

Arthritis Care:

Submission to the Kennedy Review on valuing innovation

3 April 2009

1. Arthritis Care is very pleased to provide input to this review, which we hope will lead to important improvements in the services and treatments for service users.
2. Arthritis Care believes that innovation is important and can benefit the individual and society in a myriad of ways, including through:
 - improvements in non-health related quality of life, such as happiness and wellbeing;
 - increased convenience for the service-user, such as being able to access a technology closer to home;
 - increased dignity for the service-user, such as a reduction in assistance by another;
 - positive economic impact for the individual and society, such as the potential to return to or enter work and reduced benefit claims; and
 - a reduction in social inequality and the associated negative effects it has on health.
3. Innovation has to be recognised as a long-term process in which investments are made now against improvements to the health of the nation in the future. However, it is important that the review takes a broad understanding of “innovation” that is not limited to “medical” innovation, i.e. innovation in drugs or technologies, but includes innovation in treatment methods and innovation in the decision-making process. In order to demonstrate genuine commitment to innovation, NICE should embed the principles of innovation in everything it does.
4. In particular, it is paramount that the needs, views and experiences of service users are not only taken into account but placed at the heart of the decision-making process regarding services that affect them. We are concerned that at present, the voices of those for whom services are designed are not sufficiently being used to inform both the design and delivery of these services.
5. In this respect, we would like to see innovation in the way in which NICE involves user-led organisations such as Arthritis Care in the decision-making process. Arthritis Care alone has over 80,000 supporters and every month receives around 1,000 enquiries via its helpline, as well as 40,000 unique visitors to its website, which means that we are directly aware of the experiences and the needs of people with arthritis.
6. Consultations are a useful channel of engagement, but they must form part of a broader canopy of engagement channels aimed at gathering qualitative as well as quantitative

information. Engagement with user-led organisations must also be meaningful, and NICE should demonstrate that the recommendations made by these organisations have in fact been taken on board and are reflected in the outcome.

7. Arthritis Care is concerned that NICE places excessive emphasis on clinical evidence at the expense of that which could help form a better understanding of the potential impact of health conditions and technologies on the life of the service-user, and wider society. The use of the narrow QALY measure as the overriding factor in determining access to technologies does not sufficiently take into account the diversity of service-user experience and the often significant gains that can make a real difference to someone's actual quality of life.
8. There is the risk that over-reliance on the QALY measure, and taking decisions too early in the assessment process based on this measure, may in fact lead to the stifling of innovation and the loss of long-term benefits as a result.
9. Principle 3 of its Social Value Judgements (Second Edition, May 2008) states that *'Decisions about whether to recommend interventions should not be based on evidence of their relative costs and benefits alone. NICE must consider other factors when developing its guidance, including the need to distribute health resources in the fairest way within society as a whole.'* However, there is a distinct lack of transparency in how such factors are considered, which factors are looked at and how influential in the overall decision-making process these factors really are. Arthritis Care is concerned that in practice, this dimension is lost or ignored in favour of the QALY.
10. This lack of transparency hinders innovation and does not encourage trust and confidence in NICE's consultation or decision-making process. It is important for service users to be able to understand how decisions are reached, as this will encourage greater involvement among service users and will give more credibility to NICE's decisions, as well as its commitment to innovation. There are a number of studies on the issue of measuring the benefits of less tangible innovation and NICE may wish to draw on sources such as the *Wellness Index* and the *Quality of Life Index*.
11. Methods of gathering and employing quantitative and qualitative data from service users should be regularly reviewed and updated to ensure that they facilitate involvement and produce information that can be taken into account in the development process. Channels such as the NICE website, workshops, targeted meetings, and bodies such as the Citizens' and Partners' Councils should themselves be used to gather feedback on their efficacy.
12. NICE should seek to use a combination of traditional and new media methods of gathering information from service users to shift the responsibility for participation from the latter to the organisation. NICE should develop innovative methods to make it as easy as possible for all service users to participate.

