

## ESSENTIAL GLOSSARY FOR RIGHTCARE

Language creates reality, it does not describe it. That is one of the principles that has emerged from anthropology, linguistics and philosophy from authors as diverse as Ludwig Wittgenstein, John Searle and Benjamin Lee Whorf. Confusion about language and the meaning of the terms being used is one of the main causes of arguments, fruitless arguments, which disappear if everyone shares the same understanding of the term. At BetterValueHealthcare we developed the 21<sup>st</sup> Century Healthcare Glossary with the principles of clarifying the meaning of commonly used terms to improve dialogue and decision making. The glossary consists of 1000+ terms and their meanings in use. Some of these ostensive definitions are long and can be unwieldy for everyday use so we have, where appropriate, presented a shorter, more useful definition, which we call the bottom line for that term.

Tremendous progress has been made over the last forty years due to the second healthcare revolution, with the first healthcare revolution having been the public health revolution of the nineteenth century. Hip replacement, transplantation, and chemotherapy are examples of the high tech revolution funded by increased investment and, in the last twenty years, optimised by improvements in quality, safety and evidence based decision making. However there are still three outstanding problems which are found in every health service no matter how they are structured and funded: One of these problems is huge and unwarranted variation in access, quality, cost and outcome, and this reveals the other two

- Overuse which leads to
  - waste, that is anything that does not add value to the outcome for patients or uses resources that could give greater value if used for another group of patients
  - patient harm, even when the quality of care is high
- Underuse which leads to
  - inequity and
  - failure to prevent the diseases that healthcare can prevent , stroke in atrial fibrillation for example.

In addition the services will have to cope with rising need and demand without additional resources.

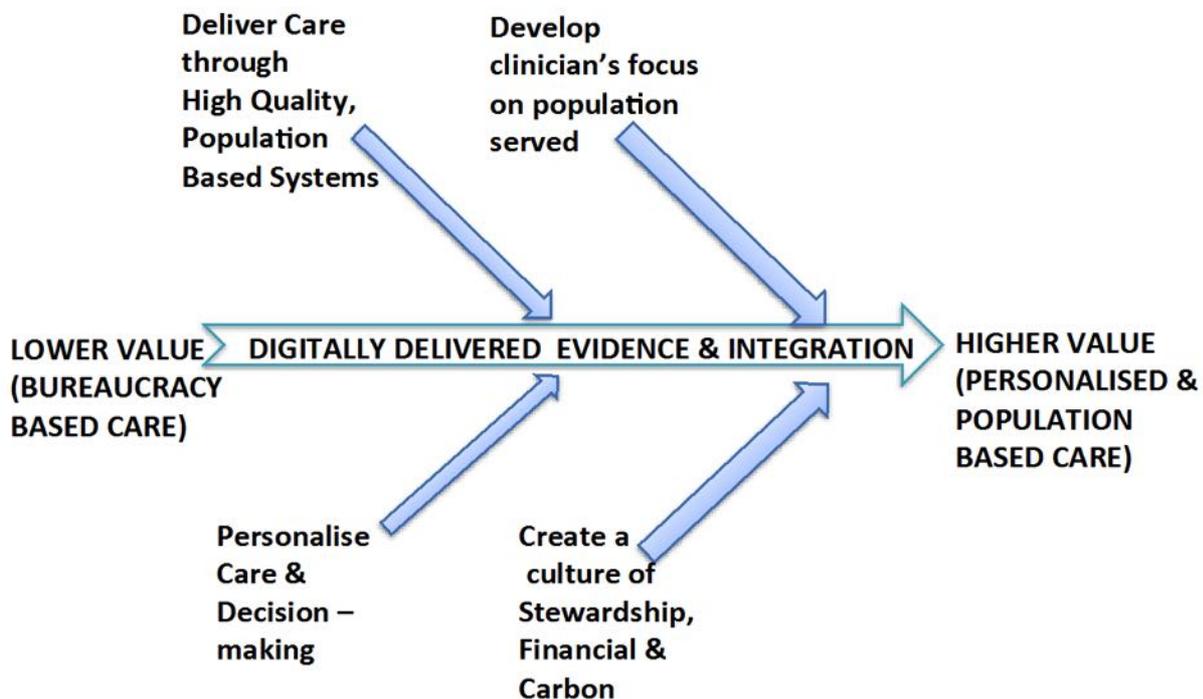
More of the same, even better, quality, safer care is not the answer. The focus has to be on value, on better value for individuals and populations. To achieve this we need

- Personalised services for all the people affected in the population
- Optimal allocation of resources
- Development of collaborative systems and networks with patients & carers as equal partners

- Faster adoption of high value interventions and technologies
- Clinicians acting the stewards of the population’s resources

A new paradigm is needed not a new structure. In an era in which there will be insufficient money to meet need and demand we need to harness the forces driving the third healthcare revolution – citizens, knowledge and the smartphone

We need a transformation with the new focus on triple value. This will not be brought about by more money, even if more money were available. Nor will it result from structural reorganisation because the bureaucracies which are necessary are organisations that operate in a linear fashion whereas health and healthcare issues are complex or ‘wicked’ problems and require new types of intervention shown in the diagram below



Here are definitions of the key terms

- **Value** – “What is gained relative to what we give up – the benefit relative to the cost but not only to the direct cost, which is the efficiency of a service, but the Opportunity Cost, or the Opportunity Lost to put it another way and there are three dimensions to value in healthcare
  - **Allocative value**, determined by how the assets are distributed to different sub groups in the population
  - **Technical value**, determined by how well resources are used for all the people in need in the population
  - **Personalised value**, determined by how well the decisions relate to the values of each individual
- **Quality** - The quality of a service is the degree to which it meets pre set standards of goodness. Low quality care is of low value but even high quality care may be of low value depending on what else could be done with the resources required to achieve the improvement in quality
- **Waste** - Waste is any activity in a process that consumes resources without adding value for the patient
- **Cost effectiveness** - The relationship between the cost of an intervention and its impact. Interventions that are not of proven cost effectiveness are of low value but even interventions deemed cost effective may not be of high value depending on what else could be done with the resources that would be required to introduce it
- **Overuse and optimality** - Optimality is reached when resources or productivity create maximal benefit with the least harm. Beyond optimality there is overuse.
- **Equity** is a subjective judgment of unfairness.
- **Programme budgeting** - The fundamental idea behind programme budgeting is decision making based on explicit criteria related to the wellbeing of the whole population, as opposed to decision making by compromise among various institutional, parochial, or other vested interests.
  - Marginal analysis - Starting with a particular mix of services and analyzing changes in that mix. If resources can be shifted to produce greater benefit then this should be done.
  - Opportunity cost - The value of the next best alternative forgone as a result of the decision made.
- **System** - A set of activities with a common set of objectives with an annual report, for example a system of care for people with epilepsy or people with back pain or people with multiple morbidities.

- Network - If a system is a set of activities with a common set of objectives, the network is the set of organizations and individuals that deliver the systems.
- Pathway - The actual care process of care experienced by each individual patient/client; also described as maps that define best practice.
- Programme – a programme is a set of systems for example the programme for people with musculoskeletal problems, or a programme for people with respiratory problems
- **Population healthcare** –the design and delivery of the care with a primary focus on the population in need, not the healthcare institutions, where the populations in need are defined not bureaucratically but by the optimum population size for high value care for individuals and the group in need **Population medicine or population clinical practice** – a style of practise in which the clinician feels, and is given responsibility for, all of the people in the population in need whether or not they have been referred
- **Culture** - “Culture is the shared tacit assumptions of a group that is has learned in coping with external tasks and dealing with internal relationships.”

This Glossary is about Personalised and Person Centred Care the latter being a style of management which always considers the patients’ perspective as the most important and is committed to increasing patient Engagement, Empowerment or Involvement, which may be regarded as synonyms. Personalised care is an element of patient centred care and is the other side of the coin from population care. This is a diffuse and fast moving field with language evolving at a rapid rate. Here are the key terms and concepts.

- **Personalised Care or Personalised Medicine** – the tailoring of care to take into account each individual’ s unique needs, preferences and values. The term has become popularised recently to describe clinical decision making in the era of the genome but another term for clinical decision making incorporating genomic information is
  - **Stratified Medicine** – decision making based on the patients degree of risk, including risk suggested by genomics and based on the long standing practice of risk stratification of elderly people based on social and medical, but not genomic characteristics
  - **Precision Medicine** – decision making taking into account genomic information either in diagnosis – ‘molecular diagnostics’ –or choice of drug treatment – ‘pharmacogenomics’.
- **Principal and Agent** – legally the patient is the principal, the clinician the agent, even if there is no money involved. Some people feel the shift in the balance of power occurred with the founding of the NHS when the patient was not charged for consulting the GP. The pendulum swung further because of

- **Information Asymmetry** - the fact that the clinician has, until the advent of the Internet much more technical knowledge
- **Trust** - Faith in another to perform a task that is not in the other's interest
- **Autonomy** - Freedom to make decisions or act without reference to others
- **Informed Consent** - Consent to treatment given with full understanding of the magnitude and probabilities of the good and adverse outcomes
  
- **Empathy** – In his book on *Emotional Intelligence* Daniel Goldman identifies three types of empathy – cognitive empathy is the ability to understand what another person is thinking. Emotional empathy is the ability to feel what another person is feeling. Empathic concern is the ability to sense what another person needs for you.
- **Evidence and Value based decision making** - Decision making that ensures the patient is fully informed about the strength of evidence about the probability and magnitude of both risks and benefits of the options being considered and that the patient has been helped to reflect on, clarify and express their preferences based on the value they place on the possible benefit, the possible harm and on the risk they are taking.
  - **Health Literacy** – The cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand and use information. The term **Statistical literacy** – the ability to understand and communicate probabilities which is shared by both patients and clinicians, sometimes called risk literacy is increasingly used
  - **Framing** - the conscious or unconscious presentation of data in ways that influence their interpretation and decision making
  - **Shared Decision Making** – is a style of decision making in which clinicians and patients are both involved
  - **Preference Sensitive Decision Making** – is a style of decision making in which the patient's preferences are explicitly elicited, to avoid
  - **Silent Misdiagnosis** – namely failure to diagnose accurately the patient's values and preferences even though their disease has been correctly diagnosed
  - **Patient Decision Aids** - a tool to support the patient during decision making, particularly before and after the face to face consultation and they are increasingly delivered using digital means variously called eHealth, mHealth, digital health or Telemedicine which may be regarded as synonyms
- **Patient defined and reported outcomes** are objective measures using validated tools subjective measures of outcome, including the degree to which the treatment addressed the problem that was bothering the patient most, rather than their diagnosis and the patient's experience.

**Necessary, Appropriate, Inappropriate or Futile Classification of interventions based on the probabilities of benefit and harm**

**Burden of Treatment** – the impact of the process of care on the affected individual and their carers