

## **Ethical Decision-Making Framework for Individual Funding Requests** **(IFRs) v1.1**

### **1. Introduction**

- 1.1 This Ethical Framework sets out the values that South London IFR Panels and South London CCGs will apply in making decisions on IFRs. South London CCGs will use it in all decisions, ranging from those which may affect a cohort of patients reviewed at the IFR Triage meeting to those that affect individuals heard at IFR Panels. This framework should be used in conjunction with the South London IFR Policy for dealing with IFRs

### **2. Purpose of the Ethical Framework**

- 2.1 Public bodies are required to be transparent about their decision-making processes, accountable to their service users and should be able to demonstrate that these are reasonable. South London CCGs have to demonstrate that their decisions about health policies and IFRs are based on sound principles and have been made after careful consideration of all the relevant factors, with reference to local conditions, and with a conscious intent to avoid discrimination.
- 2.2 CCG's have to take difficult and sensitive decisions about what will be funded and what will not. The way in which decisions are made is fundamental to their democratic acceptability and contributes to whether a decision is judged as fair.
- 2.3 This framework is designed to provide guidance to decision makers to help them make fair and consistent decisions which respect the needs of individuals and the community.
- 2.4 The purpose of an ethical framework is to:
- to demonstrate that decisions about health policies and IFRs are based on sound principles and have been made after careful consideration of all the relevant factors, with reference to local conditions, and with a conscious intent to avoid discrimination
  - Provide a coherent structure and framework for decision-making that ensures all the important aspects of each issue are considered.
  - Promote fairness and consistency in decision-making
  - Ensure that the reasons behind decisions that have been taken are clear and comprehensive.
  - Provide transparency and support CCG to

### **3. Legal Duties**

- 3.1 South London CCGs have certain legal duties as public bodies and their decisions and actions should be able to withstand scrutiny with regards to:
- Meeting statutory duties
  - Legality
  - Reasonableness
  - Proportionality

- Procedural Propriety
- Legitimate expectations
- Equality and non-discrimination

#### **4. Equality Statement**

- 4.1 South London CCGs and the SLCSU have a duty to have regard to reduce health inequalities in access to health services and health outcomes achieved as enshrined in the Health and Social Care Act 2012.
- 4.2 South London CCGs and the SLCSU are committed to ensuring equality of access and non-discrimination, irrespective of age, gender, disability (including learning disability), gender reassignment, marriage and civil partnership, pregnancy and maternity, race, religion or belief, sex (gender) or sexual orientation. In carrying out their functions, South London CCGs and the SLCSU will have due regard to the different needs of protected equality groups, in line with the Equality Act 2010.
- 4.3 This document is compliant with the NHS Constitution and the Human Rights Act 1998. This applies to all activities for which they are responsible, including policy development, review and implementation.

#### **5. Five core principles for decision-making**

- 5.1 In line with the legal and ethical duties to CCG populations, it is expected that the following key principles will be applied to all decisions.
- 5.2 These key principles are the need for decisions to be
- rational;
  - socially inclusive;
  - clear and open to scrutiny;
  - take economic factor into account , and
  - themselves must promote health for both individuals and the community

##### **Principle 1: Rational**

- 5.3 South London CCGs have a responsibility to make rational decisions and to act fairly in balancing competing claims on resources between different patient groups and individuals.
- 5.4 Aspects of this principle include:
- Ensuring that the decision is based on evidence of clinical effectiveness
  - Being logical in reasoning towards a decision
  - Making a realistic appraisal of the likely benefit to patients
  - Weighing up all the relevant factors, including risks and costs
  - Taking into account the wider political, legal and policy context
  - Ensuring individuals involved in decision making are appropriately trained
- 5.5 Where available, existing national standards, policy and authoritative guidelines must be considered; such as national directives, guidance from the National Institute of Health &

Clinical Excellence, Department of Health directives etc. Local factors, including existing provisions must also be considered. Decisions should be taken within the political and legal context.

- 5.6 South London CCGs are committed to evidence-based healthcare. Decisions should therefore be made on the basis of a reasonable evaluation of the available evidence of clinical effectiveness. Those involved in decision-making have an obligation to seek out the best evidence of clinical effectiveness to inform their decisions.
- 5.7 The approach to accessing the validity and credibility of evidence should be broad but maintain high standards of critical appraisal. South London CCGs will follow the well-developed scientific approach to hierarchy of evidence. Where appropriate, both qualitative and quantitative evidence will be taken into consideration.
- 5.8 Outcome measures should be considered in terms of their importance to the patients. This is particularly significant in the treatment of illness where no cure can be expected, in palliative care, and the care of people who are terminally ill. Rational decisions will weigh up likely outcomes, the wider contexts in which treatments can be provided, the implications for service delivery, clinical pathways, and the scale and nature of benefits, costs and risks.
- 5.9 The position, qualifications and skills of decision makers will be appropriate to ensure due deliberation of all the relevant factors.

## **Principle 2: Inclusive**

- 5.10 The term inclusivity may be interpreted as including:
  - Reinforcing the concept of equal opportunity of access to health care.
  - Ensuring patient and public engagement in decision-making.
  - Balancing the rights of individuals with the rights of the wider community to achieve equitable and consistent resource allocation between individuals and groups in society.
- 5.11 There are proven links between social inequalities and inequalities in health, health needs and access to healthcare. Access to funding of services should be governed, as far as practicable, by the principle of equal access for equal clinical need. Individual patients or groups should not be unjustifiably advantaged or disadvantaged on the basis of age, gender, sexuality, race, religion, lifestyle, occupation, social position, financial status, family status (including responsibility for dependants), intellectual / cognitive function or physical functions.
- 5.12 Effort should be made to ensure broad based participation in decision-making groups and committees. Decision-making should be non-partisan and individuals will need to be able to take an objective view of the topic, and maintain an open mind about the evidence. As far as possible consensus decision-making will be used.
- 5.13 Decision-making should not discriminate on characteristics which are irrelevant to health conditions and the efficacy of treatment. Consideration of factors such as age and ethnicity will only be considered where this is clinically relevant.
- 5.14 Decisions should take account of local and societal sensitivities.

- 5.15 There should be an active attempt to engage patients, carers and the wider public in the decision-making process to ensure that the perspectives of both health care providers and consumers are fully taken into account.
- 5.16 The aim is to achieve consistent and equitable opportunity of access to health care, between individuals and groups in society, and to avoid the kind of arbitrary discrimination sometimes referred to with the term 'postcode' as in 'postcode lottery' (of health service provision).
- 5.17 Policies should work in favour of patient choice at the individual level, respecting the individual's preferences, in particular, the ethical framework calls for sensitivity to the patient's perspective and the individual nature of choices based on quality of life.
- 5.18 South London CCGs will respect patient choice about where an IFR treatment, if agreed to be funded, is delivered, as far as this is compatible with IFR Panel's judgments as to the clinical and cost effectiveness, against costs quoted that were presented for their decision making, and having regard to whether proposed providers have been commissioned by the NHS for the treatments in question.

### **Principle 3: Clarity, consistency and transparency**

- 5.19 The values and principles at all levels of decision-making must be consistent. IFR decisions and the way they are determined, will be clearly specified, consistent, easy to understand, and open to public scrutiny.
- 5.20 This should also be the case with the roles and responsibilities of individual's involved in the process, accountabilities, governance arrangements, and the patient's right of appeal.
- 5.21 The formal process set out for the identification, prioritisation and review of policy issues has been designed with the need for clarity and scrutiny. However, IFR Panel members undertaking decision-making have a responsibility to work towards achieving these goals. Decision makers will provide the rationale for their decisions; and all facts that have influenced a decision will be clearly stated in the records of meetings.
- 5.22 The process of decision-taking will also be carefully documented, to show that it has conformed to the agreed process and to record consensus. Communication throughout a decision-making process is required to be clear and effective and communication about decisions need to be unambiguous and articulate.

### **Principle 4: Taking into account economic factors**

- 5.23 South London CCGs must ensure that the decisions they take demonstrate value for money and an appropriate use of NHS funding based on the needs of the population it serves. Given the finite resources available to CCG's, their budgets must be managed responsibly so the cost of an intervention must be considered alongside the evidence of effectiveness.
- 5.24 Investing in one area of healthcare inevitably diverts resources from other areas. Decisions will be based on careful consideration of the trade-offs between costs and benefits, both in the short and longer term, but also recognise that complex trade-offs cannot necessarily be reduced to simple cost-benefit calculations.

- 5.25 South London CCGs will consider the extent to which the individual will gain a benefit from the treatment. They will also balance the needs of each individual against the benefit which could be gained by alternative investment possibilities to meet the needs of the community.

South London CCGs should only invest in treatments and services which are of proven cost-effectiveness unless it does so in the context of well-designed and properly conducted clinical trials that will enable the NHS to assess the effectiveness and/or value for money of a treatment or other healthcare intervention. In general, low-cost treatments with high effectiveness will be preferred, whereas high cost treatments with low effectiveness are to be discouraged.

### **Principle 5: Promote health for both individuals and the community**

- 5.26 Each CCG is required to identify priorities for its population, decide how healthcare resources are to be allocated, and determine the priority to be assigned to a service or a particular health care intervention.
- 5.27 Decisions about the allocation of health care resources should be based on a clear understanding of the health needs of the population, whom decisions will affect, and the scale and nature of benefits- health needs assessment and JSNA. There is a requirement to balance the needs of the individual with the needs of the wider community.
- 5.28 Policies which promote health and avoid people becoming ill are considered alongside curative treatments and other interventions. There may be times when it is appropriate to target some demographic groups or health issues in order to reduce inequalities and promote the well-being of the community as a whole. Priority may be given to health services targeting the needs of sub-groups of the population who currently have poorer than average health outcomes (including morbidity and mortality) or poorer access to services.

## **6. Considerations**

- 6.1 South London CCGs seek to achieve a balance between the ethical principles and to meet the legal duties of public bodies. When making resource allocation decisions, the following considerations should be taken into account:
- The standard treatment options available to the patient.
  - The clinical needs of the patient, and the nature of the intervention including the clinician's treatment plan
  - The scientific evidence of clinical effectiveness of the proposed intervention and where in doubt, normative practice
  - The cost effectiveness of the intervention
  - The balance of risk and benefit for the patient and the capacity to benefit
  - The impact of provision of this treatment on South London CCG resources and whether needs can be met with an alternative provider
  - Consistency in decision-making and the impact of providing similar treatment to other patients with similar needs
  - The impact of the funding decision on other services or interventions for which money is then not available
  - Patient views
  - Potential human rights considerations and proportionality

- Procedural propriety in decision-making, transparency and probity
- The legality of the funding decision

## 7. References

7.1 In constructing this ethical framework, a number of existing ethical policy documents have been referred to, including:

- NHS South West London *Ethical Decision Making Framework for Individual Funding Requests*
- NHS North West London *Ethical Framework for decision-making*
- NHS Commissioning Board *Ethical Framework for priority setting and resource allocation*
- NHS Kent and Medway *Ethical Framework*
- NHS Brighton and Hove *Ethical Framework*