

# NICE Citizens Council



## Report of the first meeting of the NICE Citizens Council

### Determining “Clinical Need”

21st-23rd November 2002  
Salford

## **ACKNOWLEDGEMENTS**

Thanks go first and foremost to the expert witnesses who presented evidence to the Citizens Council during its deliberative process. Thanks also go to staff within NICE, particularly Ela Pathak-Sen, who put much time and effort into making the first Council meeting a reality, and to members of both the Vision 21 and Nexus teams who assisted with facilitation and organisation of the meeting, and media relations activity.

<b>CONTENTS</b>	<b>PAGE</b>
<b>1. INTRODUCTION</b>	<b>4</b>
<b>2. EXECUTIVE SUMMARY</b>	<b>6</b>
<b>3. THE CHOSEN TOPIC</b>	<b>8</b>
<b>4. HOW DECISIONS WERE MADE</b>	<b>10</b>
<b>5. WHAT IS CLINICAL NEED?</b>	<b>11</b>
<b>6. FEATURES OF DISEASES OR CONDITIONS</b>	<b>15</b>
<b>7. FEATURES OF THE PATIENT</b>	<b>19</b>
<b>8. STAKEHOLDERS</b>	<b>23</b>
<b>9. OTHER KEY RECOMENDATIONS</b>	<b>24</b>
<b>10. DEVELOPING THE CITIZENS' COUNCIL</b>	<b>25</b>
<b>APPENDICES</b>	
<b>'A' COUNCIL MEMBERS</b>	
<b>'B' EXPERT WITNESSES</b>	

## 1. INTRODUCTION

The National Institute for Clinical Excellence's Citizens Council was formally established in November 2002 following a comprehensive recruitment process to attract members of the public to fill the 30 places. Over 35,000 enquiries were made for the Citizens' Council, of which 4,327 people eventually applied. The final 30 members of the Council – stratified to reflect the wider public – were confirmed at an induction meeting in London on Friday 1<sup>st</sup> and Saturday 2<sup>nd</sup> November 2002.

The first full Citizens Council meeting took place on the 21<sup>st</sup>, 22<sup>nd</sup> and 23<sup>rd</sup> November 2002 in Salford and this report details the Citizens Council members' conclusions and recommendations on the topic set for them:

### **'What should NICE take into account when making decisions about clinical need?'**

The process followed during the three days can be summarised as follows:

- Briefing on the topic by Professor Sir Michael Rawlins, chairman of NICE.
- Discussion on the witnesses to be called and questions to ask them.
- Working through case studies pertaining to clinical need.
- Calling of expert witnesses in public – see Appendix B.
- Deliberative sessions to discuss and identify key issues to come from the evidence presented.
- Informal discussions amongst Council members during the course of the event.
- Workshops to finalise the Citizens Council's conclusions and recommendations.

The Council meeting was facilitated and managed by Vision 21, media relations activity was co-ordinated by Nexus Structured Communications, and the process

was continually evaluated by staff from the School of Health and Social Welfare at the Open University, and the College of Health.

A summary of Citizens Council members' findings and recommendations to the question: 'What should NICE take into account when making decisions about clinical need?' is provided in section two.

Section three details why clinical need was chosen as the topic for consideration, how it was chosen, and how it was approached during the three day Council meeting.

Section four explains how the Council made their decisions, whilst section five helps briefly define clinical need.

Section six considers the Council's recommendations specifically regarding the most important features of diseases, or conditions, that should be taken into account when deciding clinical need, whilst section seven establishes the Council's recommendations relating to the most important features of patients.

The Council's views on the weight the Institute should give to the views of each of the various groups of stakeholders in deciding clinical need are detailed in section eight.

Other key recommendations are discussed in section nine, and lessons learnt for future work undertaken by the Citizens Council are set out in section ten.

## **2. EXECUTIVE SUMMARY**

### **FEATURES OF DISEASES OR CONDITIONS**

In the Council's opinion the following - in no specific order - are the most important features of diseases, or conditions, that should be taken into account when deciding clinical need:

- How bad is the pain and how severe are the symptoms?
- Is it potentially fatal?
- Is it contagious?
- Are there no alternative treatments available?
- What is the long-term effect of the condition on the individual?
- What are the chances of good clinical outcome?
- What is the number of patients affected?
- What is the effect of the disease on the quality of life for the individual patient?
- What is the effect of the disease on the length of life for the individual?
- What are the psychological effects of the condition?
- What is the level of disability and/or independence of the individual?
- Is the condition time limited?
- Are there fluctuations in the individual's condition?
- Is the disease or the condition cosmetic?
- What are the side effects encountered by the patient?
- Is there any stigma related to the condition?
- What are the resources available, such as cost and equipment?

## **FEATURES OF THE PATIENT**

In the Council's opinion the following - in no specific order - are the most important features of patients, rather than their condition, that should be taken into account when deciding clinical need:

- What values does the patient have?
- What is the patient's ability to make an informed decision?
- What is the age of the patient?
- How fit is the patient to undergo treatment?
- What are the patient's other conditions?
- How able is the patient to self-manage their condition?
- What is the family history, and are there any genetic or hereditary issues for the patient?
- Has a holistic approach for the patient been considered?

## **FEATURES THAT SHOULD NOT BE CONSIDERED IN DETERMINING CLINICAL NEED**

- Social and economic factors
- Whether it is a 'self-induced' disease or condition
- How loud the 'voice' of the patient is
  
- Citizens Council members felt there should be no discrimination in determining clinical need, on grounds such as ethnic background, sex, or location.

### 3. THE CHOSEN TOPIC

It is worth remembering at this stage that the clinical standards which NICE develop have two key components, which are: firstly, clinical content; and secondly, implicitly, reflecting the hopes, expectations, values and priorities of people generally. The Citizens Council members have a critical role to play in offering advice on the latter component.

The National Institute for Clinical Excellence need the Citizens Council to help provide a public perspective on the key values used to make their judgements. With this in mind NICE drew up a list of key values on which they would like a public perspective, prioritised them and then determined that 'clinical need' was the first topic on which they would like advice.

They concluded: "The Institute in its Directions and Framework document is required to take six matters into account when undertaking appraisals of health technology. The first, and arguably the most important, is 'the degree of clinical need of patients with the condition or disease under consideration'".

For information, the five other matters that NICE are asked to consider are:

- the Secretary of State's and National Assembly for Wales' broad clinical priorities (as set out for instance in National Priorities Guidance and in National Service Frameworks, or any specific guidance on individual referrals);
- the broad balance of benefits and costs;
- any guidance from the Secretary of State and the National Assembly for Wales on the resources likely to be available and on other such matters as they may think fit;
- the effective use of available resources;
- the longer-term interests of the NHS in encouraging innovation of good value to patients.

Recognising that this was not the most simple of topics for a new Council to deliberate over, NICE and Vision 21 staff worked to develop the concept of clinical need into a series of questions or statements - always referring it back to the work of NICE, to help retain focus.

The end result of this process was a primary question of: **‘What should NICE take into account when making decisions about clinical need?’**

Supplementary statements were also offered to help unpack this for NICE, including asking the Citizens Council members to consider:

1. The most important features of diseases, or conditions, that should be taken into account when deciding clinical need.
2. The most important features of patients, rather than their condition, that should be taken into account.
3. The weight the Institute should give to the views of the various groups of stakeholders (consultees) in deciding clinical need.

During the course of the Council meeting, to help focus deliberations, these supplementary statements were slightly revised by Citizens Council members to turn them from statements into questions, though the context remained the same. Indeed, these questions were the guiding framework by which Council members worked throughout their programme, and hence the structure of their report.

#### **4. HOW DECISIONS WERE MADE**

As outlined above, the Citizens Council members spent three days learning and discussing the topic, by working through case studies pertaining to clinical need, calling and questioning expert witnesses in public, and going through a process of deliberative sessions to discuss and identify key issues to come from the evidence, informal discussions amongst Council members during the course of the event, and a number of workshops to finalise the Citizens Council's conclusions and recommendations.

Most of the final day was spent working in small groups and as a full Council, to pull these discussions together and agree the content of their report to NICE. Most decisions were reached by consensus, but on a couple of points where there was no clear agreement, a vote was taken. Where the vote was close and the Council therefore felt unable to make a unanimous or strong recommendation, this is indicated in the report.

## 5. WHAT IS CLINICAL NEED?

No definition of clinical need was given by the Institute in setting the topic because of the variety of such definitions, and because they wished the Citizens Council to have as open a brief as possible. It was anticipated that expert witnesses would give a wide range of opinions on the definition of clinical need from their perspective, for the Citizens Council members to consider. The remit of the Council was to investigate and decide what 'clinical need' meant from a general public perspective, and therefore what should be taken into account by NICE when determining it.

As one of the Citizens Council members said, in trying to clarify this difficult topic: "Clinical need is what you've got when you're ill," though there was much debate over the three days about defining this concept. Some of the witnesses did offer suggestions on how to frame clinical need and these proved helpful.

"Doctors often have a narrow view of clinical need, which just looks at the state of the disease. Clinical need is no longer just what your doctor says it is." Chris Spry OBE, Director of OD Partnerships

"Pain isn't always at the top of a patient's list of concerns – except when it really hurts." Jacqui Pollock, Expert Patient Programme

"The key problem we face is the growing complexity of the values bearing on assessments of clinical need. We need to develop the knowledge and skills to work as effectively with complex questions of value as we work with complex questions of scientific fact. In a word, we need Values-Based Medicine (VBM) alongside and on an equal footing with Evidence-Based Medicine (EBM)!"  
Professor Bill Fulford, University of Warwick

“The trouble with the public deciding about clinical need and deservedness is that children always do well, but the elderly and the mentally ill don’t come out so well.” Dr Hugh Reeve GP, Director of Clinical Governance, Morecambe Bay PCT

“Demand always exceeds supply, in economics and in health.” Chris Spry OBE, Director of OD Partnerships

“We should not treat people based on who shouts loudest. We should provide what is required within the limited resources to make the most difference.” Nigel Hughes, British Liver Trust

“The NHS is not culturally neutral; it has learned norms, values and behaviours. Health is understood differently by different cultures. We need to provide culturally sensitive care.” Stephanie Sulaiman, Wandsworth PCT

“Guidance in terms of treatments is all very well, but one size doesn’t fit all, and people respond very differently.” Dr Richard Tiner, Medical Director ABPI

“There are individual wants that we have to respond to, but the trouble is that we pay as a society. We can’t look at individuals apart from society.” Dr Ruth McDonald, Research Fellow, University of Manchester

“Patients should always be given a choice. This should be top of the agenda.” Stephanie Sulaiman, Wandsworth PCT

“My disease was really well controlled by the doctors, but my whole life wasn’t part of the package.” Jacqui Pollock, Expert Patient Programme

“In the babble of demand, there are some more muscular players who distort where the money goes – including Government priorities, NICE, acute hospitals.” Chris Spry OBE, Director of OD Partnerships

“GPs pride themselves on trying to take a more holistic view of clinical need than other clinicians – but they have to see up to 50 patients a day and have only 10 minutes to see each one.” Dr Hugh Reeve GP, Director of Clinical Governance, Morecambe Bay PCT

“How do we decide which medicines to progress if we have limited choices? It depends on the number of patients requiring it, the chances of it working, and whether it would cure someone or save a life.” Dr Richard Tiner, Medical Director, ABPI

“Clinical need is capacity to benefit. From our limited resources we choose what produces the most health gain.” Dr Ruth McDonald, Research Fellow, University of Manchester

“Disease can be like a pendulum – it affects your life in different ways at different times.” Jacqui Pollock, Expert Patient Programme

“The population nowadays is healthier but more anxious. Doctors spend a lot of time trying to separate demand from need.” Dr Hugh Reeve GP, Director of Clinical Governance, Morecambe Bay PCT

“Clinical need is assessing your population needs.” Stephanie Sulaiman, Wandsworth PCT

“There is a 50/50 chance of a woman becoming a carer by the time she is aged 59. But carers are being ignored – we need to listen to their needs too.” Gavin McGregor, Carers UK

“Often people will choose quality of life over length of life.” Dr Richard Tiner, Medical Director, ABPI

“We have to try to balance the value of one treatment in terms of clinical need with the overall clinical needs of the population.” Carole Longson, NICE

“A patient’s pain is what they say it is.” Nigel Hughes, British Liver Trust

“Norms, beliefs, values and behaviours tend to be taken for granted and so lie below the conscious level of awareness. This means that unless trained to do otherwise, care providers tend to treat everyone in the same way – the colour-blind approach – despite the fact that this will be inappropriate and promote inequity.” Stephanie Sulaiman, Wandsworth PCT

“You have a choice to screen a whole population and as a result save the lives of 100 people. That’s the fairest way, say the public. Or you could target it, screen half the population with a better but more expensive method and save 150 lives. That’s better, say the economists.” Dr Ruth McDonald, Research Fellow, University of Manchester

“As a result of managing my disease and the empowerment I feel, am I any better? Are my blood tests any better? Well, I feel better. Whose agenda is it?” Jacqui Pollock, Expert Patient Programme

Council members considered the evidence from the expert witnesses and concluded that in health terms the response to clinical need should be: “to provide without prejudice or political, geographical, economic or social preference, the best care or treatment that can be provided within the resources available, to make the most improvement to a patients’ life or well-being.”

## **6. FEATURES OF DISEASES OR CONDITIONS**

The Citizens Council members were first asked to decide what they wanted NICE to take into account - in terms of the features of diseases or conditions, regardless of who was suffering from them - when judging clinical need.

In the Council's opinion the following - in no specific order - are the most important features of diseases, or conditions, that should be taken into account when deciding clinical need:

- **How bad is the pain and how severe are the symptoms?**

The Citizens Council members felt that diseases or conditions that cause great pain should be seen as a high priority, although they wanted NICE to recognise that pain and severity of symptoms can fluctuate during the course of an illness or condition.

- **Is it potentially fatal?**

The Citizens Council members felt that saving lives, or the 'rule of rescue' is extremely important.

- **Is it contagious?**

The potential affect on the wider population should be considered – not just the person with the disease or condition, but also the clinical need of those who may catch it.

- **Are alternative treatments available?**

The Citizens Council members felt that treatments for diseases or conditions where there is only one form of existing treatment should be prioritised over those where there is a range of treatments already available.

- **What is the long-term effect of the condition on the individual?**

Treating chronic diseases or conditions should be seen as more important than treating those which have a shorter effect on someone's life – unless the short-term disease is potentially fatal.

- **What are the chances of good clinical outcome?**

The Citizens Council members felt that it was important to consider whether or not there is a good chance of survival or recovery. Therefore, priority should be given to treatments that have the most positive effect.

- **What is the number of patients affected?**

The Citizens Council members felt that NICE should consider how many patients the disease affects. Therefore, if only a small number of people are affected by a particular condition, although their need may be severe, in overall terms this should be less of a priority.

- **What is the effect of the disease on the quality of life for the individual patient?**

The Citizens Council members felt that when considering clinical need, the effect of the disease or condition on the whole of a patient's life should be considered. This should include the effect on their emotional and mental well-being, their occupation, their social life and their families as well as the physical effects. So, the greater the adverse affect, the higher priority it should be.

- **What is the effect of the disease on the length of life for the individual?**

The Citizens Council members felt that NICE should consider whether the disease or condition is likely to shorten someone's life expectancy, or if the treatment is going to extend life.

- **What are the psychological effects of the condition?**

The Citizens Council members felt that it is extremely important to consider the effect on the patient's well-being as well as the physical effects of any disease or condition, when considering treatments.

- **What is the level of disability and/or independence of the individual?**

The Citizens Council members felt that, when considering clinical need, any disabling effect of the disease on a patient should be considered important.

- **Is the condition time limited?**

The Citizens Council members felt that NICE should consider whether or not the illness is chronic, or whether it is likely to be an inherently time-limited condition. Higher priority should be given to the former.

- **Are there fluctuations in the individual's condition?**

The Citizens Council members felt that it was important to consider whether or not the disease or condition remained constant or fluctuated in its affect on the patient's life – and to take into account the range of states that a patient might pass through during the course of an illness.

- **Is the disease or the condition cosmetic?**

The Citizens Council members felt that if a condition was solely cosmetic then it should receive less of a priority when considering clinical need. However, they felt that some seemingly cosmetic conditions may have an adverse effect on the patient's mental health and emotional well-being, and in such cases this should be taken into account.

- **What are the side effects encountered by the patient?**

Citizens Council members decided that the side-effects as well as the main effects of the disease should be taken into account when determining clinical need.

- **Is there any stigma related to the condition?**

The Citizens Council members felt that patients with illnesses or conditions that had a stigma related to them might experience an extra level of clinical need –

the effect on an individual's social and mental life should be taken into account as well as their medical condition.

- **What are the resources available, such as cost and equipment?**

The Citizens Council members felt that it was important to recognise that resources are limited, and that therefore in some cases individual choice should sometimes be limited in the interests of the overall population.

## **7. FEATURES OF THE PATIENT**

In the Council's opinion the following – in no specific order - are the most important features of patients, rather than their condition, that should be taken into account when deciding clinical need:

- **What values does the patient have?**

Although the members of the Citizens Council recognised the importance of making clinical decisions within a framework of limited resources, they felt it was important not only to make a strict cost-benefit analysis, but also to consider the individual values held by patients. Therefore, factors such as the individual's value system and their cultural and religious views should be taken into account.

People's values and beliefs influence the symptoms and the need they feel. There should be no discrimination on these grounds, but the health service should be sensitive to the different value systems and cultural needs of different people and groups of people within the population.

- **What is the patient's ability to make an informed decision?**

Citizens Council members felt that it is important for patients to be able to make an informed decision about their clinical need. They agreed that education and information are important, and that there shouldn't be an assumption that the 'clinician knows best'. Even children, for example, should be allowed to have more of a voice in deciding their own clinical needs.

- **What is the age of the patient?**

The Citizens Council felt that the age of a patient should be taken into account when deciding on clinical need.

- **How fit is the patient to undergo treatment?**

Citizens Council members felt that the overall medical condition of the patient should be considered when deciding their need for treatment for a specific disease or condition. This is related to the capacity of the patient to benefit. It is

better to prioritise treatments that are most likely to be effective, or treatments for those people who are most likely to recover their health.

- **What are the patient's other conditions?**

If the patient has other illnesses or conditions – as well as the one for which treatment is being considered – then this should be taken into account. The existence of other illnesses or conditions may actually mean that they have a greater clinical need for treatment for this particular illness or condition. For example, someone who is already visually impaired may have a greater clinical need to receive treatment for potential hearing loss than someone who is fully sighted. Another example might be someone who has diabetes, who may be in greater clinical need of a flu jab than someone who is otherwise healthy.

- **How able is the patient to self-manage their condition?**

Citizens Council members thought that the ability of the patient to manage their condition, and to have an effect on their own health should be taken into account. Council members felt that people should take some responsibility for their own health – and also that managing their condition as far as possible is part of empowering patients and can help them feel better.

- **What is the family history, and are there any genetic/hereditary issues for the patient?**

The Citizens Council narrowly decided that a patient's family history, and genetic or hereditary issues should be a factor in deciding clinical need.

Those who argued in favour of considering these issues when determining clinical need said that it might be important to prioritise people who are more at risk of certain conditions because of hereditary factors.

Those who argued against this being a factor said there was a danger of labelling people, and that clinical need should be determined according to an individual's circumstances, rather than according to their family history.

Because it was not possible to reach consensus on this issue, a vote was taken and 17 people voted to include it as a factor, 12 voted against including it, and one person abstained. Therefore, the Citizens Council didn't want to make a strong recommendation on this point, and suggested it was an issue that needs further discussion.

- **Has a holistic approach for the patient been considered?**

Citizens Council members thought it was important that all aspects of a patient's life are considered when determining clinical need – not just their physical condition, but their mental and emotional health, and the effect on their family, work and social lives. These should not be factors that are used to discriminate between patients on a population level, but clinicians should ensure that they had regard for an individual patient's circumstances and the impact that treatment (or lack of treatment) would have on their lives.

## **FEATURES OF PATIENTS THAT SHOULD NOT BE CONSIDERED**

### **Social and economic factors**

Members of the Citizens Council decided that the social and economic circumstances of patients should never be a factor in determining clinical need. Clinical need should be determined without regard to an individual patient's income, social class or position in life, and there should be no discrimination in the health service.

### **'Self-induced' diseases or conditions**

The Citizens Council unanimously decided that NICE should not consider whether a disease or a condition was 'self-induced' to be a factor at all. In their view, this should make no difference. This was partly because the Citizens Council members appreciated the difficulty in assessing and untangling all the factors that would help decide whether or not a condition really was self-inflicted. It also

reflected their view that this aspect of 'deservedness' should not be a factor in determining clinical need.

**How loud the 'voice' of the patient is**

Members of the Citizens Council agreed with a number of the witnesses who said that some voices were 'louder' than others. They decided that clinical need should not be determined by only listening to the voices of more powerful, better known or more 'popular' groups in the population.

## 8. STAKEHOLDERS

In the Council's opinion the weight the Institute should give to the views of each of the various groups of stakeholders in deciding clinical need are:

- A - Most important:
  - Patients.
  - Health care professionals.
- B - Next most important:
  - Family and partners (regardless of sexual preference or marital status).
  - Carers.
- C - Next most important:
  - Patient groups.
  - Wider public/society.
  - Charities/voluntary sector.
  - Local, regional and national government.
- D - Next most important:
  - Pharmaceutical and other medical supply companies.

The above were considered most important though the Citizens Council also felt that others who should have their views taken into account were, in no particular order, budget-holders and economists, private health providers, educational establishments, and employers.

The Council were also particularly keen to emphasise that 'less well heard voices' – such as children, those with chronic illnesses, older people, and the mentally ill – should be well recognised by NICE when considering relevant procedures.

## **9. OTHER KEY RECOMMENDATIONS FROM THE CITIZENS COUNCIL**

Members of the Citizens Council were keen to stress that there should be avoidance of any 'postcode variation' in treating patients.

They also felt that empowering patients to make informed decisions about their own clinical need is important. The Citizens Council decided to describe this concept as 'informed decision-making' rather than full 'patient choice', because they felt that individual needs and preferences had sometimes to be balanced with the needs of the population as a whole. However, this was the subject of some heated debate – many members felt strongly about the concept of choice - and may deserve further exploration at Citizens Council meetings in the future.

Members of the Citizens Council feel that the voice of patients should be heard more within the health service – the days of 'doctor knows best' are over; there should be more flexibility from health professionals to accommodate the lives and needs of patients; and there should be a partnership in decision-making between patients and clinicians.

## 10. DEVELOPING THE CITIZENS COUNCIL

Citizen Council members wish to make a number of suggestions and recommendations about how the Council develops in the future. These include:

- Extending the length of tenure for Council members – although it is acknowledged that it was stated throughout the recruitment process that the Citizen Council would be refreshed every 12 months, with 10 members being replaced yearly over three years, some Citizens Council members wanted to recommend to NICE that they retain all 30 members for at least two years.

The reasons for this are:

- There is a steep learning curve and it will take members at least two meetings to become fully familiar with the type of topics being discussed.
  - Some Council members were unhappy at the idea of a 'lottery' to decide the length of tenure of individuals.
- Being told the topic in advance of future Citizens Council meetings. This would enable members of the Citizens Council to think about the subject in advance, so that they could 'get up to speed' more quickly and engage with discussions more fully at the meetings themselves.
  - Having more involvement in selecting the type of witnesses who will present to future Citizens Council meetings.

## **APPENDIX A – COUNCIL MEMBERS**

Members of the Citizens Council are as follows:

- John Baldwin, an electrician who lives in Widnes, Cheshire.
- Auriol Britton, presently an unemployed aspiring writer who lives in Bristol, Avon.
- Brian Brown, an electrical engineer, from Chester-le-Street, County Durham.
- Jennifer Brown, a clerical officer who lives in Derby, Derbyshire.
- Sylvia Brown, a retired local government officer who lives in London.
- Scott Chapman, a printer who lives in Corby, Northamptonshire.
- Tracey Christmas, an accountant who lives in Hull, East Yorkshire.
- Rod Crowshaw, a store assistant who lives in Castle Bromwich, West Midlands.
- Trevor Davison, a supervisor scaffolder, who lives in Lincoln, Lincolnshire.
- Marie Goorun, a dress-maker and part-time French tutor who lives in Gillingham, Dorset.
- Mark Handley, a project manager who lives in Kingston-upon-Thames, Surrey.
- Susan Jones, a retail clerk who lives in Cardiff, Glamorgan.
- Rashad Khan, an administrator who lives in Keighley, West Yorkshire.
- Deborah Lee, a part-time advertisement make-up artist and housewife who lives in Bournemouth, Dorset.
- Raymond Longstaffe, a former builder who lives in Brecon, Powys.
- John MacGlashan, Retired security officer, Liverpool, Merseyside.
- Melanie McClure, a mother of one who lives in Hebburn, Tyne and Wear.
- Susan McNeill, a secretary who lives in Market Harborough, Leicestershire.
- Anthony Messenger, an insurance broker who lives in Windsor, Berkshire.
- Sharon Morgan, a milliner who lives in Birmingham, West Midlands.
- Sunita Nanda, a local government officer, who lives in Middlesex.

- Bob Osborne, a retired former pilot who lives in Horsham, West Sussex.
- Paul Pendlebury, an assembly worker, who lives in Preston, Lancashire.
- Audrey Pestell, a retired head teacher, who lives in Woodhall Spa, Lincolnshire.
- Marie Raynor, a housewife, who lives in Sale, Greater Manchester.
- Ian Simons, a taxi driver, who lives in London.
- Colin Stewart, a self-employed IT systems advisor who lives in London.
- Fiona Taylor, a wine marketing assistant, who lives in Sidbury, Devon.
- Peter Thomas, a teacher, who lives in Rhondda, Cynon Taff.
- Judith Ward, a wood turner, who lives near Stoke on Trent, Staffordshire.

## **APPENDIX B – EXPERT WITNESSES**

Those giving evidence to the Citizens Council first meeting were as follows:

- Chris Spry CBE, Director of OD Partnerships, a network of NHS organisations. He was a NHS Chief Executive for nearly 25 years, in Glasgow, the South Thames region, Newcastle and Nottingham.
- Jacqui Pollack is currently working for the Expert Patient Programme, a Department of Health pilot dealing with chronic disease self management. She is a former student at Manchester University, and was diagnosed with juvenile rheumatoid arthritis when she was eight years old.
- Dr Richard Tiner is the Medical Director of the Association of the British Pharmaceutical Industry. He has held junior doctor posts in Kettering and Taunton and was a Principal in General Practice in Somerset for 17 years.
- Dr Hugh Reeve is Medical Director and Director of Clinical Governance at Morecambe Bay Primary Care Trust and is also a part-time GP in Windermere. He was previously a GP in Stockport and central Manchester.
- Professor Bill Fulford is Professor of Philosophy and Mental Health at the University of Warwick and an Honorary Consultant Psychiatrist at the University of Oxford. He holds a number of other academic positions, is the founder chair of the Philosophy Special Interest Group in the Royal College of Psychiatrists, and is a fellow of both the Royal College of Psychiatrists and The Royal College of Physicians.
- Dr Ruth McDonald is a research fellow at Manchester University's Department of Applied Social Research. She is a former NHS finance director with 11 years experience and has held posts at Liverpool University's Prescribing Research Group, and the Nuffield Institute for Health at Leeds University. She is also a non-executive director of South Liverpool Primary Care Trust.

- Stephanie Sulaiman is a registered nurse and midwife and has worked for many years as a Midwifery Manager in South London. She was instrumental in establishing the Haemoglobinopathy Service, and has a keen interest in the work of managing diversity within the NHS and empowering the BME population to look after their health.
- Dr Carole Longson is a NICE Appraisal Programme Director and previously spent eight years at Glaxo Wellcome Research and Development. She has also undertaken a number of academic secondments including research at The Institute of Molecular Biology in Geneva, and the University of California in Irvine, USA.
- Dr Gillian Leng is a NICE Programme Director with responsibility for clinical guidelines. She is also editor of the Cochrane Review Group on peripheral vascular diseases and an honorary senior lecturer at University College, London. She formerly worked at Bedfordshire Health Authority as a consultant in public health medicine.
- Dr Tom Dent is a NICE Programme Director for interventional procedures, and prior to this worked for six years as a consultant in public health medicine at a health authority and latterly a primary care trust in Hampshire. He is also a visiting senior lecturer with the National Coordinating Centre for Health Technology Assessment at the University of Southampton.
- Gavin MacGregor is North of England Manager for Carers UK, an organisation of carers which provides information and advice to carers and those working with carers.
- Nigel Hughes is chief executive of the British Liver Trust. He is a former clinical nurse specialist in HIV and virology at an NHS Hospital Trust in Kent, a former chair of the Whole Person Therapy Trust, a former chair of the national

charity Mainliners and a former co-chair of the Hepatitis Nursing Forum. He is also a former member of the executive board of the Royal College of Nursing HIV Society.