NHS
Leicester City
Leicestershire County and Rutland

Real Accountability Annual Report 2010 – 2011

Consultations and public engagement projects to inform decisions on commissioning healthcare

Real Accountability Annual Report 2010-2011

Introduction

Real involvement is a requirement under the statutory guidance in Section 242 of the NHS Act 2006. Primary Care Trusts (PCTs), NHS trusts and Strategic Health Authorities have a statutory duty to involve patients and the public whether by consulting or providing information, or in other ways. Such involvement and consultation is required in:

- planning the provision of services
- the development and consideration of proposals for change in the way services are provided, and day to day processes, commissioning, prioritising and service re-design
- decisions to be made affecting the operation of services

The July 2010 White Paper *Equity and excellence: Liberating the NHS* said "We will put patients at the heart of the NHS, through an information revolution and greater choice and control." The Paper set out the following:

- shared decision-making will become the norm: for patients this must mean "no decision about me without me"
- we will also look at existing mechanisms, including relevant legislation, to ensure that public engagement is fully effective in future, and that services meet the needs of neighbourhoods
- we will proactively seek and build continuous and meaningful engagement with the public and patients, to shape services and improve health
- we will lead continuous and meaningful engagement with clinicians to inform strategy, and drive quality, service design and resource utilisation.

In April 2010 the Department of Health published new guidance for the NHS, which asked local PCTs to produce an annual report about how they have acted on feedback from patients and the public, and to highlight forthcoming consultations. This requirement is called 'Real Accountability'. The report must also include influences that have been made as a result of the consultation.

This is the second report covering all consultations from April 2010 to March 2011. It is a joint report for both NHS Leicester City and NHS Leicestershire County and Rutland, which began working collaboratively as a single PCT cluster in the autumn of 2010. The Cluster has already begun transferring increased responsibility to the three clinical commissioning groups (CCGs) for our area – Leicester City CCG, West Leicestershire CCG and east Leicestershire and Rutland CCG. The groups are due to take full legal responsibility for most local commissioning functions by April 2013, subject to Parliamentary approval of the Health and Social Care Bill and the successful authorisation by the Department of Health for these CCGs to undertake their relevant commissioning duties.

Foreword

The people of Leicester, Leicestershire and Rutland 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 Secretary of State for Health presented to Parliament the White Paper *Equity and excellence: Liberating the NHS* in July 2010. It includes the policy to phase out primary care trusts and create a lead role for clinical commissioning groups in future. It also gives weight to the principle of "fuller engagement with primary care professionals, patients and the public" and sets out "to ensure that public engagement is fully effective in future, and that services meet the needs of the local neighbourhoods".

The engagement expertise we have developed in Leicester, Leicestershire and Rutland will prove a valuable asset to future local commissioning bodies. So in the interim we need to maintain the standard we have set, as an example of best practice for those who follow us. The practice based commissioning groups, who played such a vital role on our former Commissioning Executive, provided an ideal forum for this expertise to be shared and its legacy continues in its successor body, the clinical Collaborative, and during the 'shadow clinical commissioning group' phase of the ongoing NHS reforms.

Our clinicians know that Leicester, Leicestershire and Rutland is a complex area. What suits one area may not suit another. There is no longer a place for a 'one size fits all', or 'top-down' mentality when it comes to designing clinical pathways and other areas of our healthcare services. If we cannot make the service fit the local need – clinically and culturally – we are not doing our job to the standards required by the principles of 'equity and excellence' set out by the government.

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".

Catherine Griffiths
Chief Executive

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Background

NHS Leicester City, Leicestershire County and Rutland along with all other NHS trusts are required to proactively engage with all stakeholders in all groups: staff, public, patients, partner organisations, voluntary, independent and private sector to collect and collate their feedback on consultations. This is not only a legal duty, but it is also best practice to feedback outcomes form the consultations locally. This is to be fed into the Real Accountability report once a year. This will further underpin the vision of the organisation to reduce inequalities and to represent, support and enable the population of Leicester Leicestershire and Rutland to have their say on such major changes.

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 and NHS Leicestershire County and Rutland have been making great strides in involving local residents in the development of these services. Our goal is to ensure that Leicester residents are among the most informed and empowered in the country. It is also our ambition that we are as demographically representative of the city and two counties as is realistically possible to ensure that typically hard-to-reach and seldom heard groups also have appropriate opportunity to have their say. The two PCTs' new Cluster Board and the area's three CCGs are using the feedback and insight into patients' needs and wishes in order to inform improvements in health services.

In future we need to illustrate best practice engagement and lead the way ready for the time when legal responsibility for engaging with the population of Leicester Leicestershire and Rutland transfers to our CCGs. There are various high quality patient and public groups available, who have been or can be contacted to feed into future engagements. NHS Leicester City and NHS Leicestershire County and Rutland are looking into the facilitation of the transition of engagement from local trusts to the CCGs to empower GPs and their clinical colleagues to meaningfully engage with their patients in future.

Part I: Joint partnership engagements

Adult mental health strategy

What was the issue?
The Joint Commissioning Strategy for Mental Health sets out the commissioning intentions of NHS Leicester City and Leicester City Council in respect of services for people with mental health over the next 18 months. As the key partners to this plan NHS Leicester City is responsible for commissioning health services locally and Leicester City Council is responsible for commissioning social care services. In the summer of 2010 consultation took place about the commissioning priorities with service users and family carers, facilitated through voluntary organisations and existing forums.

Who was consulted?
The strategy has been developed through the NHS Leicester City Mental Health Programme Board, which brought together a range of stakeholders who are interested in mental health and wellbeing. The role of the Programme Board was to develop the strategic direction for commissioning and delivery of mental health services in Leicester and monitor its implementation. In drawing up this strategy we took into account the needs of service users, expert and clinical knowledge, evidence of what works and most importantly how the people who use services would like to see them developed. The stakeholders consulted included:

- staff and clinicians working for Leicester City Council and the Leicestershire Partnership Trust
- services users and carers
- residential Care providers within Leicester City
- other independent Providers of mental health services within Leicester City
- GPs and primary care staff
- voluntary organisations

Additional focus groups were also held with the South Asian community, a Bengali women's group and the Somalian community.

The focus groups were facilitated by the following local voluntary sector organisations and they also supported the completion of questionnaires:

- LAMP (Leicestershire Action for Mental Health)
- Adhar (meaning 'support' – for adults with mental health problems and their carers)
- Network for Change
- Akwaaba Ayeh (advocacy and advice on mental health for BME communities)
- Community development workers

What information was given?
A covering letter was sent to stakeholders via email and through the post which outlined the intentions for the Joint Commissioning Strategy for Mental Health. Information with a link to the questionnaire was also put on the PCT and local authority websites including links on the voluntary sector organisations' website. A presentation was given in the focus groups meetings explaining the need for a new strategy highlighting the identified priorities for discussion. In all engagement it was explained that the feedback would be used to inform the development of the strategy.

What were people asked to comment on?
Consultation about the priorities, their current experiences and the type of services they would like in the future took place over August and September 2010. An online survey was developed including the provision of paper based surveys to gather people's views. Furthermore, a series of focus groups took place across the city. The focus groups were held with groups with which the organisations do not often engage. The service users and carers were given the draft priorities and asked to state whether they agreed or disagreed. They were then asked to rate the importance of each priority. Questions were asked about the different types of support on offer with recommendations for improvements.

Summary of feedback
From the respondents, a total of 79% of the respondents were mental health service users and 21% were carers.

In total 65% of the respondents were female and 35% were male. The ethnic breakdown of the respondents is as follows:

- Asian/Asian British – 56%
- Black/Black British – 8%
- Chinese – 0%
- mixed/dual heritage – 1%
- White – 23%
- other Ethnic Group 4%
- non-respondents 8%

When analysing the ethnicity data it is pleasing that we had such a high percentage response from the Black Minority Ethnic groups. This is vital in a diverse city like Leicester.

Just fewer than 54% of the respondents considered themselves to have a disability.

Over 96% of the respondents considered their mental wellbeing to be very important. The respondents considered that the following were **very important** to their wellbeing:

- physical Health – 86%
- housing – 86%
- financial position – 76%
- local environment – 73%
- employment – 59%

Over 86% of the respondents felt that access to mental health support was important. When asked what type/s of services/support people accessed when they or a family member/friend needed support; we received the following responses:

- GP – 70%
- family members – 54%
- psychiatrists – 41%
- friends – 40%
- counselling services – 28%

A total of 39% of the respondents indicated that they/friend/family member were an inpatient in a mental health hospital. Only 4% did not access any support for their mental health issue/s.

Over 83% of the respondents felt it was very important to have mental health services that are local i.e. within 3-5 miles of where they live. Over 89% said that services need to be easily accessible i.e. convenient opening hours, parking, meets their specific cultural and religious requirements, good disability access and public transport links.

People were asked what types of services would have met/would meet their or their family member/friend's needs. The following types of support were highlighted by the respondents:

- group support – 64%
- drop-in services – 56%
- 1:1 support – 49%
- community based services – 49%
- peer groups – 39%
- support into education – 24%

Only 42% wanted hospital based services.

Just over 68% felt it was important to be able to choose the services or packages of support would help maintain their mental wellbeing if they were given the money to do so.

Decisions made
The feedback supported the identification of the joint commissioning priorities and the development of the strategy and the implementation plans. These were shared back with service users, carers, stakeholders and partners.

CFS (Chronic Fatigue Syndrome) and ME (Myalgic Encephalomyelitis)

What was the issue?
There are many different possible causes for these conditions, which are better known by their abbreviated title CFS/ME. Potential causes include neurological, endocrinal, immunological, genetic, psychiatric and infection-based factors. All have been investigated, but the diverse nature of the symptoms cannot yet be fully explained.

The World Health Organisation (WHO) classifies CFS/ME as a neurological illness. Leicestershire's CFS/ME services are currently provided by Leicestershire Partnership Trust (LPT) and predominantly cover the psychological aspects of care. Following the NICE guidelines (2007), nationally the majority of CFS/ME services now sit in acute care services, mainly within neurology. We needed to know if we were providing the most clinically appropriate services for people with this condition.

Who was consulted?
In 2010/11 a local task and finish group engaged with ME Positive (the local user group) and collated feedback on the current service and views on what a future service should look like.

What information was given?
The current service based at LPT was discussed with the group, who were already familiar with many aspects of it, and the service specification documentation and NICE guidelines were scrutinised.

What were people asked to comment on?
ME Positive, a patient representative group were asked to comment on the current service specification, the NICE guidelines and draft a proposed new pathway for CFS/ME sufferers.

Summary of feedback
The main recommendations from this engagement were:

- more GP engagement on CFS/ME to ensure better diagnosis within primary care
- a neurological rather than a psychological pathway for CFS/ME patients
- improved availability of alternative therapies
- a personalised approach to the management of the condition and symptoms.

A proposed pathway was also developed by the group with recommendations for a redesigned service. The current service specification was examined and suggestions were made based on direct patient experiences.

Decisions made
Discussions are currently taking place about the service review and proposed pathway redesign. The next step in this process includes wider engagement with clinicians, stakeholders and other user groups.

Children and Adolescent Mental Health Service strategy

What was the issue?
NHS Leicester City and NHS Leicestershire County and Rutland reviewed the Children and Adolescent Mental Health Service (CAMHS) for the period of 2011 to 2014. This is to provide clear, timely and honest information about the direction of travel for CAMHS in Leicester, Leicestershire and Rutland. It was not possible for this consultation to be a simple strategy review or questionnaire, as this is a complex part of the health service.

Not only does the CAMHS strategy need to reflect the needs of a diverse community, it also needs to prioritise actions and service requirements to suit the needs of the patients, who are young people, and be sensitive to their needs. As the patients have mental health problems, NHS Leicester City led the consultation to identify all stakeholders who needed to participate in the service redesign. The communication and feedback channels had been designed to enable patients to express their views without bias.

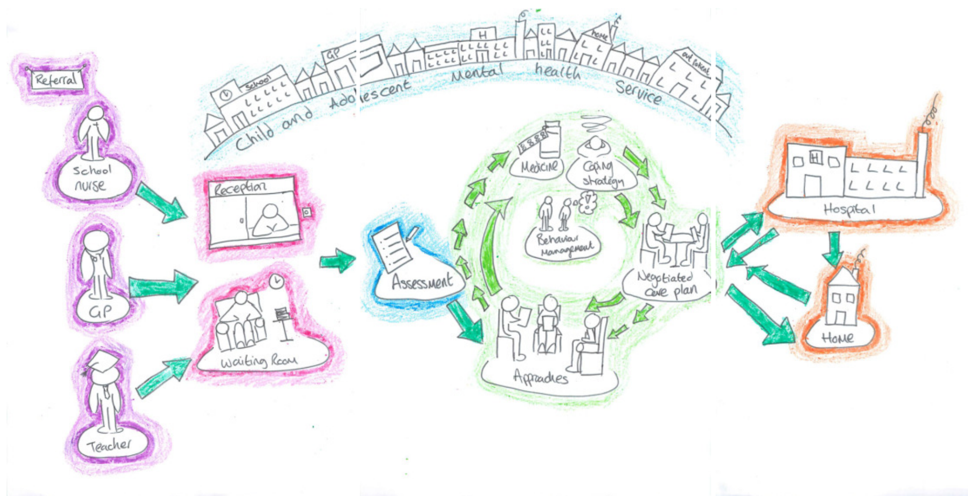
Who was consulted?
There were several groups of people involved in the project. The approach taken led to several groups being consulted. There were several media releases promoting feedback throughout September 2010 to February 2011. There was a publically available questionnaire for patients, public, children and young people, parents and carers, service staff and partners of the CAMHS service.

There was an easy read questionnaire with instructions of how to help the child or young person fill in the questionnaire. There was a questionnaire written by specialist nurses, with supporting pictures, to enable children with mental health and learning disabilities to be able to contribute to the consultation.

There were several stakeholders meeting from November 2010 to February 2011 to collect stakeholder and partner organisation feedback on the strategy. There were also some focus groups with children and young people with an interest in the CAMHS service who took part in the consultation.

What information was given?
Existing information was used to design the questionnaires and surveys. Local partner organisations shared feedback from their patients to help design which issues needed to be considered as priorities for the period of 2011 to 2014. Alongside this, there was easy read information describing the purpose of the consultation and why people need to feedback honestly.

The pathway and service delivery was also described in basic English along with a visual interpretation of the CAMHS system. This was done using a hand-drawn graphic illustration of the process (please see image): -



What were people asked to comment on?
The public, children and young people, carers, parents, staff and partners were all asked to comment on the principle and priorities, which had been selected from previous feedback. This was done by selecting on a rating scale of how important this would be to them. Alongside this we asked for their reasons. These included which conditions or mental health categories they felt needed prioritising for Leicester, Leicestershire and Rutland.

In the focus groups, people were shown the pathway diagram and asked to feedback on experience and potential improvements for each stage and the transfers between stages, including communication.

Once the draft strategy was completed, the draft document was consulted with the stakeholders to make it an appropriate document to be used by partner organisations across the city.

Summary of feedback
Some of the comments leading to the redesign included:

- there is a lot of untreated childhood anxiety
- families need to be more involved in children's and young people's treatment
- service delivery locations need to be child friendly in a comfortable environment
- children and young people should get a say in the treatment they receive.

The stakeholders wanted the assurance that plans developed were fed back to interested stakeholders and people who participated, complying with the standards of engagement for all organisations involved.

Decisions made
Using this feedback, the CAMHS service is working on:

- maintaining and developing mental health promotion and prevention to increase resilience and reduce risks
- ensuring that good links with adult services are maintained is relation to transition from children to adult services and taking th*e 'whole family approach'* work forward
- making all services child and young person friendly

- continually getting feedback from patients, carers and partner organisations about the service they are providing, and acting upon realistic suggestions or improvements.

Children and young person's needs assessment

What was the issue?
This is a needs assessment for Leicester City, which was aimed to outline the priorities for services in different areas. It was designed jointly between NHS Leicester City, Leicester City Council, Voluntary Action Leicester, Connexions and associated partners. Engaging with children and young people is one of the least practiced and they are nationally seen as a 'seldom heard group'.

This needs assessment identified groups in particular need:
- disabled children
- children in care
- young offenders
- teenage parents
- young people not in education employment and training
- young carers
- children and young people with parents who use drugs and alcohol

Who was consulted?
The Children Trust was the vehicle for consultation. Therefore, representatives from this group was asked to use the presentation and executive summary to deliver the key findings from the needs assessment and then feedback into the process. A wide range of partners were consulted, many of whom did not provide written feedback however, written feedback was received from:

- Leicester City Children's Trust and associated thematic groups
- Investing in Children's Priority Board Leicester City Council
- Parents of young offenders
- Parenting strategy Advisory Board
- CAMHS partnership
- NHS Leicester City Childrens Commissioner and Safeguarding lead
- Drug and alcohol commissioning manager
- Leicester city PE and school sports Board
- Healthy weight strategic group
- 12 Neighbourhood Advisory Boards 0-12 and 13-19
- Early Prevention Services Strategy team Leicester City Council
- Voluntary and community sector - feedback from 21 organisations.

What information was given?
Stakeholders and members of the public were informed of the discrepancies of the quality of life in different areas of the city. A presentation was used to give examples of a child growing up in two areas in the city and how different their expected outcomes were due to the area they lived in. Information included health outcomes, educational outcomes, and other life indicators.

There was also a needs assessment summary which was shared for comment including the priorities the city would have to improve the health and quality of life outcomes of areas that are lower than the national standards.

What were people asked to comment on?
People were asked if the summary of the needs assessment was accurate in the context of their knowledge of the city and the areas within the city, and, if not, why. They were then asked if there was any significant information in the needs assessment that had been missed out, that they felt needed to be included. After the presentation these questions were posed by the presenter and feedback collated and returned to public health.

Summary of feedback
The life course stories of two children in different parts of the city resonated with those that fed back on the work. A range of feedback received including the identification of some groups that had been missed in the earlier iterations and these have now been included, along with more recent data that was included in the final version.

Decisions made
The revised Leicester City Children and Young People's Plan has now been published and the focus on outcomes reflects the needs of the children and young people in the city. City youth advisors have commented and agreed on the plan.

Community consultation on equality outcome objectives

What was the issue?
NHS Leicester City, and NHS Leicestershire County and Rutland and Leicestershire Partnership NHS Trust needed assistance to identify and meet its Public Sector Equality Duty (PSED) under the Equality Act 2010. They needed to identify and agree with the NHS workforce and community stakeholders a set of equality outcome objectives and priorities for 2011-12.

Who was consulted?
Internally we consulted staff members throughout NHS Leicester City, NHS Leicestershire County and Rutland, University Hospitals of Leicester NHS Trust, Leicestershire Partnership NHS Trust. Externally; service users, voluntary and community groups including service level agreement organisations reflecting ethnicity, disability and sexual orientation were consulted. Also involved were Leicestershire Working Together Forum which represented all protected characteristics across Leicestershire.

What information was given?
Information was given on the new integrated equality service for NHS Leicester City, Leicestershire County and Rutland, along with an overview of Equality Act 2010 including:

- public sector equality duty – due regard
- analysis of equality (equality impact assessment)
- equality delivery system (the Department of Health Framework for Equality, Diversity and Human Rights in all we do)
- organisations to assess their equality performance against 12 outcomes grouped into four objectives.

Participants were also given a detailed overview including evidence to support each proposed equality outcome objective and enabler.

What were people asked to comment on?
Internal and external stakeholders were asked to comment and provide preferences on a set of draft equality outcome objectives and priorities. This included an opportunity to vote on each objective and outcome.

Summary of feedback
Feedback included comments that could be grouped under the following themes:

- focus on outcomes not process
- be clear in communications
- make more of what we have
- don't lose quality and focus in the drive for greater efficiency
- keep it real
- involve local people and groups
- be transparent.

Decisions made
The project planning and implementation is still ongoing at the time of going to print.

Community development worker project

What was the issue?
The aim was to review the effectiveness of a three-year project to improve referrals within Black and Minority Ethnic (BME) communities to access mental health services in Leicester City, Leicestershire and Rutland. It had been set up as part of a national Department of Health programme called Delivering Race Equality (in mental health).

The ethnicity of the Leicester City, Leicestershire and Rutland population is diverse. In Leicestershire and Rutland nearly 95% of the population are from white ethnic groups. The main minority ethnic group is south Asian with large populations in Loughborough and Oadby and Wigston.

Approximately 40% of Leicester's population has an ethnic minority background and evidence suggests that it is becoming more diverse. Statistics show that 28% of the Leicester population are Gujarati Indians, originally either from East Africa, especially Uganda and Kenya, or from Gujarat. Other smaller communities in the city include the African Caribbean and Somali communities, at around 3% each, as well as people from Pakistan, Bangladesh, along with other African or Chinese communities. The age profile of these population groups is younger than average with 54% of Leicester's school pupils from a minority ethnic background.

The project's host organisation was Age Concern, who had employed a team of CDWs to run the project. The project lead wanted to review the service and identify if there were any gaps which were not covered by other existing services in Leicester City, Leicestershire County and Rutland. This was important as not only are there various communication barriers, but there can also be a lack of knowledge of services available and unwitting negative stereotyping within the service. Therefore a consultation was run from October to November to gain feedback on the knowledge and attitudes of the service provided, and gaps that would be left if there was to be no replacement service, following the end of the existing project contract arrangement in March 2011.

Who was consulted?
There were three separate consultations. The host, Age Concern, and relevant staff were consulted about services they had provided and referral success rate. They were also asked for details of activities and successful projects during the three-year project.

The partner organisations who worked closely with the CDW project were also consulted. This was done by an online and paper questionnaire going to each member of staff working with the CDW project. Finally service users were also asked to complete a questionnaire either online or a paper copy.

What information was given?
NHS Leicester City, and NHS Leicestershire County and Rutland shared information and agreed that an evaluation of the service was needed. The overall objective of the evaluation was to assess the extent to which the CDW project had successfully contributed to the delivery of the DH's wider agenda of achieving equality and tackling discrimination in mental health services.

The evaluation reviewed the service against the four main roles as set out in the policy guidance and the output specification, as set out by the two primary care trusts as commissioning bodies. It also aimed to assess the value-for-money element within the current climate of financial constraints. Finally, the evaluation aimed to identify the ways in which the agenda for tackling discrimination and achieving equality in mental health services might be sustained.

What were people asked to comment on?
To assess the impact of the CDW project, all people consulted were asked for feedback on the extent to which the following project aims had been achieved in the past three years:

To act as a change agent by:
- raising levels of understanding of the mental health needs of BME population groups
- identifying gaps in services
- improving communication between BME community services and statutory services.

To facilitate access to mental health services by:
- identifying the barriers which prevent BME communities from accessing timely and effective mental health services
- helping to overcome those barriers.

To develop services by:
- advising on training and education of staff
- highlighting the importance of cultural awareness in service systems and practice
- developing joint working between statutory and community services.

To build community capacity by:
- helping the BME population group to develop grassroots solutions to mental health issues
- supporting the development of BME community resources for mental health
- helping local groups and networks to develop the relationships and know-how which will enable them to make their views known and play an effective role in local partnerships for mental health.

Summary of feedback
Overall, the CDWs were seen as having been fairly successful in engaging with community organisations and undertaking specific programmes which have contributed to the raising of awareness of mental health issues within the BME community. Much of the work by the CDW team has included developing and managing relationships with key stakeholders, partners and services, aimed at raising the profile of the CDWs and the Delivering Race Equality (in mental health) programme.

It has been through the development of such links that the CDWs have been able to gather intelligence about gaps in service provision for BME communities and begin to devise and implement some solutions. Feedback showed that the CDWs had undertaken awareness raising sessions and had made contact with a number of voluntary and statutory organisations, users and carers to promote further awareness.

The project has been less successful in demonstrating the outcomes of the initiatives and their sustainability. There were areas where there appeared to be a lack of continuity and evidence of CDW work which demonstrated the need for capacity building.

The feedback also suggested that the CDWs were strong in identifying gaps in services, but had not been sufficiently innovative, had missed opportunities for greater integration and had not become sufficiently effective agents of change.

Decisions made

It was decided that the existing contract could be terminated at the end of the third year, March 2011. There would still be a service gap for the African Caribbean community, therefore a CDW would need to be commissioned specifically for this community.

Drug and alcohol strategy

What was the issue?
The National Drug Strategy (NDS) 2008-2018 emphasizes the need to focus more on families, addressing the needs of parents and children as individuals, as well as working with whole families to prevent drug use, reduce risk and get people into treatment. The NDS also clearly states that we need to deliver new approaches to drug treatment and social re-integration. The Alcohol Harm Reduction Strategy for England: Safe. Sensible, Social, (2007), outlines the next steps in the alcohol strategy. Priorities include engaging harmful and dependent drinkers with prevention and treatment services, tackling alcohol-fuelled crime and disorder; and promoting sensible drinking. Services were being re-designed to reflect local and diverse needs. We were also seeking to test the market in line with Leicester City Council's procurement policy and EU (European Union) procurement law.

The Safer Leicester Partnership (SLP), Drug and Alcohol Action Team (DAAT) are responsible for the commissioning of adult and young people's substance misuse treatment services. NHS Leicester City is responsible for commissioning adult alcohol prevention and treatment services. SLP DAAT and the NHS Leicester City are in the process of undertaking a re-commissioning (and service redesign) of their adult treatment service with the aim of improving access to and quality of service provision and to develop an integrated drug and alcohol treatment model.

Who was consulted?
Questionnaires were available on-line, and paper questionnaires were disseminated across the city via council run locations and drug and alcohol treatment providers.

Stakeholders, including the general public were made aware of the consultation process, and how to respond through a variety of promotional means, including email alerts, web site signposting, and use of the media. Specifically this included adverts, posters, radio interviews and local publications across the city, in particular, faith, language and cultural based publications (Leicester Link, Ramadan Publications, Kohinoor Newsletter, Clasp Newsletter, Service Users News (SUN), Helping Hands Newsletter, NHS customer and patient involvement newsletter. Participants were given the opportunity to give their views via the website, or via paper and electronic questionnaires. Translated questionnaires, special needs versions (large print / Braille) and translators were available on request.

In addition to the completion of questionnaires, a community engagement approach was adopted to target key groups to provide their views. Community and neighbourhood support groups for feedback were organised to support the inclusion and involvement of vulnerable and underrepresented people and communities.

Small informal discussion groups, with target groups were undertaken, alongside presentations, displays interviews, exhibitions, and advertising, to promote and encourage participation.

A single large event for key stakeholders was organised, focus groups were used to feedback their responses to the questionnaires.

What information was given?
All people including stakeholders were given a briefing note and access to other informative resources before given the questionnaire or attending one of the groups or meetings. Information included:

- a background to the Drug and Alcohol Services
- The current treatment system
- gaps and weaknesses in the current drug treatment system
- gaps and weaknesses in the current alcohol treatment system
- key changes being proposed included those to address the following topics:
  - accessibility
  - the range of services available
  - moving towards primary care services
  - quality of life issues
  - criminal justice role
  - one single point of access / treatment
  - one venue for both drugs and alcohol services.

Finally there was information on why people should take part in the consultation process by providing views and comments on the proposed changes to drug and alcohol treatment services, also there was information on where to get a questionnaire and alternative feedback methods available.

What were people asked to comment on?
There were questions based on a combined drug and alcohol pathway including:

- accessibility of services
- a wider range of services
- having services accessible through primary care, ie, GPs
- should 'quality of life' services (for example housing support, relapse prevention, education and life skills training) be included in drug and alcohol treatment
- should the service be flexible to suit the service users needs
- should the service be community based
- should the service be in a neighbourhood setting
- should there be a single drug and alcohol service for people in the criminal justice system (before sentence and following release)
- should non-drug and alcohol children and young person agencies have support available
- should there one venue for both drug and alcohol services

People who worked with alcohol services only were asked an additional question about an assessment of treatment being completed in a single point of access.

Summary of feedback
There were sufficient responses for the adult and young person's surveys.

The stakeholder groups within the adult and young person's community engagement group varied from those having no experience or knowledge of drug and alcohol services to those who were currently or had previously been in receipt of services or had worked in services and this was reflected in their responses.

Those that had less knowledge and experience were able to make valuable contributions. For example, the positive impacts of accessible community based services, and the contributions that families and communities could make to support both service users and services at local level.

Overall people were supportive of the changes. Negative responses centred on adult drug and alcohol users receiving treatment within GP surgeries. There was overall support for this change, but on the principle that this service would be located within a different part of the surgery and at different times to regular GP appointments.

There was positive support for the proposed changes to young people's drug treatment services. One community based service for young people was principally supported on the basis that young people should feel safe and that the service was available especially for them.

Service providers gave mixed responses to the service redesign changes. Better accessibility received the most positive responses, including weekend and late opening and operating times, with neighbourhood based services meaning less travelling was involved. Negative responses highlighted drinkers not wanting to associate with drugs users and the potential barriers due stigmatisation of drug and alcohol users within the community.

Service providers considered the impact of equality issues within their stakeholder event, relating to the proposed changes to treatment services. This will contribute to the Equality Impact Assessment for service redesign and change.

Decisions made
The redesign of young person's alcohol and drug services is being carried out in conjunction with the adult drug and alcohol treatment redesign. It is proposed that the end product of the redesign process will be a specialist treatment service that will deliver treatment and support the delivery of information, advice and guidance in mainstream services.

Based on the findings of the adult and young person's stakeholder consultation, it was recommended the feedback and proposed changes to drug and alcohol treatment are implemented and should inform the commissioning and service redesign processes.

End of Life Care

What was the issue?
We aimed to develop a strategy to deliver the best quality care pathway for all those of 18 years and over who are approaching the end of their lives.

Who was consulted?
Broad and wide engagement took place to inform the strategy. Two stakeholder events took place attended by staff across Leicester, Leicestershire and Rutland and included staff from University Hospitals Leicester, LOROS, Community Health Services, East Midlands Cancer Network, local authorities, Leicester University, East Midlands Strategic Health Authority, Voluntary Action Leicester, Foundation Housing, Hospice Hope, Confederation of Indian Organisations, NHS Leicestershire County and Rutland, NHS Leicester City, GPs, palliative care consultants; out-of-hours GP services, pharmacists, the public and carers.

A questionnaire was developed and sent to all those who had joined the NHS Leicestershire County and Rutland membership scheme and members of NHS Leicester City membership scheme who had previously expressed an interest in end-of-life care.

What information was given?
The first event held in May 2010 was designed to identify the improvements that stakeholders felt were important. It was themed around the National End of Life Strategy.

The second event held in July 2010 was designed to confirm and challenge the three supporting documents developed to deliver the improvements. Therefore, information given included the NHS Leicester, Leicestershire and Rutland End of Life Care Strategy, Action Plan and the High Level Care Pathway.

The questionnaire was designed to canvas the views of members about the strategy. Its purpose was to provide a local snapshot, in time, to gauge local current awareness and views of the population on end-of-life care.

What were people asked to comment on?
At the first stakeholder event, people were asked to comment on improvements they felt to be most important. The objectives of the event were:

- to achieve a common understanding of what was happening currently across Leicester, Leicestershire and Rutland
- to identify and understand current gaps in the services.

At the second event people were asked if they were happy that the priorities identified at the first stakeholder event could be identified in the three documents including the strategy, the action plan and the care pathway. If not, stakeholders were asked to challenge this apparent omission.

Summary of feedback
The priorities identified were at the first stakeholder meeting were:

- choice
- co-ordination of processes

- assessment
- 24hr access to services
- verification of death
- care after death

Following the event these priorities were reflected in the action plan.

At the second stakeholder event held in July 2010 the stakeholder group were asked to confirm and challenge the three documents listed above. It was agreed that all the priorities identified at the first stakeholder group meeting had been included in the documents.

Information gathered from feedback from the questionnaire sent out to members told the trusts that 60% of LCR members and 75% of LC members wished to die at home.

To support 'choice to die at home' people felt it was important to be able to access a full range of services including specialist services, equipment and support for carers and family. These themes were also highlighted as the reasons people die in hospital rather than at home.

To help people to talk about 'planning a good death'; the top two themes were to provide leaflets in GP surgeries and raise awareness through the television and radio.

The majority of respondents agreed that hospice care should be reserved for the most complicated cases. However, this was contradicted when the majority responded that, even if they did not meet the criteria for hospice care, they should still be allowed access. Alternative arrangements identified would be to provide hospice at home or nursing care home.

Decisions made

The PCT Trust Boards agreed the strategy on 14 October 2010. With the introduction of the High Level Care Pathway, all patients approaching end of life, and their carers will:

- have their physical, emotional, social and spiritual needs and preferences assessed by a professional with appropriate skills and competencies
- have an effective care plan
- have their needs, preferences and care plan reviewed as their condition changes with the appropriate systems in place to ensure that this information can be accessed by all relevant health and social care staff

By 2014 end-of-life care will:

- be effectively co-ordinated across all sectors
- ensure patients and carers will feel well supported
- provide good quality of care in the last months, weeks and days of life
- have effective processes in place for the verification and certification of death and care after death
- ensure that quality and effectiveness of care will be robustly monitored
- ensure that there will be equality in access to and provision of end of life care services

- ensure that all carers report their experience as ‘the best possible’.

All those who had taken part by attending meetings and completing the questionnaire were informed of the results via the media, by publishing the strategy and our Trust Board papers online, and via the membership schemes’ newsletters. Members were also emailed the decisions taken.

Greater Choice and Control and the Information Revolution White Paper

What was the issue?
The Department of Health released two White Papers - *Greater Choice and Control* and *The Information Revolution*.

In *Greater Choice and Control*, the DH proposed a vision of an information revolution in which people have the information they need to stay healthy, to take decisions about and exercise more control of their care, and to make the right choices for themselves and their families. This includes an accurate record of their care which is available to them electronically. Health and adult social care information will be liberated from a closed, bureaucratic system in order to serve patients and the public, and to help drive better care, improve outcomes, innovation and better use of resources.

In *The Information Revolution* the DH proposed moving:

- away from information belonging to the system to information enabling patients to be in control of their care
- away from patients and service users merely receiving care to being active participants in their care
- away from information for administrative and technical needs to information based good clinical and professional practice
- away from top-down information collection to a focus on meeting the needs of individuals and local communities.

NHS Leicester City, and NHS Leicestershire County and Rutland's objective was to capture the voice of all stakeholders, public members and communities in the city by inviting them to provide feedback on the consultation and inform them on the changes which will be happening as a result of these White Papers.

Who was consulted?
The consultation was organised on behalf of Leicester City Council, NHS Leicester City and NHS Leicestershire County and Rutland. A number of communication channels and methods were used to gather the feedback required. Emails and letters were sent to local stakeholders. Emails and letters were sent to NHS Leicestershire County and Rutland and NHS Leicester City's public members, who had chosen to provide feedback on health topics. Stakeholder briefings also took place.

There were press releases to local media hubs for both radio and newspaper release. There was a session on Kohinoor Radio, a multi-lingual radio station, informing various communities of the proposed changes for public health. There was a fairly rounded response in terms of demographics, many of the communities invited either attended the consultation event or sent back their feedback via a questionnaire.

What information was given?
A briefing of the main points of the White Paper was given out with the questionnaire and was presented at the consultation events. The easy read version of the White Paper was sent with the questionnaire to people requesting paper copies.

What were people asked to comment on?
The *Greater Choice and Control* consultation, launched on 18 October 2010, asked for views on:

- what extending patient choice could mean and how it could work in practice
- whether the proposed choices are the ones that people want
- how shared decision-making can become the norm, in particular the 'no decision about me without me' ethos
- having the right information, technology and infrastructure in place
- arrangements to support choice of any willing provider, such as pricing
- possible new duties on healthcare providers and professionals
- personal health budgets.

The Information Revolution consultation, launched on 18 October 2010, asked for views on:

- transforming the way information is collected, analysed and used by the NHS and adult social care services
- providing good information for patients and their families in line with the 'no decision about me without me' principles and a culture that enables people to make use of it
- publication of data for public accountability
- the role of information in improving outcomes for patients and service users
- professionally endorsed and universally applied standards for recording care, including the role of informatics as a profession
- giving people control of their care records and allowing them to share it as they see fit with others
- encouraging greater use of technology and information to provide more convenient care and means of communication, and to create efficiencies to free up resources
- an information strategy, including the NHS Commissioning Board and Department of Health's role in setting clear national informatics standards for both the NHS and adult social care.

Summary of feedback
The responses of the people of Leicester, Leicestershire and Rutland to the specific questions asked in this national consultation have been submitted to the Department of Health.

Based on the feedback from consultation channels, local respondees detailed that the way people can have greater choice and control over their care is to have GPs offer more consultation time. In addition they would like to have the statistics about the success or otherwise of operations performed by surgeons. In conclusion, people wanted hospital success rates so they could choose where they go based on treatment outcomes. The discussion prompted comments on topics not directly connected to the consultation issues, such as inadequate hospital parking and public transport to healthcare providers.

Decisions made
Feedback was sent to the Department of Health as part of the national consultation process and the draft legislation, based on the principles of these White Papers is currently going through Parliament.

Maternity and neonatal services review

What was the issue?
The engagement process for the Next Stage Review – Leicester, Leicestershire and Rutland maternity and neonatal services took place throughout November 2009 aimed at service improvement in line with the vision report published in 2008. A summary of the 2009 engagement process and its impact is included in this 2010-11 report, because the engagement informed Trust Board decisions taken in December 2010.

Who was consulted?
Questionnaires were sent to mothers who gave birth during a six-week period earlier in the year. Questionnaires were sent out to Sure Start centres across Leicestershire county and Leicester city, where staff helped parents to complete them. Also, questionnaires were sent to nursery and toddler groups and primary schools in Leicestershire. Members of the two PCTs' public membership schemes received information about the questionnaire and were invited to attend the events.

Teams also attended other events and meetings to speak to harder-to-reach groups, including asylum seekers, younger mums, those living in rural areas, women from the south Asian community and gypsies and travellers. A special easy read version of the questionnaire was also created for those with learning disabilities.
People attended the public events, and many more people were made aware of the questionnaire via the media and the distribution processes described.

What information was given?
Presentations were given at the events to inform people on the NHS Leicestershire County and Rutland vision for the service and the challenges associated with making that vision a reality. This was followed by an overview of the current service. An introduction to distributed questionnaires also described the relevant information.

What were people asked to comment on?
People were asked to comment on maternity services and the care of newborn babies (eg, special care units). Women of childbearing age were asked to comment on the distances they were willing to travel to access maternity services and appropriate services for their newborn babies.

Summary of feedback
A range of people had their say on the future of maternity and newborn services in Leicestershire and Rutland as part of an engagement programme. Their views were fed back into the ongoing planning for local maternity and newborn services.

Decisions made
During the financial year 2009-10, as a result of this consultation the NHS health community covering Leicester, Leicestershire and Rutland improved early access to maternity services with new support workers and specialist midwives. A number of other options were developed for the future of maternity and newborn care in Leicester, Leicestershire and Rutland.

In December 2010 these other options went to the Trust Board of University Hospitals of Leicester NHS Trust, NHS Leicestershire County and Rutland and NHS Leicester City. This was publicised via the local media and the trust websites, to

inform the people who took part in the maternity and neonates engagement activities of the outcomes of the review.

Maternity Service Liaison – designing a 12-month rolling programme

What was the issue?
NHS Leicester City and NHS Leicestershire County and Rutland's Maternity Service Liaison Committee (MLSC) identified a need for a dialogue with mothers regarding a variety of issues in maternity services. Mothers are perceived as a difficult group to communicate with due to childcare and work responsibilities. To communicate successfully, two focus groups were set up, one in the city and one in the Leicestershire to identify the best communication channels. This research informed the design of a 12-month rolling programme of interaction to identify key issues and look for solutions.

Who was consulted?
Initially two small focus groups of mothers were consulted, which grew into a mailing list.

What information was given?
It was explained that there was no extra funding available and not everything could be solved immediately, but wherever possible service changes and improvements could be made. There was also information on joining the liaison committee as a patient representative and options for communication.

What were people asked to comment on?
There were four main subjects for discussion initially, which informed the planning of the 12-month engagement plan. The subjects were essentially questions:

- How did they want to be involved?
- What do they think of having a workshop?
- How did they want feedback to be given to them?
- What topics did they want to discuss throughout the programme?

Summary of feedback
People wanted to be involved using both newsletters and websites together, or through communication from children's centres, Sure Start and interviews.

They thought focus group were not appropriate, as the times of mothers' availability varied.

They said that feedback should be via website or a newsletter and include signposting to other available services and that topics should include ante-natal services, parent craft, communication, having the baby, post-natal care, breast feeding and bottle feeding and complaints.

Decisions made
A newsletter has been produced covering specific topics of interest, and this is fed out via email, websites and relevant mother and baby groups and organisations.

Naming the IAPT service

What was the issue?
As part of the government's £170 million investment in Improving Access to Psychological Therapies (IAPT) programme - which was designed to open up easy to access, effective mental health services to people in need - we have developed two new services to provide better access to talking therapies for people living in Leicester, Leicestershire and Rutland.

The two PCTs consulted with the communities of Leicester City and Leicestershire and Rutland to rename the IAPT service to something more meaningful. This had to cover a variety of target groups, including the young and old, male and female and those of different ethnic origins.

Who was consulted?
NHS Leicester City, and NHS Leicestershire County and Rutland consulted various patients, representative groups, community leaders and members of the two trusts to devise a list of potential titles and then vote on their preferred names from that list.

There was a media release explaining when and how voting was taking place, explaining that it was open to all stakeholders and the public to vote on the preferred name.

What information was given?
In the focus groups, members were given a brief background of what the service was about and why a new name had to be created to be meaningful to residents. This information was then put in a briefing for a media release, which was available on the website and was sent to the membership for the voting process.

What were people asked to comment on?
The focus groups were asked to respond to various parts of communicating about the service, this included:

- creating some names for the service
- commenting on how information should be communicated to patients, such as posters, leaflets and other paper based media
- commenting on where the information on the service should be readily available
- explaining how the service should be described including what type of language would be understood by the various communities.

Summary of feedback
Comments were grouped under the following shared themes:

- certain words related to mental health need to be avoided as they increase stigma and will reduce referral rates
- leaflets which are discrete were chosen as the best paper based medium to promote the service as they can easily be slipped into a pocket or a bag
- information to be available at relevant community locations such as support groups, local services, GP surgeries and pharmacies
- radio and media releases would be a positive way of promoting the service.

Decisions made
For people living in Leicestershire County and Rutland the service is called **Good Thinking.**

For people living in Leicester City the service is called **Open Mind.**

The patients chose leaflets to be the best form of information to be used and wrote the content together with the service commissioner via a reader's panel format to reduce stigma and increase understanding.

The leaflets are available in GP surgeries and relevant community groups services to increase self referral.

Media releases were sent out to promote the service and information on where the service is and further information was also included in the media releases.

Older Persons Month

What was the issue?
This was a project between numerous partners. The consultation was on behalf of NHS Leicester City, NHS Leicestershire County and Rutland, Leicester City Council and Leicestershire County Council.

Older Persons Month is a local month of awareness-raising for issues affecting people over the age of 50. During this month, events are run to raise awareness of issues, promote tools and solutions to problems and help people interact and be active. This happens across Leicester City, Leicestershire County and Rutland. In September 2010, the city and the county joined forces to promote the event across the whole area. The problem which arose was that the city and the two counties have very different demographics and organisers needed to know what the key health issues were and what types of events would prove most effective for city residents.

Who was consulted?
Members of NHS Leicester City, community groups and local representative groups

What information was given?
All members involved were given a briefing explaining what the purpose of older persons month was and where there is thought to be health gaps which need consideration throughout the month.

What were people asked to comment on?
People were asked to comment on what they thought were health issues affecting people over 50 and what types of events would be useful to promote the different health issues in those areas. This was done in community meetings and at events.

Summary of feedback
There were some enthusiastic responses resulting in further partnership working for running different types of events across the city. People highlighted isolation, low activity and fitness, safety, healthy eating and mental health as key issues affecting older people. They felt awareness events and activity events should be based on these issues and should be taken to the individual communities not be city centre based as this would result in less attendance of people who need to be targeted.

Decisions made
The following events were run:

- two mental health and wellbeing activity sessions in a care home
- a Health and Safety event in Saffron
- A Caribbean Culture Celebration Day was held in partnership with the Caribbean Court and delivered in Highfields
- A Senior Citizens Health awareness event in Belgrave
- An Older Person’s Fun Day including dance activities
- A Young At Heart event including activity sessions in New Parks
- A health talk on Alzheimer’s and dementia in partnership with Leicestershire Partnership NHS Trust was held in Braunstone
- A health talk on Alzheimer’s and dementia in partnership with Leicestershire Partnership NHS Trust was held in St Marks

Pharmaceutical Needs Assessment

What was the issue?
NHS Leicester, and NHS Leicestershire and Rutland has 206 pharmacies and 19 dispensing doctors in the Leicestershire County and Rutland, ie, a doctor's surgery which is able to supply medicine and which provides an increasingly wide range of services. We asked patients who access NHS services to tell us what they think about the service pharmacists and dispensing doctors currently provide. This is called the Pharmaceutical Needs Assessment (PNA).

By law, all primary care trusts in England must publish a Pharmaceutical Needs Assessment by the 1 February 2011 to:

- highlight whether there are gaps in the services provided by pharmacists
- show pharmacists and dispensing doctors which services are required, where and by whom
- assist NHS LCR with their commissioning of high quality services.

The aims of the Pharmaceutical Needs Assessment are:

- to gain a complete picture of the population within the NHS LLR area
- to identify specific communities with particularly poor health
- to enable comprehensive 'benchmarking' comparison with comparable populations
- to give a clear view of unmet needs.

Who was consulted?
In order to produce a meaningful Pharmaceutical Needs Assessment it was necessary to understand what people thought about current services offered by pharmacists and dispensing doctors and how services should be shaped for the future. Therefore, an engagement process was undertaken from mid June 2010 to mid July 2010. Engagement was broad and far reaching and included a questionnaire (available online, in hardcopy and as an easy read version) alongside face to face engagement with a variety of community groups, including community forums throughout Leicestershire and similar meetings in Rutland. The following seldom heard groups were also included:

- people with learning disabilities
- gypsy/travellers
- older people
- young people
- asylum seeker and refugees
- people with visual impairment
- carers
- people living in areas of health inequalities
- BME groups
- people living in rural isolation.

In the Leicester City area, Officers organised meetings with relevant stakeholders who had interest in community pharmacy services, these included:

- ADHAR - an organisation that provides support for Asian people with mental health conditions

- LOROS - (Leicestershire and Rutland Organisation for the Relief of Suffering) a local charity providing skilled nursing and specialist care within Leicester, Leicestershire and Rutland
- WISCP – (West Indian Senior Citizens Project) an organisation who provide a support service for the elderly Afro – Caribbean population
- VAL – (Voluntary Action Leicester) a key voluntary organisation that involves volunteers in improving life in Leicester and Leicestershire
- CLASP – (Carers of Leicestershire, Advocacy and Support project) a charity that provides support services for carers in Leicester, Leicestershire and Rutland
- A young mothers group
- A Travellers group

An easy-read presentation was developed for these groups.

Questionnaires were sent out to all pharmacies across Leicester, Leicestershire and Rutland for them to distribute to customers, and NHS LLR members were invited to complete the questionnaire.

Leicester, Rutland and Leicestershire LINks invited their members to complete the questionnaire, and Rutland LINk steering group also received a presentation. By working in partnership with Voluntary Action Leicestershire and Rutland we were also able to invite members of the voluntary sector to be part of the engagement process.

The second phase of this process began on 1 September, in the form of a 60-day consultation on pharmaceutical needs, which ended on 30 October 2010.

What information was given?
When attending meetings a presentation was given to explain what the PNA was and why feedback was needed from the public on current services to ensure it was fit for purpose. As an introduction to the online questionnaire and the hard copy questionnaires a full briefing was attached. This included information on the purpose of the final PNA document.

In the second phase of this process information was given on the feedback from the engagement process.

What were people asked to comment on?
During the engagement process stakeholders and members of the public were asked:

- Who uses pharmacists and dispensing doctors?
- Which services offered by pharmacies are used most?
- Whether or not people think pharmacies and dispensing doctors are convenient
- Whether people would like more services from their local pharmacy.

During the consultation people were asked:

- Do you agree that the eight smaller areas (localities) best reflect the areas of Leicester, Leicestershire and Rutland, and that they are the right areas?

- From the information in the PNA and your personal experience do you believe your pharmaceutical needs are met?
- Do you feel that the purpose of the PNA has been explained sufficiently?
- Do you feel the pharmaceutical needs of the population of Leicester City, Leicestershire County and Rutland have been adequately reflected?
- Do you feel that we have responded to the needs shown in the feedback through the engagement process and included the into the PNA document?

Summary of feedback
The questionnaire responses received in the engagement phase were used to develop the draft version of the PNA which was released for further feedback. Following the release of the final draft of the PNA the PCT received online responses and further comments by letter from stakeholder organisations including the Local Pharmaceutical Committee (LPC) and neighbouring PCTs and LPCs.

From the engagement and consultation process the PCTs have gained a wealth of knowledge. Overall findings identified that one fifth of respondents use a GP dispensary to obtain their medicines. Most respondents use pharmaceutical services on a regular basis for ongoing medical conditions and for the collection of medicines. A high percentage of respondents use the same pharmacy on a regular basis and this was mostly due to the convenient location and continuity of care. A high number of respondents are happy with their arrangements for repeat medication and more than half have never had any problems with their medicines. A high proportion of respondents reported that they had received enough information about their medicines and that the information was helpful. In Leicestershire and Rutland only 8% had experienced problems in finding a pharmacy to meet their needs within the last 12 months. Of those, the problem was not generally related to access but more to the supply of medicines. There was a general awareness of some of the other services available from local pharmacies.

Decisions made
Members of the public and stakeholders involved in the engagement and consultation process were informed when the PNA was to be agreed at the Trust Board in January 2010. The PNA was made available to view via the website and hard copies made available on request. They were also informed that the PNA would be used by the PCT as a commissioning and market-entry tool, ie, a tool to help them understand on what basis services are commissioned. It will also be used by the public as an information document.

Enhanced service commissioning from community pharmacy is led by need, crucially a need that can be addressed by community pharmacy. The PCT currently commissions a range of enhanced services aimed at meeting needs that exist, across the City. This PNA has not identified any current health need that would require an enhanced service from community pharmacy and in the current economic position is not, realistically, likely to secure funding for such a service. However the PCT will continue to work with community pharmacy to understand the health outcomes from the range of non-commissioned services which are predominately related to health improvement, with a view to developing models for future enhanced services, should funding become available.

Public Health White Paper

What was the issue?
The Department of Health released a national White Paper for consultation entitled *Healthy Lives, Healthy People: Our Strategy for Public Health In England.* It sets out the Coalition Government's new approach to public health and some of the structures and processes that will support delivery. The vision is to protect the population "from serious health threats, helping people live longer, healthier and more fulfilling lives; and improving the health of the poorest fastest".

There were important factors to be considered when inviting stakeholders to take part to ensure all community voices were heard. Leicester's predominant ethnic minority community is of south Asian origin. Leicestershire County and Rutland's demographic profile is very different and has an ageing population, so it was important to gather a representative response to support the national consultation.

NHS Leicester City, and NHS Leicestershire County and Rutland wanted to capture the voice of all communities, stakeholders and public in the city and county by inviting them to provide feedback on the consultation and inform them on the changes which will be happening as a result of this White Paper.

Who was consulted?
NHS Leicester City, and NHS Leicestershire County and Rutland undertook an engagement exercise including surveys, questionnaires and consultation events. The consultation events were held for patients, members of the public, NHS staff, clinicians, local authorities, voluntary sector organisations and seldom heard groups to ensure a wide range of views was collected.

What information was given?
A briefing of the main points of the White Paper was provided with the questionnaire and was delivered verbally at the consultation events. An easy read version of the White Paper was sent to people requesting paper copies of the questionnaire.

What were people asked to comment on?
Everyone was asked to comment on the proposals being made in the White Paper, along with any concerns and potential solutions that all needed to be taken into consideration both locally and nationally.

Summary of feedback
The strong partnerships across the city, two counties, local authorities and other statutory bodies have enabled us to gather a wide range of views.

This indicated broad support for:
- the focus on preventative health
- the new role for the local authority, the establishment of Public Health England as a means of ensuring consistent health protection
- the local focus – critical for effective services in response to people and their needs
- the emphasis on the voluntary sector and wider contributions by individuals and communities

- the Health and Well being Board as the local focus which may provide and ensure local coherence in the commissioning by the local authority for adults social care and public health and GP-led commissioning groups for health care
- the ring-fenced budget for public health funding and the health improvement functions to be performed by the local authority.

There were concerns that:

- health may worsen due to the economic circumstances and the continuing effects of poverty, particularly on children
- the voluntary sector may not be intact to work with local authorities and GP consortia in the provision of services and input that improve health and public health
- the public health budget in general and for local authorities in particular will be insufficient. (The White paper itself says that funding has not gone into prevention and there was a concern that in the transition to these new arrangements might raise expectations but lower funding)
- the Health and Wellbeing Board will lack the authority to create coherence in the local approach to health care, health protection and health improvement
- the public health premium may distort the issues focussed on locally.
- there is potential for performance indicators to be politicised locally and nationally – “long term outcomes do not benefit from changing goal posts”, was one expression of this.

Decisions made
This information was fed back to the Department of Health and used to inform the current changes being delivered to the reforms of public health.

Quality, Innovation, Productivity and Prevention (QIPP)

What was the issue?
NHS Leicester City and NHS Leicestershire and Rutland have taken several opportunities during 2010-11 to engage with the public on QIPP. Our aim was for the public to understand the current financial climate and challenges facing the NHS. The first QIPP event in September 2010 was a joint event without two PCTs, University Hospitals of Leicester NHS Trust (UHL) and Leicester Partnership Trust (LPT).

Who was consulted?
Members of the public and major stakeholders including both PCT's public memberships along with people from UHL's and LPT's membership schemes.

What information was given?
Those attending were informed that each person in our area was allocated a per capita healthcare funding amount of £1,600 to pay for treatments, medicines and equipment, and that some also covered other costs such as the management of buildings, running vehicles and employing staff. A series of examples of the cost of services was also given. For example, the average cost for attending the Urgent Care Centre (open 8am – 6.30pm) is £40. Attending the Minor Injuries Unit is £59 an hour, and attending the GP out-of-hours service (available 6pm – 8am) is also £59. Attending the Accident and Emergency Department is also £59 and the average cost of an overnight stay in hospital is £147. Along with some 'did you know that' information, for example, the cost of a hip replacement is £6,000, a knee replacement is £6,000, a Caesarian section is £2,000 and a normal, uncomplicated birth is £1,000.

What were people asked to comment on?
Participants were then asked to vote by choosing options to answer a variety of questions about making services more cost-effective and efficient while maintaining quality of care. Participants used voting pads to feed back on how they thought unnecessary admissions could be avoided, where people would consider going for diagnostic scans, and where they would consider accessing minor surgery; and more.

Summary of feedback
Feedback indicated that members of the public were willing to consider alternative options for service delivery.

Decisions made
The public received immediate feedback totals from the voting system and were told that information gathered would be used for future QIPP considerations by healthcare commissioners and providers. This event was also used to inform the content of further QIPP engagement work.

Quality Innovation, Productivity and Prevention: Strategic Operating Plan

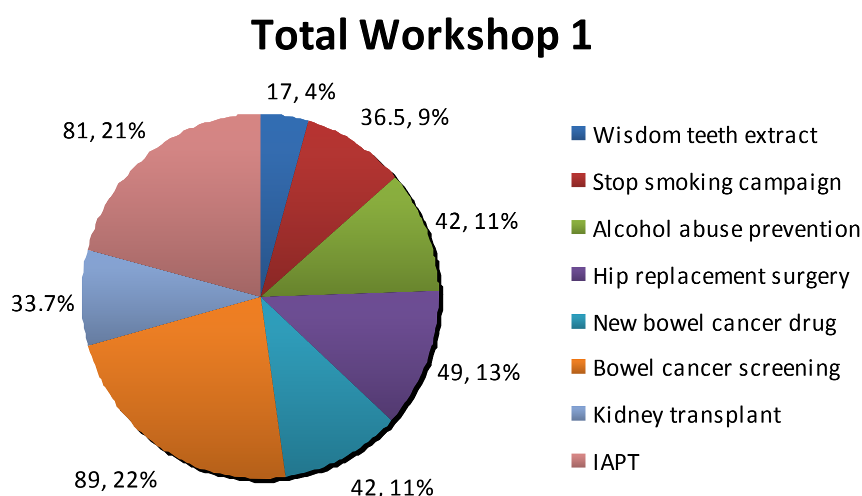
What was the issue?
As part of the engagement about our spending priorities in our Strategic and Operating Plan for 2011-12, NHS Leicester City and NHS Leicestershire County and Rutland held a public event and workshop on the morning of 31 January 2011.

Who was consulted?
Members of both organisations' membership schemes were invited. In addition to this, key stakeholders from the voluntary sector and Local Involvement Networks were also invited, together with representatives of seldom heard groups, including people with learning and other disabilities, gypsy travellers, and people from BME groups.

What Information was given?
During the event, there were presentations about the financial context from Sue Bishop, Director of Finance for NHS LCR, and Dr Tim Daniel, Consultant in Public Health Medicine at NHS LCR.

What were people asked to comment on?
The participants were asked about their views on health spending via a number of simple statements. During the workshop, they decided by a vote how they would theoretically allocate funding to a number of common procedures and treatments, including drugs and preventative treatments. They were then given more information about each of the procedures, including their costs, success rates and clinical effectiveness, and were asked to vote again in the light of the new information. During feedback, they had opportunities to make comments, which were also captured.

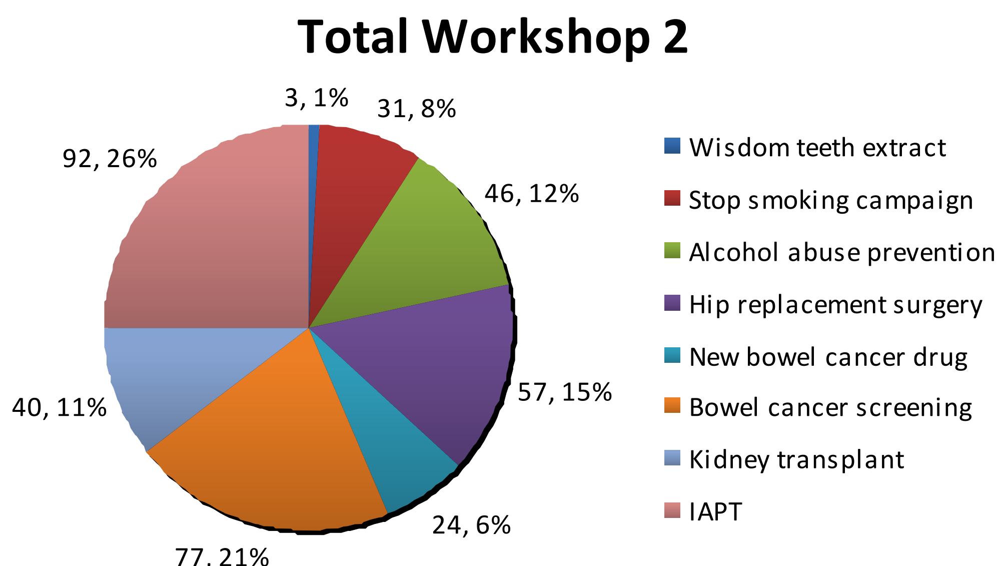
Summary of feedback
The notional budget at this event was in the form of a sheet of adhesive peel-off 'dots'. Attendees allocated as dots to each procedure in line with their priorities and preferences. The first time they voted, participants divided up their notional money in the following ways (the first figure refers to the number of peel-off dots, the second figure is the percentage of the notional budget):



Comments included:

- prevention and public education is a priority
- knee replacement - it is up to the individual to make the most of it, if it is to be effective and improve quality of life
- treatment should not be age related
- kidney transplants are saving lives and are cheaper than dialysis
- mental health has additional costs
- more investment and support for carers is needed
- prevention must take priority - what is the benefit of alcohol treatment?
- mental health had the most votes while wisdom teeth had a low priority

After further explanation about the conditions and treatments, their costs, success rates and clinical effectiveness, participants voted again. These are the results:



In the second vote less was allocated to wisdom teeth extraction (just one per cent), stop smoking campaigns, a new bowel cancer drug which prolongs life for a few weeks, and bowel cancer screening. More was allocated to alcohol abuse prevention, hip replacement surgery, kidney transplant, and psychological therapies.

A major theme in the discussion and feedback was the importance of prevention, including screening, eg, for different cancers, monitoring of school children. People also debated quality of life. Mental health was seen as important, and people were interested in the comparative costs of a transplant as against regular dialysis. A strong point was also made about the importance of support for carers.

Other key themes included the importance of good health education, a sense that people should take some responsibility for their own health costs, concern about mental health issues, concern about the cost of drugs and the potential for saving some of the money spent on them.

Decisions made

The findings from the event have been used to inform the planning for the financial year 2011-12 and will also help public health teams in their planning. All members attending the event were made aware that this is how there feedback would be used.

Quality Innovation, Productivity and Prevention (QIPP) event 3: Right Care – Planned Care

What was the issue?
NHS Leicestershire County and Rutland and NHS Leicester City wanted to improve their approach to planned care and proposed changes which would help GPs decide the right care at the right time for patients through standardised referral thresholds for access to some services. This was intended ensure that the referral process was based on clinical need and benefits, and was fair and transparent for everyone.

Who was consulted?
A briefing event took place to inform stakeholders of the proposed standardised referral thresholds for right care. Taking part were those from the membership schemes of the NHS Leicester City and NHS Leicestershire County and Rutland, members of the public, the Local Involvement Networks, while representatives from seldom heard groups were invited to attend the briefing. Those who attended were asked to complete a hard copy questionnaire at the event, and an online version was also made available. Those who had been invited to the briefing, but were unable to attend, were made aware of the online questionnaire and invited to complete it.

What information was given?
Information given identified that the proposed changes were based on the expertise of local GPs, hospital consultants and other healthcare professionals in the city and two counties. In addition, recommendations on right care at the right time had also been drawn from evidence from across the region.

People were also informed that the number of planned care procedures had risen exponentially over the last few years. Some of these procedures are shown to have limited clinical value in terms of improvements to the quality of life of patients.

Procedures under consideration were:

- primary knee replacements
- primary hip replacements
- carpal tunnel (wrist) and minor hand surgery
- cataract removal
- tonsillectomy
- some hernia repairs
- assistive conception services.

People were also reassured that, in identifying these procedures, consideration had been given to the following factors:

- the evidence base to support their development
- the impact that their introduction will have for patients
- clinical support for their introduction
- the wider impact for the local health and social care economy.

It was also explained how assessments would be made for each condition when using a standardised referral system.

What were people asked to comment on?

Following the information giving session, people were given the opportunity to ask questions. They were then asked to complete a questionnaire. People were asked if they agreed or not with standardised referral thresholds for each of the conditions identified. If people did not agree, they were asked to explain their reasons so that these could be taken into consideration by the trusts.

Summary of feedback
At the briefing event 92% of people who completed the questionnaire feedback agreed with the standardised referral thresholds for all the conditions identified.

Decisions made
Following the consultation with the public, patients, carers and clinicians around the Right Care thresholds a final list of surgical and referral thresholds were developed. These have been circulated to primary care clinicians and within local providers. The referral thresholds have been in use from the 1st of June 2011 and their impact will be reviewed on an ongoing basis.

The consultation with the public provided invaluable in informing the development of the thresholds and ensured that the work we were undertaking was as responsive to local need as possible in what is a challenging time for the NHS.

Transforming community services

What was the issue?
It was necessary to carry out engagement about the planned transfer of community services out of PCTs and into other provider arrangements, in line with national policy to separate healthcare commissioners from actual providers. Nationally it had been know as Transforming Community Services (TCS). The change was essentially a transfer of management arrangements, rather than a change to frontline services, but it was felt important to engage with the public and stakeholders to give them an understanding of what was happening.

Who was consulted?
Members of the public and stakeholders were consulted at public meetings in Market Harborough, Leicestershire, and Oakham, Rutland, as well as at a stall as part of the pre-meeting 'wellbeing markets' at both NHS Leicestershire County and Rutland's and NHS Leicester City's AGMs, and at community forums in Wigston and Oadby. Key stakeholders had opportunities to comment after regular updates at quarterly stakeholder briefings during the period April 2010 to January 2011.

What information was given?
Information was given about the national policy to separate commissioner and provider functions, our locally planned changes to community services and the perceived benefits.

What were people asked to comment on?
People were given information about the local plans for Transforming Community Services and asked to comment on how important they felt it was to create 'one-stop shops', to have care closer to home, to have health services that are efficient and cost effective, including efficient use of buildings and support services. They also had the opportunity to record any concerns about the plans, and to suggest improvements.

Summary of feedback
In general, people were supportive of improving services in the suggested ways. The concerns they expressed were to do with whether re-organisation was needed and some cited the many reorganisations there have been in the NHS in recent years, whether re-organisation would improve services, and whether the process would b expensive. Suggestions for improvements tended to be about better, more convenient access.

Decisions made
The TCS steering committee and Boards of both PCTs noted the feedback as they continued with plans to transfer community services. The transfer was completed on 31 March 2011, involving the move of most of the services provided by both city and county community health services to Leicestershire Partnership Trust.

The White Paper Equity and excellence: liberating the NHS

What was the issue?
The Department of Health published a White Paper for NHS reform entitled *Equity and excellence: liberating the NHS* in July 2010. The paper has wide-reaching implications for future of the NHS in England.

On 22 July 2010, the DH launched a period of public consultation on the White Paper, specifying three key issues:

- transparency in outcomes - a framework for the NHS
- increasing democratic legitimacy in health
- commissioning for patients

NHS Leicester City, and NHS Leicestershire County and Rutland wanted to capture the voice of all communities, stakeholders and public in the city and county by inviting them to provide feedback on the consultation and inform them on the changes which could happen as a result of the proposals in the White Paper. There were important factors that had to be considered to make sure all community voices were heard. Leicester's predominant ethnic minority community is of south Asian origin, while Leicestershire and Rutland do not share this characteristic, but have a larger ageing population than the city. There are major differences, too, in the levels of deprivation and affluence between the city and county areas, and we felt it was important to gather a demographically representative response from across this diverse area.

Who was consulted?
NHS Leicester City led on the consultation on behalf of both PCTs. The main channels of consultation were:

- both PCTs websites
- NHS Leicester City and NHS LCR holding consultation events for local residents of Leicester and other interested stakeholders
- Questionnaires, both hard copy and electronically, were sent to NHS LCR and NHS Leicester City membership
- attendance at community events with those stakeholders who possessed 'protected characteristics' under the Equality Act 2010.
- briefing and engagement with key patient groups, ie, LINk
- a specially convened briefing and question and answer session with elected members of Leicester City Council as well as briefings for Leicestershire and Rutland County Councils.
- consultation sessions with clinicians, especially GPs.

What information was given?
All people involved were given information on the key principles of the changes:

- PCTs and Strategic Health Authorities to be abolished from 2013
- GPs to have responsibility and budgets for planning and paying for services
- Greater emphasis on outcomes for patients, rather than simply meeting targets
- putting patients and the public first
- a greater degree of independence for health care providers and reduced bureaucracy

- health improvement will be the responsibility of local authorities

What were people asked to comment on?
Everyone was asked to comment on the proposals in the White Paper, to express their concerns and/or to offer potential solutions which could be taken into consideration both locally and nationally. They needed to understand that the reforms would see radical changes across the NHS landscape and the provision of health and social care.

Summary of feedback
Overall the proposals have been met with some support but also apprehension from a great many key stakeholders - both clinical and non-clinical. However, the predominant view of all who see the NHS as a vital national resource, is that it needs to work more effectively to ensure patients are its prime focus and that people's lives and health are improved.

Decisions made
The information gathered was sent to the Department of Health as part of the national feedback process, and the relevant legislation based on these White Papers is still on its way through Parliament at the time of this report's publication. However, during 2010-11 PCTs started the process of implementing the key principles of these reforms, and GPs began the formation of clinical commissioning groups in readiness to take over most local healthcare commissioning functions from April 2013.

Part 2: Leicester City engagements

Beaumont Leys Surgery – procurement training

What was the issue?
NHS Leicester City had entered in to an open tender process to secure a new provider for the Beaumont Leys surgery. Patient representation on the evaluation and interview panel was sought to ensure that patient views were taken in to account as part of the process. Training was to be provided.

Who was consulted?
Patients registered at the Beaumont Leys surgery.

What information was given?
Patients attending the training session were given information about procurement and the steps involved in the tender process.

What were people asked to comment on?
Patients attending were asked to consider whether they would be able to participate in the procurement process.

Summary of feedback
The attendees found the sessions useful and informative.

Decisions made
Unfortunately those patients who attended the session were not available to participate on the evaluation dates, providing lessons to be learned in engaging patients in the stages of the procurement process normally undertaken by trained professionals. Alternative representation was secured to ensure that the process ran smoothly in future.

Belgrave Medical Centre closure and patient registration

What was the issue?
In September 2010, the Belgrave Medical Centre, a surgery situated in the heart of Leicester, was closed following the death of the doctor who held the PCT contract. Due to unforeseen circumstances the lease extension for another GP to occupy the same premises could not be agreed and the GP in question was unable to secure alternative premises within the locality meaning the Belgrave Medical Centre had to be closed. The patients registered at the centre had to seek alternative arrangements at a 'caretaking' practice for a period of three months to ensure continuity of care.

The patient list of the former practice reflected not only an extremely diverse population, but special consideration also had to be taken of those in need of specialised communication, such as those who were elderly, vulnerable and those for whom English was not their first language.

Who was consulted?
All patients at the practice were initially consulted of the surgery's closure via letter sent on the 1 September 2010. A patient meeting was arranged for the 10 November 2010 to update them of the situation, gather feedback about individual issues and discuss a way forward with potential options.

Patients who are unable to attend this event were given the opportunity to submit their comments by returning a patient questionnaire with translations offered. From the questionnaires submitted to Leicester City PCT all comments were recorded and fed into the decision making process. This was followed by 6 patient registration sessions to support patients to register at alternative practices. Interpreters were available at these sessions.

What information was given?
Initially the situation and caretaking procedure was explained to the patients on the surgery's list. This was carried out by letter in September 2010, with the option to phone a translation service. There was then a meeting in November 2010 where full details of the caretaking and possible options for future services were discussed. Following the meeting, once the PCT Board agreed the way forward, information was sent to patients through the post about alternative practices available and how to register. This was followed by six 'drop-in' sessions arranged for patients to speak to a member of the PCT primary care directorate about local practices and the best choice for their requirements.

What were people asked to comment on?
Patients were asked about any potential issues arising from the closure and for their help in deciding the best way forward from a selection of potential options. This was followed by comments on the type and location of practice they might like to be re-located to.

Summary of feedback
The main themes that emerged from the engagement process, which patients commented on were the following:

- practice quality

- practice accessibility
- appointment availability,
- practice location
- disabled access
- parking access
- location convenience
- services available
- choice of practice

Decisions made
It was concluded that list dispersal provided a logical and sensible way forward. Prior to the implementation of dispersal of the patient list, NHS Leicester City requested that the patients could be assured of the capacity and quality of the local practices to ensure accessible, quality care was available to all patients.

Patients were able to continue to receive care from the Caretaker practice until 31 December 2010 before dispersal. The patient registration department and the PCT Customer Services team assisted patients throughout this process.

The six patient registration drop-in sessions helped to register patients. However, any patient who was not registered with another practice by the end of the caretaking arrangements were contacted by Patient Registrations and offered additional assistance.

“Call time on drink” campaign

What was the issue?
As a result of rising hospital admissions relating to alcohol, a social marketing project was embarked on to help reduce alcohol consumption in the city. This had to be designed to specifically target communities in particular locations. Therefore the marketing team engaged with members of the specific communities to design an appropriate campaign.

Who was consulted?
After an analysis of hospital admission data and mosaic profiling, the project focussed on three areas of the city, New Parks, Braunstone Park and Rowley Fields, as well as Eyres Monsell. It was decided to target the 25 to 44 year-old group to tackle problem drinking at an early age to prevent hospital admissions in later life.

Residents of the three areas within the target age-group were consulted on their behaviours and attitudes towards alcohol and ideas were generated for interventions that would help to reduce their alcohol consumption.

What information was given?
Background and current information about alcohol campaigns was provided.

What were people asked to comment on?
People were invited to join in discussions and activities with researchers in groups of three and in larger focus groups of 12. The discussions covered drinking behaviours, attitudes towards alcohol and campaigns as well as intervention ideas.

Summary of feedback

- Drinking is a by-product of socialising, therefore solutions would still need to provide opportunities for this.
- The campaign needed to be more hard-hitting than existing national campaigns.
- Units and recommended drinking levels were not well understood.
- Liver disease was a well-quoted side effect of excessive drinking, therefore the campaign also needed to address the wider spectrum of conditions.
- The audience was comfortable with receiving support in pharmacies for smoking cessation services and requested similar support for alcohol.

Decisions made
A hard-hitting campaign was produced promoting the dangers to health of drinking too much and providing tips on cutting backing while still maintaining a social life. Drinking limits were discussed in terms of popular drinks as well as units. The campaign offered 10-minute brief advice in pharmacies in the three selected areas.

Medicines Use Review survey

What was the issue?
A benchmarking exercise was carried out to identify training issues for community pharmacists in order to support them to deliver effective Medicines Use Reviews (MURs) with patients.

Who was consulted?
We sent three individually tailored online questionnaires to community pharmacists, GPs and members of the public who had received an MUR in the previous six to 12 months.

What information was given?
A basic description of an MUR was given in the questionnaire.

What were people asked to comment on?
Community pharmacists were asked about the MURs performed recently including the number of medicines people are currently taking, the type of information given, the reason for conducting the MUR and any training needs.

GPs were asked about any MURs received, the quality and usefulness of MURs, reason for the MUR and the effect on patient.

Patients were asked about the reason they had an MUR, their understanding of the process, how useful it was and the quality of information given to them.

Summary of feedback
Community pharmacists highlighted their MURs were performed for a variety of reasons and that most patients chosen were on multiple repeat medications.

GPs highlighted that they felt many MURs were a waste of time and NHS resources, and that patients were often confused by conflicting information given by pharmacists.

Overall, some patients stated that they found MURs to be useful but some did not understand why they were having a review at the time it was undertaken.

Decisions made
The Local Pharmaceutical Committee (LPC) felt that the results were inconclusive as not all community pharmacists and GPs completed the survey. As a result the Pharmacy Development Group (based at NHS Leicester City) decided that a PR exercise was needed with GPs and community pharmacists to better understand the role of MURs and their purpose.

Since then the Pharmacy Development Group has disbanded, and with the ongoing restructuring of the NHS, there has not been sufficient resource to carry out the planned PR campaign. However, a newsletter was sent out to signpost community pharmacists to training which was readily available.

New arrivals engagement

What was the issue?
During the winter months local NHS services are put under considerable pressure, particularly the Accident and Emergency Unit (A&E). Extensive delays are caused often because people do not know where else to go. This project specifically takes a targeted approach, and looks at new arrivals to Leicester City. One of the ways of understanding why new arrivals attend A&E is to engage with a number of different groups gaining better insight.

The New Arrivals Strategy (2006) defines new arrivals as "Asylum seekers, refugees, migrant workers, EU nationals who have chosen to make Leicester their home. A person, who has arrived in Leicester from abroad, and who, because of being new to the UK, has a significant need for support in accessing services and/or who needs different services to those of other residents."

The New Arrivals Strategy also states that, regarding the Leicester population and A&E interaction, it can mean that new arrivals may initially use emergency services unnecessarily and may require referral or signposting to mainstream services.

This project aimed to explore and work with residents who have newly arrived (within 0 to 24 months) in Leicester/UK and/or settled in Leicester and are using A&E for non-urgent primary care needs. This engagement exercise mainly focused on new arrivals, including students, who were new to Leicester and did not speak or understand English, either at all or well.

Who was consulted?
Asylum seekers, refugee groups, Somali, Polish communities, and students were identified as new arrivals to Leicester. Attendees at A&E were also consulted when visiting the service.

What information was given?
Information was given and gathered in a variety of ways. Members of the public who attended A&E were asked to complete a questionnaire. One-to-one interviews were also conducted with members of public when they came in for their GP appointments to the ASSIST surgery, a special Leicester City service for asylum seekers. Information was also given and gathered through focus groups, conducted at Sure Start centres targeting parents who had newly arrived to Leicester.

What were people asked to comment on?
We wanted to know:

- who uses A&E?
- why people use A&E?
- what is their experience of Primary Medical Care?
- are the Choose Well materials helpful?
- does Choose Well help you go to the right place for medical care?

Summary of feedback
The general consensus from engaging with asylum seekers and refugee groups was that when people come into the country, initially they are not aware of the provision of primary health care through GPs. Once given the information they are hesitant to

use them due to the fear of being sent back to countries that they have successfully managed to escape.

In trying to gauge a better understanding from newly arrived communities there is ample evidence to show that further work needs to be done in reaching out to these groups. There needs to be a targeted approach to educate, give information and signpost individuals to the correct service. The Choose Well campaign, launched nationally and locally should address some of these issues; increasing patients awareness of where to go to for the right treatment and also publicising the location, opening times and services offered in these centres. This, however, is only useful for those who can read English.

The following recommendations were made with consideration to the findings from the new arrivals engagement:

- work in partnership with the New Arrival Strategy group and deliver targeted campaigns to address the issues.
- work on an ongoing basis with educational intuitions to create a better understanding particularly amongst International students.
- promote the message that pharmacy services are available on the high street and can give people expert, confidential advice and treatment for a wide range of minor illnesses and ailments, without having to wait for an appointment.

Decisions made
Work is ongoing to ensure new arrivals to the city receive the most appropriate information about accessing health care services. The report of the findings was fed back to the New Arrivals Strategy group and the marketing department to use as a basis for developing a new, more targeted Choose Well campaign.

Out of Hours Service

What was the issue?
NHS Leicester City's Quality Directorate needed to review the out-of-hours service and monitor improvements to patient's experience. There had previously been a low response rate to questionnaires sent to the homes of patients after being seen. It was then decided that a team would interview patients after using the service to analyse their experience and observe the process during a visit to one of the out-of-hour options, an Urgent Care Centre, next to Leicester Royal Infirmary's A&E unit.

Who was consulted?
Staff from NHS Leicester City attended the city Urgent Care Centre unannounced to interview service users on a one-to-one basis. This was done on three occasions, one being a Saturday.

What information was given?
Patients were told who the team were, where they were from and that the service review was an inspection to suggest improvements, and had not been undertaken with the intention of closing the centre.

What were people asked to comment on?
Seven broad questions were identified, with the option for the patient to identify key words in relation to each question:

- Booking/ arriving for appointment
- Information at reception
- Waiting time to see doctor/ nurse
- Meeting with doctor/ nurse Treatment offered
- Information given about condition
- Information given about follow up

They were then given an opportunity to give reasons why and comment on any other aspect of the service.

The result was that patients were able to give NHS Leicester City staff an overall snapshot view of their experiences.

Summary of feedback
The following concerns and improvements were suggested for the service to improve:

- approximate waiting times need to be available
- the Jayex digital messaging display board could be used to show useful telephone numbers and health messages
- provide Department of Health information on why prescriptions may not be the most appropriate treatment in the leaflet stand
- provide NHS and trust magazines on information stand
- provide a water cooler or information about where to get a drink of water
- provide fans to ensure that the environment is comfortable for patients
- have televisions or other media available to reduce 'boredom'
- provide directions to a vending machine nearby
- provide a static information display board for the waiting area

- can there be signs saying if there are any problems to report them to reception?
- chlamydia tests could be available in the toilets
- better communication to patients for why you are testing or treating them, especially where there are language barriers
- have alternative methods for printing off information if patients request it
- ensure that information is displayed to inform patients and carers how they can make a complaint
- the notice board in the corridor outside the Urgent Care Centre was very crowded and it was difficult to read some of the notices – this needs to be regularly checked and updated
- maintain a comfortable temperature in the facilities
- ensure that the board at reception displaying which staff were on duty is accurate each day.

Decisions made

Many of the suggestions have already been adopted and the others are being investigated for the best possible solutions to improve the patient experience as part of a wider overall review of A&E, unscheduled and urgent care.

Patient Participation Group event

What was the issue?
A Patient Participation Group (PPG) is a practice-based forum, which involves patient representatives and practice staff, who meet to contribute to the improvement of their GP services. The role of the group is to work together with the practice to improve services for patients and support good practice development. People who are involved with PPGs have said that they feel really involved and understand much more about how their views and feedback help to improve things for patients and service users.

In Leicester City, although a growing number of GP practices now have a PPG in place, there are still many practices which have asked for support in setting up and running a successful PPG. A number of existing PPG members also asked for support with networking with other PPGs.

In winter 2010 NHS Leicester City organised a public event to raise the profile of PPGs, to encourage practice managers, GPs and members of the public to set up new ones and to share ideas and best practice with those that already existed.

Who was consulted?
GPs, practice managers, PPG chairs and members of the public were invited to attend.

What information was given?
Presentations at the event outlined the purpose of a PPG, how to structure the group and recruit to ensure demographic representation. There were also presentations from local practices and patients who are part of PPGs who shared new ideas and best practice.

What were people asked to comment on?
The event gave attendees the opportunity to network with other PPG members and practices whilst encouraging questions from tables. A workshop session encouraged attendees to share ideas with topics of starting a PPG, health promotion, and planning for the future.

Summary of feedback
Feedback from the event highlighted the need for improved communication between the Trust and PPGs with individuals asking for further information regarding setting up and running a successful PPG. There were many comments made asking for advice on how to handle difficult situations (such as complaints from patients and individual members) and comments were made on the design of the current information booklet with suggestions of how to make it more visually appealing. Through examination of the evaluation forms, most attendees found the session to be very informative, with the networking opportunity as the most valuable element.

Decisions made
One of the outcomes from the event is that the Local Involvement Network (LINk) is now working to establish a PPG forum to offer consistent support to PPG Chairs and Practice Managers in the city. In addition a number of attendees expressed interest in starting their own PPGs and we are working to support them.

Sexual health website

What was the issue?
The public health team wanted to develop a website that would be meaningful to all ages and cultures using the internet to be informative and cover all aspects of sexual health of interest to the residents of Leicester City. This is one of many approaches the public health team have been using to contact communities across the city.

A key issue was that there are many different preferences in design and language between different cultures and members of those cultures, including differences between various target group members, depending on their gender, age and their sexual orientation or religion, among other social and cultural factors.

Who was consulted?
A 'scatter-gun' approach of the membership was chosen to select people who were from a range of different backgrounds. We also engaged with various community organisations and groups to feedback information on specific preferences and examined evidence from previous research on preferences for both sexual health information, language and website design.

What information was given?
People were informed of the website proposition and purpose, and they were asked to review the proposed information pages and the website design. Members of our NHS trust membership scheme with online access were sent links to similar websites, to help them decide what styles they liked or disliked. They were also informed that, although it would not be possible for them to be identified through the process, their equality data was needed for the team to analyse what issues affected which cultures.

What were people asked to comment on?
A simple questionnaire was designed for residents to comment on the information they wanted, the language they wanted, the website to use, the website design preferred and any other comments or concerns they had. They were also asked to feedback their equality information, but it was emphasised that this information would not be used to identify them, and it was only necessary to analyse which communities had particular issues or preferences to better inform the project's approach.

Summary of feedback
People gave comments on topics they wanted to see, the layout preference, their preferred language, with explanations of why some words were inappropriate to their community and what other features they wanted to see on the website.

Decisions made
The feedback is currently being used as a basis for the website development taking into account all the concerns and additional interests of the different communities.

Part 3: Leicestershire County and Rutland engagements

Bowel cancer and bowel cancer screening awareness

What was the issue?
To inform a social marketing campaign aimed at raising awareness of the symptoms of bowel cancer, and the uptake of the bowel cancer screening programme.

Who was consulted?
The campaign was focused on 'seldom heard' groups and people from areas of health inequality. Six focus groups were held with people from Charnwood and North West Leicestershire, including people from a BME background.

What information was given?
Questionnaires were sent to people in the membership scheme in older age brackets, and to members from a BME background to gain an understanding of their awareness of bowel cancer symptoms and the screening programme.

What were people asked to comment on?
People were asked questions about the symptoms of bowel cancer and whether they would seek medical advice. They were also asked if they were aware of a bowel screening programme and how confident they felt in the ability of screening to detect early symptoms of bowel cancer.

At the focus groups information to be gained included:

- what they knew about what effect bowel cancer has, and what it can lead to
- what they knew about treatments for bowel cancer
- what they knew about the symptoms of bowel cancer
- what they knew about the test for bowel cancer (including showing them what they would receive if invited to take the test)
- what were the barriers to them taking the test, if any
- what would encourage/facilitate them to take the test
- what were the barriers to them sharing suspicious symptoms with their GP.

Summary of feedback
From the completed questionnaires and six focus group sessions which took place all feedback was collated. The feedback showed that more interventions were needed to improve awareness of symptoms to encourage so that people realised the importance of bowel screening. It also showed that people were more likely to take part in the screening process if their GP contacted them about it.

Decisions made
The results of the focus groups and questionnaires have been used as insight to inform decisions about interventions to improve awareness of symptoms, and increase uptake of screening in at risk groups. A social marketing campaign has taken place including posters, radio, TV and bus advertising to increase awareness of the symptoms and the value of screening and including GPs contacting individual patients and asking them to take part in the screening process.. Further research planned in 2011 will evaluate the success of the campaign.

Dental access

What was the issue?
People were not taking up available dental appointments that had been made available following public feedback saying they could not get a dental appointment. Therefore an event was arranged to inform the public of the importance of dental health and to engage with them on dental access.

Who was consulted?
Members of the public living in areas of high health and social deprivation

What information was given?
A public health specialist registrar and a practicing dentist spoke on the following:

- importance of eating healthy food to keep teeth healthy.
- negative effects of poor dental hygiene.
- Self-help tips on what you can do at home to prevent tooth decay, infection and cavities.
- NHS dental charges.

A video was shown on how looking after your teeth from an early age can help prevent painful dental problems, such as abscesses.

People attending then took part in a quiz to assess their understanding of the information given.

What were people asked to comment on?
A question and answer session took place where people could pose questions directly to the experts.

Summary of feedback
People felt better informed and aware that they could access dental appointments

Decisions made
To repeat this event annually.

Health care for older people, patients and carers

What was the issue?
An event was organised to address feedback from the NHS Leicestershire County and Rutland's "Be Healthy, Be Heard" membership scheme. Members felt that many people suffer with dementia, Alzheimer's and Parkinson's in particular, and wanted to learn more. In September, when the event was held, it was also Older Person's Month, a celebration of older people involving a range of events organised by the public, private and voluntary sectors.

Who was consulted?
"Be Healthy, Be Heard" members and members from NHS organisations across Leicester, Leicestershire and Rutland, along with volunteer organisations such as LINks and Carers Action and the Neurological Associations.

What information was given?
Presentations were given on Alzheimer's, Parkinson's, and arthritis. After the presentations, the attendees had an opportunity to take part in a seated exercise and a 'laughter yoga' session.

What were people asked to comment on?
Following each presentation members of the audience were given the opportunity to ask questions. They were also asked to complete an evaluation form to assess the success of the event.

Summary of evaluation feedback
Attendees enjoyed the event and felt it was `excellent in all respects'. The presentations received a very good rating as the audience felt their needs had been addressed. Members of the audience also stated that they would have preferred more time for each topic.

The aims of the event were achieved. Attendees felt more informed of the symptoms and prognosis of the conditions and felt motivated to discuss with their peers, friends, families and colleagues. Following the exercise participation sessions, attendees felt they could take away the simple and effective exercises they had been shown and continue at home.

Decisions made
To do more individual topic-specific events such as this one.

Loughborough University health and wellbeing event

What was the issue?
The vent aims were to:
- to encourage staff to consider the importance of their own health
- to pick up risk areas for individuals via screening and offer direction to services to minimise this risk
- to raise awareness of current, relevant cultural health issues
- to promote staff feeling supported and cared for in their working environment
- to maximise uptake of good services available within the university community and Charnwood region.

Who was consulted?
University staff were invited to attend via notifications on online notice-boards, newsletters and signage in communal staff areas. Reminders and requests to promote attendance were sent to heads of departments, sections and administrators to encourage staff to feel supported in attending by their managers.

What information was given?
Approximately 10 different organisations attended to give information on healthy lifestyles including the NHS Leicestershire County and Rutland.

Summary of feedback
This was a very useful engagement event as it gave the opportunity to promote key health messages to a hard to reach group - those who work full time.

Decisions made
A follow-up session has been arranged. This will be appointment based and specifically focus on the most popular tests cholesterol, blood sugar, blood, pressure and body weight / composition measures.

Membership Consultation

What was the issue?
In March 2009 NHS Leicestershire County and Rutland started a membership scheme called ‘Be Healthy, Be Heard’. The aim of the membership scheme was to help the public of Leicestershire and Rutland become as healthy as possible, and to provide a mechanism for people to feed back their views into the organisation on policies and service development by taking part in consultations.

The engagement team has also attended a multitude of community events including farmers’ markets, family wellbeing clinics and events held by charities such as VISTA and the neurological society.

A number of talks were given throughout the county called “community medicine for members”. Members attending these talks received up-to-date information and key health messages from health experts on a variety of topics, such as prostate cancer, women’s cancers, dental health, diabetes and staying healthy for older people.

A quarterly newsletter delivers key health messages to members and keeps the members updated on the work of NHS Leicestershire County and Rutland. In each issue members are invited to give their views by taking part in current consultations, enter competitions and find out what events are happening in their area.

In November 2010 a membership questionnaire was sent to all members of ‘Be Healthy, Be Heard’ (almost 10,000 people) to find out if the aims of the membership scheme were being achieved.

What were people asked to comment on?
The questionnaire invited responses to the following statements:

- being a member has helped me to be more healthy and to feel better
- as a member I have felt more informed about ways to stay healthy
- as a member I have had the opportunity to feedback on health services, for example, the opportunity to feedback my concerns about any proposed changes, and how I would like services to look in the future.
- I find the information I receive as a member easy to understand
- I find the information I receive as a member interesting
- I would like to see more information on…….
- one suggestion I would like to make on how to improve *Healthy Times* the membership newsletter is ……..

Summary of feedback
When considering the aims of starting the ‘Be Healthy, Be Heard‘ membership scheme the results of the membership questionnaire indicate that the membership is indeed helping members to be more healthy and has given people a mechanism to feed back their views into the organisation.

Over 50% of respondents agreed that being a member has helped them to be more healthy and feel better. Over 80% of respondents feel more informed about ways to stay healthy. More than 80% of respondents also agreed that membership gave them the opportunity to feed back their views and over 94% agreed that the

information was easy to understand, along with over 85% of respondents agreeing that the information was interesting.

The comments have provided a rich source of information on topics members would like to know more about and reflects the findings of the quantitative analysis. We have already begun to use this information in the planning of articles for our newsletters and in the planning of future events. For example, we have already held an event on dementia and have an event planned in the spring on how to navigate your way through the NHS.

The demographics of our membership reflect that we have a representative membership including members from seldom heard groups such as people with physical disabilities, people with learning disabilities, older people and people from areas of high social and economic deprivation. The ‘Be Healthy, Be Heard’ brand is recognised and trusted in the community. We know this by the feedback we receive from the public at community events and by the number of invitations we now receive to attend community events. We always receive a good response from our members to all of our surveys. We are also aware that some of our members are eager to become more involved and are interested in becoming member volunteers. We also have over 100 corporate members and are currently working together to improve occupational health.

We can therefore conclude that the NHS Leicestershire County and Rutland membership scheme is a successful scheme that engages with a large number of people from all walks of life, helping them to become healthier, be more informed and have a voice of influence in the decision making process for our organisation. In the future we hope to develop the scheme further as the membership along with our seldom heard strategy gives NHS Leicestershire County and Rutland a robust and meaningful way to engage with the public.

Decisions made

NHS LCR will continue to have a membership and recommend it to our CCGs for future engagement and consultations. We also plan to stage some of the events suggested by members.

Pacesetters Bowel Cancer Screening Awareness Project

What was the issue?
The NHS Pacesetters Bowel Cancer project was established to increase awareness of bowel cancer and the NHS bowel cancer screening programme amongst the South East Asian community in North West Leicestershire and Charnwood.
Bowel cancer is the third most common cancer in the UK and the second most common cause of cancer death. It has been particularly noted that there is poor uptake of cancer screening programmes by Black and Minority Ethnic groups. There is a clear need to reduce the barriers to screening by raising awareness and increasing access through culturally sensitive and community based interventions.

Pacesetters is a national programme that encourages the involvement of local communities The importance of community engagement and consultation was central to the successful delivery of this project. This provided an opportunity to increase community awareness of bowel cancer screening and also to enable identification of the barriers to participating in the screening programme. This project involved attending a Well Family Clinic multi-agency event and also a series of Asian elders focus groups.

Who was consulted? And what information was given?

There were three events:

- **Well Family Clinic Event**
  Attendance at this multi-agency session provided an opportunity to engage in a general health event in an effort to promote bowel cancer awareness and the screening programme. The plan was to ascertain baseline information about the knowledge of bowel cancer and the bowel cancer screening programme from the individuals attending the ‘clinic’. A questionnaire was used to collect this information and on completion a discussion was held with the individual based on the responses given.

  The Well Family Clinic was well attended. Several individuals approached the bowel cancer screening stand, in a very busy multi-agency ‘clinic’ with numerous displays, and illustrates the difficulty in reaching all attendees at a general health awareness event. This consolidated the decision to hold a single, focussed event and in doing so, highlighted the need to consult the South East Asian community.

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- **Asian Elders Focus Groups**
  Six focus group sessions were held with Asian elders. This helped raise awareness of bowel cancer screening by identifying community knowledge of bowel cancer signs and symptoms, the risk factors for bowel cancer and the NHS bowel cancer screening programme. The barriers to participating in screening were discussed and the discussions suggested that the main barrier within this community was lack of awareness of the screening

programme. The focus groups helped to shape the development of the final event by highlighting the activities that would encourage participants to attend.

When it came to naming the project and final event, there was unanimous agreement within the focus groups that we should avoid using a 'strap-line' for the project as this was seen as having a hidden agenda. It was felt that advertising the event as an 'NHS Bowel Cancer Awareness Event' was more transparent.

- **Bowel Cancer Awareness Event**
  The aim of the day was to raise awareness of bowel cancer and of the NHS bowel cancer screening programme. There were presentations on bowel cancer, the NHS screening programme and diet and a healthy bowel. A highlight of the event was a presentation from a service user perspective that was delivered in Gujarati.

  A series of activities were delivered, based on the suggestions from the earlier focus groups: two vegetarian cooking demonstrations, smoothie making, yoga sessions, chair exercises and health screening (blood pressure and body mass index calculation). Attendees also had the opportunity to have a private consultation about bowel cancer screening and volunteer to become a community health champions, The event was attended by individuals from the South East Asian community.

Summary of feedback
This project highlighted that the South East Asian community in North West Leicestershire and Charnwood are willing to participate in health events and will participate in NHS screening programmes if they are aware of the importance of the programme. Evaluation of the event demonstrated that the methods used in this project can reach a significant part of a community to deliver health promoting messages and activities suited to their needs. It was also noted that event was primarily promoted through local groups, friends and family. This reinforces the importance of community health champions to promote a health message within these communities.

Community health champions are the key to sustaining the delivery of health messages and converting these messages to actions that will result in significant changes in lifestyle and behaviour. As a result of this project three individuals have volunteered to train as community champions with a number of interested individuals requesting further information. It is also hoped that by disseminating this report within this community further individuals will be encouraged to become community champions. Ultimately this project has demonstrated that partnership working across health, social and voluntary agencies can successfully deliver a health improvement message to a South East Asian community.

Decisions made
Knowledge and awareness of bowel cancer screening is a barrier to screening uptake. Information needs to be provided to communities in a format that is easily accessible and understood. The focus groups indicated quite strongly that the General Practitioner should be involved in this process of raising awareness of the bowel cancer screening programme, promoting it to eligible patients and encouraging participation.

The report will be used to inform the Countywide project working with General Practice to improve cancer awareness and promote screening to support early diagnosis.

Patient experience

What was the issue?
The aim was to gather a range of quantitative data provided by patients while also identifying some questions about the equality and diversity issues facing patients and carers. This information was gathered to inform the NHS Leicestershire and Rutland Patient Experience Strategy 2010-13. Also, information gathered would help the organisation to understand the needs, expectations and preferences of the public.

Who was consulted?
Members of the PCT's membership scheme "Be Healthy, Be Heard".

What information was given?
People were informed of progress made in responding to the experience of local patients and how this was currently assessed through Patient Advice Liaison Service (PALS), complaints, comments and compliments, patient safety incidents and patient experience surveys. Members were informed on how their feedback would be used.

What were people asked to comment on?
People were asked about their experiences either as a patient; using the services or as a carer of someone using the services. People were also asked to consider recent experience and what they believed would make future experiences better.

Summary of feedback
Fifty people responded to the questionnaire. Taking the feedback into consideration the Patient Experience Strategy was developed.

Decisions made
The Patient Experience Strategy was approved by the Trust Board and is now being implemented by the Quality Directorate.

Perinatal psychosis

What was the issue?
The aim was to understand the views of women of childbearing age about services for perinatal psychosis, in order to create an East Midlands-wide specialised mother and baby mental health service.

Who was consulted?
Women of childbearing age were selected from the membership database and asked for their feedback. Two meetings of BME women in Loughborough were also asked their views.

What information was given?
Documentation explained plans for caring for women who become mentally ill before or following the birth of a baby. It covered plans for the whole of the East Midlands, including Leicester, Leicestershire and Rutland. The information was followed by a short questionnaire, to feedback views on these plans.

Perinatal psychosis was also explained along with a description of current service provision for those who became ill.

What were people asked to comment on?
People were asked where they would prefer to go to if they needed to go to hospital with mental health problems after having a baby. They were asked if they felt they would be able to approach health professionals on any mental health issues they may experience during pregnancy or following the birth of their child. People were asked to give reasons if they felt they could not approach a health professional. Views on how to improve awareness on mental health services were also asked for.

Summary of feedback
All respondents answered that they would prefer to go to a local mother and baby unit with their baby, if they needed mental health care, and 89% said they would be able to talk to a health professional.

Feedback collected from the BME women's groups included:
- more information needed from the doctors or midwives – the information is unsuitable to the audience as the information given is too complicated
- need for interpreters
- time spent with doctor or midwife is limited
- did not know what mental health was – it needs explaining by the midwife
- maybe midwife needs to take more of a role in looking for changes – possibly have more appointments
- accessing information at home, eg, the internet
- leaflets that can be taken away, and which can be translated
- post-natal classes to provide support.
- need parenting classes or support classes to make sure they are aware of what is available to them and how to do things correctly
- most new mums not sure of what to do in terms of good diet, creating a routine, feeding, etc
- need to learn about planning a routine, balancing old life with new
- help with how to include mothers' partners

- language and other barriers – midwifes and doctors do not understand the religious side or culture sufficiently
- current leaflets are too complicated to read.

Decisions made
The results will help with planning for treatment of women with perinatal mental health issues in the East Midlands, particularly those from a BME background. All those who took part in the consultation process were informed that this is what their feedback would be used for.

Public Consultation on the proposed closing of Ketton and Gretton branch surgeries by Uppingham General Practice

What was the issue
Uppingham GP practice approached the NHS Leicestershire County and Rutland Primary Care Panel with a request to close down the Uppingham GP practice branch surgeries at Ketton and Gretton.

Who was consulted?
All patients who attend the Ketton and Gretton surgeries received a questionnaire to share their views and were also offered the option to complete the questionnaire online at the NHS LCR website or at the Uppingham practice website. They were also invited to attend one of three public meetings taking place in Ketton and Gretton to find out more and share their views with NHS LCR and the practice GPs.

What information was given?
Information given included how many patients registered at Uppingham surgery lived in Gretton and Ketton and surrounding villages.

What were people asked to comment on?
People were asked if they accessed care in other places and what would they believed would change if the surgery closed. They were also asked to comment on benefits to them if the surgery closed, how often they had visited the surgery in the last 12 months, where the usually attended if they wished to see a GP, where they usually attended if they wished to see a nurse, if they had any objections to the closure of their branch surgery and the reasons for those objections.

Summary of feedback
The feedback focused mainly on issues of access if patients needed to go in to Uppingham to see a doctor. There were also useful suggestions from both Ketton Parish Council and Corby Borough Council with regard to how to progress.

Decisions made
Once all feedback had been collated and considered the NHS LCR Trust Board on the recommendation of the NHS LCR Primary Care Panel was to keep Gretton branch surgery open.

As requested by Ketton Parish Council the board gave a three-month period for suitable, alternative accommodation to be sought so that Uppingham branch surgery may remain open.

Smoking, diabetes and eyes event

What was the issue?
To raise awareness of the effects of smoking with particular reference to diabetes. Also, to discuss eye disease in general and in relation to diabetes.

Who was consulted?
Members of the public were invited to attend an engagement event.

What information was given?
Before the event talks started members of the audience were asked to complete a questionnaire to assess their knowledge of the subjects to be talked about.

Presentations were given on diabetes by the Deputy Director of Public Health for NHS Leicestershire County and Rutland, on eyes by an optometrist, and on the effects of smoking on health by a smoking cessation specialist for the PCT.

What were people asked to comment on?
Following each speaker members of the audience were invited to ask questions of the experts to improve their understanding.

Summary of feedback
Members were asked to complete an evaluation questionnaire following the presentations. In all, 100% of the audience stated that they were now better informed.

Decisions made
To continue to engage people through this type of event to keep people better informed on key health topics

Women’s Cancer Event

What was the issue?
The aim was to raise awareness of women’s cancers.

Who was consulted?
Members of the “Be Healthy Be Heard” PCT membership scheme were invited to attend along with members from University Hospitals of Leicester NHS Trust; NHS Leicestershire Partnership Trust and NHS Leicester City.

What information was given?
Speakers presented on ovarian and cervical cancer, cervical screening, background to cancer research, current research trials for women’s cancers and genetics.

What were people asked to comment on?
Following each presentation women were encouraged to ask questions and the health specialists answered.

Summary of feedback
This was a successful engagement event which informed women about women’s cancers and emphasises the importance of early intervention.

Decisions made
The women enjoyed the event and gave very positive feedback finding the information given informative and useful. Therefore a similar event will be repeated in the future.

Part 4: East Midlands Specialised Commissioning Group (EMSCG) engagements

East Midlands Specialised Commissioning Group is an organisation hosted by NHS Leicestershire County and Rutland.

Introduction

The EMSCG is committed to ensuring it is accountable for the decisions it takes on behalf of the people of the East Midlands and uses patient feedback and proactive patient and user involvement as an integral part of service review and service redesign.

We have Lay Members on our Board who provide the voice of the public and we engage with a variety of individual patients and patient groups to ensure the needs of patients are considered in all we do.

As well as undertaking our own engagement and consultation we support national initiatives. A national review of children's congenital heart services is being undertaken (Please visit www.specialisedservices.nhs.uk/safe_sustainable/childrens-congenital-cardiac-services). The review is being led by the national Safe and Sustainable team on behalf of the 10 Specialised Commissioning Groups and their constituent Primary Care Trusts, and the EMSCG works hard at a regional level in support of the associated public consultations.

Foreword

Julia Cons
"It has been fascinating to be a part of the work of the EMSCG. More importantly, it has been a privilege to be involved in the guidance of this highly proficient organisation, particularly in these times of great change. Every person with whom I've had professional contact has been visibly motivated and passionate about the NHS. Each individual member of staff so obviously understands the imperative to provide the best possible care to the most possible patients under ever tighter budgetary constraints, and works hard to add their utmost to the process.

"I have attended EMSCG board meetings and Clinical Priorities Advisory Group (CPAG) meetings, where my opinions and input have been actively sought and valued, both as an individual and a representative of the 'man in the street'. It has been impressive to be made to feel no less valued on the rare occasion when I have felt the need to metaphorically bang the table than when high praise has been due or decisions have been straightforward and courses of action obvious.

"I was also actively involved in the designation process for the genetics services in the East Midlands, taking part in site visits and staff interviews in Nottingham and Leicester, where I was able to ask questions to help ensure that the services provide the best possible service from the point of view of patients and carers.

"During the early part of 2010 I was a member of the team that peer reviewed the burn care services in Birmingham, Nottingham and Leicester, taking part in all-day visits to each service and reviewing the information and services provided. I was hugely impressed by the care in all of the services, by the obvious dedication of the staff, and by the positive views of the patients. It was gratifying to receive such a warm welcome at each hospital, and to be provided with such comprehensive information to demonstrate their compliance - and more - with the Burn Care Standards. I was so impressed with the provision of burn care in the Midlands that I was thrilled to be asked to join the Midlands Burn Care Network as a lay member, and to be invited to be a member of a national team who are currently reviewing the Burn Care Standards.

"The last year has been most rewarding. I hope I have added as much - preferably more – to the organisation and the NHS, and I look forward to being an active part of the EMSCG in the coming months."

Lee Bartholomew
As well as involvement in the EMSCG Board and Clinical Priorities Advisory Group, EMSCG Lay Advisor, Lee Bartholomew was invited to Chair the Project Board for the National Haemoglobinopathies Project. This one year project to define the designation standards model service specification and commissioning framework for Sickle Cell Disease and Thalassaemia.

Lee said "I have found the work of the Project Board a fascinating insight into the challenges faced by patients, providers and commissioners. The efforts the Project Team has made to consult as widely as possible with the stakeholders are to be commended. I am sure their efforts will produce an invaluable set of tools for the health community to use."

Teenage and Young Adults Cancer (TYA)

Why?
To ensure that the East Midlands service meets the needs of teenagers and young adults, the EMSCG involved patients in developing and improving the service.

What did we do?
We sought patients' views and suggestions on:
- Current service provision
- How the service can change to incorporate both the medical model and psychosocial model of care
- Improvements for physical facilities (to ensure the hospital surroundings stimulate and motivate teenage/young adult cancer patients).

This was achieved in a variety of ways including:
- Informal discussions at youth groups in order to build trust enabling patients to share their experience of the diagnosis, treatment and hospital care
- A user experience questionnaire which provided a confidential method for capturing experiences of patients and assisted in understanding things from a patient perspective.
- A media campaign, newsletters, direct mail and business card distribution, providing a comments book for thoughts, posters, and work with clinical teams to encourage them to seek feedback on patient views.

Some of the key issues identified were the need for:
- A quicker referral from GP to the acute sector and the early identification of TYA patients
- Improvements in communication i.e. in the explanation and understanding of diagnosis, treatment and consent to treatment
- Psychosocial support services that meet specific age group needs, such as alone time, access to peer support, support relating to feelings of isolation, fear and motivation
- Information on health care needs - body image, puberty, diet, health promotion, pathway journey
- Good facilities with choice, a contact person and a care plan
- Access to outreach support, moving on back in the community.

What was the impact?
The following actions were taken forward:
- Update our policy with the responsibilities of the key worker role, ensuring the role is managed and service allocated according to patient need at the TYA multi-disciplinary meeting
- Develop an information leaflet for patients and a communication and marketing plan to raise awareness of the service amongst patients and clinicians
- Ensure age appropriate facilities incorporate patient requirements: i.e. the look of the building and provision of specific facilities including a complementary therapy room, WIFI access, area for space and education
- Develop specialist posts such as the TYA Childrens Nurse Specialist (CNS) role to provide outreach support.

East Midlands Renal Network (EMRN)

Patient and Carer Forum
The EMSCG hosts the East Midlands Renal Network and provides specialised commissioning expertise to assist the Network in their aim to continually improve kidney care for patients and carers living with kidney disease. During 2011 the East Midlands Renal Network established a Patient and Carer Forum.

Why?
The renal network believes that patient and carer involvement is integral to the work of the network to ensure services are patient focused. The main purpose of the group is to provide the Renal Network with a perspective of the quality and experience of care from the viewpoint of patient and carers.

The basis of the forum is that there is always a story to be told from an experience and we focus on how the Network can best tell that story in a way that others can learn from and users can benefit from.

What did we do?
Information about the East Midlands Renal Network and the proposed patient and carer forum was circulated liberally around renal dialysis units, local kidney patient associations and other relevant areas. This information asked for expressions of interests to joint the group. Further information was then provided and the first meeting took place. Meeting are held every 3-4 months.

What was the impact?
The forum is in its infancy and is working on ideas for assessing renal units from a patient and carer perspective. The forum provides a means of gaining patient and carer input in policy/guidelines development and service improvement initiatives. One quote was provided to the network manager in an e-mail following one of its meeting as follows;

“I think the forum will do a great job in making the units all work as one and bringing them all to a certain high standard to give the patients peace of mind that they are getting the best.”

(Patient: EMRN Patient and Carer Forum).

Midland Burn Care Network (MBCN)

Why?
To understand the needs of those that use the burns services in the East Midlands.

What did we do?
The MBCN has continued to develop patient surveys. The MBCN team has also developed a website which provides a means of providing information on burn care to the local the population. Results from the patient surveys and comments from patients are available from: www.midlandsburnnetwork.nhs.uk

What was the impact?

The development and participation of patients completing surveys has had a positive impact on Burns services in the East Midlands. Patient experience has been improved in the Dressing Clinic / Outpatient departments after patient feedback. Length of time for appointments has been slightly increased and this has led to more patients reporting that they have been seen on time. There has been an increase in appropriate patients being seen by the Therapy teams. Following patients answering questions on pain / discomfort actions have been taken to improve patients' pain control and the advice given on analgesic medication. In the most recent survey patients / carers report an increase in satisfaction with their care.

Safe and Sustainable - National Paediatric Congenital Heart Surgery Review

Why?
To engage patients and their carers in the consultation process of the national review of children's heart surgery services and obtain their views on the proposed service model and configuration options.

What did we do?
Extensive consultation documents and feedback mechanism have been made available by the national team supported by EMSCG. EMSCG worked with NHS Lincolnshire to engage with the local populations of Lincoln and Sleaford and have worked with Leicestershire Links. The engagement culminated in two events held on 16 June attended by around 500 people. As part of the review the National Team commissioned an independent Health Impact Assessment (HIA). Individual interviews were held with parents and two events, supported by EMSCG, for hard to reach and disproportionately affected groups where held in the Belgrave and Highfields areas of Leicester.

What was the impact?
The views of patients from across the East Midlands have been fed into the reconfiguration decision making process. An interim HIA has been published and a report of the responses to the consultation is expected in the last week of August 2011.

East Midlands Haemophilia Management Group

Why?
EMSCG facilitated the establishment of the East Midlands Haemophilia Management Group to allow sharing of expertise and good practice, quality assure and inform commissioning decisions. This group has multi-professional representation from the haemophilia centres across the region and includes two patient representatives.

What did we do?
Patients are involved in the discussions and able to influence the decisions of the group.

What was the impact?
The introduction of a patient contract and a patient education event was held on the 16 March 2011 attended by patients and their relatives.

National Commissioning documents for Haemoglobinopathy

Why?
The EMSCG were commissioned by the Department of Health to produce a series of national commissioning documents for haemoglobinopathy services.

What did we do?
Patient group representatives were part of the Expert Working Party which informed the development of the documents. A patient workshop was help in London with patients from across the country in attendance.

What was the impact?
Patient views are explicitly represented in the final documents which will be used to inform the commissioning of local services for patients.

Involvement of regional Expert Patient Committees in the commissioning and development of Specialised Perinatal Mental Health Services in the East Midlands

Why?

The East Midlands Perinatal Mental Health Clinical Network was set up to improve the care and treatment of pregnant and postpartum women who are seriously mentally ill. Working in collaboration with the EMSCG, the key principles of the Network are to support the development of comprehensive and integrated perinatal mental health services providing high quality care that meets the needs of mothers and their infants. Ex-patients have been involved in advising the Network on the various work programmes that have been set up to support this. From the outset, patients have actively participated in short life working groups, workshops and regional conferences.

What did we do?

In 2009, as part of the NHS East Midlands Next Stage Review regional priorities programme, five Expert Patient Committees were established, one in each mental health trust. These are now a constituent part of the formal organisational structure of the Network. The emphasis has been to ensure that, through the Expert Patient Committees, the views and experiences of service users across the Network are adequately represented in the planning and implementation of changes in service provision and delivery for perinatal mental services, taking into account regional and national initiatives and to give advice and recommendations to the Network Executive Committee and Management Board.

Over the period April 2010 – March 2011, the Expert Patient Committees have contributed towards the development of:

- Quality standards for in-patient mother and baby units, perinatal community psychiatric teams and infant welfare.
- A quality of life measure and care and treatment questionnaire developed by the Network in conjunction with a clinical software company, FACE (Functional Analysis of Care Environments).
- Antenatal screening midwifery training programme, incorporating both an e-learning and tutorial component.
- Regional care pathway and management guidelines.
- Patient information leaflets.
- Research proposals and grants.

What was the impact?

Patient involvement in service redesign/development has had an important impact on service delivery, as follows:

- Evidence of real patient influence on the Network, with patient representation on the Network Management Board and Stakeholder Reference Group and input into all Network work programmes.
- Evidence that recommendations made by the Expert Patient Committees are integrated into network planning and regional strategic decision-making (i.e. outcome measures, standards, training).
- Input into the development of quality standards, training programmes and care pathways, which has led to improvements in:

- Clinical practice, skills and decision-making in maternity, psychiatric and primary care services.
- Management and referral of patients in a timely and efficient manner.
- Promotion of good/best practice in accordance with national guidelines/peer-review; this has also promoted continuing professional development and learning.
- Collaborative working between clinicians and an increased capacity for shared/joint learning.
- Understanding and management of perinatal mental health disorders together with increased skills and capacity in primary care.
- Emphasis on improving and streamlining the patient journey has helped ensure rapid access to the most appropriate level of care.
- Development of Patient Related Outcome Measures, which are tailored to the specific needs of women who are under the care of Specialised Perinatal Mental Services, enables patients to provide feedback on the quality of services and provide a self-assessment of their personal situation.

Policy Development

The EMSCG draft policies are routinely sent out for engagement with patients and the public via our regional Primary Care Trusts. Draft policies are also sent to known patient support/interest groups (national and regional) for comment, and we place draft policies on our website to give people the opportunity to provide us with their views. We review our draft policies in light of all the comments we receive, making changes and amendments where appropriate before a final copy is sent to the Board for approval. The case study below shows the details of policy consultations.

EMSCG Commissioning Policy for the use of Pre Implantation Genetic Diagnosis (PGD)

Why?
Pre Implantation Genetic Diagnosis (PGD) enables couples who are at a high risk of passing a serious genetic disorder to their children, from avoiding the conception of a child with the genetic disorder (an 'affected' child). It uses in vitro fertilisation (IVF) to create embryos, tests one or two cells from each embryo for a specific genetic problem and identifies embryos without the genetic problem for transfer to the uterus.

A revised (second version) of the policy already in existence was proposed, with changes in access criteria. These were to include the removal of the criteria of 'no living unaffected children from their current relationship.' This would mean that couples with child/children who had not inherited the genetic condition could still apply for PGD. The number of IVF cycles would be changed from the first version which offered 'three completed' cycles to an 'unlimited' number of cycles instead, and proposed to allow PGD treatment on the NHS to couples who had previously paid for the treatment privately.

What did we do?
The policy was posted on the EMSCG website. Leicestershire County and Rutland (LCR) PCT posted a link from their website to EMSCGs, and NHS Leicester City posted it on their website, on Facebook and Twitter. It was sent electronically with a plain English Question and Answer paper on June 8 2010 to the interest groups outlined in 'Patient Interest/Support Groups'. Responses were received from the following:

- Association for Improvement in Maternity Services (AIMS)
- The CF Trust
- East Midlands Public Health consultants (3)
- Bassetlaw PCT
- National Cystic Fibrosis (CF) Trust
- Clinical Genetics, NGH
- Derbyshire county public representative
- Haematology, LRI
- CARE Fertility, Nottingham
- Leicestershire LINk
- IVF patient representative
- FAP Gene Support Group

What was the impact?
The following reflects the recurrent themes that arose through the comments that were received, and the EMSCG response to these:

Comment: “There is Inequity in comparing the criteria for the IVF Tertiary Infertility policy and the PGD policy”.
Response: The IVF and PGD policy are two separate policies because the IVF policy is for infertile/subfertile couples, whereas the PGD policy is for fertile couples and to avoid the risk of having an affected child, not as a necessity to aid them in conceiving per se. Unlike sub fertile couples, fertile couples could conceive an affected child. So if tight criteria for access were put in place it could be argued that the EMSCG endorse an illogical policy because it does not make financial sense. This is because it may be a false economy not to fund PGD because the costs of funding an affected child would be far more than paying for PGD.

Comment: “There is concern regarding the unlimited access to PGD, the open ended access criteria and its links to affordability”.
Response: It would cost the NHS far more to pay for a child affected by a genetic condition, in comparison to PGD.

PGD in relation to conditions currently not licensed by the HFEA.
Response: The HFEA advises that for practices who are licensed to carry out PGD and wish to offer PGD for a new genetic condition (i.e. a condition that has not previously been licensed by the Authority) then they must apply to the Authority to do so, setting out how they consider the genetic condition in question meets both the significant risk and seriousness requirements in the HFEA Act (2008). (http://www.hfea.gov.uk/5259.html).

Comment: “How successful will PGD be?”
Response: Data from the Human Fertilisation and Embryology Authority (HFEA) shows that in 2006, for women receiving PGD, the percentage of cycles started that resulted in a live birth was 33.3% for women aged under 35; (9/48) for women aged between 35-37; and (2/27) for women aged between 38-39. (Percentages are not calculated where there are less than 50 cycles. Figures in brackets show cycles resulting in a live birth/all cycles started).

Comment: “The need to consider the child’s welfare statement in the criteria for the policy is very subjective”.
Response: There needs to be regard to the interest of the potential child (as per the HFEA Act 1990). However, this has not been classed as ‘mandatory’ criteria in the policy and these needs have now not been classed as ‘paramount’ as they were in the previous version – as there is not a ‘test’ to be passed or failed by the presenting patient.

Comment: “Would PGD for infertile couples be decided under the PGD or IVF criteria?”
Response: If a couple were subfertile/infertile and were carrier(s)/had a genetic condition, then the couple would be considered under the IVF criteria. If they met the criteria under the IVF policy then they would be provided with IVF in accordance with that policy, whilst allowing them to also have PGD. This will be clarified in the policy document.

Comment: “What happens if the patient has one abandoned cycle?”
Response: Policy has been amended to allow for more than one abandoned cycle.

Comment: “Since some of these inherited conditions are under diagnosed, poorly understood or insufficiently researched, potentially the policy could discriminate against these populations.”
Response: There will be equal access to the policy if they meet the clinical criteria, and the condition is licensed by the HFEA for PGD testing.

Comment: “This policy could increase the risk of multiple births.”
Response: Within the policy, single embryo transfer (SET) will take place so only one embryo will be transferred.

Amendments made to the final policy as a result of engagement were:

- Clarification within the policy document that couples who are infertile but also have or carry a genetic condition to be subject to the criteria for IVF as set out in the tertiary infertility policy, but also provided with PGD for that one cycle if they meet the IVF tertiary infertility policy.
- Policy amended to delete reference to PGD testing on frozen embryos. The inclusion of using remaining frozen embryos from self funded IVF in conjunction with PGD will remain in the policy.
- The policy was amended to allow for more than one abandoned cycle.
- The criteria requirement for a Clinical Pathology (CP) accredited lab amended within the policy to advise should be working towards CP Accreditation (in line with the HFEAs 2007 requirements).
- The criteria requirement that ‘the centre must have a HFEA licence to provide PGD for the condition being considered’, amended as if the lab has a HFEA license which includes PGD it can test for any of the conditions on the HFEAs central approved list.
- Clarification on the position on Human Leukocyte Antigen (HLA) matching to an existing affected child within the policy. Policy amended to include the position in line with the HFEAs regulations (as per CPAG recommendation 03/09/10).

Patient interest/support groups

- Cystic Fibrosis Trust (national)
- Cystic Fibrosis Trust (regional)*
- Familial Adenomatous Polyposis (FAP)
- Fragile X Society (National)
- Genetic Alliance UK (National)
- Huntingdon’s Disease association, Nottingham
- Muscular Dystrophy Campaign (National)
- Nottingham Department of Clinical Genetics
- Nottingham Sickle cell and thalassaemia service - Mary Potter Hostel, Hyson Green, Nottingham.
- OSCAR Organisation for Sickle cell anaemia research
- Sickle Cell and Thalassaemia Centre – Charnwood Health Centre, Leicester
- The Haemophilia Society
- The National Childbirth Trust (sent 12/07/10 – extended deadline for comments to 20/07/10)

- The Sickle Cell Society (national) (sent 12/07/10 – extended deadline for comments to 20/07/10)
- Twins and Multiple Births Association (TAMBA)
- UK Thalassaemia Society

Other networks/interest groups:

- CARE Nottingham
- Community specialist nurses for the sickle cell and thalassaemia service in Nottingham and Leicester.
- Derby City General Hospital Haematology Department
- East Midlands Directors of Public Health (DPHs).
- East Midlands Genetic Network Group
- East Midlands Specialised Commissioning Group (EMSCG) lay representatives
- Embryologist and Director, CARE Fertility Nottingham
- Embryologist and molecular geneticist. Genesis Genetics, Nottingham
- Equality and Diversity leads within the 9 East Midlands Primary Care Trusts (PCTs).
- Human Genetics Commission
- Individual Funding Request (IFR) Managers within the East Midlands PCTs
- Individual Local Involvement Networks (LINks) leads within the East Midlands.
- LINks lead for the East Midlands.
- Members of the East Midlands Clinical Priorities Advisory Group (CPAG)
- East Midlands Public Health Consultants* (3)
- PPI/EMSCG liaison leads in the 9 East Midlands Primary Care Trusts (PCTs).
- Primary Care Trust Chief Executives
- Primary Care Trust Contract managers
- Provider (Trust) Chief Executives * (NGH)
- The East Midlands (EM) cancer network.

References

Department for Business, Innovation and Skills (BIS) (2010) *'Producing a Summary of Responses'.* Available from http://www.bis.gov.uk/policies/better-regulation/consultation-guidance/summary-of-responses. Accessed 14/04/2010.

Human Fertilisation and Embryology Authority (HFEA), http://www.hfea.gov.uk/, accessed 17/08/2010.

How to contact us

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Lakeside House, 4 Smith Way,
Grove Park, Enderby,
Leicester,
LE19 1SS

For general enquiries: 0116 295 7500 (Mon-Fri 9am - 5pm)

Email: info@nhslcrmembership.org

EMSCG

EMSCG
Fosse House
6 Smith Way
Grove Park, Enderby
Leicester, LE19 1SX

For general enquiries: 0116 295 0849

Email: info@emscg.nhs.uk

Customer Services
Our joint Customer Services team handles complaints, Freedom of Information requests, and helps 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 (Monday to Friday 9am to 5pm)

Email: customerservices@leicestercity.nhs.uk or customerservices@lcr.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 (9am to 5pm)
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.

NHS Leicestershire and Rutland Membership
NHS Leicestershire County and Rutland has set up a scheme to enable us to work together to reach this aim and for you to have a say in how local NHS services are provided. It is called “Be Healthy, Be Heard”. We have a dedicated interactive website where you can access a wealth of information about the membership scheme, find out about the benefits of becoming a member, join online and much more.

To join online, visit the website www.lcr.nhs.uk. Fill in the interactive form and submit it. If you would like to join by post please download and print the relevant form from the website, complete it and send it back to by post to:

NHS Leicestershire County and Rutland (Membership), Lakeside House, 4 Smith Way, Grove Park, Enderby, Leicester, LE19 1SS

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 731 9432

You can also write to Leicester LINk at:
Freepost RSBR-AKKG-XAHC
Leicester Link
Unit 55 Business Box
3 Oswin Road
Leicester
LE3 1HR

Email: LeicesterLINks@carersfederation.co.uk

For Leicestershire and Rutland LINk telephone: 0116 229 3103

You can also write to Leicestershire LINk at:
Beaumont Enterprise Centre
Boston Road
Leicester
LE4 1HB

Email: info@leicestershirelink.org.uk

* Please note that all LINKs will transform into HealthWatch groups under the terms of the Health and Social Care Bill, subject to Parliamentary approval.

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 જોઇતી હોય તો મહેરબાની કરીને **0116 2954743** પર ફોન કરો.

ਜੇਕਰ ਤੁਹਾਨੂੰ ਇਸ ਦਸਤਾਵੇਜ਼ ਦਾ ਵਿਸ਼ਾ ਵਸਤੂ ਸਮੱਝਣ ਲਈ ਮਦੱਦ 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 कृप्या 0116 295 4743 पर फ़ोन कीजिए।

اس دستاویز میں دی گئی معلومات کو سمجھنے کے لیے آپ کو مدد چاہیے تو برائے 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.

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