds of public policy (e.g. late termination of pregnancy on non-medical grounds or euthanasia)

Providing **compassionate care** – how do we still provide this in a relentlessly technical environment, where there may be less patient contact and a multiplicity of providers?

It may be possible to use technology to free up professional time so that patient contact time is used to strengthen the personal relationship.

## 8 Person centred healthcare in the context of *My healthy future*

*My healthy future* envisages health systems that increasingly use a wide variety of new technologies to help people stay as healthy as possible. Through the project we wish to explore the challenges of providing person centred healthcare within a system of personalised or precision medicine where new technologies such as genomics are being used to identify and assess risk or to detect disease early and offer personalised prevention. In this section we introduce some of the arguments advanced around the opportunities and barriers for PCH arising from new technologies and some of the wider issues that may arise.

### 8.1 Genomics, digital technologies and personalised prevention

#### Personalised medicine

Genomics and other 'omics' technologies including the transcriptome, proteome, metabolome and even the exposome (a theoretical measure of internal and external environmental exposures over a lifetime) offer unprecedented opportunities for individuals to find out about their risk of disease or detect its onset early – making it possible to prevent disease or ameliorate the effects. Increasingly, these opportunities create a new dimension for prevention which is increasingly personalised. They enable assessment of individual risk with the aim of offering an intervention appropriate to that risk. Delivery of preventive healthcare in this way would form an important strand of the increasing push to more personalised medicine within the entire health system.

Whereas genomic tests would largely be provided by the health sector, individuals are nowadays accessing information about their health from wider sources: in the future we can envisage a range of biomarkers being available via wearable sensors such as Fitbits, sensors in the environment or new technologies such as AliveCor, which can provide detailed 24 hour ECG monitoring. It seems likely that increased personal access to technologies will drive health system demand by increasing patient self-monitoring and alerting them to early disease, for which they will seek advice. This may be accompanied by increased patient motivation to reduce risk of disease (for example by lifestyle modification) and ability to manage their conditions safely. Person centred healthcare will surely be an important element in this scenario, and will require the availability of a trusted professional to provide support and assist in decision-making both in general terms and over particular times of concern.

#### Genomics and personalised prevention

The use of genomic data to assess risk and predict future disease has most utility in the case of single gene disorders where risk of future disease may be extremely high and effective treatments are available.

Increasingly genomic risk assessment will also include measurement of so-called susceptibility variants, where a combination of many variants (often in excess of 100) is used to assess risk of common chronic diseases such as heart disease or cancer. The population can then be stratified according to risk and preventive options tailored to the risk level. This has the theoretical advantage of minimising the harm that can arise from unnecessary testing, or treatments for low risk people providing little benefit. Interventions may target those at highest risk, in the hope that this group will have a greater chance to benefit and may be more motivated to change their lifestyle or comply with treatment. Ultimately, this will also be more cost effective for the health system.

Using genomic information for prevention is extremely complex leading some commentators to question whether and how important aspects of PCH can be delivered. These challenges in delivering person centred healthcare are likely to apply to the future delivery of other complex technologies.

In genomics, particularly in the context of wide genomic screening (e.g. whole genome sequencing), people may find out about a wide range of potential diseases, some very rare. In the context of clinical symptoms and family history, such information can be strongly predictive and lead to useful treatments or preventive interventions for patients (for example diagnosis of inherited cardiac arrhythmia gives ability to provide drug treatment or implantable cardioverter defibrillator (ICD) to prevent sudden cardiac death.) However, much of the data generated from genomic screening is at present of limited utility, either because it only indicates, at best, a small increase in disease risk (e.g. increased susceptibility to diabetes or heart disease) for which only general advice can be given (e.g. stop smoking, good diet and increase exercise) or because the implications, in the absence of clinical disease or family history, are difficult to assess. There is a further problem that currently the vast majority of physicians are unprepared to help patients interpret genomic test results and take action. Yet the stakes are high: genetic risk factors might seem to justify interventions that are invasive and potentially harmful and there is concern that non-expert clinicians and patients might not understand how to contextualise genetic risk factors. At the individual level, getting decisions wrong could be costly on many dimensions, whereas for health systems there is the question of how to deal with increased demand and how to optimise benefit for the whole population.

### Genomics and person centred healthcare

Some commentators have argued that genomic medicine undermines patient empowerment because it potentially provides an authoritative medical justification for clinicians to act in a particular way. Where genomic information provides most clarity such as in precision medicine 'patient-driven decision-making seems almost completely jettisoned'. Juengst highlights that it is only where relative risks and benefits of treatment choices are uncertain that 'patients' preferences about how to gamble are given significant weight'<sup>23</sup>.

A driver for implementing direct to consumer testing has been that this empowers individuals to be 'in control' and enables them to take a more active role in their healthcare. Critics argue that the rhetoric of empowerment in the context of direct to consumer genomic testing is false since information is frequently provided without providing support or guidance to consumers/patients as to how to act.

Instead, some argue that the onus placed on parties such as DTC companies and professionals should be to act with the best interests of patients in mind, even to the extent that information that has no clinical and/or personal utility should be withheld. Part of the emerging role for professionals might be 'responsibility coaching' where they use their expert knowledge to advance the patient's best interests.

Whilst pursuing a person centred care approach might provide health professionals with a justification for exploring wider structural health disparities with their patients, care is needed to ensure that in so-doing, this does not exacerbate existing social or political disparities. This aspect will be explored within the *My healthy future* project in a separate roundtable discussion.

### Digital technologies

Digital technologies are neutral, but can be used either to promote or act as a barrier to person centred healthcare. Technology can promote person centredness by providing a mechanism for a patient to provide their clinician with critical information about themselves, relating to their functioning and well-being. This may be particularly useful if it enables information related to disease processes or well-being to be more continuously monitored (e.g. through wearable sensors), or to be gathered remotely, for example at home.

Technologies may also be used to enable care to take place through a different medium rather than a personal face to face interaction. For example, diagnosis and prescription of appropriate antibiotics for chlamydia infection (a sexually transmitted disease) can take place with online support for the patient to submit samples, receive results, obtain treatment and even provide information to potential contacts. However, we must be aware that through enabling healthcare via a different medium (e.g. changing the technology through which information is exchanged), we are changing the interaction between the patient and the healthcare system. It is not merely the same clinical interaction enacted through a different medium, but instead will impact how patients understand and react to information.

Similarly, the clinician can use technology to integrate this information with their medical knowledge and improve patient care. It can also help patients share information with their family and friends, and with other patients (e.g. social networking sites), as well as helping multiple members of the care team update and share critical information.

With medical technology there is also a counter argument that increased use tends to depersonalise both sides of the health relationship. Although digital technologies may provide an acceptable, or even preferable substitute for some patients it is important that this is not just a cost-cutting exercise and that attention is given to those groups who may not so readily access these technologies (e.g. older people or individuals without access to a computer), or who need the personal contact as part of the caring, curative experience.

There may also be a fundamental threat to the relationship between patient and doctor when diagnoses and even recommendations on best treatments are handled by computer, using artificial intelligence and based on a set of algorithms that access data about the patient (usually in comparison with a large number of other 'similar' patients). How will the human side of the interaction be retained under such circumstances?

A further potential problem is that of health anxiety. Will the introduction of constant monitoring lead to greater societal pressure to conform to a certain way of being 'healthy'? This threatens the autonomy that characterises PCH.

### 8.2 Wider challenges

Finally there are many more general challenges to providing person centred healthcare, particularly in the context of disease prevention in an environment that explicitly values personal autonomy and healthcare that is adapted to the individual's holistic needs rather than a 'one size fits all' provision. These include the potential for different approaches to screening, challenges arising from the concerns about overdiagnosis (this will be explored more fully in a separate workshop) and the tension that exists between personalised prevention and major population orientated public health programmes.

### Screening

Finding out about disease risk or attempting to detect disease at an early stage in healthy people are activities that in the UK fall under the label of screening. Where these attempts are organised and state-led the National Screening Committee (NSC) has the responsibility for determining which new programmes will be set up, the precise nature of the offer and follow-up services and the overall running and monitoring of the screening programme. Decisions are taken following detailed evidence review and judgments against a set of 'screening' criteria based on those originally set out by Wilson and Jungner<sup>24</sup>. In this decision-making there seems little room for personalisation for individuals about what screening each may choose to access. For example in the area of newborn screening for rare inherited disease, there is no leeway for individuals to ask for a broader range of testing that might fit their own sets of concerns and preferences (for example if they have experience of a particular condition, or social circumstances which would mean that they were unable to cope with a child with significant health problems).

Although NHS provision of screening is limited by decisions of the NSC, increasingly individual screening tests are offered through the commercial sector either direct to consumer or via private healthcare providers. When faced with the overwhelming variety of options presented by the commercial sector which allow for a greater degree of personal choice (e.g. which screening tests to undertake, at what age to take them, how regularly?), the tests offered through the NSC may seem relatively limited in comparison. Help to navigate a wide range of screening offers will be an important aspect of person centred healthcare going forward, in particular where these offers come from the commercial sector and are motivated by profit through fee for service.

### Over-diagnosis

Risk assessment and early detection have to be balanced with the potential of harm (sometimes broadly termed over-diagnosis) which may occur when a healthy individual seeks to identify increased risk or early disease. It is possible that learning about personal risk or receiving a positive result may lead them to become anxious, undergo invasive tests or even potentially harmful treatment, despite the fact that the disease may not be present or might in the future not cause any harm.

For person centred healthcare there is a tension between the view that knowledge is intrinsically good and that the individual knows what is best for himself/herself and the need for guidance and advice based on the utility of tests assessed at a population level, including the holistic experience of individuals who have received positive and negative test results.

Within *My healthy future*, this topic will also be examined in more detail through a separate roundtable.

### Individual vs population based approaches

In this highly technical, information rich environment it seems clear that the systematic provision of person centred healthcare across all populations ideally should enable individuals to stay healthy and have the best quality of life through acute or chronic disease. However, this requires interaction between the health system and individuals receiving care, through which the health system is enabled to understand user needs and provide tailored support. In disease prevention terms this seems currently to be at odds with the major population focused disease prevention programmes designed to improve health through shifts in population averages (e.g. campaigns or structural interventions to reduce salt intake, cut tobacco consumption or increase physical activity).

As technological advances and commercial provision increasingly enable personalised preventive medicine it seems likely that both personal and population approaches will be essential and that person centred healthcare should be a central element of the former.

The development and provision of preventive person centred healthcare based on genomics will be hampered by the fact that most public health professionals have not embraced these technologies as a useful means of personalised prevention on a population basis. Most are still of the opinion that genomics is about rare disease and not relevant to the major chronic diseases of the population. They are also concerned that different messages for different people according to risk – i.e. the idea of personalised prevention – will only serve to confuse and people may just respond by doing nothing. Finally, healthcare professionals are ill equipped to support personalised prevention and there is no single group of health professionals with the training, experience and support systems to undertake this work.

## 9 Findings from the life stage workshops

Between January and June 2018, four life stage workshops were held as part of the *My healthy future* PHG Foundation programme focused on future technologies and health. In each workshop participants were asked to identify issues that would arise with the increasing use of digital and genomic technologies aimed broadly at disease prevention.

Throughout the workshops concerns were raised about the impact of new technologies on person centred healthcare. The predominant concern was that new technologies might undermine person centred care – even though it was acknowledged that, at times, technologies could enhance the ability to provide it. In an era when individuals will be creating and accessing vast amounts of data about themselves from a wide range of sources – more time and attention needs to be given to establishing the roles of health professionals in guiding people through the health related decisions. Overall the importance of the human factor was stressed and there was recognition that the art and craft of the medical professional could not simply be replaced by technology.

One generic concern was that technology, such as the use of data and apps, would be used to replace human interaction. This may be introduced as part of cost containment.

The view was expressed that person centred healthcare can be more expensive and resource intensive than standard care. It involves treating patients with dignity and taking the time to understand them as people. Rather than characterising PCH as 'just a cheaper, consumerist thought based on providing a range of treatment options' it should be 'about dignity, time and value and is not just a decision aid or the provision of lots of choice'.

Person centred healthcare can also help individuals have more realistic expectations about what medicine can (and cannot) deliver. Technology developments might imply that there are solutions to every problem, which is not always true. The healthcare professional has an important role to manage expectations. Otherwise there may be disillusionment with healthcare, confusion, wasted energy and more.

Below, we have outlined some specific concerns related to the various facets of person centred healthcare: holistic understanding of the individual; autonomy, empowerment and decision-making; and compassion dignity and respect.

### 9.1 Holistic understanding of the patient

As data proliferates, there is a risk that an individual is reduced to their data excluding other important factors relevant to the well-being of the patient. Concern was expressed that use of a dumbed down dataset might be exacerbated if systems rely on structured input data, and if human intervention in the form of knowledgeable individuals is removed from the system with the danger that clinical practice would be reversed.

In the future, machine-learning driven analytics may be able to engage with an individual's dataset, including health service derived data, and personal data obtained through apps to extract information relevant to particular health problems (for example, evidence of early disease). A combined dataset might then be used to prompt information or signpost to relevant advice. This could enable individual drivers for lifestyles to be identified, this may be particularised for different age groups (e.g. young people vs older people) and even be personalised at an individual level to understand a person's particular drivers, concerns, motivations and what might get them to change behaviour and maintain those changes.

For young people digital data may also enable a better understanding of competence, maturity and capacity (relevant for personal decision-making). For example, it could be used to judge capacity and impulsiveness (through brain scans) for use in healthcare settings.

### 9.2 Autonomy and empowerment

There was discussion about what level of human support will be needed to assist decision-making. It was assumed that some therapists and clinicians will provide support but overall it was doubtful whether health services would have sufficient capacity to deal with all of the data that was driven by individuals (young people workshop) and that there would need to be a balance between digital and in person support. This would change in different circumstances: for example, being driven by personal characteristics such as self-reliance (often thought of as a general characteristic of adolescence), the condition and management in question, and the circumstances.

An understanding of the personal context of the information would be vital including their emotional response and their level of understanding and processing. The potential of life story work was introduced in the older person's workshop as something that might help an individual learn from personal past experience and hence inform their decision-making or motivation. An example was given where collecting highly personalised life story information (for example, what form of exercise is preferred at different stages of life) may help an older person assess what might be a useful strategy in later life.

This idea was further developed into the idea of a virtual life assistant designed for health care (see below):

The assistant would have an understanding of the individual, their circumstances and behaviours, and would respond with advice and prompts reinforced by knowledge of the local environment and opportunities available. It would receive data on bioassays such as urine tests and could provide reminders, prompts or changes based on these. A life assistant might detect when an individual is unwell and actively encourage behaviour change. It would be highly personalised, to the extent that it might take on some social aspects during an interaction i.e. being caring and empathetic. It might realise when an individual is down or lonely and make suggestions it knows would help.

### 9.3 Dignity, compassion and respect

In an era of decreasing social connectedness it was important to recognise that dealing with illness, which may be an emotionally challenging situation may require a human interaction. Although individuals may be signposted digitally to a particular advice, diagnosis or management service it will often be important for them to experience the personal component of healthcare delivery.

The example was given of a service for sexually transmitted disease which has been developed to be delivered online. However, developers were aware that, for many there would still be the need for human interaction. For some, face to face would be the best and preferred media for care. Even for those accessing care digitally it would be important to provide follow up learning and continuation of care that is age appropriate and personalised.

### 9.4 Recommendations from the life stage workshops

Going forward, the life stage workshops made recommendations to ensure that the adoption of new technologies enhances overall person centred healthcare (rather than detracting from it):

- Consider and establish guidelines on the roles of health professionals in this technology changing era
- What does success look like in PCH? We should set some objectives including how it will be measured. Health should be regarded as a means to an end rather than an end in itself and research on outcomes should be based on an understanding of the basic human needs that we are trying to meet. For example, for older people, we should not be restricted by current 'expectations on what a healthy life looks like as you age'. In particular researchers should be interested in outcomes that stretch beyond the basic activities of daily living and may include an extension of previous activities rather than simply maintaining them
- Technology development should build in mechanisms to take account of heterogeneity in individual values
- With new developments consider the balance of digital and in person support recognising that this may be different for different individuals, conditions and settings
- For AI in diagnostics it would be important that the AI is trained not to behave inappropriately – i.e. that it is able to deliver empathic responses. It will be important to think about how we build these robots and how they are programmed. How will they manage the compassionate or wellbeing side of healthcare?
- Education will be pivotal to the constructive use of technologies amongst individuals, schools, policy makers, developers and evaluators
- The anti tech feeling is likely to increase with increased reliance in the future. It will be important that there is a healthy debate in society about how best to use technologies and how people will make personal choices. The anti-tech debate should be part of functioning society
- User experience should be embedded into development work

## 10 Conclusions

It is widely acknowledged by policy makers and healthcare leaders that putting person centred healthcare in place is the right thing to do for a health system aiming to deliver high quality, safe and efficient care. However, many feel that this is jeopardised by the increasing technological basis of modern medical practice, the multiplicity of providers and the fear that machines and technology will be used to replace, rather than augment, the human knowledge, experience and relationships that, it is believed, are fundamental to healthcare.

In this paper we have identified, and attempted to clarify some of the background issues.

Going forward, we shall aim to address the overarching question 'What will person centred healthcare look like in 20 years time?'. In order to explore this, we have noted some initial questions that arise.

In an era of new technologies aimed at personalised disease prevention:

- How could PCH for disease prevention be promoted and implemented both within and outside the health system?
- Is PCH still important beyond the health system and interactions with healthcare professionals? Why?
- What are the most significant challenges that might arise and how can we mitigate against these?
- Is PCH redundant in an era of personalised (technology enabled) medicine? If not, how can it be used to support personalised medicine?
- How do we build and use new technologies in ways that will facilitate and strengthen person centred healthcare? (For example, how could digital technologies help us develop a holistic understanding of the individual?)

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PHG Foundation is a health policy think tank with a special focus on how genomics and other emerging health technologies can provide more effective, personalised healthcare