



Real Accountability Annual Report 2009-2010

Consultations and public engagement projects
to inform decisions on commissioning healthcare

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Introduction

The duty to involve the public under section 242 of the NHS Act 2006, and the associated policy and practice guidance *Real involvement*, raises the bar for the way NHS organisations are expected to involve and consult people, and respond to the feedback received. As a result, more and more people across the country should feel better informed and encouraged to have a say about what really matters to them about their area's healthcare services.

NHS Leicester City has been making great strides in involving people, and our staff and Trust Board are using the feedback and insight into patients' needs and wants in order to inform improvements in health services.

The new duty to report on consultation places a legal duty on all primary care trusts like NHS Leicester City, and on regional strategic health authorities to report annually on the influence people's views have had on their decisions.

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Foreword

The people of Leicester have every right to make their voices heard on the healthcare services which their NHS commissions for them. Good engagement must be integral to all commissioning decisions. It is not only a legal duty, but it also makes good sense – socially, financially, clinically and strategically - and no business case for a new or modified service will succeed without it.

The engagement expertise we have developed at NHS Leicester City has been invaluable and will prove an equally valuable asset to future commissioning bodies. Leicester is a complex city. What suits one sector may not suit another. There is no longer a place for a 'one size fits all', 'top-down' mentality when it comes to designing clinical pathways and all the other facets of our healthcare services. If we cannot make the service fit the local need – clinically and culturally – we are not doing our job to a world class standard.

There is more to engagement than good market research. We want to invite more members of the public to become active participants in the commissioning process. That's why we are encouraging people to be part of the commissioning procurement stage of service provision – so they also sit on the panels making the key decisions on how money is spent.

In the last two years we have developed a membership pool of more than 5,000 local people (at September 2010). It is increasing month by month. It includes many people interested in being involved in local NHS developments. They are regularly invited to take part in members' meetings and readers' panels, engagement events and surveys, and are kept informed about the activities of their local NHS. This database, and the information volunteered by members, helps to ensure that NHS commissioners, wishing to involve local people in reviews of services, have access to people with relevant interests and experience, who want to play a part in shaping local healthcare.

Good public engagement can only help us better meet the health needs of the people we serve. Backed by clinical data, public health statistics, the known health outcomes – especially of best practice here and elsewhere – it will help us ensure that the services we commission will meet the needs of the people we serve.

And because engagement is not only part of the service development and procurement process, but also an essential part of the evaluation process, the public will have a major say in the 'last word' on whether our commissioning decisions worked. As the Secretary of State for Health, Andrew Lansley, has said on behalf of patients: "There should be no decision about me without me".

Tim Rideout
Chief Executive

Children's complex care

What was the issue

The Diana Complex Care Children's Nursing service provides nursing care for a variety of children within Leicester, Leicestershire and Rutland who have disabilities or life-limiting or life-threatening conditions. The small number of families who have experience of these specialist services are frequent users with continual contact with a wide variety of NHS and social care staff. Therefore they understand what works and where there are gaps in services, providing a resource that can be tapped into.

Who was consulted

The NHS Leicester City engagement team carried out a one-to-one interview with the mother of a child with complex care needs. By carrying out the interview at their home early in 2010, the team recognised that traditional engagement techniques such as focus groups would be difficult to attend due to caring responsibilities. This approach provided the time to explore the family's wide experience of services. Such interviews also allow people to express their feelings and concerns more easily.

What information was given

As the parent and patient were both very familiar with the treatment and care process, there was little need for additional information to be given.

What were people asked to comment on

Overall quality of treatment and care, knowledge and use of equipment, along with suggestions for improvements.

Summary of feedback

From just one interview we were able to glean several ideas for improvements that have either minimal or no cost implications, but that make a big difference to the quality of the service received by the families involved. The following comments were obtained:

- Parents should be informed of what is happening, who different people are and what their role is.
- The importance of listening to patients and parents and appreciating their feelings.
- Lack of training to use equipment. Equipment that could be re-used is being thrown away.

Decisions made

The insight gained informed the revision of the service specification to include improvements, such as better communication for patients by staff providing documentation outlining the different agency roles involved in delivering care.

The necessity of writing to patients and families to confirm what is happening, who is involved and what their roles are, was included in the new service specification ensuring that it is something the service must do. We also emphasised within the new specification the importance of listening to patients and parents and appreciating their feelings.

Equipment: There are some bespoke or single-use items that cannot be recycled, however, we will ensure that the new specification makes clear that anything that can be safely reused, should be. The new specification makes clear that it is compulsory to ensure all patients and carers are fully competent in the use of all equipment before they are left alone to use it. It also makes clear any re-ordering process and ensures parents and carers understand whose responsibility it is.

Dental patient survey

What was the issue

NHS Leicester City has not achieved its targets for the number of NHS dental treatments provided. In the early summer of 2009 and in early 2010 we conducted dental surveys to find out if there were additional demand for NHS dentistry within Leicester City, beyond the existing demand already recorded. If extra demand for NHS dentistry services were supported by the evidence, we would commission additional surgeries or further appointment time within existing surgeries.

Who was consulted

During May/June 2009 a dental survey was sent to all those interested in dental services in NHS Leicester City's membership scheme to see if residents were able to access NHS dental treatment when and where they needed it. The response rate was quite low.

What information was provided

Online information was available to find a dentist near the patient, using a postcode-based search system.

What were people asked to comment on

They were asked via questionnaires to comment on the levels of satisfaction with existing NHS dental services in Leicester City and what could be done to improve them.

The second survey (in February and March 2010) was commissioned through the Strategic Health Authority to find out what the demand of NHS dentistry was within Leicester and to see if people could get an appointment.

Summary of feedback

Based on the responses to the first survey, it was clear that people on the whole were satisfied with the NHS dentistry they received. However, the respondents indicated they would like to attend their dentist in the evening or at weekends and would also like to attend a dentist closer to their homes.

These results showed that two thirds of people last went to a NHS dentist within the last two years, which is the same across the SHA. The main 2 reasons for not accessing an NHS dentist are that they have stayed with their private dentist or that they have not needed a dentist within the last two years.

Decisions made

From these initial results and other information we had we procured new dental activity across the city that would be closer to people, who had to travel further to

access NHS Dentistry. As part of the procurement we built into the contract a condition that the new practice must be open either at the weekends or in the evening. The contract has been given to Genix, who share premises with a GP practice and a young people's health advice service in Bowling Green Street in the city centre.

Along with this data and other data that we have gathered, we believe that our new procurement will improve access to NHS dentistry to the residents of Leicester City who require it.

Ongoing surveys

In the national GP survey questions are asked about whether patients are able to access NHS dentistry and the results are published on a quarterly basis. These will be monitored to ensure people can access NHS dentistry and to see if there is more needed to be done in this area. There is an on-going survey done by Dental Services at the NHS Business Services Authority to check to see if the patients of the dentists are happy with the treatment they received. The results are monitored on a regular basis to ensure the dental providers are providing a good quality service.

Dermatology – care closer to home

What was the issue

Arising from our Next Stage Review *Excellence for All* public engagement programme in 2008, there was a clear wish among patients for there to be more care services closer to people's homes. The following public consultation concerned dermatology services, which were historically hospital based. It was started in 2008 and completed in the summer of 2009.

Who was consulted

Initially two members of staff attended a hospital out-patient clinic to see how the clinic is run and what patients thought of the service they received. Feedback was recorded. Then, members of staff attended a community-based dermatology clinic in order to see how services are working. Patient feedback was recorded.

A questionnaire was developed with the support of members from our Readers Panel and colleagues from our Equality and Human Rights Team. The questionnaire was designed to seek general views on NHS Leicester City's intentions to 'Move Care Closer to Home'.

The questionnaire was sent out to a range of individuals and local organisations and was also placed on the 'Get Involved' page on our website. The *Leicester Mercury* published an article about the consultation to encourage more people to get involved.

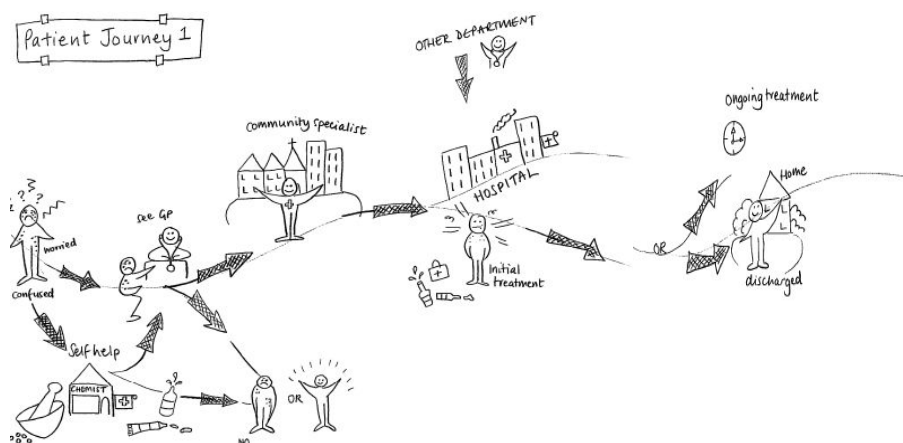
Another questionnaire was designed with the support of patients, specifically aimed at patients who use skin condition services. The purpose of this questionnaire was to briefly explain the proposals for a redesigned skin service that could be based in a community setting, when care should be delivered in a hospital setting and seek patients' views on these proposals. Questionnaires with a covering letter requesting these to be given to patients who have a skin condition were sent to

- 64 general practices across the city
- 73 community pharmacies in the city

We held two discussion groups, one in the Highfields area of Leicester and one in Braunstone. In total, 28 patients (including adults and children) from a range of communities across Leicester attended the workshops.

What information was given

We used a process called graphicking (see illustration below) to show the journey that patients may currently make through skin services, that is, hospital based and community based. Our third patient journey showed the new proposed dermatology services, again we asked attendees for their views on this journey.



What were people asked to comment on

We asked everyone in discussion groups to tell us how they felt at different points of their journey. At these workshops and in questionnaires, patients were asked about waiting times from referral, also waiting times until prescriptions were issued, modes of transport used, and their overall experience with the services provided. In terms of quality of the environment and the treatment itself. These applied to both hospital based and community services. Views were also sought on a new proposed patient pathway.

Summary of feedback

Their overall experience of the GP phase of the current patient pathway was generally good, rated at 66% satisfaction. These results alongside the verbal comments made by participants indicate a need for more information to be given to patients at this stage in their journey, and some said GPs needed more training in this field.

Treatment times in the community setting were rated as good, with almost 80% satisfaction. The most common forms of transport used were bus and car. Satisfaction with the quality of the environment, in terms of cleanliness and car parking were good, while satisfaction with the quality of treatment was high at around 80%.

Patients using patient journey 2, the hospital out patient department, were asked to give their views on their experience. Satisfaction with treatment and prescription times was good at 66%. Car travel dominated, but car parking charges were an issue. Satisfaction with cleanliness was about 60%, and with treatment the satisfaction rate was 66%. More information was requested.

Our third patient journey showed the new proposed dermatology services, again we asked attendees for their views on this journey. Patients' general views on the proposed new journey were very positive as detailed in strengths shown in the following table:

Strengths	Weaknesses
√ For children specialist nurses may be better qualified and more skilled	× Nurses have limitations, particularly in prescribing, those limitations need to be understood by patients
√ Making light therapy more accessible, may be beneficial, however this needs further exploration.	× Worried about this cost, and particularly privatising this kind of service
√ The success of the new service is dependant on the quality of the relationships between the GP and other providers. Would like to see more time spent diagnosing patients	× Worried that the ambulance service may not know where patients need to be taken
√ Improvement in community based prescription services	
√ All agreed that the new care pathway will be shorter	

People asked for:

- High quality and safe care to be delivered in a community setting
- A one-stop shop to speed up diagnosis and treatment
- Provision of prescriptions by local pharmacists
- Information on who, how and when to seek help.

Decisions made

Using the knowledge and understanding of what patients want from the new service identified gaps in service that had not previously been highlighted. We also agreed to:

- Buy services that are safe, of high quality and offer a one stop shop in a community setting
- Set performance standards that will ensure information will be available and accessible to all patients and carers throughout the patient journey
- Work with local pharmacists to enable the provision of prescriptions.

A service plan for the redesigned community care journey was completed by Summer 2009 based on the comments and feedback received through this consultation process. Service providers interested in this new service were invited to put forward their bids to begin providing the new community based service.

Diabetes services

What was the issue

Local research indicates that more than 18,000 Leicester people have diabetes and 1 in 7 people have pre-diabetes, and that without preventative action they would have diabetes within 10 years, bringing with it significant risk of developing cardiovascular disease, one of the leading causes of premature death in Leicester. Research has shown that training for people with pre-diabetes helps them significantly reduce their risk factors for developing cardiovascular disease. The Health Care Commission found that in Leicester people's knowledge of their diabetes, its management and the numbers who have had training to manage their condition was less than the national average. In line with our strategic priorities, there was a need to improve diabetes services, including addressing variations in approach within primary care, and enhancing patient self-management.

Public consultation on the diabetes plans took place between the end of December 2008 and the 27 March 2009, and the process of analysing feedback and making decisions took place in 2009-2010.

Who was consulted

The consultation was publicised at a Diabetes UK Leicester Support Group meeting, through the NHS Leicester City web site, press releases with 3 articles published in the Leicester Mercury, Leicester LINK magazine, VISTA information service for blind people, and posters in GP surgeries, pharmacies and hospital Diabetes Out-patient clinics. Questionnaires were distributed to GP surgeries, anyone expressing an interest, the NHS Leicester City patients' panel members, Diabetes UK Leicester support group members, VISTA and people attending DESMOND. Questionnaires were available in different languages on request.

A public consultation meeting was chaired by Diabetes UK to mark the end of the consultation and questions from the public were answered by a panel comprising NHS Leicester City's Director of Primary Care, the chair of NHS Leicester City's Professional Executive Committee, a GP, a Professor and Consultant in Diabetes Medicine and the Director of DESMOND.

In all, 45 people participated in the public consultation meeting, 222 people completed and returned a questionnaire which included 625 comments. Equality monitoring suggested respondents were fairly representative of the diverse population in Leicester. Following the public meeting, questions and comments on the plans were received from the Leicester Mercury Patients' Panel and the Leicester Local Involvement Network (LINK).

What information was given

Following interdisciplinary clinical engagement with those with wide experience and expertise in diabetes care, a proposed improved diabetes pathway was under

consideration. During the public consultation, information was given on a set of proposals arising from the clinical engagement phase. They included proposals for:-

Prevention and patient self-management providing awareness raising, voluntary support and patient training to help people prevent and manage diabetes. These plans are complemented by NHS Leicester City plans for cardiovascular disease prevention and the early detection of diabetes which include the new NHS health check programme for people aged 40 and above, a Healthy Communities Collaborative pilot to be led by people in the community in partnership with professionals and building on existing initiatives such as the fit and active buddies scheme.

Develop primary care to reduce variation and increase skills and capacity to help people manage their diabetes effectively.

An integrated community diabetes service to provide expert care and advice in the community for people who have blood sugar that is difficult to control who need insulin and to provide support for primary care in managing complications that are difficult to control such as high blood pressure. The service would provide training and advice for primary care professionals for example GPs and Practice Nurses and an accreditation programme for primary care professionals skilled in initiating insulin for people with type 2 diabetes.

Improve hospital care for people with diabetes who need in-patient care. The specialist diabetes service will continue to care for people with complications, and be a centre of excellence for research and training. The specialist service will work closely with the Integrated Community Diabetes Service on research and training and provide them with advice when needed.

What were people asked to comment on

People were asked to comment on the proposals under the above four headings, especially whether the clinical engagement process had properly address patient needs, and whether the following proposed commissioning plans were appropriate.

Summary of feedback

Prevention and patient self-management

People indicated they were enthusiastic in their support for these plans. They said we should provide shorter and more training places as soon as possible for people newly diagnosed and with established diabetes, many of whom had received little or no formal support or information. These training sessions should be provided at times convenient for people who work, and there should be alternatives for vulnerable people, who cannot attend group training.

Develop primary care

People said they want GPs and other primary care professionals to have training and advice from experts so people with diabetes receive consistent care and advice. They want the accreditation programme so they know that professionals providing insulin initiation in GP practices have the knowledge and skills to help patients

manage their diabetes. People asked for information on the GP practices with a GP or nurse accredited to initiate and manage insulin. People asked for GPs and Nurses who diagnose and support them to implement minimum standards for providing information and involving them in planning and reviewing their care. People also suggested ways to encourage patients to attend their GP practice for the annual review of their diabetes.

An integrated community diabetes service

People said they supported the plans for an Integrated Community Diabetes Service, with some support being subject to qualification to address issues not covered in the plan:

- Clinics should be provided in the evenings for people who work
- Clinics should be available across the city and on bus routes so they are closer to home and accessible
- There should be transport to clinics for people transferring from intermediate care provided in hospital who had an ambulance or hospital transport

Improve hospital care

People support the plan for hospital specialist diabetes services and recognise the University Hospitals of Leicester's specialist diabetes service as a centre of excellence for research. Individual people asked why they still had to attend a specialist clinic when their GP provided the same care, another said they never saw the same person when they attended the hospital clinic and they received conflicting advice. One person asked why the Balmoral unit at the University Hospitals of Leicester (Leicester Royal Infirmary) had stopped doing blood tests on the day of their consultation, resulting in the person seeing the specialist, being sent away for a blood test and having to come back on another date to discuss results and changes to their care. People's experience of in-patient care reflects the findings of the Health Care Commission. People want ward staff to recognise that the patient is often the expert and to listen to them when they say how to manage their diabetes. People want ward staff to be trained so they have a better basic understanding of diabetes and its management and when they are not sure about what the person with diabetes is telling them to seek specialist advice and involve them in managing the diabetes.

Decisions made

In response to people comments and concerns, we proposed the following amendments to the proposals arising from the clinical engagement stage:

Prevention and patient self-management

- Ensure the training programme for people with pre diabetes can be accessed by vulnerable and working people. We will do this through service specifications and contracts.
- Consider with the voluntary sector how a partnership for voluntary support groups and peer educators can be taken forward as quickly as possible. The specification for the service will incorporate people's suggestions for voluntary groups to be based in communities or GP surgeries.
- Ensure the voluntary services provide consistent messages about diabetes by commissioning the Integrated Community Diabetes Service to provide training for support groups and peer educators.

- Review the contract and specification for DESMOND and commission different options for training, increasing the number and range of places available to people with type 2 diabetes. If UHL are not able to provide the training, other providers will be given the chance through a tendering process.

Develop primary care

- In 2009/10 develop and implement an accreditation programme for GPs and practice nurses initiating insulin for people with type 2 diabetes
- In 2010/11 publish a list of GP Practices and their staff accredited to initiate insulin
- The integrated community diabetes service will provide the accreditation programme from April 2010, as this would ensure a consistent approach and integration with intermediate care
- The integrated community diabetes service will train primary care professionals to implement the patient held care plan process and ensure they give people the Leicestershire Diabetes Handbook and Diabetes UK leaflets when they are diagnosed
- Ensure that GP Practices have systems in place for annual reviews that promote uptake and support this by disseminating the consultation findings to GPs

An integrated community diabetes service

The specification for the new integrated community diabetes service will include requirements to provide clinics in at least 8 different areas of the city with at least 3 areas offering clinics in the evening. Information provided for patients will include the choice of clinics and arrangements for travel including bus routes.

On an individual basis we will address the access transport needs of people transferring from hospital intermediate care to the new community service.

Improve hospital care

Ensure the University Hospitals of Leicester responds to people's views about specialist diabetes services through developing the service specification and through contracts.

Ensure the University Hospitals of Leicester's plans to improve in-patient care for people with diabetes and monitoring people's experience. We will do this through contracts, and specialist services will report progress to the Diabetes Implementation Group.

Following these amendments, the Trust Board approved the following plans:-

Prevention and patient self-management

- Pre diabetes training will provide access to vulnerable and working people
- Establish partnerships for voluntary support groups and peer educators will be explored and be based in communities and GP surgeries
- Intermediate Care will provide training for voluntary support to ensure consistent messages for people with diabetes

- The contract for DESMOND will be revised to provide different types of training at different times to respond to people's needs.

Primary care development

- In 2009 implement an accreditation programme for GPs and Practice Nurses initiating insulin in type 2 diabetes. The programme will be managed by the Integrated Community Diabetes Service from 2010
- In 2010 publish a list of GP practices with healthcare professionals accredited to initiate insulin
- Train primary care professionals on the person held care plan process
- Ensure GP practices have systems in place for patient annual reviews.

An integrated community diabetes service

- Delegate authority to the Commissioning Executive to approve the Full Business Case for a tender for the integrated community diabetes service
- The specification for the Integrated Community Diabetes Service will include clinics across the city and evening clinics
- Access - transport needs will be addressed on an individual basis for people transferring from hospital intermediate care to the integrated community diabetes service.

Hospital care and specialist diabetes care

- Ensure the University Hospitals of Leicester respond to peoples' views about specialist services
- Ensure the University Hospitals of Leicester plan to improve the in-patient care experience for people with diabetes

Implementing the plans included an ongoing survey of people with diabetes to assess progress in improving people's experience and knowledge in managing their condition. Contracts included services to monitor people's satisfaction and outcomes. We established patient panels to help inform the selection of services contracted through a tender process and continue to engage user and voluntary groups in the Diabetes Implementation Group.

Gender dysphoria

East Midlands Specialised Commissioning Group (EMSCG)

What was the issue

Gender dysphoria is a condition where a person feels that they are trapped within a body of the wrong sex. The condition is also sometimes known as:

- gender identity disorder
- gender incongruence
- transgenderism

People with long-lasting and extreme gender dysphoria are known as transsexuals. A person with gender dysphoria may:

- experience anxiety, uncertainty and persistently uncomfortable feelings about the gender they were born with
- believe that their gender identity is different from their anatomical sex

The aim of the consultation was to identify amendments which needed to be made to EMSCG's policy and service specifications:

- to ensure equality and that they do not discriminate against groups/individuals
- to ensure the policy will meet the needs of the patients that it will impact upon
- to ensure the policy is workable and up to date with current practice/evidence
- to ensure compliance with all relevant legislation.

The engagement period ran for twelve weeks from the 27 April to the 27 July 2009.

Who was consulted

A number of key people to contact with the engagement documents, both internally and externally, were identified, and an internet search was conducted to obtain contact details for lesbian, gay, bisexual and transgender and other transsexual interest and support groups across the East Midlands and nationally.

The engagement documents were mainly sent out via e mail and posted on the internet. As the EMSCG is hosted by NHS Leicestershire County and Rutland and works on behalf of the nine primary care trusts in the East Midlands, the information was sent out to Patient and Public Involvement Groups and Local Involvement Networks leads. There was a face-to-face engagement conducted by the Social Inclusion manager at NHS Nottingham City, and the documents were sent out to Principia whose aim is to make the NHS more responsive to the Nottinghamshire community.

NHS Leicester City placed the engagement invitation and documents on their website. Easy to read versions of the policy were also sent out to groups in order to make it easier for both the facilitators and the patients themselves to understand the policy in order to make informed comments or recommendations. There were 24 responses in all out of more than 60 individual or groups contacted.

What information was given

Information was provided on the relevant legislation and the current EMSCG policy and service specification.

What were people asked to comment on

People were asked to use their experience of care services and to identify issues and gaps in provision in the range of care services for people with gender dysphoria. There was no prescribed list of topics for participants to comment upon, and the engagement process was left open ended.

Summary of feedback

The main themes that emerged from the engagement process, which people commented on were the following:

- equality
- involvement
- operation of the policy
- patient pathways
- referrals and psychiatric assessment
- the 'real life experience' (RLE)*
- surgery
- other interventions
- providers
- training and resources
- financial implications
- evidence
- presentation/use of words.

* Patients who want gender confirmation surgery will first need to live in their preferred gender identity full time for at least a year. This is known as real life experience (RLE) and will help confirm that permanent surgery is the right decision.

Decisions made

Key amendments made to the policy and service specification as a result of the engagement process:

- A sentence has been added to the policy advising that it may be possible to bypass a stage in the patient pathway, if this is reasonably acceptable.
- The sentence that 'patients may be discharged once they have a stable gender identity' has been taken out, as patients may have a stable gender identity but may still require support.
- The idea of 'patient led in-house support groups' has been taken out, as this may not be current practice in Gender Identity Clinics. However, patient information about local groups remains included, as this may provide some of the peer support required by some patients.
- Elective revisions of surgery would not be routinely commissioned.

- Regular participation in some form of psychological participation during the one-year Real Life Experience phase has been amended to 'although some patients may not be requiring of it, regular participation where required in some form of psychological input during these sessions will be made available'.
- A clause has been included to advise that 'discretion rests with the clinicians regarding what is reasonably practicable regarding whether it is possible for the patient to start the RLE phase without hormone therapy or not'.
- The requirement for 12 months RLE prior to surgery remains included within the policy, but an addition has been made that patients have the opportunity to apply via Individual Funding Requests, if they feel they are exceptional in requiring surgery before 12months.
- The need to have undergone penectomy (penis removal) and orchiectomy (castration) prior to being able to undertake breast augmentation has been taken out, as it may not be possible and/or patients may not be requiring of either.
- The policy has been amended to take out most of those procedures mentioned, which are not core surgical procedures in the policy, eg, facelift. For the non-core procedures, it has been made clear what will and will not be routinely commissioned.
- The procedure of phalloplasty (the construction of a penis) has been amended to include those that can be performed as part of this, ie, glans sculpting, placement of testicular and penile prosthesis for clarity.
- The service specification has been amended with regards to follow-up after surgery. This will be done within or at 12 months.
- The service specification has been amended to advise that if a patient does not meet the requirements within the policy in order to undertake an assessment, the letter explaining this will offer patients the opportunity to make an appointment to see the referring clinician to explain the decision and discuss.
- The incidence and prevalence data has been updated to reflect the recent publication of Incidence and Prevalence by The Gender Identity Research & Education Society (GIRES) (2009). Similarly, a narrative review by Gijgs and Breways (2007) has been added to the policy.
- The service specification has been amended in terms of the make-up of the Multi-Disciplinary Team members as follows: 'There is a requirement for 'Psychiatrist, Psychologist, Psychotherapists (unless there is a suitably qualified member of the team capable of combining all of these roles competently)'. Also, the urologist or plastic surgeon (or both), and sometimes a colorectal specialist have been added to the requirements within the MDT (for surgery).'
- Within the service specification, the following sentence has been added 'or other nominated suitably qualified clinician required by extant clinical guidelines' in the criteria for referral for gender re-assignment surgery, in order to reflect current practice.
- The sentence for providing 'support and style to aid passing as member of opposite gender' has been taken out, and simply reads 'to provide support and advice on style.'

GP service contract procurement – a case study in greater patient involvement

We invited members of the current practices' Patient Participation Groups to nominate one member to attend a training programme and sit on the panel assessing GPs bidding for new GP practices. As one practice was to be completely new, a member living in the relevant area of the city, where it would be located, was invited to sit on the panel.

The participants undertook three evening sessions of training facilitated by an independent consultant, with staff also participating in the process.

The first session provided an overview of the procurement process and encouraged participants to discuss the skills required to be on a panel.

The second session enabled participants to develop questions and scoring criteria.

The third session split participants into staff and patients/public. Staff were separated into two teams (in order for the patients to draw comparisons) and given a title of a presentation with time allowed to develop a presentation with materials including pointers.

The patients were given information on non-verbal communications looking at how body language can reveal certain things such as voice pitch rising when you are lying.

The staff then presented in turns and the participants watched and asked questions. The staff chose one team to provide a bad presentation and the other a better one but included some slides which were identical to see if the panel perceived any difference. This proved useful as differences were noted on slides which were identical, highlighting how biases operate. This was then followed by a de-brief session asking how the patients found the experience, what they thought of the presentations, if they noticed any differences/ similarities.

Three patients attended the interviews, asking the questions devised in the training sessions and scoring all of the questions asked by the panel. At the end of the session the whole panel reviewed the scores given and debated why they had scored what they had, this gave the panel an opportunity to change their scores upon reflection as some of the participants found that their opinions changed once they had seen a few of the potential providers as they had more of an idea of what a good response should contain.

Learning from this approach

The training allowed participants the opportunity to watch and review the staff performing a mock panel/ presentation which provided good experience.

The panel were able to draw up the questions which meant that they were able to ask what they wanted as opposed to scoring on questions which they had no involvement in.

The training gave patients useful information on the principles needed to perform effectively on a panel and reinforced the notion that they were there as representatives rather than individuals.

The patients were also given the opportunity to visit existing practices managed by the potential providers and the chance to inspect and review the services provided. Feedback from the patients highlighted how important this part of the process was and how it should be completed as soon as possible after the interviews whilst the information remained fresh. They also mentioned that their papers from the interviews were collected at the end of each session and not returned when visiting which meant there was nothing to prompt them.

We learned that the training programme was too long and often contained a variety of information which was not relevant and at times created confusion.

The training sessions took place in the evening and the interviews took place in the daytime which meant that some of the participants were unavailable to attend due to work commitments. The time required for the interviews was not specified at the outset, which led to some frustration from the participants.

Patients expressed an interest in receiving the financial information from providers as this bore significant relevance for the decision making process. It was suggested that an affordability criteria should be set for future procurements to ensure any prospective providers would be financially viable when entering the interviewing stage.

Heart attack and stroke services **(East Midlands consultation with Leicester, Leicestershire and Rutland input)**

What was the issue

Cardiovascular disease (CVD) death rates in Leicester are significantly higher than the national average and contribute 8% of the life expectancy gap. This is compounded by the high rates of diabetes particularly in the South Asian community. More than half of CVD-related deaths are from coronary heart disease (CHD), and a quarter are from stroke. As a result, CVD was identified as one of NHS Leicester City health priorities.

NHS East Midlands was proposing to concentrate skills in new specialist centres which will have the most experienced and skilled staff working with the most modern equipment all in one place, providing the best treatment possible. Evidence shows that patients requiring urgent medical care have a better chance of survival and recovery if specialist experience and equipment is concentrated in one place. Ongoing treatment and recovery can then be offered in a local hospital nearer to the patient's home. We required a review of existing heart attack and stroke services, and of patients' experiences and expectations, to help identify key areas for improvement.

Who was consulted

We undertook consultation across the Leicester, Leicestershire and Rutland area. A communications and engagement event took place at High Point, Leicester, on 14 December 2009. Between December 2009 and January 2010 hard copy questionnaires were distributed to interest groups, and we held online surveys on both heart attack and stroke services. Discussion groups were also set up.

Numbers recorded as having attended events or contributed to the surveys were 309, made up of:

- High Point 89
- Hard copy questionnaires – heart attack 77
- Hard copy questionnaires – stroke 89
- Online survey – heart attack 33
- Online survey – stroke 21

Of those taking part in the hard-copy and online surveys, 15% had suffered a heart attack or stroke, and 53% said a member of their family had suffered one or the other.

What information was given

The current patient pathways were described. Currently patients are often taken to their local hospital if they require urgent medical care following a heart attack. Not all hospitals can provide 24-hour access to the most appropriate treatment.

The range of options for delivering an improved service, and the key stages of a revised procedure, were explained.

What were people asked to comment on

People and patients were asked about their experience of the patient pathway, where relevant, and their expectations of what the service should provide. Issues identified for comment included: response times and handling, the distance to the location of the hospital, forms of transport for patients being discharged and for family visiting, clinical and other responses needed at the receiving hospital, continuity of care after discharge, and communications with both patients and their families.

Summary of feedback

Heart attack

Response handling

There were expectations of a rapid response from the emergency services with onsite diagnosis and initial treatment. People expected the paramedics to be trained and knowledgeable. Expectation that patient would be stabilised with treatment continuing en route. Calls to an operator should see the operator asking about chest pains. Expectation that specialists will be on standby to cope with the hospital admission.

Distance to the location of the hospital

Event delegates in general thought the patient should be transferred to a specialist (cardiac) centre – up to about 30 minutes away.

Transport for patients being discharged and for family visiting

Most of the comments considered transport issues – both for the patient, ensuring a smooth transfer, and particularly for family in terms of ease of travel, access to the hospital and any parking costs. The ability of paramedics to provide resuscitation during the journey was mentioned.

Clinical and other responses needed at the receiving hospital

Patient care was a concern in that respondents wanted reassurance that they would be fit enough to make the journey and whether it is essential that the journey to specialist care is made. They wanted to know a bed would be available upon arrival. Care for the individual was of paramount concern and this depended on the individual respondent with replies stating deafness, memory loss, wheelchair-user and consideration of other existing medical conditions (eg, diabetes). People wanted to be reassured that a specialist team would be ready at the receiving centre. They also wanted to know what support would be available in the first 72 hours at the hospital. Language could be an issue and the need for an interpreter was raised.

Continuity of care after discharge

People wanted to see that there would be continuity of care in any move and wanted to know what support would be available in the community/community hospital/from GPs/ social services and provision of general rehab. Respondents wanted to know

that their medicines, oxygen and healthcare records would be transported as well and that they would be well enough to make the journey back.

Communications with both patients and their families

There were many mentions of the need to make sure that family/carers could support the patient in their new hospital, with a need for clear communications to the patient and family.

Stroke

Response handling

Event delegates said initial patient care should be based on the FAST approach (facial weakness, arm weakness, speech problems, time to call 999). Paramedics were expected to carry out FAST appraisal. Patient to be checked out and family medical history sourced. There was an expectation that the patient would be transferred to hospital/specialist centre and taken into the care of a stroke team.

Distance to the location of the hospital

Event delegates mentioned a specialist stroke unit or the most appropriate place for the condition. One table's response was summarised as: "doesn't matter which hospital as long as the staff are fully trained." In general, some people commented that they wanted a hospital/unit that was 'near' as in 'a local hospital equipped for rapid response'.

Transport for patients being discharged and for family visiting

One concern expressed was the need for transport home after treatment. One person mentioned the 'golden hour' with implied concern about distance and effect upon condition. The effect on patient care was put, bluntly, by one respondent: 'how to keep me alive during the journey'. Re-assurance was sought that patients would not be at increased risk due to the journey. Another wanted reassurance on facilities available in the ambulance. On the same theme of the journey, another asked for a member of their family to accompany them. A couple of people stated they wanted 'clean ambulances'. One person mentioned: "higher travel costs impacting on PCT funds". Other comments received related to taxis and wheelchair access. Many responses stated that the location chosen would have to be suitable for visiting by family/other visitors. Costs of family visiting was an issue, eg, cost of transport and parking. Access by public transport seen as important for family.

Clinical and other responses needed at the receiving hospital

Decisions taken concerning a new centre would depend upon the impact on the patient with one saying "the time limit for urgent clot busting treatment" was important. Several respondents mentioned ambulances/paramedics, looking at what care could be provided in the ambulance and that the paramedics should be in touch with the specialists. One comment received implied the decision may be related to the age of the patient: 'for some older people, travelling might be out of the question'.

Continuity of care after discharge

Respondents were interested in care during the hospital stay and afterwards so they knew how to cope when they returned home. There was also the issue raised of the need for integrated care among hospital staff and different agencies. One comment

received related to local NHS staffing: “make sure smaller, community hospitals have therapy staffing to cope with higher demand of stroke rehab”. One called for the “availability of specialised stroke treatment, such as physiotherapy, to enable the best possible recovery.” People wanted to see the patient involved in planning the move and receiving the best possible care. Home adaptations may be required as part of rehab. People wanted to see joined-up systems in support of travel arrangements, communications and rehab.

Communications with both patients and their families

It was seen as important to consider the family in any move, especially to give advance notice of any move due to ability to make visiting times. Event delegates said that a dedicated person should be available to talk to patients and families – and that same person should be in charge of communications with staff on the same ward. On-going patient records should be made available for both the hospital and patient’s GP. People wanted to see as much information/communications provided as possible.

Decisions made

Improvement work is underway in prevention, acute care, rehabilitation and long-term self-management for patients with cardiovascular disease. These plans will also ensure ‘care closer to home’ by providing continuing care and rehabilitation in the community. The pathway for transient ischemic attacks (also known as ‘mini strokes’) in Leicester, Leicestershire and Rutland has been redesigned to provide a seven-day, one-stop service and 24/7 treatment to tackle blood clots.

Specialist centres are being developed across the East Midlands, offering patients vital assessment and treatment for stroke and heart attack. Stroke services at Leicester General Hospital are being relocated close to the Accident & Emergency (A&E) unit at the Leicester Royal Infirmary, where patients will be admitted directly to a specialist stroke unit.

The proposals for the East Midlands region also mean that services will be enhanced for heart attack patients by the increased availability of highly specialist care. A treatment which unblocks the artery carrying blood to the heart, is being extended. The service will be offered 24 hours a day, seven days a week, with direct admission to the cardiac unit at Glenfield Hospital, Leicester. Work has already begun on these developments.

Intermediate care and rehabilitation

What was the issue

Intermediate care has been defined by the Department of Health as “a range of integrated services to promote faster recovery from illness, prevent unnecessary acute hospital admission, support timely discharge and maximise independent living.” The consultation included looking at the current patient journeys of care and aimed to give patients and the public the opportunity to discuss experiences, pre-admission and post-admission, to hospital. This work was intended to inform us of possible reasons for change to improve intermediate care and rehabilitation.

Who was consulted

CLASP, the Leicester carers' association, and NHS Leicester City members were invited to a discussion event in July 2009. Patients and other carers, were invited along with representatives from the voluntary and independent sector, and representatives from care homes. A total of 25 attended. The group was representative of the population of Leicester, with many patients attending coming straight from residential care with their carers. Other attendees included representatives from different long term condition groups, organisation group leaders and councillors. Following the event, the engagement team were asked to present to the BME Elders Forum at Age Concern. The team conducted the session with members from many of the seldom heard groups and communities with the findings feeding into the overall feedback.

The consultation was also promoted on our web site and we asked people to fill in a questionnaire, if they or someone they knew had experienced intermediate care.

What information was given

The patient pathway was drawn in graphic style to simplify the patient journey in order to gain feedback on what patients experience as they go through the service. Suggestions were made by the engagement team on possible areas of improvement, to promote discussion.

What were people asked to comment on

Respondents were asked to agree what was meant by intermediate care and to decide what could be improved from the current procedures. They were also asked to identify opportunities and agree reasons for changes and to agree what patients would want to have in a personalised care plan to help them better understand their treatment and manage aspects of their own condition.

Summary of feedback

It has highlighted that many patients are unaware of what they are entitled to from social care. As the criteria are becoming stricter there are so many patients who, once discharged from hospital, are no longer under the care of the NHS, but are not

eligible for assistance from social care. Therefore it is vital that organisations accept responsibility for these patients. It was noted that there are not only issues with long in-patients stays but also problems with discharging too early. It was noted that issues surrounding discharging and full care packages were key areas for improvement and would be addressed through the personalised care plans.

The attendees agreed that there was a need for the role of different agencies to be clear when attending to them at home as this often leaves patients confused about who has seen them. This is work that requires integration with social services. Transport was highlighted as an issue with an attendee referencing her experience of when a nurse waited two hours after the end of a shift as patient could not be taken home.

It was highlighted that young adults will have different care needs throughout their lives and services need to be responsive to this. A representative from the city's Rainbows Hospice for Children and Young People raised awareness of the organisation as providing a service for children and now young people too. People said that a personalised care plan should be easy to use, something that would allow them a dialogue with the clinical professionals handling their case, and that would give them confidence and encouragement in self-care. There should be space for contacts and supporting information, such as web sites, and a section for their personal goals. Patients liked the fact that these plans would deal with their case as a whole, and not simply the main condition for which they were being treated.

Decisions made

We have developed a clearer understanding of demand, the choice of providers and future service needs, including numbers of beds required. We examined the alternatives and drew up an intermediate care strategy to procure new local community-based intermediate care, while saving on hospital beds used for intermediate care. The above feedback informed the basis for revised service specifications in discussions with University Hospitals of Leicester and Leicester City Community Health Service.

On the issue of better communication and patients not knowing what they were entitled to or what would happen to them after treatment, Leicester City Community Health Service prepared a booklet, which describes the journey of receiving intermediate care within the city, and which is made available in GP surgeries for preventative measures and at the hospitals once patients have been discharged to go to a city based Intermediate Care unit.

Discussions have started with Leicester City Council regarding improved arrangements for those needing social care, with a closer integration of health and social care responsibilities.

The patient transport system is currently under review.

Personalised care plans for patients with long-term conditions are being introduced for patients to receive and complete with a clinical professional, including advice on medication, healthy eating, self-care and where to go for additional support.

Major trauma

(East Midlands regional consultation with local input)

What was the issue

Major trauma is used to describe serious and multiple injury where a patient has less than 10% chance of survival, such as after a serious road accident, an explosion, fire or grievous assault. There are about 660 cases a year in the East Midlands. We did not have a major trauma system in the East Midlands region. We aimed to develop a high quality, safe and effective system with 24-hour access to a major trauma team.

Who was consulted

Throughout the summer and autumn of 2009, primary care trusts in the East Midlands sought the views of patients and the public. Each trust identified the key audiences to talk to in their area, including groups who will be specifically affected by the proposals, voluntary groups and community groups. Across the region more than 400 members of the public took part. They were made up of the 283 people who took part in 20 face-to-face discussion events held in a range of community venues in each county, while 125 people responded to an online survey.

Many engagement activities involved groups who had a particular interest in trauma, or who were likely to be specifically affected by the proposals. These included:

- the Headway patient group (Leicestershire)
- people involved in horse riding and agriculture (Derbyshire)
- motorcyclists (Lincolnshire)
- young people and youth workers (Nottingham)
- prisoners (Nottingham)
- motocross riders at an Amateur Motorcycle Association event (Northampton)

What information was given

A schematic chart reproduced at events and in reports showed the worst case scenario now, resulting in possible long-term ill health for the patient. A framework for a proposed revised system was also explained. We said we wanted to create a specialist major trauma system for the East Midlands. This centre will have specialist doctors and nurses, trained to deal with major trauma, who will be available 24 hours a day, seven days a week to treat patients. This centre will be based at a large hospital in the region and it will always accept a major trauma case through its doors. This major centre would be supported by a number of trauma centres based at other hospitals across the region, that will stabilise and care for less serious cases. The ambulance service will be trained to better identify major trauma patients and take them straight to the nearest trauma centre rather than the local emergency department. The potential benefits include:-

- saving lives (20% reduction in lives lost)
- significantly improving chances of making a full recovery
- improving access to specialist services no matter where major trauma occurs

What were people asked to comment on

Respondents to the consultation were asked to:

- help design the major trauma system
- engage with the different scenarios that have been written
- say what they felt the major trauma system should provide
- share comments/experiences to help build a robust, patient friendly system

Questionnaires were produced, both hard copy and online, in July 2009. They asked respondents to say what their expectations were of major trauma services, starting at the scene of the incident, then moving on to a place of treatment, considering what issues would arise if it were to be a substantial distance away, and what issues needed to be taken into consideration when transferring patients to a local hospital for the next stage of treatment and recovery, including what information should be made available to families and carers.

Summary of feedback

In November 2009 a report was published with a summary of engagement events and feedback. It said that at the scene of an accident, people expect a quick response by a well equipped ambulance staffed by trained paramedics.

Most people expressed a desire to be taken to the hospital best equipped to deal with their injuries, even if this meant a slightly longer journey. Some patients expressed concern about longer journeys, especially for injuries they thought could be treated by a local A&E.

People felt that longer travel times could be justified if a major trauma centre could deliver better care, if a bed was guaranteed on arrival, and if people could be transported in safety.

People also expressed a desire that families be kept informed and offered support while visiting loved ones some distance from their homes. This included practical considerations like good public transport to the trauma centre, the availability of parking, and help finding accommodation.

When being transferred to a local centre for on-going care, people expressed a preference for choice of hospital, sought reassurance that transfers would happen when clinically appropriate, and commented on the importance of continuity of care. It was felt to be necessary that families or carers be consulted to provide support.

Patients and their families expect clear, plain-language information about their condition and treatment, with support for people with first languages other than English. People expect to be involved in decisions about their care and to be able to talk to consultants. The people consulted saw a need for emotional as well as clinical support.

There was general support for a major trauma centre for the region.

Decisions made

A multi agency/professional programme board has been established to steer this initiative. This includes an air ambulance representative. There are various sub-groups established that then take specific pieces of work forward. In addition there are two appointed joint clinical leads who support the programme. Work has been underway to identify the right configuration of services that will enable patients to access the right service at the right time. This includes considering the plans of other health regions for major trauma service development.

In order to do this NHS East Midlands is working with hospitals, the voluntary sector, patients and the public, primary care trusts, health overview and scrutiny committees and local clinicians, to finalise details taking into account public comment.

The timescale the programme is working to is as follows:

- June-September 2010 – finalise proposals for a major trauma system for the East Midlands and the recommended configuration of services including designating Nottingham University Hospitals as a major trauma centre.
- September/October 2010 – present the final proposals to Overview and Scrutiny Committees.
- October 2010 – NHS commissioning organisations to approve the major trauma system for the East Midlands, approve the designation of Nottingham University Hospitals as the region's major trauma centre and decide on the configuration of major trauma units.
- December 2010 - the system and network management processes to be in place and service improvements implemented.
- April 2011 – the major trauma system is in place and beginning to treat patients.

Maternity and neonatal services

What was the issue

Following the publication of *Excellence for All: taking it to the Next Stage* in 2009, which set out how the NHS in Leicester, Leicestershire and Rutland would take forward the development of services, engagement plans were devised in specific service areas, including maternity and newborn services. We needed to know more about women's attitudes to having their care in hospital or in community based services. We also wanted to know how far people would be willing to go for specialist care, and where that specialist care should be available. NHS Leicestershire County and Rutland was given the task of leading the engagement process on behalf of the health community, and NHS Leicester City provided support through its engagement team.

Who was consulted

We held a number of open public events in November 2009 when people had the opportunity to have their say. These were on 11 November in Leicester (52 attendees), 18 November in Hinckley (25 attendees) and 19 November in Melton Mowbray (28 attendees).

We targeted women of childbearing age and specific minority groups where difficulties in eliciting a response had previously been encountered. A series of events with 'seldom heard' groups including travellers (11 attendees), South Asian women (60 attendees), young people (4 attendees) and asylum seekers (18 attendees). In addition a Pacesetters Maternity Project had earlier conducted interviews with 15 Bangladeshi women and this was fed into the engagement process. The age structure of the survey respondents reflected that of the user population. However, there was some under-representation of younger adults and teenagers. The survey was successful in reaching people in different parts of Leicester, Leicestershire and Rutland.

Questionnaires were made available, both online and in hard copy, including at events. An easy-read version was also developed. In total 814 questionnaires were completed. Half the questionnaires were returned by post, 27% were completed online. The remainder came from a variety of sources including the engagement events. An independent report on the consultation was compiled by the Health Policy Research Unit at De Montfort University.

What information was given

The general background to the Next Stage Review and the vision outlined in *Excellence for All*, published in July 2008, was explained. A summary of proposals was made available online and in hard copy in a supplementary report *Excellence for All: taking it to the next stage*. It included:-

- Building up services in the community so that women can choose where they can get advice and give birth

- Developing specialist midwifery roles and specialist nurses to deal with specific problems which may arise in the first few weeks following the birth of the baby
- Working with vulnerable groups, including teenagers and women with mental health problems, to develop appropriate services
- Improving care for very sick newborn babies by developing a specialist unit in one centralised hospital
- Improving communication between family doctors, maternity services and children's centres throughout pregnancy and childbirth so that everybody has up-to-date information about their pregnancy.

What were people asked to comment on

The questionnaire invited respondents to rate the importance of a range of issues, including the safety of maternity services, midwives' clinics and scanning facilities being closer to home, antenatal clinics having extended opening hours, birth and postnatal care being closer to home, and receiving an explanation of newborn care, facilities and staff available. They were also asked how far they would be prepared to travel for some services, and to rate the importance of home births.

Summary of feedback

Safety was regarded as paramount. Priority was also placed on access to services when birth complications arose. Respondents welcomed extended opening times for antenatal clinics and postnatal care.

Proximity to services was also an issue, with large majorities of people stating that it was important to have midwife clinics, scans, childbirth facilities and postnatal care close to home (ie, within five miles). However, respondents seemed more willing to travel to specialised baby care facilities and to access scans and examinations, compared to midwife clinics and birth facilities.

Respondents placed importance on information, such as that given to parents when expecting a baby. Choice was seen as important. A majority of respondents considered it important that where it is safe to do so, home births should be possible. Only a minority, however, stated that they would choose home births in future. Two-thirds said they would opt for a main hospital maternity ward with 30% opting for a midwife unit.

When questioned about the availability of services, respondents gave most support for active birth methods and a majority supported the availability of a birthing pool. Alternative therapies were supported by a smaller, but still substantial, proportion of respondents.

Some of these themes were reflected in the comments made by respondents. Many expressed gratitude and praise for local services and staff, and identified good practice. However, respondents also conveyed criticisms and suggestions for improvement in several areas, including low staffing levels, communication (both between health professionals and between service providers and users), continuity of

care, access to services, and choice. Issues were also raised about admissions, discharges and the birth environment.

Respondents identified areas where services could be extended or improved. These included midwife-led units, more postnatal support (notably for breastfeeding), greater support for first time parents, and improved access to antenatal care and additional content for antenatal classes.

The study detected some differences in views between demographic groups. These merit further investigation, in order to develop services around specific needs and preferences. For example, there were differences between white and BME groups on a range of issues including: choice of location for future births, access to facilities and extended hours of services. There were also some differences between age groups, between disabled people and those without disabilities, between men and women, and between people residing in Leicester, Leicestershire and Rutland.

Decisions made

The NHs health community covering Leicester, Leicestershire and Rutland has improved early access to maternity services with new support workers and specialist midwives. We have been recruiting additional midwives and aim to establish more frequent appointments.

A number of other options has been developed for the future of maternity and newborn care in Leicester, Leicestershire and Rutland. These will go to the trust boards of University Hospitals Leicester, NHS Leicestershire County and Rutland and NHS Leicester City during 2010.

Medicines management – patient letters

What was the issue

We recognise that future additional investment in patient care will need to be generated through the release of funds currently in our existing cost base, by improving the cost-effectiveness of many practices and procedures. This includes reductions in inappropriate clinical variation using evidence based approaches such as improvements to medicines management.

For example, we aimed to disinvest in “black traffic light” drugs, ie, those with little or no proven clinical effectiveness, the implementation of stricter adherence to the Leicestershire Formulary, introduction and improvements in medication reviews, improved patient involvement with medicine waste initiatives, introduction of central purchasing processes and switches to generic medication. This would mean changes to many patients’ current prescriptions, especially for those with long-term conditions.

The process of change of medication can be very upsetting for such patients, and we recognised the need for careful handling. The issue was how to ensure the communication process explained the reasons and encouraged co-operation and patient satisfaction.

Who was consulted

In April 2009 the Medicines Management team sought to organise a patient group to discuss letters given to patients informing them of changes to medicines.

In all, eight members of the public expressed their interest, having long-term conditions and experiencing changes to their medication in the past.

A workshop was held to discuss what happens when medicines are changed and how patients receive the information. The process was illustrated in a graphic style to explain that most patients only find out about changes when a letter arrives through the post.

The group discussed their experiences of changing medication and their feedback was gathered. New ideas were discussed offering new more effective ways of informing patients.

What information was given

An outline of the process of change was given, using a ‘graphicking’ illustration of the process, along with the reasons for change, such as consistency of prescribing with national and local guidelines, as well as clinical effectiveness and cost.

What were people asked to comment on

People were asked about their previous experience of medicine change, and:

- What happened?

- How did they find out about the change?
- Did they understand it?
- Did they talk to anyone about it?
- How did they feel about it?

They were also asked how they would prefer to be informed about changes to medication if they were:

- a young person
- hard of hearing
- non-English
- unable to read
- an older person

They were also asked to comment on the style and approach of a sample patient letter.

Summary of feedback

It became apparent that all of the patients wanted more information on why medication was changing.

It was also said that if letters were simpler and picture leaflets printed to go with the letters, patients would really understand more, be reassured and less worried.

Decisions made

It was agreed that the Medicines Management team would create a leaflet to go alongside a letter from the GP. The GP letter was also re-written to make it more patient-friendly.

The group were contacted at home to make comments on the leaflet and the letter during the design stages.

The resulting communications included elements commented on by the group, such as the following extract:-

BEING INVOLVED IN DECISIONS ABOUT YOUR MEDICINES

Making a decision about taking medicine

Your healthcare professional should:

- make sure that you have the chance to be involved in decisions about medicines so that you can make an informed choice about your treatment.
- talk with you about your preferences and ask you what you hope the treatment will achieve.

- understand that you might have different ideas from them about the benefits, risks and side effects of a medicine.
- You and your healthcare professional should decide together the most appropriate medicine for you.

Orthopaedics – care closer to home

What was the issue

We undertook a review of orthopaedics - muscle and bone services - commissioned by NHS Leicester City. The public and patient views will influence the service planning for a redesigned patient care journey, based on previous engagement findings (eg, from the Next Stage Review in 2008) that patients wanted care closer to home.

Who was consulted

During the autumn and winter of 2009 we involved the public and patients with muscle and bone conditions. We used questionnaires to collect data from the musculoskeletal department at the local hospital. There was a survey of 69 out-patients and we recorded the responses from two patient workshops. NHS Leicester City community development workers and the Patient Advice and Liaison Service were asked to share any concerns or issues patients discussed with them regarding their experience of muscle and bone services.

What information was given

Historically it had been difficult to gather detailed information from service users, so we reminded patients of the key stages in their treatment using Experienced Based Design, a relatively new tool available from the Institute of Innovation and Improvement. It is designed to help patients remember their journey throughout the different stages of the service, and brings patients and staff together to share the role of improving care and re-designing services. Information was given on three patient pathways, one hospital-based, one community-based, and a proposed revised patient pathway.

What were people asked to comment on

Using a series of key touch points in the patient's journey, members of staff interviewed patients in the out-patient departments of hospitals about their experience through each stage, with prompts to assist in understanding what this experience meant for them personally, for example, were they anxious, or in pain.

The 69 interviews lasted up to 10 minutes each and an equality monitoring form was included to gather information about the range of people interviewed. People were asked to comment on all three patient pathways, the hospital one, the community based one, and the proposed revised version.

Summary of feedback

Question	Positive	Negative
Waiting time to see a specialist following GP referral	Waiting time was acceptable. Took 2-4 weeks to be referred into the service.	Some patients had to wait several months and some well over a year to wait for a referral
Arriving for appointment	Some service users were happy with this. Some mentioned improved parking since charging was introduced.	Disabled parking was too far from the clinic. The clinic itself was hard to find and some patients had their appointments cancelled without any reason given.
Information at reception	Many service users were indifferent or happy with the reception staff. Glenfield received much more favourable comments than the other sites.	Patients were not told how long they had to wait which increased their anxiety. The waiting time board was not updated and some patients experienced difficulty understanding the staff.
Meeting with specialist	Many patients had a good experience with their consultant / specialist e.g. they described them as knowledgeable, friendly, helpful and had all the notes available.	Some patients were disappointed because they expected to see the consultant but saw the junior doctor instead. Some patients felt they were given false hope. There was a general lack of co-ordination between GPs and consultants and there were some problems understanding the specialist
X-ray or further investigation	Quick service with a good explanation given	Difficult to find, long walk
Treatment offered	Good, happy	After-care poor, three years of tests, good at Glenfield but other sites poor, pharmacy long way from clinic
Information given about condition	Lots of information verbal information given	A lot of patients felt they did not receive enough information as specialist did not have time

Below are the key issues that were identified using the experience based survey with 69 out-patients and the responses from two patient workshops:

- Better parking and access
- One-stop shop facility
- Key performance indicators
- Telephone helpline / email consultation needed

- More information in reception is required
- More written information about condition, and specifically about their condition
- Lower waiting times / let patient know how long the wait is
- Integrated package of care (including after-care)

Participants felt a need to have access to a translator when required and information to be produced in different languages. Participants also suggested a rolling training programme for older clinicians to ensure their methods and techniques are up to date with modern practices. They were supportive of the new pathway and were keen to see it in action.

Decisions made

A service plan for the redesigned community care journey is being prepared based on the comments and feedback received through this consultation process. Service providers will be invited to put forward their interest in providing this new service.

Stroke improvement project

What was the issue

Cardiovascular disease (CVD) is the biggest cause of death for those living in Leicester. It accounts for 35% of all deaths in the city and 25% of those deaths are as a result of stroke. A quarter of those who suffer a stroke are aged under 65. The current pathway for stroke is highly complex, involving a range of interventions from emergency care to short or long-term rehabilitation. The recognition, that improvements to quality of care and outcomes for patients receiving treatment were needed, was the starting point for the stroke improvement project.

Who was consulted

Sustained engagement gave a core group of around 50 stakeholders the opportunity to shape the stroke pathway. The group's membership was determined via stakeholder analysis and included representatives from LINK, stroke survivors, The Stroke Association, carers and stroke support groups, commissioners and clinicians. Clinicians included allied health professionals, a stroke consultant, a neuropsychologist, GPs and social workers. Workshops brought this group together to provide clear direction on the process.

What information was given

Details of the current patient pathway were explained, together with examples of patient experiences. Suggestions for improvements were made to stimulate discussion.

Individuals can enter the pathway from a number of routes. Firstly, a patient may suffer a transient ischaemic attack (TIA), also known as a mini-stroke, and seek emergency medical help. In October 2008 a specialist TIA clinic was commissioned at University Hospitals of Leicester NHS Trust as part of our local implementation of the Next Stage Review. This is a 'one-stop' service which offers diagnostics under one roof and fast access to a consultant. The TIA clinic is able to offer next day referral to surgery if needed and to provide advice and information on medication and condition management.

Patients can also be referred to the TIA clinic by their GP if a mini-stroke is suspected. An individual's risk of TIA is calculated in general practice using the recognised ABCD2 risk measurement technique which gives a risk rating based on an person's age, blood pressure, clinical features (symptoms), duration of those symptoms and as a secondary measure considers whether diabetes is present.

Yet, for many patients entry is due to a major stroke. Those suffering a stroke will be taken to Leicester General Hospital's stroke unit for treatment. In March 2009, in response to the recommendations of the *National Stroke Strategy* (DH 2007), a 24/7 thrombolysis service was introduced. Up to 15% of patients potentially meet the clinical criteria for suitability for thrombolysis, a procedure which breaks down the blood clots responsible for brain attacks. Thrombolysis is most effective when

administered as soon as possible after the stroke. In recognition of this staff from East Midlands Ambulance service (EMAS) have been trained to identify the potential signs of stroke.

The patient journey for those who have received standard treatment for stroke or thrombolysis converge during recovery and rehabilitation. Following medical stabilisation at the Leicester General Hospital patients stay in the specialist stroke unit. Currently the average length of stay in the acute sector is 20.1 days. In 2008-09, 94% of patients were cared for exclusively in the acute sector prior to discharge. A multidisciplinary team will decide when a patient is ready to be transferred or discharged from the acute sector. Options for patients are:

- Discharge to their usual place of residence (family home or residential care home) with a social care package or alternatively a series of follow-up out-patient appointments in the acute sector
- Referral to community therapy services as part of an intermediate care package
- Transfer to a social care bed at Brookside Re-ablement Centre
- Individuals under 65 may be admitted to the Young Disabled Unit in the acute sector
- Transfer to a community hospital in Leicestershire.

A minority of patients, just six per cent, will be transferred from the acute sector to a community hospital. In this setting the average stay for a stroke patient is 85.3 days. Community capacity for those who have suffered stroke is currently limited.

The stroke journey links into the end of life care pathway as 20% of those who suffer a stroke will die. Patients have access to palliative care and can exercise choice on whether they want to die at home or in a clinical environment.

What were people asked to comment on

The sessions allowed stakeholders the opportunity to analyse the current pathway, review the current patient journey and determine what elements should be redesigned and how to take the project forward.

Summary of feedback

Patients experienced concern and confusion on first being assessed and treated, and wanted to know more about what was wrong than “You’ve had a stroke”. They needed advice on what they could and could not do. There were also concerns about the conditions of the wards and the quality of the food. However, most patients said the staff were good, caring and attentive. Patients also needed more information about what was happening during the transition from healthcare to social care.

This investigation revealed a number of key areas where there was opportunity for improvement. It was noted that the mini stroke service was working well but also that it had now been commissioned for a year and this was an appropriate milestone for review – with the aim to consolidate and build on its success. Secondly, work was needed to raise awareness of stroke amongst health and social care professionals,

especially GPs, and better public awareness could improve stroke victims' likelihood of getting vital emergency care. It was recognised more patients were getting to the acute stroke unit quickly but considerable numbers still go through A&E at the Leicester Royal Infirmary first.

The stroke unit at Leicester General Hospital provides good stroke-specific rehabilitation but many patients stay there for longer than they need to because there are not appropriate services to refer them onto. Further, there is not enough capacity in community services to ensure systematic and consistent referral for stroke patients. There are a large number of different services in place but they all enforce admission criteria that restrict access, for example, time limits on length of stay or age requirements. This could lead to clinical variation so it was identified as a risk area within the pathway.

Finally, examination of prevalence data on stroke showed some discrepancies within local GPs' Stroke Registers and a drive to encourage more complete, consistent data across practices was prioritised.

Decisions made

The business case was approved and plans are afoot to implement the new pathway. As we moved into the procurement phase of this project at the end of 2009 we had a clear direction on where changes were needed for a demonstrable impact. We were able to examine exactly how costs lie within the current pathway and to map them onto the existing model of care. As our redesign of the balance of interventions develops into a service specification, we can also evidence how we have shifted levels of financial investment to respond to recognised gaps in care.

How to contact us

NHS Leicester City
St John's House
30 East Street
Leicester LE1 6NB

For general enquiries: 0116 295 1400 (Mon-Fri 8.30am - 5pm)
Email: enquiries@leicestercity.nhs.uk

Customer Services

Our Customer Services includes complaints handling, Freedom of Information requests, and help with queries from patients, carers and members of the public.

Post: Customer Services, St John's House, 30 East Street, Leicester, LE1 6NB
Tel: 0116 295 7011
or 0116 295 7017 for dental matters, including registering with a dentist.
Email: pals@leicestercitypct.nhs.uk

NHS Leicester City Membership

NHS Leicester City Membership scheme enables people from all sections of the community to participate in our work in a way that suits them. The main aims are:

- to develop two-way communication between NHS Leicester City, patients, community and voluntary groups, and frontline staff
- to keep members informed of developments in healthcare
- to reflect the diversity of the local population
- to recognise the knowledge and experience of Leicester residents and our staff

Tel: 0116 295 4183
Fax: 0116 295 1513
Email: getinvolved@leicestercity.nhs.uk
Post: Freepost RRUE JRBR RGGT, NHS Leicester City, St John's House, 30 East Street, Leicester, LE1 6NB.

LINKs - Local Involvement Networks

Local Involvement Networks (LINKs) are a network of people, organisations and groups who want to strengthen the quality of health and social care services.

For Leicester LINK telephone: 0800 7319432

You can also write to Leicester LINK at:

Unit 55, Business Box
Brailsford Industrial Estate
2 Oswin Rd
Braunstone
Leicester LE3 1HR

Email: LeicesterLINKs@carersfederation.co.uk

Do you need help understanding this report?

Our annual report can be provided in other languages and formats on request, including large print.

If you require help understanding the contents of this leaflet, please telephone 0116 295 4743 for translation or other formats.

જો તમને આ દસ્તાવેજમાં આપેલ માહિતી સમજવા માટે મદદ જોઈતી હોય તો મહેરબાની કરીને **0116 2954743** પર ફોન કરો.

ਜੇਕਰ ਤੁਹਾਨੂੰ ਇਸ ਦਸਤਾਵੇਜ਼ ਦਾ ਵਿਸ਼ਾ ਵਸਤੂ ਸਮਝਣ ਲਈ ਮਦਦ ਦੀ ਲੋੜ ਹੈ ਤਾਂ ਕ੍ਰਿਪਾ ਕਰਕੇ ਇਸ ਨੰਬਰ ਤੇ ਟੈਲੀਫੋਨ ਕਰੋ **0116 295 4743**

अगर आपको इस दस्तावेज़ में शामिल जानकारी समझने में सहायता चाहिए तो कृपया 0116 295 4743 पर फ़ोन कीजिए।

اس دستاویز میں جو کچھ ہے اس کی معلومات کے لیے براہ کرم **0116 2954743** پر ٹیلیفون کریں۔

Hadii aad u baahantahay in lagaa caawiyo fahmida qoraalka ku qoran documintigaan fadlan nagala soo xiriir telefoonkaan 01162954743.

Jeśli potrzebujesz pomocy w zrozumieniu treści tego dokumentu prosimy o telefon pod numer 0116 2954743.



**NHS Leicester City
St John's House
30 East Street
Leicester LE1 6NB**

September 2010