Fairclough, Nick
Field, Victoria_Brook
Field, Victoria_fpa
Field, Victoria_NAT
Field, Victoria_SHOG Out of hospital
Field, Victoria_Terrence Higgins Trust
Foster, Beth
Foster, Beth_Older People's event
France, Les
Fraser, Moria_Bromley
Fraser, Moria_Feedback_form_1
Fraser, Moria_Feedback_form_2
Fraser, Moria_Hastings Mind oct2005
Gallichan, Julie
Gant, Sarah
Goldsworthy, Jane
Hagues, Linda
Hassan, H_ASAT
Henry, Claire
Hincks, Sarah_Mendip PCT
Holt, Liz
Horton, Marilyn
Houldin, Laura
Hughes, Martin
Hurst, Angela
Jolly, Janice
Thank you for your help with your health, your care, your say.

This feedback form is intended for both local and national organisations or groups to report on the findings their own devolved listening exercise as part your health, your care, your say.

Can I check, are you responding to this questionnaire as:

- A local organisation or group  [yes]
- A national organisation or group  
- Other (record details below)  

All the information you submit will be analysed alongside the public’s response and the views obtained from other local and national organisations and groups and will feed in to the development of plans for improving community health and care services.

Please note the feedback form is in three parts:

- Section A: Thinking about the community health and social care services people use, what currently works less well?
- Section B: what do you think of the suggestions for improving health and social care services?
- Section C: details about your organisation and your listening exercise

If you haven’t covered Section A or all of the options under Section B, please just leave those questions blank.

Please make sure that you give us this feedback by 4th November, or earlier if possible. You can find out where to return this feedback by referring to the resource pack website, www.yoursayresources.nhs.uk

As you will see, most questions ask you to tick a box like this:

Tick one box only

Other questions give you space to record how you reached your decisions:

Please feel free to write as much, or as little, as you like.
Your health, your care, your say

Lambeth ACCORD, 336 Brixton Road, London SW9
Monday, 31 October 2pm - 5pm

An engagement event organised by Lambeth PCT and Lambeth Council’s adult and community services.

How can people look after themselves? How can we help you take care of yourselves and support you and your family in your daily lives?

How can people look after themselves?
- Up to individual – can't force anyone.
- Keep fit, exercise at home, walk more, active walking groups.
- Good diet. Less fat/salt.
- Stress management/yoga/meditation.
- Sleep management.
- Good relationships with neighbours.
- Seek out information, in lots of ways: internet, leaflets,
- Complementary therapy and treatments.

How can we help you take care of yourself & support you and your family in your daily lives?

Public health
- Lend out gym equipment for home use.
- Provide personal fitness trainer.
- GP exercise referral schemes.
- Gym membership, fitness training etc should be free of charge.
- Offer exercise classes to specific groups: general gym sessions can feel competitive.
- Promote better diets: lead by example.
- Offer stress management, complementary therapies.
- Offer well person’s check up at age 18.
- Do follow ups checks at regular intervals.

GP/community health services
• Friendly and easy access.
• Direct people to the correct services at the right time.
• Swift response to patient’s needs. Quicker appointments, more choice.
• Wider spread of clinic times. Doctors and health professionals on a rota.
• 24 hour walk in surgery.
• Evening and weekend clinic sessions. Flexible.
• Choice of appointment time.
• Help people prepare for appointments.
• Make sure staff are prepared to receive you. Know why you are coming.
• Have your own medical notes.
• Clear communication with all involved.
• Smooth running of GP practices. Better management of practices.
• GP to be better at signposting to other local services.
• Customer care focus.
• Move services into the community e.g diagnostics, chiropody.
• And move them around the community.
• Home visits for consultations/ diagnostics.
• Help patients understand more about their condition so that they can take part in the management of their condition.
• Better after care following diagnosis.
• Be timely: get all help arranged at diagnosis or within two weeks.
• Aspire to high standards set in palliative care for all conditions.

Responding to the community’s needs
• Use venues where people go rather than clinic settings, especially those who access services less e.g younger people.
• Be culturally sensitive with service provision, information etc.
• Provide computers to book an appointment if needed (choose and book).
• Provide odd-job service, small jobs around home.
• Promote schemes like LETS etc.
• Provide direct payments, but tell users about services they can purchase.
• Do holistic assessments: look at family, community.
• Ask people what they need and about their support needs. Be proactive.
• Target older people and those who do not usually access services.
• Strengthen community: faith groups/ministers, voluntary groups as sources of information and advice.
• More support for carers.

Managing/providing information
• Message in a bottle.
• Hand held records, so information is up to date.
• Education programmes for patients and carers particularly after discharge.
• Family education programmes.
- Information “one stop shops” that park in supermarkets, libraries etc.
- Link with utility companies so when a new householder registers for electricity they can be sent a directory of health/social care services.
- Link with a computer operator, so that an NHS guide is automatically installed when you purchase a computer.
- Websites for GP practices – so that you can book your appointment on line, get health advice without having to go and see someone.
- Use txt messaging for appointment reminders.
- Empower service users by providing accurate and precise information including telephone numbers of available services.
- Single advice helpline number for all health and social care services.
- Help all staff providing services to be good sources of general information.
- Don’t rely too much on on-line information. Use other channels.
- Provide directory of local services: what, where, how.
- Guide to using the NHS.
- Produce ‘introduction pack’ to locality with information such as ‘How to Register to a GP’, access services, counselling and other issues.
- Advertise services.
- Always give phone numbers

**Whom/where**
- Nurses
- Reception staff
- Community (with training)
- Schools
- Libraries
- GP practices
- Pharmacists
- Internet
- A&E
- Walk in centres
- Advice centres.
- One-stop shops.
- Community centres, neighbourhood centres.
- Open days.
Section C: details about your organisation and your listening exercises

To help us analyse the information you have given us, we need to find out a little bit more about your organisation and your listening exercise.

A. How many people took part in your devolved listening exercises?

   Write in below

   13

B. What sort of listening exercise was it?

   (Please tick one box only)
   - A day long session (from 5 to 8 hours long)
   - A half day session (from 3 to 5 hours long)
   - Up to 3 hours long: Yes
   - Other (record below)

C. How many of each of the following types of people took part in your listening exercise?

   (Please put a number in each box even if it is zero)
   - Members of the general public (i.e. with no specialist interest in health and social care): 11
   - Members of the public who are involved with health and social care services e.g. PPI forum members: 1
   - Paid staff from your organisation: 1
   - Voluntary staff from your organisation
   - Other (record below)
D. Please tell us how many of the people who took part – whether members of the public or staff - were from any of the specific sectors of the population listed below.

<table>
<thead>
<tr>
<th>Sector</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Children and young people</td>
<td></td>
</tr>
<tr>
<td>Older people</td>
<td></td>
</tr>
<tr>
<td>Pregnant women (and their partners)</td>
<td></td>
</tr>
<tr>
<td>Socially disadvantaged people</td>
<td></td>
</tr>
<tr>
<td>Disadvantaged children</td>
<td></td>
</tr>
<tr>
<td>Smokers</td>
<td></td>
</tr>
<tr>
<td>Excessive drinkers</td>
<td></td>
</tr>
<tr>
<td>Obese people</td>
<td></td>
</tr>
<tr>
<td>Substance misusers</td>
<td></td>
</tr>
<tr>
<td>Disabled people</td>
<td></td>
</tr>
<tr>
<td>People in prison</td>
<td></td>
</tr>
<tr>
<td>Black and minority ethnic groups</td>
<td></td>
</tr>
<tr>
<td>Travellers</td>
<td></td>
</tr>
<tr>
<td>Homeless people</td>
<td></td>
</tr>
<tr>
<td>People with mental health problems</td>
<td></td>
</tr>
<tr>
<td>People with learning disabilities</td>
<td></td>
</tr>
<tr>
<td>People in hospices/residential care</td>
<td></td>
</tr>
<tr>
<td>Asylum seekers</td>
<td></td>
</tr>
<tr>
<td>People with long term conditions</td>
<td></td>
</tr>
<tr>
<td>People with caring responsibilities</td>
<td></td>
</tr>
<tr>
<td>Other (record below)</td>
<td></td>
</tr>
</tbody>
</table>
E. Of the people that took part in your listening exercise, can you please tell us how many were from each of the ethnic groups listed below

- White British
- White Irish
- Any other white background
- White and Black Caribbean
- White and Black African
- White and Asian
- Any other mixed background
- Indian
- Pakistani
- Bangladeshi
- Any other Asian Background
- Caribbean
- African
- Any other Black background
- Chinese
- Rather not say

F. Which of the following best describes the sector to which your organisation or group belongs / where you work:

(Please tick one box only)

- PPI forum or other patient group
- Community-based NHS services
- Local authority social care services
- Private sector health or social care services
- Voluntary sector health or social care services
- Other (record below)
G. If your listening exercises mostly involved staff rather than patients or service users please can you identify from the list below which groups they most often have contact with or provide services for:

(Please tick all relevant boxes)

<table>
<thead>
<tr>
<th>Group</th>
<th>Ticked</th>
</tr>
</thead>
<tbody>
<tr>
<td>Children and young people</td>
<td></td>
</tr>
<tr>
<td>Older people</td>
<td></td>
</tr>
<tr>
<td>Pregnant women (and their partners)</td>
<td></td>
</tr>
<tr>
<td>Socially disadvantaged people</td>
<td></td>
</tr>
<tr>
<td>Disadvantaged children</td>
<td></td>
</tr>
<tr>
<td>Smokers</td>
<td></td>
</tr>
<tr>
<td>Excessive drinkers</td>
<td></td>
</tr>
<tr>
<td>Obese people</td>
<td></td>
</tr>
<tr>
<td>Substance misusers</td>
<td></td>
</tr>
<tr>
<td>Disabled people</td>
<td></td>
</tr>
<tr>
<td>People in prison</td>
<td></td>
</tr>
<tr>
<td>Black and minority ethnic groups</td>
<td></td>
</tr>
<tr>
<td>Travellers</td>
<td></td>
</tr>
<tr>
<td>Homeless people</td>
<td></td>
</tr>
<tr>
<td>People with mental health problems</td>
<td></td>
</tr>
<tr>
<td>People with learning disabilities</td>
<td></td>
</tr>
<tr>
<td>People in hospices/residential care</td>
<td></td>
</tr>
<tr>
<td>Asylum seekers</td>
<td></td>
</tr>
<tr>
<td>People with long term conditions</td>
<td></td>
</tr>
<tr>
<td>People with caring responsibilities</td>
<td></td>
</tr>
<tr>
<td>Do not deal with specific sectors of the community</td>
<td></td>
</tr>
<tr>
<td>Other (record below)</td>
<td></td>
</tr>
</tbody>
</table>
If you work with specific ethnic groups, which of these groupings do you represent or work with?

- White British
- White Irish
- Any other white background
- White and Black Caribbean
- White and Black African
- White and Asian
- Any other mixed background
- Indian
- Pakistani
- Bangladeshi
- Any other Asian Background
- Caribbean
- African
- Any other Black background
- Chinese
- Do not deal with specific ethnic groups
- Other (record below)
I. If you are a regional organisation, please tick the box below for the region you mainly work in

<table>
<thead>
<tr>
<th>Region</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>North East</td>
<td></td>
</tr>
<tr>
<td>North West</td>
<td></td>
</tr>
<tr>
<td>Yorkshire &amp; the Humber</td>
<td></td>
</tr>
<tr>
<td>East Midlands</td>
<td></td>
</tr>
<tr>
<td>East of England</td>
<td></td>
</tr>
<tr>
<td>South East</td>
<td></td>
</tr>
<tr>
<td>London</td>
<td></td>
</tr>
<tr>
<td>South West</td>
<td></td>
</tr>
<tr>
<td>National Organisation</td>
<td></td>
</tr>
<tr>
<td>Not applicable</td>
<td></td>
</tr>
</tbody>
</table>

J. What is the name of your organisation?

Lambeth PCT and Lambeth Council’s adult and community services

K. What type of organisation are you responding as?

<table>
<thead>
<tr>
<th>Type</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>A local organisation</td>
<td>yes</td>
</tr>
<tr>
<td>A national organisation</td>
<td></td>
</tr>
<tr>
<td>Other (please record below)</td>
<td></td>
</tr>
</tbody>
</table>
L. Would like to be listed as a contributor to the consultation?

<table>
<thead>
<tr>
<th>Yes</th>
<th>yes</th>
</tr>
</thead>
<tbody>
<tr>
<td>No</td>
<td></td>
</tr>
</tbody>
</table>

K. If you would like to receive a summary of our findings, please enter your contact details or email address in the box below:

Nick Fairclough
Assistant director of communications and patient & public involvement
Lambeth PCT
1 Lower Marsh
London SE1 7NT
020 7717 4701
nick.fairclough@lambethpct.nhs.uk
your health, your care your say response

Introduction

Brook, a registered charity, is the country’s leading sexual health organisation for young people, offering young women and men up to the age of 25 free and confidential sexual health advice and services. Brook has over 40 years’ experience of providing services through specially trained doctors, nurses, counsellors, and outreach and education workers to over 100,000 young people each year.

Brook’s national Young People’s Information Service provides a sexual health information and signposting service for over 17,000 young people a year through a telephone helpline, a confidential on-line enquiry service via the Brook website and a text messaging service.

This response focuses on how services outside hospitals can be strengthened to promote the sexual health of young people and is structured around the 3 key questions asked at the Your health, your care, your say listening events.

Question 1: How can people look after themselves? How can we help you take care of yourself and support you and your family in your daily lives?

Issues: Support from range of health professionals, tackling things that cause ill health, support for people with disabilities

In relation to sexual health, one of the key areas for Government action to help people take care of themselves is to make sex and relationships education compulsory in schools. Recent research carried out by the University of Southampton on behalf of Brook showed that school was the most important source of information on sexual health for young people but that there were still significant gaps in their sexual health knowledge. The findings of the research suggested that young people particularly needed support around the concept of risk and how to translate general concern about the risk of sexually transmitted diseases into behaviour that would protect them from personal risk.

Young people outside of schools also need access to better information and support. The national sexual health media campaign which aims to increase understanding of the risks of unprotected sex and the benefits of condom use must be reinforced by local health promotion activities for the general population and targeted work aimed at high risk groups including young people.
There is scope for a much greater role for nurses in leading and delivering sexual health services. The creation of more nurse consultant posts to provide clinical leadership for community based sexual health services and an increased use of nurses working to patient group directions would enable more services to be provided in a range of community locations. More support to increase training capacity for nurses in sexual health would also help to deliver the expansion in services required to meet the level of need and allow rapid access to services. Delays in access to abortion could be reduced if suitably trained nurse practitioners were allowed to provide early medical and surgical abortions in both the NHS and non NHS sector. Better training and support for pharmacists in promoting sexual health and working with young people would also increase the choice and accessibility of sexual health promotion and treatment for this group.

Models such as healthy living centres have combined treatment and care with wider social opportunities, welfare advice and training with the aim of tackling poverty and social exclusion. Within the sexual health field Brook Centres offer a model that sees clinical services combined with counselling, health promotion and community development work such as activities for young parents and other excluded groups. This integrated provision not only seeks to ensure that young people have the information and accessible treatment they need to protect their sexual health but also that they have sufficient self esteem and sense of opportunity to want to avoid risky behaviour and early pregnancy.

Sexual health provision for people with disabilities is a particularly neglected area and it is important that sexual health services offer appropriate information and outreach work as well as accessible services to meet their needs.

**Question 2: When you and your family need help and support how when where and from whom do you want to get it?**

*Issues: extended opening, convenient locations, community rather than hospital based services, services for hard to reach groups, role of the voluntary sector*

When Brook has consulted young people about their ideal sexual health services they have told us that they want confidential and free services; open at times convenient to them; in locations they can easily reach; provided by friendly, non-judgemental staff in a way that minimises embarrassment. Furthermore they want integrated services that provide contraceptive advice and supplies (including free condoms), pregnancy testing and counselling, STI testing, treatment and counselling, information and leaflets, and counselling for emotional, relationship and other issues such as family problems, bullying, depression, stress, eating problems and sexuality. They also want access to expert advisers in sex and sexuality, drugs, alcohol, and nutrition to provide one to one advice and educational seminars.

Confidentiality is vitally important to young people using sexual health services. In a recent survey of Brook clients 53% of all respondents and 62% of respondents under 16 said it was the single most important factor for them when seeking sexual health advice.

Like other age groups young people deserve choice about where they can go to get advice and
treatment on sexual and other health matters.

Currently 80% of GUM services are provided in the hospital sector and there needs to be a fundamental shift to a variety of accessible community based provision that young people can use easily and without stigma.

The current system of GP registration limits choice and flexibility and all too often Brook receives complaints from young people that the treatment they have received in general practice has been judgemental, obstructive or failed to respect their right to autonomy and confidentiality. Respondents to a recent Brook survey overwhelmingly supported the idea of specialist GPs for teenagers and felt that they would be more confident in using these services. Given the current limitations of general practice as a setting for young people-friendly provision, sexual health promotion, contraception and treatment also need to be provided with a range of young people’s services, for example through the operation of satellite provision in youth centres, clubs and colleges where young people can access them easily and discretely.

The poor experiences young people often have of health services highlight the need for health and other professionals to be recruited and trained specifically to work with young people, especially those under 16.

Voluntary sector organisations have an important role to play in increasing the volume and accessibility of provision. Organisations such as Brook have a track record in listening to their client groups and responding flexibly to their needs. Through outreach work with marginalised communities and satellite provision in acceptable and easily accessible locations they have been able to engage with groups who find mainstream provision difficult to use and have developed a reputation for being trustworthy. Such organisations will therefore be well placed to take up some of the provider functions of Primary Care Trusts in a reconfigured NHS.

**Question 3: How can we help you get the right services when you need them and ensure your care and support is properly co-ordinated?**

**Issues: Single needs assessment, better information and signposting**

There is still considerable lack of awareness amongst young people, and young men in particular, about the services available to them. The planned sexual health media campaign will clearly play a role in ensuring young people have better information about sexual health services. This campaign must utilise as many media as possible. Confidential information services such as the on-line, telephone helpline, and texting service provided by Brook have an extremely important role to play in signposting young people to services. It must also be backed up by better local publicity for services, in particular in the places young people regularly meet.

It is crucial that services are open at times convenient to young people, particularly after school and at weekends. The majority of hospital based GUM services are currently only open during office hours on weekdays making it not only inconvenient but often extremely difficult for young
Young people’s needs could be better met by an increase in community based services with more flexible opening hours.

Whilst integrated services for young people offer a positive way forward in meeting their needs, a major caveat is that young people’s right to privacy must be respected within this type of one stop provision. Given that confidentiality is young people’s top concern when using sexual health services there can be no question of shared record keeping between co-located services which might lead to details of young people’s use of sexual health services being routinely shared with other professionals.
Health Outside Hospitals – Improving Community Health and Care Services

Overview

Sexual health services play an integral role in maximising individual and public health, and sexual health is one of the few health areas that affects the majority of the population and is relevant through the greater part of our lives. The positive impact that good sexual health can have on people’s lives cannot be overestimated, and it is therefore vitally important that community health and care services are sufficiently robust and well-resourced to provide the services that people need to enjoy good sexual health.

We believe that there are three primary principles which must be addressed to ensure that high quality sexual health services are provided across the country, and that the priorities outlined in Choosing Health are achieved:

1. Increased resourcing for all sexual health services, to maximise savings from improved public health over the long term – spend to save;
2. Integrated service provision so that a range of sexual health needs can be met whenever a person accesses a sexual health service;
3. The management of quality standards across community-based services to ensure a consistently high quality of services.

We would like to see any PCT boundary changes based on an assessment of local needs. While we recognise the benefits to be gained from boundary changes in some areas, particularly through establishing co-terminosity with local authorities, we would like to ensure that PCT mergers are not to the detriment of communities where remoteness from a distant PCT could have an adverse effect on the quality of services offered. In addition, we are very concerned that a period of change will again deflect local policy makers and commissioners from focussing on sexual health, unless steps are taken to avoid this happening.

fpa welcomes the emphasis in Commissioning for a Patient Led NHS on new community based approaches to services, which we believe will encourage innovative and flexible responses to current need. We are keen to see service development based on evidence of what works, and underpinned by robust quality assurance, clinical governance, and strong networks. However, although we recognise that the new arrangements provide opportunities for improvements and integration of services at community level to respond to people’s needs,
there are also a number of specific areas within sexual health services which we fear could suffer under the new arrangements.

*Helping people to look after themselves*

**Health promotion units (HPUs)**
The provision of high quality information to users is a vital service undertaken by HPUs, and essential to the delivery of the *Choosing Health* White Paper. In sexual health specifically, health promotion provides an important means of targeting positive messages to the needs of the local population, in particular to promote safer sex and to prevent unintended pregnancies and sexually transmitted infections (STIs). In addition to their local programmes, HPUs provide an important channel of communication between specialist national voluntary organisations such as fpa and local services, such as distributing leaflets and other materials which are often part of DH-funded information programmes.

It is unclear how health promotion would be organised under the proposed new structures, and we are concerned that this vital service may suffer in any interim handover period. Any breakdown in health promotion programmes could have a very damaging effect on public health.

**Contraceptive services**
Contraceptive services are the ultimate preventative health service, and currently save the NHS over £2.5 billion per year. Recent research commissioned by fpa has also shown that making improvements to contraceptive services could save a further £30 million per year\(^1\). Providing high quality contraceptive services enables men and women to make safe choices about their fertility and to protect themselves and their partners against unintended pregnancies and STIs.

However, we are concerned about what will happen to community contraceptive clinics under the new arrangements. With commissioning at practice level, we are concerned that in some areas GP provision of ‘additional contraceptive services’ under the GMS contract will be considered to be enough, thereby jeopardising contraceptive clinics. We know that many clinics are already suffering from budget cuts at local level, which very much goes against the priorities outlined in the Sexual Health Strategy and *Choosing Health*, and we are concerned that this disinvestment may become more common under practice-based commissioning.

\(^1\) Armstrong, N and Donaldson, C, *The Economics of Sexual Health*, fpa, 2005
Accessing help and support when, where and how it is needed

Staffing
Despite the recent commitment that “staff delivering clinical services will continue to be employed by their PCT unless and until the PCT decides otherwise”, there is still a great deal of concern and confusion among staff working in community services about their job security beyond the short term. Unless this situation is resolved, staff may feel that they have no choice but to leave services before they lose their jobs, thereby weakening existing provision of community services before new providers are in place, and making it more difficult to sustain services in the community where they are needed.

Training
Much of the training in contraceptive services is provided in contraceptive clinics. However, the demise of clinic services in some areas means that there is currently inadequate provision of training. We are particularly concerned that any further reduction in clinic services will threaten the well-established training programmes that are in place for contraception, and are keen to see measures to support existing training in clinics as well as development of practice-based training where appropriate. Unless training issues are addressed and improved, we fear that there will be a significant shortage of staff available for sexual health services – particularly contraception services – which will jeopardise the provision of high quality services at times and in places that people need them.

Fragmentation between abortion and contraceptive services
We believe that it is imperative to promote integration of abortion and contraception services in the community in order to provide holistic care. There should be more community abortion services, linked to contraception services, able to provide early medical abortions as well as early surgical abortions under local anaesthetic. This would not only provide a community based, joined-up service which meets women’s needs, but would also help to make economic savings. However, the fragmentation of services which is likely to result from the new commissioning arrangements will make this much more difficult to achieve.

Contestability
We are concerned that the new requirement for contestability will threaten community services, in particular those which provide services also provided in general practice, such as contraceptive clinics. Contestability will force services to compete, and could result in general practices undercutting community-based services and using practice-based commissioning to build up their own practices at the expense of other local services.

Patient Choice
Patients have always valued choice in accessing sexual health services. The taboos around sexual health which are still present in many communities mean that patients may prefer not to go to their general practice to receive sexual
health advice and treatment, and alternative community-based providers play an important role here. However, we are concerned that patient choice could be curtailed if practice-based commissioning causes the decline of community services, as outlined above.

Ensuring that care and support is properly coordinated

School health services
Schools are a valuable means of engaging with young people about their health, both through the provision of Personal, Social and Health Education (including Sex and Relationships Education) and the delivery of school-based health services. This means of engaging young people in health improvement is likely to increase further in the future with the development of health services within extended schools, as well as an increase in the number of Healthy Schools. In order for these school-based health services to be most effective, they must be linked in to local networks and broader community services, and new commissioning arrangements must take account of this.

School nurses
School nurses play a vital role in the delivery of health promotion and health services to young people, but it is unclear who will be responsible for employing and managing school nurses under the new arrangements. It is vital that there is appropriate commissioning to ensure that school nurses and other health professionals are employed to deliver these services, and to link these in to other services in the community.
About fpa

fpa (Family Planning Association) is the UK’s leading sexual health charity working to improve the sexual health and reproductive rights of all people throughout the UK. fpa wants to see a society with positive and open attitudes to sex, in which everybody enjoys sexual health and where sexual and reproductive rights are respected. fpa’s purpose is to enable people in the UK to make informed choices about sex and to enjoy sexual health free from exploitation, oppression and harm.

We run a comprehensive information service, including a national telephone helpline, which responds to over 100,000 queries each year on a wide range of sexual health issues. We also produce a variety of publications to support professionals and the public, and provide resources including training courses for those involved in delivering sexual health services. fpa provides a national voice on sexual health issues and works with the public and professionals to ensure high quality information and services are available to all who need them.

For more information, please contact:
Caroline Davey
Policy Manager
fpa
2-12 Pentonville Road
London N1 9FP
Tel: 020 7923 5215 (direct line)
Fax: 020 7837 6785
E-mail: carolined@fpa.org.uk
YOUR HEALTH YOUR CARE YOUR SAY

NATIONAL AIDS TRUST COMMENTS ON COMMUNITY HEALTH AND SOCIAL CARE

The National AIDS Trust welcomes the Government’s concern to improve community health and care services and trusts that some initial brief comments will be a useful contribution to the drafting of the White Paper.

The National AIDS Trust is the UK’s leading independent policy and campaigning organisation for HIV, working to prevent the spread of HIV, secure equity of access to treatment and eradicate HIV-related stigma and discrimination.

NAT organised seminars for people living with HIV in London, Newcastle, Bristol and Leicester in 2004 to gather their views and experiences around involvement in health and social care. Some of the key points below emerged from this consultative process and as such reflect the voices of affected individuals. The full report of the seminars is available at the NAT website www.nat.org.uk.

Improvement of health and social care for those living with HIV will be inseparable from questions of patient and public involvement. Effective involvement of those living with HIV at the local and service level will drive the design of services in the community which genuinely reflect people's needs. NAT is currently working on a project to identify some of the key challenges and opportunities around involvement for those living with HIV and will share the conclusions and recommendations with the DH.

At the outset, NAT would emphasise the value of managed sexual health networks and joint commissioning of HIV services by PCTs and local authorities as two processes which will have a vital contribution to improvement of community health and care services. It is also necessary to ensure consistent quality in community health and care services, as now set out in, for example, MedFASH standards, and appropriate resourcing.

**Question 1: How can people look after themselves? How can we help you take care of yourself and support you and your family in your daily lives?**

Effective community healthcare for HIV must start with health promotion. NAT welcomes the Government’s ambition to roll out the provision of sexual health services into community settings. It is, however, currently hampered by high levels of ignorance around HIV, pervasive HIV-related stigma and discrimination, and a continuing belief that HIV as a ‘special case’ must be dealt with elsewhere.

Necessary interventions include:
The redesign of GMS contracts to provide an incentive for GPs to identify possible sexual health issues and risks, and then either provide basic testing and discussion themselves or refer the service user to an appropriate provider.

The systematic retraining of primary care staff through accredited courses both to identify possible HIV-related symptoms and to discuss issues relating to HIV in a supportive, respectful and non-discriminatory manner. At present up to 50 per cent of those eventually diagnosed with HIV have previously seen a GP with an HIV-related symptom which has gone unrecognised.

There is considerable evidence of HIV-related stigma experienced from primary care staff other than GPs, with dentists in particular often being complained of by those living with HIV. Appropriate training must be rolled out throughout primary care.

All primary care services should have a clear and advertised policy of confidentiality and non-discrimination around HIV in accordance with the MedFASH standards.

Actions such as the introduction of Health Trainers and the Healthy Schools initiative should be integrated into national and local sexual health strategies.

Sex and relationships education should become a mandatory part of the curriculum in all schools, and provide information on same sex relationships.

More needs to be done to meet the sexual health needs of those living with HIV. This includes support to prevent onward transmission and easy access to diagnosis and treatment of other STIs. The planned reduction in GUM waiting times and the rolling out of sexual health services to more accessible locations will assist in this. But there should also be explicit consideration by those designing sexual health services in the community of the particular needs of those living with HIV.

Many of those living with HIV are socially disadvantaged, often because of residency status. Lack of resources can impose severe constraints on diet and on housing conditions, and this can have implications for health, confidentiality, adherence to medication, mental health and security. NAT would urge the Government to take such health inequalities into account when assessing appropriate social care. The current meagre provision for those seeking asylum and the absence of provision for those who fail in their application or are otherwise undocumented has a direct impact on the health of many living with HIV, is a serious impediment to their well-being, and an indirect contributor to onward transmission.

An example of how processes in the community can fundamentally affect health and well-being has been around the dispersal of asylum seekers living with HIV
where there is not as yet effective coordination between secondary care, primary care, housing providers and social care provision. The broader assessment of need identified as important by the consultation documents should take place before dispersal occurs. The responsibility to ensure such an assessment takes place and a care pathway established must rest with NASS.

**Question 2: How can we help you get the right services and make sure your care and support is properly joined-up?**

The seminar participants found that health and social care services were not coordinated and standards of treatment and care varied considerably. The commissioning and delivery of services requires greater integration. The MedFASH standards for NHS HIV Services include important recommendations on the integration of health and social care for those living with HIV such as combined needs assessment for those being discharged from inpatient care, involvement of Social Services in managed sexual health networks and accessible literature for those living with HIV which has information on both health and social care provision.

Self-management programmes such as the Expert Patients Programme and Living Well need to be fully resourced and made widely available for all those living with HIV.

There needs to be greater coordination between both primary and secondary care services and networks of peer support for those living with HIV. For example, for women diagnosed with HIV during the ante-natal screen the impact can be devastating and isolating. It is important for clinicians to be able to link such people up with support networks, whether formal, informal or via the voluntary sector.

**Question 3: When you and your family need help and support, how, when and where and from whom do you want to get it?**

At each of the seminars participants raised the question of opening times of HIV clinics and advocated later and more flexible opening hours. It was felt that service design was still based on the outdated premise that those with HIV did not work.

People should be able to access health services near where they work, including register with GPs. There should also be greater accessibility of sexual and HIV-related health services in locations used by vulnerable and affected groups, through accessible literature and through user-focussed web resources.

As other sexual health services are rolled out, for example chlamydia testing in pharmacies, there should be explicit and strategic consideration of how other
STI, contraceptive and abortion services can appropriately contribute to the greater accessibility of HIV testing. Again, training will be necessary for staff in identification and discussion of possible HIV-related risk. Consideration will also be necessary of referral pathways and of the possibility of HIV testing also being available on site.
Dear Sir

YOUR HEALTH, YOUR CARE, YOUR SAY

We are writing as the principal national sexual health and HIV charities in the UK to contribute to the above consultation exercise about healthcare out of hospital.

In broad terms we very much welcome the emphasis which is being placed upon the development of services out of hospital and believe that this will bring real benefits to the provision of sexual health services.

To realise these benefits we believe that there are three key principles which should be established to inform the delivery of community based sexual health services in the future. These are:

- Sexual health services should be integrated, where possible, at the point of delivery in order to ensure a seamless experience of care for the person using them

- All NHS funded sexual health services should operate to a consistent set of standards and should be delivered as part of a managed network

- Sexual health services should be adequately funded to not only improve individual sexual health but also to improve public health. This will require additional investment, for example, to provide capacity for health promotion within and outside services, based on local evidence of need.
We believe that there should be an increase in the level of sexual health provision delivered in community settings however, we do not believe that this can be achieved simply by expanding the range of services delivered through existing General Practices. It is clear that existing models of GP services are not attractive to some of the communities with the poorest sexual health, and therefore new primary and community care approaches are needed. Some ideas for these are included within our individual organisational submissions to this consultation.

To effect a shift in the level of community based sexual health provision it will also be important to take parallel steps to address the stigma about sexual health and lifestyle which still often exists outside of specialist sexual health services.

We would be happy to discuss in greater detail any of the issues which we have raised in this letter and in our submissions.

Yours sincerely,

Jan Barlow, Deborah Jack, Ruth Lowbury, Nick Partridge, Anne Weyman,
Chief Executive, NAT Chief Executive, Brook Chief Executive, Medfash
Chief Executive, Terrence Higgins Trust Chief Executive, fpa
Terrence Higgins Trust

Your Health, Your care, Your say

A consultation response

October 2005
1. INTRODUCTION

1.1 England’s sexual health has deteriorated markedly over the past decade. Diagnoses of the most common Sexually Transmitted Infections (STIs) have risen significantly, with increases of nearly 200% in the number of chlamydia diagnoses between 1995 and 2003, and increases of 135% & 1100% for Gonorrhoea and Syphilis diagnoses respectively over the same period. Annual HIV diagnoses have risen by 300% since 1996, and the UK continues to have the highest levels of teenage conceptions in Western Europe.

1.2 Poor sexual health disproportionately affects people experiencing other health inequalities, with young people, gay men, and some BME communities experiencing the poorest sexual health. Indeed, HIV infection and unintended teenage conception often further compound the inequalities. This presents a major public health challenge. As such, improving sexual health will be a major step in improving public health.

1.3 It is not surprising that services have struggled to cope. Less than half of all people seeking treatment in NHS Genito Urinary Medicine (GUM) clinics are seen within 48 hours, with 25% of people having to wait more than two weeks. This is compounded by poor and inconsistent access to contraception services in many parts of England.

1.4 To address this, in 2004 the Department of Health established four Public Service Agreement (PSA) Local Delivery Plan (LDP) targets to improve sexual health and services.

2. CURRENT SERVICES

2.1 Sexual health services differ across England. However most will have the following components:

- Sexual health promotion services, largely provided by Primary Care Trusts (PCTs) with some provided by voluntary & community organisations (VCOs)

- Contraception and family planning services, largely provided by PCTs and GPs, with some VCO provision. Some of these also include STI services
• Abortion services, provided by NHS and Foundation Acute Trusts, PCTs, GPs, and VCOs

• GUM services, providing open access diagnosis and treatment for STIs. More than 80% of GUM services are provided by NHS & Foundation Acute Trusts with the remainder run by PCTs.

• Specialist HIV clinical services, the majority of which are managed as part of GUM services. In many areas these are supported by GP based primary care services and by community support and social care services, often run by VCOs.

2.2 In many areas the basic model of service has changed little over many years, even though needs have changed and increased markedly. The following changes in need are particularly important:

• Significant changes in sexual behaviour, with more people having more sex with more partners and at an earlier age
• Large increases in demand for contraception and STI services as a consequence
• A shift of HIV from a fatal to a debilitating long term condition for many people
• Changes in patient expectations about service access and patient experience
• Changes in technology enabling new approaches to diagnosis and treatment

2.3 Community health and care services need to develop and improve in response to these changes, and to ensure that PSA/LDP service and health targets can be met. In particular, major change is needed to help people stay healthy, to help people have easy access to help and support, and to help people in greatest need get the right long term care services. As such it will be important to ensure the full utilisation of the extra £250million funding announced by the Dept of Health for PCTs to help achieve improvements in sexual health.

3. PRINCIPLES

3.1 The following principles have been used to inform how community health and care services should be developed within the sexual health field:
• Services should be needs led, and should involve people using them in their design and delivery
• Services should be easy to access
• Services should be delivered in an integrated way and to a high standard
• Services should promote independence and dignity
• Carers should be supported to fulfil their role

3.2 Staying healthy – helping people look after themselves and improving public health
With high long term human, social and economic costs resulting from HIV infection, teenage conception and infertility, there is a strong case for strengthening sexual health promotion services. However, a fresh approach is needed within community health and care services to improve sexual health. This approach should include:

• Expanding sexual health promotion work in sexual health services, in social/community settings used by people at greatest risk of poor sexual health, and in general healthcare settings (eg GP surgeries). This should be complemented by a strong focus on consistent sex and relationships education, and by strengthened sexual health promotion work in schools

• Ensuring a range of health promotion services, including print and web based information campaigns and booklets, as well as telephone advice, face to face work and outreach work. These should be focused on those people at greatest risk of poor sexual health and should form a multi layered service which people can tailor to meet their needs

• Establishing coordinated programmes to maximise the impact of this work by integrating it across clinical and community settings, and by integrating it with national campaigns and initiatives

• Community leadership so that those people at greatest risk and the charities and community groups which work with them have an important role in the development and delivery of these programmes

3.4 This work should be jointly commissioned by PCTs and Local Authorities. In those parts of England where people live, work and socialise in different PCT areas, for example in London, some interventions such as information campaigns and resources will be best commissioned by a number of PCTs working together.
3.5 Underpinning all of this work there should be easy and rapid access to high quality sexual health diagnostic and treatment services.

3.6 Easy access to help and support when it is needed – improving services

Community health and care services need to be strengthened to enable rapid access to contraception, STI and HIV help and support. In many areas, a fresh approach will be needed, which might include:

- **Expanding the range of community services** so that contraception and STI services are increasingly available in health centres, walk in centres and community pharmacies as well as in non health care settings such as high streets, and community/leisure centres. These services should maximise the appropriate use of new diagnostic technologies.

- **Increased choice for people** so that in any area there is a choice of opening hours, location, and service approach. This should enable people to be able to use services before or after work, at weekends, and be able to use services close to where they live or close to where they work. In addition, people should have a choice of using a service geared to the needs of a specific community, for example young people’s services, or gay men’s sexual health services.

- **Improving primary care** so that there is an increased level of sexual health service available from family doctor services. This could be done in many ways, for example by establishing Local Enhanced Service arrangements covering a number of practices and offering rapid access to contraception and STI services.

- **New approaches to primary care** for people who want an alternative to existing services. These should include enabling people to use GPs where the service is not dependant upon registration, enabling people to register with GPs close to where they work, and enabling people to register with a GP with a specialist interest in sexual health or in the needs of their community of interest.

- **Use of Patient Group Directions** as an increasingly common way of providing treatment, enabling people to have all of their needs met without having to use a specialist or hospital service.
3.7 Wherever possible and appropriate contraception and STI services should be integrated at the point of delivery, and should offer easy access to specialist services for those who need them.

3.8 These new service approaches will have implications for the workforce, with increasing roles for community workers, nurses, and pharmacists.

3.9 To ensure consistency of standards and efficiency, services should be delivered as part of managed sexual health network bringing together all agencies providing and funding services. It should provide a focus for coordinating service development and delivery, as well as overseeing standards, workforce/capacity planning, and public health surveillance work.

3.10 As well as leading the network, local specialist services should be available for people in greatest need, and for people who choose to access their service in this way. This is a particularly important consideration in the sexual health field where GUM clinics (and indeed VCO services) offer complete anonymity to the patient in a way which existing GP services are unable to.

3.11 **Strengthening long term care – getting the right care services when they are needed**

As a result of drug treatments, for the majority of people, HIV has become a manageable long term condition. Community health and care services need to be strengthened to enable HIV to be managed as such. Whilst progress has been made in some places, in many areas a fresh approach is needed to the management of HIV, and this might include:

- **Strengthening primary care** to increase knowledge about HIV amongst GPs and primary care staff. This could be done by establishing HIV Local Enhanced Services covering a number of practices as well as by establishing either full or part time GPs with a specialist HIV interest. Specialist GP services could be co-located with other HIV clinical and community services to provide ease of access.

- **Enhancing self management** by the establishment of structured HIV self management programmes. These could include HIV Expert Patient Programmes and structured sexual health improvement programmes for people with HIV as well as the establishment of HIV service navigator roles, and the use of web based personal healthspaces to
record individual patient information about health and treatments.

- **Integrating HIV health and social care** for people in greatest need. Some people with HIV have high levels of health and social care need, requiring heavy usage of both NHS and Local Authority funded services. As such, it will be important to ensure strong HIV community support, support for carers, care management and case management services. For greatest impact, the commissioning and delivery of these services should be integrated, and this could be done by using Health Act 1999 Section 31 flexibilities.

- **Strengthening specialist services** to oversee the management of HIV treatment. Despite advances in drug treatment, there is still much which is unknown about the long term consequences of HIV treatment. As such, specialist services will need to continue to be strengthened to manage the increasing numbers of people in receipt of long term HIV treatment, and to provide treatment and care for people with serious HIV related illnesses.

3.12 Supporting communities to help themselves – the role of voluntary and community organisations

3.13 VCOs have an important role to play in the delivery of sexual health promotion, primary care, community sexual health services and HIV long term condition management. This is for a number of reasons:

- **Expanding service capacity.** Increasing the role of VCOs in service provision is a means of being able to expand capacity in an area where services are under considerable pressure. This will be particularly important given the need to achieve the PSA/LDP access targets for 48 hour access to GUM services by 2008.

- **Expanding service access.** Specialist VCOs are well placed to increase access to services because they often have a stronger link with the communities most affected by poor sexual health than do NHS organisations or independent GP contractors.

- **Enabling service redesign.** Many VCOs have a track record of innovation and flexibility, which will be important in supporting and achieving local service redesign work.
• **Ensuring service quality.** Specialist VCOs have access to a range of the specialist knowledge and skills needed to deliver high quality services.

3.14 New contracting approaches such as Alternative Provider Medical Services (APMS) as well as the introduction of national payment by results tariffs will help facilitate VCOs to take on a greater service delivery role. This will be important given the Government’s separate policy proposals for PCTs to divest themselves of their service delivery work.

4. CONTACT DETAILS FOR THT

For further information on THT’s work in this area, please contact:

Paul Ward – Deputy Chief Executive  
Tel: 020 7816 8603  
[paul.ward@tht.org.uk](mailto:paul.ward@tht.org.uk)
Thank you for your help with your health, your care, your say.

This feedback form is intended for both local and national organisations or groups to report on the findings their own devolved listening exercise as part your health, your care, your say.

Can I check, are you responding to this questionnaire as:

A local organisation or group
A national organisation or group x
Other (record details below)

All the information you submit will be analysed alongside the public’s response and the views obtained from other local and national organisations and groups and will feed in to the development of the Government’s plans for improving community health and care services.

Please note the feedback form is in three parts:

- Section A: Why do community health and social care services matter to the nation as a whole?
- Section B: what do you think of the suggestions for improving health and social care services?
- Section C: details about your organisation and your listening exercise

If you haven’t covered Section A or all of the options under Section B, please just leave those questions blank.

Please make sure that you give us this feedback by 4th November, or earlier if possible. You can find out where to return this feedback by referring to the resource pack website, www.yoursayresources.nhs.uk.

As you will see, most questions ask you to tick a box like this:

Tick one box only

Other questions give you space to record how you reached your decisions:

Please feel free to write as much, or as little, as you like.
Section A: Why do community health and social care services matter to the nation as a whole?

We want to make community-based health and social care services better for everyone. To help us reach the right decisions, we want to know what the people at the listening exercises you ran thought about community-based health and social care services at the moment.

Q1. What did people think were the five main reasons why community health and social care matter to the nation as a whole?

(RECORD BELOW IN PRIORITY ORDER)

1. Respect for the whole person
2. Known staff who developed relationships with people
3. Nurturing of people at a time of crisis/ Support groups
4. Creativity
5. Care for the whole family

RECORD BELOW WHY PEOPLE THOUGHT THESE WERE IMPORTANT:

1. Each person spoke about the hospice as a place where they were welcomed as individuals, not numbers or patients, as a place where their whole self was cared for. Many did not know the diagnoses of those they met at the hospice, although they all attended the day centre each week, but each knew the other’s concerns anxieties/ hopes and fears.

2. The respect for the community specialist nurse was widespread and universally praised. The specialist nurse was one who would offer advice, come into the home, see though surface politeness to what a person was really feeling. For example, if someone said, “I’m feeling fine” because the nurse looked in a hurry, a good nurse might say, “You didn’t sleep well last night did you?” or ask, “Have you been taking your morphine?”

3. The importance of being pampered when you feel you are disappearing/ unimportant was cited as very significant – the beautician/ the hairdresser/ the masseur and the nurturing role of a good lunch were all cited as important within the hospice.

3a. Younger people/ the London user group felt that a significant aspect of hospice care was the support groups on offer that enabled them to find their voice as individuals/ find out information about treatment/ find solace/ take away stigma, fear and isolation

4. All spoke of how creativity** in the hospice had offered them a voice when they felt fragile and how important it was to retain a voice when you are feeling unwell. One person cited how a community artist had helped design a funeral service for her, another of how the writing of a song had helped her realise her life still mattered,
another of how a project had kept her going through chemotherapy. One family mentioned how the making of a video had helped bring a whole family together.

5. The rural group from North Kent did not value this highly but although many cited that their carers had not taken advantage of the counselling/support that was on offer at the hospice, all cited how important it was to know that their family members had somewhere to turn at a time of crisis and all who had lost a partner cited how well bereavement care had supported them afterwards.

** Both these groups had been drawn together by Rosetta Life, an artist led organisation that works in hospices and the emphasis on creativity may have resulted from all of their engagement with a creative project that enabled them to find their personal voice.

Section B: what did people think of the suggestions for improving health and social care services?

We are committed to helping people take better care of themselves, but big questions remain about how it can best do this.

...Thinking about how the NHS, Social Care and other services might help people to look after themselves more...

Q2. Which of the following did people at the listening exercises you ran think should be the top three priorities? (Please rank by writing 1, 2 or 3 in the boxes)

Promoting and supporting better health, for example through routine check ups, advice on healthy lifestyles and promoting self-care and self-assessment.

Ensuring a range of health professionals, such as nurses and pharmacists, can provide people with information and support about how to take better care of themselves and their families.

Tackling the things that cause ill health and disadvantage, such as poverty and poor housing, by developing new services in the community and by expanding the range of services available in doctors’ surgeries (eg providing jobs and skills advice), children’s centres and other locations.

Ensuring older people and those with disabilities can get the practical help and support they need to remain independent and active for longer
PLEASE SUMMARISE WHY PEOPLE SELECTED THESE PRIORITIES:

Everyone felt very clearly that access to people with specialist information was most important in enabling people to take care of themselves. No more leaflets, but better access to information from specialists. The user groups felt that specialist nurses were best equipped to offer them healthcare. There was concern that the GP was ill-equipped to offer best information and advice and that referrals to good services – particularly the hospice movement were sometimes slow and often ill informed. This ranked highest in concern throughout both user groups across London and Kent.

There was clearly a range of services on offer to some hospice users that were not on offer to others – discounted access to gyms, rehabilitation programmes, access to swimming pools. Everyone felt that this should be better available across postcodes and that better transport to local services should be available. People felt that discounted schemes/ access for the disabled/ long term ill should be better promoted. Advice on healthy lifestyles was offered but random and seemed ill co-ordinated and this therefore ranked second.

People felt that they would like access to support to remain independent and cited creativity as a tool to long term independence – please see below. However, both user groups were people living with life threatening illnesses and their particular priorities are ranked above.

New services in the community were of little concern although people felt that more hospices and expansion of the hospice movement would offer people better long term independence.
Q3. What else would people like the NHS, Social Care and other services to do to help people take better care of themselves?

A recurring theme throughout the listening exercises was the need for more specialist advice and people were very clear that this needed to come from specialist nurses – the Macmillan nurses and the Ellenor Foundation nurses were both cited as examples of good practice. Specialist nurses who knew the people they were caring for, knew their story and the kind of person they could welcome as an additional member of the family.

Both user groups said that creativity* had been of particular importance in helping people to take care of themselves at the end of their lives. They noted the importance of external stimulation and how a project can prepare you for greater independence in the community by reminding you of your strength and your identity after long term hospital/hospice stays. “Creativity offers you a voice when you are lost behind the illness” said one long term cancer patient. “It is also a chance to remind yourself of what is important, to keep going, to express things and give you the confidence to go back to work” said a carer.

*The user groups were from hospices where creativity is actively promoted under a project known as Rosetta Life, a project that enables those facing life threatening illnesses to find their creative voice and tell the stories that matter to them.

People felt that access to friends and families worldwide enabled them to keep “well” and “wellbeing” was very important for both groups. However, poor travel insurance for those facing long term/life threatening illnesses meant this was often impossible. People felt that travel insurance policies were outmoded and outdated and people felt that the Department of Health should offer better advice to travel companies for insuring people living with cancer and life threatening conditions.

Two individuals from user groups in Kent were particularly angry that private health insurance had not enabled them to access any additional services after a terminal diagnosis. A terminal diagnosis had led them to the hospice movement and there was immense gratitude for this but clear outrage that the insurers were not clearer about their inability to manage/offer treatment/services to those with terminal diagnoses. They felt that it should be legally obligatory to make clear to people when a terminal diagnosis is not covered by private insurance.
When you and your family need help and support, how, when, where and from whom do you want it?

We want to make sure people have access to the services they want, when they want them, where they want them and from whom they want them. But to do this there are some tough choices to be made.

...Thinking about how the NHS and Social Care and other services might improve how, when, where and from whom community-based services are delivered...

Q4. Which of the following did the people at the listening exercises you ran think should be top three priorities? (Please rank by writing 1, 2 or 3 in the boxes)

<table>
<thead>
<tr>
<th>Priority</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Developing and providing more services in the local community, rather than only in hospitals, so they are more convenient for families and children to use</td>
</tr>
<tr>
<td>2</td>
<td>Providing convenient services which fit around people’s lives, for example by extending opening hours to evenings and weekends at the local GP practice, pharmacy and other community services</td>
</tr>
<tr>
<td>3</td>
<td>Allowing people to choose how to receive services at the end of life and to die where they want with dignity</td>
</tr>
<tr>
<td>4</td>
<td>Developing new services for people who don’t always currently access care, such as people from black and minority ethnic groups and teenagers</td>
</tr>
<tr>
<td>None of the above</td>
<td></td>
</tr>
<tr>
<td>Don’t know</td>
<td></td>
</tr>
</tbody>
</table>
PLEASE SUMMARISE WHY PEOPLE SELECTED THESE PRIORITIES:

All participants were hospice users and felt that they were allowed to choose how to receive services at the end of life and to die where they wanted with dignity as a result of access to the hospice. This was therefore not a priority for this user group. Interestingly, they all felt that better access to hospices would allow people this choice.

All participants were terrified of finding themselves in hospital in an emergency. There was a fear that when you are in pain/trouble you end up calling the ambulance and find yourself in hospital where no-one knows your history and you have to tell your story over and over again while enduring every increasing panic. There was a fear of not finding a person who understood/knew you personally. A fear of being anonymous in a large institution. Therefore their two priorities were:

1. Better access to the community service – the hospice in particular. A night service that was well publicised within the hospice movement so that you could access care in your community. Access to your specialist nurse/colleague who knew/had access to your notes on a 24 hour basis. Specialist nurses were the most popular requested source of information – Macmillan/ Ellenor Foundation again cited as good examples of best practice.

1.a Many felt that they would be happy to accept care from a pharmacist/gp but the emphasis was on the local chemist. “I would like access to good information from lots of people, not just the GP, anyone who knew me and knew my history and who I could trust. The emphasis was always on the local and the personal and the human touch as a source of information that was accepted and trusted.

1.b Transport from outer London to inner London hospitals was a major concern for hospice users from Bexley and North Kent. Transport was often uncomfortable, lengthy and debilitating. All said they would prefer to have treatment at their hospice if possible – radiotherapy and chemotherapy as well as blood tests and xrays.

2. Access to phone lines on a 24hour basis was strongly supported, but the phone lines had to lead to someone they knew from the community services – the hospice/ the specialist cancer nurse/ Macmillan teams/ GP practice. Some people seemed to have access to a number at the hospital to call but all wanted a name/confidence that the person they speak to understood their story.

3. All people across both user groups felt that their hospice met their needs and enabled them to choose how to receive services at the end of their life and to die where they wanted with dignity. Interestingly, all felt that, although at diagnosis they might state that they want to die at home, after entering a hospice many had changed their minds and had now chosen to die in a hospice.

4. Although several women who had young teenagers at school considered that the option of better resources for their children/themselves was interesting, they both felt that their children were well supported at their local schools – mentoring and counselling – or at the local hospice – counselling/social support- and that their local hospice met their needs for their teenagers and their race.
Q5. What else would people like the NHS, Social Care and other services to do in terms of how, when, where and from whom community-based services are delivered?

More support groups throughout all services would help people make real choices about when, where and how to end their lives.

People felt that in order to make active choices about how/when/where to die, they needed to be able to talk about it openly. Support groups at the local hospice had really helped people to talk about this openly particularly when friends and family were afraid. People felt that the support groups within the hospice had enabled them to make choices. All people acknowledged the taboos around dying made open communication and decision making difficult, but most interestingly, some people felt that there was a responsibility upon those living with cancer to make it safe for the wider public to talk about dying and that this could only happen if those who were dying could change themselves and change their own fear. People felt that this happened when you were in a place with other people in a similar situation to you where you met them as people not patients. The hospice enabled people to recover their identities and self esteem. The need for creativity, nurturing/pampering and personal care and attention were the recurring themes of the conversation.

One woman attended from a hospice where there were no support groups and found the listening exercise a first chance to talk about when and where she would like to end her life and decided during the course of the user forum that she would like to end her life in the hospice.

People felt that wider acceptance of living wills was crucial if people were able to end their lives with informed choice.

People also felt that the decision on where and how you die was partly based upon age, illness and wealth. If you are alone, you do not want to die at home, whereas if you have friends and family, you may choose to die at home, but equally many said that they chose to die at a hospice surrounded by friends and family because they did not want their home to be associated with the sadness of their death/difficulty of caring for them without professional help.

Many cited that a “death plan”, rather like the birth plan of the maternity wards would help people make active choices and continue to revise them.
We want people to be able to use and find their way through health and social care services more easily. We also want these services to be ‘joined up’, even if several people or organisations are providing them.

...Thinking about how the NHS, Social Care and other services might help people find the services they need and improve the way these services are joined up ...

Q6. Which of the following did people at the listening exercises you ran think should be the top three priorities? (Please rank by writing 1, 2 or 3 in the boxes)

1. Providing effectively joined-up social care and health services to those that need them, for example through a single ‘needs assessment’. A ‘needs assessment’ would be a kind of one-stop-shop appointment instead of lots of appointments.

2. Providing people with better information about what NHS, local authority and social care services are on offer

3. Improving the availability, quality and choice of services for long-term care users and people with long-term illnesses like diabetes.

None of the above

Don’t know

PLEASE SUMMARISE WHY PEOPLE SELECTED THESE PRIORITIES:

Consistently, what was most important to people was access to joined up care through a “case manager” a single person/ team of few people who knew your history and story and could act as an advocate for you to the hospital and/or refer you on to other services.

The need for more specialist nurses was repeated throughout. There was a strong rejection of ideas such as telemedicine/ webcam links/ 24hour phone lines with an anonymous answering service. And there was a strong belief that nothing could replace the continuity of care that a singe “case manager” might offer. Equally important was the possibility of being able to welcome someone into the home as an additional member of the family. Having time to listen was equally important. People were horrified if they were told that they “kept people too long” and valued the person who would read their faces when their words were not telling the whole story. Face to face contact was critical.

People all declared that there were good links between the hospital and the hospice, but this was not repeated across all services. The GP often did not know what was happening and this seemed to depend upon the GP. Communication often broke down between the consultant and the GP. Sometimes communication between hospice and hospital was not as good as it should be although the care in Tunbridge Wells was widely praised for joined up communication between hospice and hospital.
People all felt that the hospice was not widely understood and that the community services needed to be promoted. Better referral systems and better information about the community services were important to people who had felt afraid/ intimidated/ not encouraged to use the local hospice.

Indeed, people felt that the hospice could act as a model for those living with long term illnesses and that the model of the hospice could be used to improve care for others.
Q7. What else would people like the NHS, Social Care and other services to do to help people find the services they need and improve the way these services are joined up?

All cited the absence of care for the carer. People who were carers spoke of being “a shadow/ recognition that the carer was doing the right job. There was clear need for respite care for the carer.

Some people cited that a “carer card” would be valuable. One person said that he had had a bike accident and waited for 4 hours at A&E and constantly said that he was a carer and had to return home but no notice was taken of him and so he left the hospital without being seen. He felt he was being treated as if he was queue jumping and that his concerns were not significant.
Q8. Looking across all the options we have asked about what are the top five priorities for the people at the listening exercises you ran? (Please write 1, 2, 3, 4, 5 in the boxes)

Promoting and supporting better health, for example through routine check ups, advice on healthy lifestyles and promoting self-care and self-assessment.

Ensuring a range of health professionals, such as nurses and pharmacists, can provide people with information and support about how to take better care of themselves and their families.

Tackling the things that cause ill health and disadvantage, such as poverty and poor housing, by developing new services in the community and by expanding the range of services available in doctors’ surgeries (eg providing jobs and skills advice), children’s centres and other locations.

Ensuring older people and those with disabilities can get the practical help and support they need to remain independent and active for longer

Providing convenient services which fit around people’s lives, for example by extending opening hours to evenings and weekends at the local GP practice, pharmacy and other community services

Providing care in convenient locations (for example NHS Walk in Centres near train stations so people can get quick advice on problems and health issues on their way to work) or allowing people to register with any family Doctor, not just one where you live

Developing and providing more services in the local community, rather than only in hospitals, so they are more convenient for families and children to use

Developing new services for people who don’t always currently access care, such as people from black and minority ethnic groups and teenagers
Allowing people to choose how to receive services at the end of life and to die where they want with dignity.

Providing effectively joined-up social care and health services to those that need them, for example through a single ‘needs assessment’. A ‘needs assessment’ would be a kind of one-stop-shop appointment instead of lots of appointments.

Providing people with better information about what NHS, local authority and social care services are on offer

Improving the availability, quality and choice of services for long-term care users and people with long-term illnesses like diabetes.
Q9. Why were these their five top priorities?

1. Fear of changes in the development of illness/deterioration meant that the most important thing for people was access to trusted information from a small team of people who could visit at home.

2. There was a widespread fear of hospital/travel and transport to and from hospital/encountering strange people when in a state of distress/being far from family and friends. Therefore, all said that they would welcome and desire the development of the hospice the community services to enable them to take on some of the tasks of the hospital – x-rays/blood tests/blood transfusions etc.

3. Extending the opening hours of the hospice/ offering personalised support through 24 hour phone lines was all welcomed. Access to trusted information from the local chemist/GP/hospice was all welcomed.

4. A one stop shop did not achieve widespread support/but the idea of joined up services was very significant and the hospice users from both groups both suggested a case manager representing them to all services.

5. One group was particularly clear that the model of the hospice should be extended and expanded and that it could offer people living with long term conditions better independence and better quality of life.
Q10. Below we provide a space for you to tell us about anything else which came up in the listening exercises you ran which will help us understand what people think should be done to make health and social care services better for everyone?

PLEASE WRITE IN:

All were concerned that women were much better at looking after themselves than men. Breast cancer has become an acceptable illness and the taboo of breast cancer is broken, but prostate cancer is still a difficult subject of conversation. High profile press campaigns have changed the image of women’s cancers but not men’s.

There was widespread acknowledgement that the difficulty of talking about death made open communication difficult. Support groups, hospice day centres, creative projects all enabled people to talk together about issues that were worrying them and gave them the confidence to talk to friends and families. It is the context to enable those facing death to talk about their condition without fear/stigma/isolation that needs to be supported. The hospice often provided the right context, creative projects, counselling from specialist nurses/ Macmillan teams/ Ellenor Foundation were other contexts that gave people the confidence to voice their fears/wishes and choices about dying.
Section C: details about your organisation and your listening exercises

To help us analyse the information you have given us, we need to find out a little bit more about your organisation and your listening exercise.

A. How many people took part in your devolved listening exercises?

   Write in below

   8
   10

B. What sort of listening exercise was it?

   (Please tick one box only)
   A day long session (from 5 to 8 hours long)
   A half day session (from 3 to 5 hours long)
   Up to 3 hours long

   Other (record below)

C. How many of each of the following types of people took part in your listening exercise?

   (Please put a number in each box even if it is zero)
   Members of the general public (i.e. with no specialist interest in health and social care) 0
   Members of the public who are involved with health and social care services e.g. PPI forum members 18
   Paid staff from your organisation 0
   Voluntary staff from your organisation 0

   Other (record below)

D. And now please tell us how many of the people who took part – whether members of the public or staff - were from any of the specific sectors of the population listed below.

   (Please put a number in each box even if it is zero)
<table>
<thead>
<tr>
<th>Group</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Children and young people</td>
<td>0</td>
</tr>
<tr>
<td>Older people</td>
<td>8</td>
</tr>
<tr>
<td>Pregnant women (and their partners)</td>
<td>0</td>
</tr>
<tr>
<td>Socially disadvantaged people</td>
<td>4</td>
</tr>
<tr>
<td>Disadvantaged children</td>
<td></td>
</tr>
<tr>
<td>Smokers</td>
<td></td>
</tr>
<tr>
<td>Excessive drinkers</td>
<td></td>
</tr>
<tr>
<td>Obese people</td>
<td></td>
</tr>
<tr>
<td>Substance misusers</td>
<td></td>
</tr>
<tr>
<td>Disabled people</td>
<td>18</td>
</tr>
<tr>
<td>Prisoners</td>
<td></td>
</tr>
<tr>
<td>Black and minority ethnic groups (GO TO QE)</td>
<td>4</td>
</tr>
<tr>
<td>Travellers</td>
<td></td>
</tr>
<tr>
<td>Homeless people</td>
<td>1</td>
</tr>
<tr>
<td>People with mental health problems</td>
<td>1</td>
</tr>
<tr>
<td>People with learning disabilities</td>
<td></td>
</tr>
<tr>
<td>People in hospices/residential care</td>
<td>18</td>
</tr>
<tr>
<td>Asylum seekers</td>
<td></td>
</tr>
<tr>
<td>People with long term conditions</td>
<td>15</td>
</tr>
<tr>
<td>People with caring responsibilities</td>
<td>3</td>
</tr>
<tr>
<td>Other (record below)</td>
<td></td>
</tr>
</tbody>
</table>

E. You said that some of the people who took part in your listening event were from a specific ethnic group. Please tell us how many were from each of the groups listed below:

(Please put a number in each box even if it is zero)
White British
White Irish
Any other white background
White and Black Caribbean
White and Black African
White and Asian
Any other mixed background
Indian
Pakistani
Bangladeshi
Any other Asian Background
Caribbean
African
Any other Black background
Chinese

E. Which of the following best describes the sector to which your organisation or group belongs / where you work:

(Please tick one box only)
- PPI forum or other patient group
- Community-based NHS services
- Local authority social care services
- Private sector health or social care services
- Voluntary sector health or social care services
- Other (record below)
If your listening exercises mostly involved staff rather than patients or service users please can you identify from the list below which groups they most often have contact with or provide services for:

*(Please tick all relevant boxes)*

<table>
<thead>
<tr>
<th>Group</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Children and young people</td>
<td></td>
</tr>
<tr>
<td>Older people</td>
<td></td>
</tr>
<tr>
<td>Pregnant women (and their partners)</td>
<td></td>
</tr>
<tr>
<td>Socially disadvantaged people</td>
<td></td>
</tr>
<tr>
<td>Disadvantaged children</td>
<td></td>
</tr>
<tr>
<td>Smokers</td>
<td></td>
</tr>
<tr>
<td>Excessive drinkers</td>
<td></td>
</tr>
<tr>
<td>Obese people</td>
<td></td>
</tr>
<tr>
<td>Substance misusers</td>
<td></td>
</tr>
<tr>
<td>Disabled people</td>
<td></td>
</tr>
<tr>
<td>Prisoners</td>
<td></td>
</tr>
<tr>
<td>Black and minority ethnic groups (GO TO QE)</td>
<td></td>
</tr>
<tr>
<td>Travellers</td>
<td></td>
</tr>
<tr>
<td>Homeless people</td>
<td></td>
</tr>
<tr>
<td>People with mental health problems</td>
<td></td>
</tr>
<tr>
<td>People with learning disabilities</td>
<td></td>
</tr>
<tr>
<td>People in hospices/residential care</td>
<td></td>
</tr>
<tr>
<td>Asylum seekers</td>
<td></td>
</tr>
<tr>
<td>People with long term conditions</td>
<td></td>
</tr>
<tr>
<td>People with caring responsibilities</td>
<td></td>
</tr>
<tr>
<td>Other (record below)</td>
<td></td>
</tr>
</tbody>
</table>
If you would like your organisation to be listed as a contributor to the consultation, please record its name below:

NAME OF ORGANISATION

Help the Hospices, consultation carried out by Rosetta Life

If you would like to receive a copy of the summary of our findings, please tell us what format you would like it and give us your contact details:

EMAIL c.shaw@helptehospices.org.uk
ADDRESS: Help the Hospices
33-44 Britannia Street
London WC1X 9JG
YOUR HEALTH, YOUR CARE, YOUR SAY
FEEDBACK FORM FOR LOCAL LISTENING EXERCISES
Thank you for your help with your health, your care, your say.

This feedback form is intended for both local and national organisations or groups to report on the findings their own devolved listening exercise as part your health, your care, your say.

Can I check, are you responding to this questionnaire as:

A local organisation or group  Yes

A national organisation or group

Other (record details below)

All the information you submit will be analysed alongside the public’s response and the views obtained from other local and national organisations and groups and will feed in to the development of plans for improving community health and care services.

Please note the feedback form is in three parts:

- Section A: Thinking about the community health and social care services people use, what currently works less well?
- Section B: what do you think of the suggestions for improving health and social care services?
- Section C: details about your organisation and your listening exercise

If you haven’t covered Section A or all of the options under Section B, please just leave those questions blank.

Please make sure that you give us this feedback by 4th November, or earlier if possible. You can find out where to return this feedback by referring to the resource pack website, www.yoursayresources.nhs.uk

As you will see, most questions ask you to tick a box like this:

Tick one box only

Other questions give you space to record how you reached your decisions:

Please feel free to write as much, or as little, as you like.
Section A: Thinking about the community health and social care services people use, what currently works well, and what currently works less well?

We want to make community-based health and social care services better for everyone. To help us reach the right decisions, we want to know what the people at the listening exercises you ran thought about community-based health and social care services at the moment.

Q1. What were the three key elements of community health and social care services that people though worked well?

(RECORD BELOW IN PRIORITY ORDER)

<table>
<thead>
<tr>
<th></th>
<th>Good access to GPs</th>
</tr>
</thead>
<tbody>
<tr>
<td>2</td>
<td>District Nurses support and service</td>
</tr>
<tr>
<td>3</td>
<td>Advocacy services</td>
</tr>
</tbody>
</table>

RECORD BELOW WHY PEOPLE THOUGHT THESE WORKED WELL:

The group felt that they had good access to their GP as they felt they could see their GP whenever they needed to. However care staff felt that GPs often didn’t respond to visit requests and relied too much on prescribing over the phone.

The residential home had a good access to phlebotomy services as the District Nurses visited to carry this out, avoiding the need for patients to attend clinics. The group also felt that they had good continuity of care with the District Nurses and built relationships with the nursing staff.

The group felt that advocacy services were invaluable. They found the opportunity to talk to someone about issues (health, social and economic) and for that person to act their behalf immensely useful. This often fulfils a need for patients without family support. However it was felt that this service was not sufficiently provided enough and required more consistent support in this area.
What were the three key elements of community health and social care services that people though worked less well? (RECORD BELOW IN PRIORITY ORDER)

<table>
<thead>
<tr>
<th></th>
<th>Funding of care</th>
</tr>
</thead>
<tbody>
<tr>
<td>2</td>
<td>Chiropody / Dental</td>
</tr>
<tr>
<td>3</td>
<td>Joined up care</td>
</tr>
</tbody>
</table>

RECORD BELOW WHY PEOPLE THOUGHT THESE WORKED LESS WELL:

The group felt unhappy about having to fund their care when having paid NI for their working lives. Many of the group expressing dissatisfaction about having to sell their homes to fund their residential care. There were inequities in that people who have managed their finances and saved were expected to use this to fund their residential care, whereas those without savings received funding. The group also found it difficult to separate health and social services and understand the respective roles and support.

The group felt there was a need for chiropody services to provide regular foot care e.g. nail cutting and that dental care provision needed to be addressed.

The group felt that joined up care in the health service could be better. As an example a patient choose a specialist hospital for surgery as part of Choice, but was not able to receive her follow up care and rehabilitation locally, even though it was available. The group were willing to travel to access ‘one off’ specialist care but wanted to receive ongoing care locally. Poor communication channels meant that a patient centered approach was not being realised.

What other issues did people mention? Please record any personal stories here if possible

Access to NHS dental services was an issue. A dentist did visit the home, but care was provided privately, which they considered to be not acceptable given limited finances and expectations were that NHS dentistry should be readily available to them.

A member of the group explained that she had visited her GP with ear wax. The GP recommended her ears should be syringed. However, the patient heard nothing further and has not had her ears syringed and still had difficulty hearing.
Section B: what did people think of the suggestions for improving health and social care services?

We are committed to helping people take better care of themselves, but big questions remain about how it can best do this.

...Thinking about how the NHS, Social Care and other services might help people to look after themselves more...

Q2. Which of the following did people at the listening exercises you ran think should be the top three priorities? (Please rank by writing 1, 2 or 3 in the boxes)

Encouraging and supporting better health, for example through routine check ups, advice on healthy lifestyles and promoting self-care and self-assessment.

Ensuring a range of health professionals, such as nurses and pharmacists, can provide people with information and support about how to take better care of themselves and their families. For instance pharmacists could give advice on getting the best out of the medicines you take or they could run clinics for people with high blood pressure.

Tackling the things that cause ill health and disadvantage, such as poverty and poor housing, by developing new services in the community and by expanding the range of services available in doctors’ surgeries (eg advisors to help with housing, employment and training and benefits), children’s centres and other locations.

Ensuring older people and those with disabilities can get the practical help and support they need to remain independent and active for longer

None of the above

Don’t know
**PLEASE SUMMARISE WHY PEOPLE SELECTED THESE PRIORITIES:**

<table>
<thead>
<tr>
<th>Priority 1</th>
</tr>
</thead>
<tbody>
<tr>
<td>See previous comments regarding social services / advocacy services as a means to keep more independence.</td>
</tr>
</tbody>
</table>
Q3. Did people think it would be enough for Government to only do these things to help people take better care of themselves? Why?

Q4. What else would people like the Government to do to help people take better care of themselves?
We want people to be able to use and find their way through health and social care services more easily. We also want these services to be ‘joined up’, even if several people or organisations are providing them.

...Thinking about how the NHS, Social Care and other services might help people find the services they need and improve the way these services are joined up ...

Q5. Which of the following did people at the listening exercises you ran think should be the top three priorities? (Please rank by writing 1, 2 or 3 in the boxes)

<table>
<thead>
<tr>
<th>Priority</th>
<th>Description</th>
<th>Rank</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Providing more help to people caring for others, for example with more respite care</td>
<td>1</td>
</tr>
<tr>
<td>2</td>
<td>Providing effectively joined-up social care and health services to those that need them, for example through a single ‘needs assessment’. A ‘needs assessment’ would be a kind of one-stop-shop appointment instead of lots of appointments. A case manager would be someone who plans your care with you and then coordinates it.</td>
<td>2</td>
</tr>
<tr>
<td>3</td>
<td>Improving the availability, quality and choice of services for long-term care users and people with long-term illnesses like diabetes e.g. support from people with similar conditions</td>
<td>3</td>
</tr>
</tbody>
</table>

PLEASE SUMMARISE WHY PEOPLE SELECTED THESE PRIORITIES:

Priority 1
The group felt that they wanted to know more about the services that were available and what they could expect when accessing a service.

Priority 2
The group felt that joined up care in the health service could be better. As an example a patient choose a specialist hospital for surgery as part of Choice, but was not able to receive her follow up care and rehabilitation locally, even though it
was available. The group were willing to travel to access ‘one off’ specialist care but wanted to receive ongoing care locally. The group also found it difficult to separate health and social services and understand the respective roles and support.

Q6. Did people think it would be enough for Government to only do these things to help people manage their care and make decisions?

The group felt unable to answer this question as it was felt not to be clear.

Q7. What else would people like the Government to do to help people manage their care and make decisions?

The clear message was that the group wanting funding to support care, especially to be supported to remain in their own home. Linked to this was tax relief for older people, particularly in relation to pensions and savings.

Advocacy services were also highlighted as being valued by the group, particularly by those without family support.
When you and your family need help and support, how, when, where and from whom do you want it?

We want to make sure people have access to the services they want, when they want them, where they want them and from whom they want them. But to do this there are some tough choices to be made.

...Thinking about how the NHS and Social Care and other services might improve how, when, where and from whom community-based services are delivered...

Q8. Which of the following did the people at the listening exercises you ran think should be top three priorities? (Please rank by writing 1, 2 or 3 in the boxes)

Providing convenient services which fit around people’s lives, for example by extending opening hours to evenings and weekends at the local GP practice, pharmacy and other community services, by enabling people who receive care at home to choose for example when the carer visits

Providing care in convenient locations (for example NHS Walk in Centres near train stations so people can get quick advice on problems and health issues on their way to work) or allowing people to register with any family Doctor, not just one where you live

Developing and providing more services in the local community, rather than only in hospitals, so they are more convenient for families and children to use. For example, blood tests, x-rays and some scans, minor surgery and physiotherapy could be provided locally. Also, hospital specialists could run clinics in the community.

Developing new services for people who don’t always currently access care, such as young men, teenagers, people from different ethnic groups, people with disabilities.

Allowing people to choose how to receive services at the end of life and to die where they want with dignity. (This options is about the care people receive at the end of their lives, it is not about euthanasia)

None of the above

Don’t know
PLEASE SUMMARISE WHY PEOPLE SELECTED THESE PRIORITIES:
Q9. Did people think it would be enough for Government to only do these things to help provide service how, where, when and from whom people want them? Why?

Q10. What else would people like the Government to do to help provide services how, where, when and from whom people want them?
Q11. Looking across all the options we have asked about, which of these did your group think was the most important thing to be done immediately?

Encouraging and supporting better health, for example through routine check ups, advice on healthy lifestyles and promoting self-care and self-assessment.

Ensuring a range of health professionals, such as nurses and pharmacists, can provide people with information and support about how to take better care of themselves and their families. For instance pharmacists could give advice on getting the best out of the medicines you take or they could run clinics for people with high blood pressure.

Tackling the things that cause ill health and disadvantage, such as poverty and poor housing, by developing new services in the community and by expanding the range of services available in doctors’ surgeries (eg advisors to help with housing, employment and training and benefits), children’s centres and other locations.

Ensuring older people and those with disabilities can get the practical help and support they need to remain independent and active for longer.

Providing effectively joined-up social care and health services to those that need them, for example through a single ‘needs assessment’. A ‘needs assessment’ would be a kind of one-stop-shop appointment instead of lots of appointments. A case manager would be someone who plans your care with you and then coordinates it.

Providing more help to people caring for others, for example with more respite care.

Providing people with better information about what NHS, local authority and social care services are on offer.
Improving the availability, quality and choice of services for long-term care users and people with long-term illnesses like diabetes e.g. support from people with similar conditions

Providing convenient services which fit around people’s lives, for example by extending opening hours to evenings and weekends at the local GP practice, pharmacy and other community services, by enabling people who receive care at home to choose for example when the carer visits

Providing care in convenient locations (for example NHS Walk in Centres near train stations so people can get quick advice on problems and health issues on their way to work) or allowing people to register with any family Doctor, not just one where you live

Developing and providing more services in the local community, rather than only in hospitals, so they are more convenient for families and children to use. For example, blood tests, x-rays and some scans, minor surgery and physiotherapy could be provided locally. Also, hospital specialists could run clinics in the community.

Developing new services for people who don’t always currently access care, such as young men, teenagers, people from different ethnic groups, people with disabilities.

Allowing people to choose how to receive services at the end of life and to die where they want with dignity. (This options is about the care people receive at the end of their lives, it is not about euthanasia)
Q12. Please summarise the main reasons why this option was chosen as the key priority?

**Priority 1**

See comments previously about information advocacy.

**Priority 2**

Participants recognised that long term conditions needed to be properly integrated into the care home environment from a health & social care view point, through to things like food & nutrition given through the diet (particularly regarding diabetes).

Q13. Please summarise the main points from the discussion about whether these changes address the things that work less well at the moment, and maintain and support the things that work well at the moment.
Q14. Please summarise the main points from the discussion about what else the Department of Health should be doing to make sure that community-based health and social care services meet people’s needs in the 21st century?
Section C: details about your organisation and your listening exercises

To help us analyse the information you have given us, we need to find out a little bit more about your organisation and your listening exercise.

A. How many people took part in your devolved listening exercises?

Write in below

35

B. What sort of listening exercise was it?

(Please tick one box only)

- A day long session (from 5 to 8 hours long)
- A half day session (from 3 to 5 hours long)
- Up to 3 hours long
- Other (record below)

Yes

C. How many of each of the following types of people took part in your listening exercise?

(Please put a number in each box even if it is zero)

- Members of the general public (i.e. with no specialist interest in health and social care) 35
- Members of the public who are involved with health and social care services e.g. PPI forum members 0
- Paid staff from your organisation 0
- Voluntary staff from your organisation 0
- Other (record below) 0
D. Please tell us how many of the people who took part – whether members of the public or staff - were from any of the specific sectors of the population listed below.

<table>
<thead>
<tr>
<th>Sector</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Children and young people</td>
<td></td>
</tr>
<tr>
<td>Older people</td>
<td></td>
</tr>
<tr>
<td>Pregnant women (and their partners)</td>
<td></td>
</tr>
<tr>
<td>Socially disadvantaged people</td>
<td></td>
</tr>
<tr>
<td>Disadvantaged children</td>
<td></td>
</tr>
<tr>
<td>Smokers</td>
<td></td>
</tr>
<tr>
<td>Excessive drinkers</td>
<td></td>
</tr>
<tr>
<td>Obese people</td>
<td></td>
</tr>
<tr>
<td>Substance misusers</td>
<td></td>
</tr>
<tr>
<td>Disabled people</td>
<td></td>
</tr>
<tr>
<td>People in prison</td>
<td></td>
</tr>
<tr>
<td>Black and minority ethnic groups</td>
<td></td>
</tr>
<tr>
<td>Travellers</td>
<td></td>
</tr>
<tr>
<td>Homeless people</td>
<td></td>
</tr>
<tr>
<td>People with mental health problems</td>
<td></td>
</tr>
<tr>
<td>People with learning disabilities</td>
<td></td>
</tr>
<tr>
<td>People in hospices/residential care</td>
<td>35</td>
</tr>
<tr>
<td>Asylum seekers</td>
<td></td>
</tr>
<tr>
<td>People with long term conditions</td>
<td></td>
</tr>
<tr>
<td>People with caring responsibilities</td>
<td>3</td>
</tr>
<tr>
<td>Other (record below)</td>
<td></td>
</tr>
</tbody>
</table>
E. Of the people that took part in your listening exercise, can you please tell us how many were from each of the ethnic groups listed below

- White British: 35
- White Irish: 
- Any other white background: 
- White and Black Caribbean: 
- White and Black African: 
- White and Asian: 
- Any other mixed background: 
- Indian: 
- Pakistani: 
- Bangladeshi: 
- Any other Asian Background: 
- Caribbean: 
- African: 
- Any other Black background: 
- Chinese: 
- Rather not say: 

F. Which of the following best describes the sector to which your organisation or group belongs / where you work:

(Please tick one box only)

- PPI forum or other patient group: 
- Community-based NHS services: yes 
- Local authority social care services: 
- Private sector health or social care services: 
- Voluntary sector health or social care services: 
- Other (record below): 

G. If your listening exercises mostly involved staff rather than patients or service users please can you identify from the list below which groups they most often have contact with or provide services for:

(Please tick all relevant boxes)

<table>
<thead>
<tr>
<th>Category</th>
<th>Ticked</th>
</tr>
</thead>
<tbody>
<tr>
<td>Children and young people</td>
<td></td>
</tr>
<tr>
<td>Older people</td>
<td></td>
</tr>
<tr>
<td>Pregnant women (and their partners)</td>
<td></td>
</tr>
<tr>
<td>Socially disadvantaged people</td>
<td></td>
</tr>
<tr>
<td>Disadvantaged children</td>
<td></td>
</tr>
<tr>
<td>Smokers</td>
<td></td>
</tr>
<tr>
<td>Excessive drinkers</td>
<td></td>
</tr>
<tr>
<td>Obese people</td>
<td></td>
</tr>
<tr>
<td>Substance misusers</td>
<td></td>
</tr>
<tr>
<td>Disabled people</td>
<td></td>
</tr>
<tr>
<td>People in prison</td>
<td></td>
</tr>
<tr>
<td>Black and minority ethnic groups</td>
<td></td>
</tr>
<tr>
<td>Travellers</td>
<td></td>
</tr>
<tr>
<td>Homeless people</td>
<td></td>
</tr>
<tr>
<td>People with mental health problems</td>
<td></td>
</tr>
<tr>
<td>People with learning disabilities</td>
<td></td>
</tr>
<tr>
<td>People in hospices/residential care</td>
<td></td>
</tr>
<tr>
<td>Asylum seekers</td>
<td></td>
</tr>
<tr>
<td>People with long term conditions</td>
<td></td>
</tr>
<tr>
<td>People with caring responsibilities</td>
<td></td>
</tr>
<tr>
<td>Do not deal with specific sectors of the community</td>
<td></td>
</tr>
<tr>
<td>Other (record below)</td>
<td></td>
</tr>
</tbody>
</table>
If you work with specific ethnic groups, which of these groupings do you represent or work with?

- White British
- White Irish
- Any other white background
- White and Black Caribbean
- White and Black African
- White and Asian
- Any other mixed background
- Indian
- Pakistani
- Bangladeshi
- Any other Asian Background
- Caribbean
- African
- Any other Black background
- Chinese
- Do not deal with specific ethnic groups
- Other (record below)
I. If you are a regional organisation, please tick the box below for the region you mainly work in

<table>
<thead>
<tr>
<th>Region</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>North East</td>
<td></td>
</tr>
<tr>
<td>North West</td>
<td>yes</td>
</tr>
<tr>
<td>Yorkshire &amp; the Humber</td>
<td></td>
</tr>
<tr>
<td>East Midlands</td>
<td></td>
</tr>
<tr>
<td>East of England</td>
<td></td>
</tr>
<tr>
<td>South East</td>
<td></td>
</tr>
<tr>
<td>London</td>
<td></td>
</tr>
<tr>
<td>South West</td>
<td></td>
</tr>
<tr>
<td>National Organisation</td>
<td></td>
</tr>
<tr>
<td>Not applicable</td>
<td></td>
</tr>
</tbody>
</table>

J. What is the name of your organisation?

Preston Primary Care Trust

K. What type of organisation are you responding as?

<table>
<thead>
<tr>
<th>Type</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>A local organisation</td>
<td>yes</td>
</tr>
<tr>
<td>A national organisation</td>
<td></td>
</tr>
<tr>
<td>Other (please record below)</td>
<td></td>
</tr>
</tbody>
</table>
L. Would like to be listed as a contributor to the consultation?

<table>
<thead>
<tr>
<th>Yes</th>
<th>yes</th>
</tr>
</thead>
<tbody>
<tr>
<td>No</td>
<td></td>
</tr>
</tbody>
</table>

K. If you would like to receive a summary of our findings, please enter your contact details or email address in the box below:

Maggi Morris  
DPH Preston PCT  
Preston Business Centre  
Watling St Rd  
Fulwood  
Preston  
PR2 8DY
Thank you for your help with your health, your care, your say.

This feedback form is intended for both local and national organisations or groups to report on the findings their own devolved listening exercise as part your health, your care, your say.

Can I check, are you responding to this questionnaire as:

- A local organisation or group  
- A national organisation or group
- Other (record details below)

All the information you submit will be analysed alongside the public's response and the views obtained from other local and national organisations and groups and will feed into the development of plans for improving community health and care services.

Please note the feedback form is in three parts:

- Section A: Thinking about the community health and social care services people use, what currently works less well?
- Section B: What do you think of the suggestions for improving health and social care services?
- Section C: Details about your organisation and your listening exercise

If you haven't covered Section A or all of the options under Section B, please just leave those questions blank.

Please make sure that you give us this feedback by 4th November, or earlier if possible. You can find out where to return this feedback by referring to the resource pack website, www.yoursayresources.nhs.uk

As you will see, most questions ask you to tick a box like this:

**Tick one box only**

Other questions give you space to record how you reached your decisions:

Please feel free to write as much, or as little, as you like.
Section A: Thinking about the community health and social care services people use, what currently works well, and what currently works less well?

We want to make community-based health and social care services better for everyone. To help us reach the right decisions, we want to know what the people at the listening exercises you ran thought about community-based health and social care services at the moment.

Q1. What were the three key elements of community health and social care services that people though worked well?

(Record below in priority order)

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Supported living</td>
</tr>
<tr>
<td>2</td>
<td>NHS Direct</td>
</tr>
<tr>
<td>3</td>
<td></td>
</tr>
</tbody>
</table>

Record below why people thought these worked well:

People with learning disabilities who are supported to live in their own homes (supported living model) said that this enabled them to be independent, have support when they need it and do lots of things they have not been able to do in the past when they lived in a care setting or hospital.

People said that they found that they could get good information from NHS Direct.
What were the three key elements of community health and social care services that people though worked less well?

(RECORD BELOW IN PRIORITY ORDER)

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Information not in accessible formats</td>
</tr>
<tr>
<td>2</td>
<td>People often have to have many assessments which ask the same questions</td>
</tr>
<tr>
<td>3</td>
<td>Getting a doctor at evenings and weekends is difficult</td>
</tr>
</tbody>
</table>

RECORD BELOW WHY PEOPLE THOUGHT THESE WORKED LESS WELL:

Information should be produced via leaflets, on cd and on computers, which is accessible to all. Easy words, symbols, pictures and photos should be used to make information easier to understand. Staff should be trained to communicate with people with learning disabilities.

People with learning disabilities are often asked the same questions when they use a service. There should be one assessment process that is person centred and can be used by professionals.

Some people with learning disabilities did not like having a doctor they did not know coming to see them at home. Sometimes it was difficult for people with learning disabilities to make an appointment at a time that was best for them.

What other issues did people mention? Please record any personal stories here if possible

Services often appear to not be working together, they should share information.
Section B: what did people think of the suggestions for improving health and social care services?

We are committed to helping people take better care of themselves, but big questions remain about how it can best do this.

...Thinking about how the NHS, Social Care and other services might help people to look after themselves more...

Q2. Which of the following did people at the listening exercises you ran think should be the top three priorities? (Please rank by writing 1, 2 or 3 in the boxes)

Encouraging and supporting better health, for example through routine check ups, advice on healthy lifestyles and promoting self-care and self-assessment.

Ensuring a range of health professionals, such as nurses and pharmacists, can provide people with information and support about how to take better care of themselves and their families. For instance pharmacists could give advice on getting the best out of the medicines you take or they could run clinics for people with high blood pressure.

Tackling the things that cause ill health and disadvantage, such as poverty and poor housing, by developing new services in the community and by expanding the range of services available in doctors’ surgeries (eg advisors to help with housing, employment and training and benefits), children’s centres and other locations.

Ensuring older people and those with disabilities can get the practical help and support they need to remain independent and active for longer

None of the above

Don’t know
The consultation meeting was held with people with learning disabilities who strongly believe that they should be supported and able to live their own life. They want to be able to be in control and get support when and where they need it.

Access to information is very important if you want to be in control of your own life. Information needs to be accessible in content and easily available.
Q3. Did people think it would be enough for Government to only do these things to help people take better care of themselves? Why?

Q4. What else would people like the Government to do to help people take better care of themselves?

People want to move away from the present situation where they are given limited options based on current service provision and then all to often are held within that service, people referred to this as “Serviceland”

People want to break out of this situation and use and access ordinary services and facilities.

Support must be flexible and actively support people rather than taking control and doing things for people, thus denying them the opportunity to do it for themselves.
We want people to be able to use and find their way through health and social care services more easily. We also want these services to be 'joined up', even if several people or organisations are providing them.

...Thinking about how the NHS, Social Care and other services might help people find the services they need and improve the way these services are joined up ...

Q5. Which of the following did people at the listening exercises you ran think should be the top three priorities? (Please rank by writing 1, 2 or 3 in the boxes)

1. Providing effectively joined-up social care and health services to those that need them, for example through a single 'needs assessment'. A 'needs assessment' would be a kind of one-stop-shop appointment instead of lots of appointments. A case manager would be someone who plans your care with you and then coordinates it.

2. Providing more help to people caring for others, for example with more respite care

3. Providing people with better information about what NHS, local authority and social care services are on offer

Improving the availability, quality and choice of services for long-term care users and people with long-term illnesses like diabetes e.g. support from people with similar conditions

None of the above

Don't know

PLEASE SUMMARISE WHY PEOPLE SELECTED THESE PRIORITIES:

All too often people with learning disabilities have various assessments, which ask similar questions. It was felt that a single assessment would be better because it does not waste peoples time, all the information is available and you would have an identified professional.

There needs to be consideration around the kinds of information that is needed and access and sharing of that information. One idea could be that it was used in a similar way to the proposed Electronic Health Care records with service users having access to the records and being able to update and change the records.
Q6. Did people think it would be enough for Government to only do these things to help people manage their care and make decisions?

Q7. What else would people like the Government to do to help people manage their care and make decisions?
WHEN YOU AND YOUR FAMILY NEED HELP AND SUPPORT, HOW, WHEN, WHERE AND FROM WHOM DO YOU WANT IT?

We want to make sure people have access to the services they want, when they want them, where they want them and from whom they want them. But to do this there are some tough choices to be made.

...Thinking about how the NHS and Social Care and other services might improve how, when, where and from whom community-based services are delivered...

Q8. Which of the following did the people at the listening exercises you ran think should be top three priorities? (Please rank by writing 1, 2 or 3 in the boxes)

<table>
<thead>
<tr>
<th>1</th>
</tr>
</thead>
<tbody>
<tr>
<td>Providing convenient services which fit around people’s lives, for example by extending opening hours to evenings and weekends at the local GP practice, pharmacy and other community services, by enabling people who receive care at home to choose for example when the carer visits</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>2</th>
</tr>
</thead>
<tbody>
<tr>
<td>Providing care in convenient locations (for example NHS Walk in Centres near train stations so people can get quick advice on problems and health issues on their way to work) or allowing people to register with any family Doctor, not just one where you live</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>3</th>
</tr>
</thead>
<tbody>
<tr>
<td>Developing and providing more services in the local community, rather than only in hospitals, so they are more convenient for families and children to use. For example, blood tests, x-rays and some scans, minor surgery and physiotherapy could be provided locally. Also, hospital specialists could run clinics in the community.</td>
</tr>
</tbody>
</table>

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Developing new services for people who don’t always currently access care, such as young men, teenagers, people from different ethnic groups, people with disabilities.</td>
</tr>
</tbody>
</table>

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Allowing people to choose how to receive services at the end of life and to die where they want with dignity. (This options is about the care people receive at the end of their lives, it is not about euthanasia)</td>
</tr>
</tbody>
</table>

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>None of the above</td>
</tr>
</tbody>
</table>

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Don’t know</td>
</tr>
</tbody>
</table>
People felt very strongly that services should be available when they need them. People would like to have access to doctors 24 hours a day.

More flexible opening hours for doctors and easier physical access to surgeries.

Would welcome the development of walk in centres and not having to go into hospital for everything.
Q9. Did people think it would be enough for Government to only do these things to help provide service how, where, when and from whom people want them? Why?

Q10. What else would people like the Government to do to help provide services how, where, when and from whom people want them?
Q11. Looking across all the options we have asked about, which of these did your
  group think was the most important thing to be done immediately?

Encouraging and supporting better health, for example through routine check ups, advice on healthy lifestyles and promoting self-care and self-assessment.

Ensuring a range of health professionals, such as nurses and pharmacists, can provide people with information and support about how to take better care of themselves and their families. For instance pharmacists could give advice on getting the best out of the medicines you take or they could run clinics for people with high blood pressure.

Tackling the things that cause ill health and disadvantage, such as poverty and poor housing, by developing new services in the community and by expanding the range of services available in doctors’ surgeries (eg advisors to help with housing, employment and training and benefits), children’s centres and other locations.

Ensuring older people and those with disabilities can get the practical help and support they need to remain independent and active for longer

Providing effectively joined-up social care and health services to those that need them, for example through a single ‘needs assessment’. A ‘needs assessment’ would be a kind of one-stop-shop appointment instead of lots of appointments. A case manager would be someone who plans your care with you and then coordinates it.

Providing more help to people caring for others, for example with more respite care

Providing people with better information about what NHS, local authority and social care services are on offer
Improving the availability, quality and choice of services for long-term care users and people with long-term illnesses like diabetes e.g. support from people with similar conditions

Providing convenient services which fit around people’s lives, for example by extending opening hours to evenings and weekends at the local GP practice, pharmacy and other community services, by enabling people who receive care at home to choose for example when the carer visits

Providing care in convenient locations (for example NHS Walk in Centres near train stations so people can get quick advice on problems and health issues on their way to work) or allowing people to register with any family Doctor, not just one where you live

Developing and providing more services in the local community, rather than only in hospitals, so they are more convenient for families and children to use. For example, blood tests, x-rays and some scans, minor surgery and physiotherapy could be provided locally. Also, hospital specialists could run clinics in the community.

Developing new services for people who don’t always currently access care, such as young men, teenagers, people from different ethnic groups, people with disabilities.

Allowing people to choose how to receive services at the end of life and to die where they want with dignity. (This options is about the care people receive at the end of their lives, it is not about euthanasia)
Q12. Please summarise the main reasons why this option was chosen as the key priority?

As stated earlier people with learning disabilities want to be able to take a full and active roll in their community. Service should be provided on their terms not around what is presently offered.

Q13. Please summarise the main points from the discussion about whether these changes address the things that work less well at the moment, and maintain and support the things that work well at the moment.
Q14. Please summarise the main points from the discussion about what else the Department of Health should be doing to make sure that community-based health and social care services meet people’s needs in the 21st century?
Section C: details about your organisation and your listening exercises

To help us analyse the information you have given us, we need to find out a little bit more about your organisation and your listening exercise.

A. How many people took part in your devolved listening exercises?
   
   Write in below
   
   [ ] 10

B. What sort of listening exercise was it?
   
   (Please tick one box only)
   
   A day long session (from 5 to 8 hours long)
   A half day session (from 3 to 5 hours long) ✓
   Up to 3 hours long
   Other (record below)

C. How many of each of the following types of people took part in your listening exercise?
   
   (Please put a number in each box even if it is zero)
   
   Members of the general public (i.e. with no specialist interest in health and social care)
   Members of the public who are involved with health and social care services e.g. PPI forum members
   Paid staff from your organisation
   Voluntary staff from your organisation
   Other (record below) ✓
   People with learning disabilities who use health and social care services
D. Please tell us how many of the people who took part – whether members of the public or staff - were from any of the specific sectors of the population listed below.

<table>
<thead>
<tr>
<th>Sector</th>
<th>Quantity</th>
</tr>
</thead>
<tbody>
<tr>
<td>Children and young people</td>
<td></td>
</tr>
<tr>
<td>Older people</td>
<td></td>
</tr>
<tr>
<td>Pregnant women (and their partners)</td>
<td></td>
</tr>
<tr>
<td>Socially disadvantaged people</td>
<td></td>
</tr>
<tr>
<td>Disadvantaged children</td>
<td></td>
</tr>
<tr>
<td>Smokers</td>
<td></td>
</tr>
<tr>
<td>Excessive drinkers</td>
<td></td>
</tr>
<tr>
<td>Obese people</td>
<td></td>
</tr>
<tr>
<td>Substance misusers</td>
<td></td>
</tr>
<tr>
<td>Disabled people</td>
<td></td>
</tr>
<tr>
<td>People in prison</td>
<td></td>
</tr>
<tr>
<td>Black and minority ethnic groups</td>
<td></td>
</tr>
<tr>
<td>Travellers</td>
<td></td>
</tr>
<tr>
<td>Homeless people</td>
<td></td>
</tr>
<tr>
<td>People with mental health problems</td>
<td></td>
</tr>
<tr>
<td>People with learning disabilities</td>
<td>10</td>
</tr>
<tr>
<td>People in hospices/residential care</td>
<td></td>
</tr>
<tr>
<td>Asylum seekers</td>
<td></td>
</tr>
<tr>
<td>People with long term conditions</td>
<td></td>
</tr>
<tr>
<td>People with caring responsibilities</td>
<td></td>
</tr>
<tr>
<td>Other (record below)</td>
<td></td>
</tr>
</tbody>
</table>
E. Of the people that took part in your listening exercise, can you please tell us how many were from each of the ethnic groups listed below

White British
White Irish
Any other white background
White and Black Caribbean
White and Black African
White and Asian
Any other mixed background
Indian
Pakistani
Bangladeshi
Any other Asian Background
Caribbean
African
Any other Black background
Chinese
Rather not say ✓

F. Which of the following best describes the sector to which your organisation or group belongs / where you work:

(Please tick one box only)

- PPI forum or other patient group
- Community-based NHS services
- Local authority social care services
- Private sector health or social care services
- Voluntary sector health or social care services ✓
- Other (record below)
G. If your listening exercises mostly involved staff rather than patients or service users please can you identify from the list below which groups they most often have contact with or provide services for:

*(Please tick all relevant boxes)*

<table>
<thead>
<tr>
<th>Group</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Children and young people</td>
<td></td>
</tr>
<tr>
<td>Older people</td>
<td></td>
</tr>
<tr>
<td>Pregnant women (and their partners)</td>
<td></td>
</tr>
<tr>
<td>Socially disadvantaged people</td>
<td></td>
</tr>
<tr>
<td>Disadvantaged children</td>
<td></td>
</tr>
<tr>
<td>Smokers</td>
<td></td>
</tr>
<tr>
<td>Excessive drinkers</td>
<td></td>
</tr>
<tr>
<td>Obese people</td>
<td></td>
</tr>
<tr>
<td>Substance misusers</td>
<td></td>
</tr>
<tr>
<td>Disabled people</td>
<td></td>
</tr>
<tr>
<td>People in prison</td>
<td></td>
</tr>
<tr>
<td>Black and minority ethnic groups</td>
<td></td>
</tr>
<tr>
<td>Travellers</td>
<td></td>
</tr>
<tr>
<td>Homeless people</td>
<td></td>
</tr>
<tr>
<td>People with mental health problems</td>
<td></td>
</tr>
<tr>
<td>People with learning disabilities</td>
<td></td>
</tr>
<tr>
<td>People in hospices/residential care</td>
<td></td>
</tr>
<tr>
<td>Asylum seekers</td>
<td></td>
</tr>
<tr>
<td>People with long term conditions</td>
<td></td>
</tr>
<tr>
<td>People with caring responsibilities</td>
<td></td>
</tr>
<tr>
<td>Do not deal with specific sectors of the community</td>
<td></td>
</tr>
<tr>
<td>Other (record below)</td>
<td></td>
</tr>
</tbody>
</table>
If you work with specific ethnic groups, which of these groupings do you represent or work with?

<table>
<thead>
<tr>
<th>Grouping</th>
<th>Selection</th>
</tr>
</thead>
<tbody>
<tr>
<td>White British</td>
<td></td>
</tr>
<tr>
<td>White Irish</td>
<td></td>
</tr>
<tr>
<td>Any other white background</td>
<td></td>
</tr>
<tr>
<td>White and Black Caribbean</td>
<td></td>
</tr>
<tr>
<td>White and Black African</td>
<td></td>
</tr>
<tr>
<td>White and Asian</td>
<td></td>
</tr>
<tr>
<td>Any other mixed background</td>
<td></td>
</tr>
<tr>
<td>Indian</td>
<td></td>
</tr>
<tr>
<td>Pakistani</td>
<td></td>
</tr>
<tr>
<td>Bangladeshi</td>
<td></td>
</tr>
<tr>
<td>Any other Asian Background</td>
<td></td>
</tr>
<tr>
<td>Caribbean</td>
<td></td>
</tr>
<tr>
<td>African</td>
<td></td>
</tr>
<tr>
<td>Any other Black background</td>
<td></td>
</tr>
<tr>
<td>Chinese</td>
<td></td>
</tr>
<tr>
<td>Do not deal with specific ethnic groups</td>
<td>✓</td>
</tr>
<tr>
<td>Other (record below)</td>
<td></td>
</tr>
<tr>
<td>Our service is open to all ethnic groups</td>
<td></td>
</tr>
</tbody>
</table>
I. If you are a regional organisation, please tick the box below for the region you mainly work in

<table>
<thead>
<tr>
<th>Region</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>North East</td>
<td>✓</td>
</tr>
<tr>
<td>North West</td>
<td></td>
</tr>
<tr>
<td>Yorkshire &amp; the Humber</td>
<td></td>
</tr>
<tr>
<td>East Midlands</td>
<td></td>
</tr>
<tr>
<td>East of England</td>
<td></td>
</tr>
<tr>
<td>South East</td>
<td></td>
</tr>
<tr>
<td>London</td>
<td></td>
</tr>
<tr>
<td>South West</td>
<td></td>
</tr>
<tr>
<td>National Organisation</td>
<td></td>
</tr>
<tr>
<td>Not applicable</td>
<td></td>
</tr>
</tbody>
</table>

J. What is the name of your organisation?

- Asking You! Project
- Leeds Advocacy

K. What type of organisation are you responding as?

<table>
<thead>
<tr>
<th>Type of Organisation</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>A local organisation</td>
<td>✓</td>
</tr>
<tr>
<td>A national organisation</td>
<td></td>
</tr>
<tr>
<td>Other (please record below)</td>
<td></td>
</tr>
</tbody>
</table>
L. Would like to be listed as a contributor to the consultation?

<table>
<thead>
<tr>
<th>Yes</th>
<th>✓</th>
</tr>
</thead>
<tbody>
<tr>
<td>No</td>
<td></td>
</tr>
</tbody>
</table>

K. If you would like to receive a summary of our findings, please enter your contact details or email address in the box below:

Les France  
Project Manager  
Asking You!  
Leeds Advocacy, Unit A4, Unity Business Centre, 26 Roundhay Road,  
Leeds, LS7 1AB  
asku@leedsadvocacy.org.uk
Your Health Your Care Your Say

Discussion group held on 1 November 2005 at the Peace Outreach Project, Bromley Mind, which provides support for women who experience mental health difficulties who have dependent children.

6 Participants (4 people who have experience of using mental health services, 2 staff)

What works and what doesn’t?
Participants gave the following comments about community health and care services they had used:

Adult Education services
• Positive
Helped to rebuild my confidence after becoming mentally ill. I intend to so more classes best year.
Have used adult education service, have gone on to do higher education.

Citizens Advice Bureau
• Positive
Very useful for client referrals. [They do] visits to the local mental health hospital.
Benefits
I found the CAB very useful when having problems with work.

Connexions
• Positive
Great for when kids grow older. Very popular, loved by community

Community options (Voluntary sector, community mental health support)
• Positive
How to find a good carer who helps, not boss you around.

Community Psychiatric Nurses
• Positive
Very good, gives me the will to carry on and enough courage to become what I would like to be. Took great care of the kids and I.
Bossy and doesn’t really listen. However is reliable and efficient.

- Negative

Used the service but did not find it really helpful.

**Community Mental Health Team**

- Positive

Usually helpful. No complaints generally but seem to want me to join activities that I don’t want to join, or to go back to work which I don’t think I could manage.

- Negative

They should give me time to listen to what they say not just act on their own accord. They should be careful how they label you.

Once you’re referred it takes a long time to have an assessment. Then takes a while to start seeing a CPN or shrink. After that they just always offer drugs. If you do you get sent away for a while before seeing them again. If you don’t take drugs, you see someone for like half an hour once a month. They don’t bother contacting you when they say they will. You get a CPN who doesn’t understand you or why you’re there, you always go over everything that you don’t even need help with. You get the wrong CPN for whatever problems you have. You never get the right diagnosis. Get turned away because you didn’t do something years ago that they had suggested. Never really give you time and effort to even help.

They talk about you while you’re sitting there. It would be nicer if they talked with you

They don’t understand you’re a busy mum. They call you to give you an appointment over the phone and you soon forget and miss it if you can’t think when it was, then you receive a letter, like I was in the wrong for missing it. Just ain’t understanding.

**Counselling/Talking therapies**

- Negative

The time you get is about six weeks which is not long enough. I feel also that the services should have longer hours.

**Dentists**

- Positive

[I have] The best dentist, first time my teeth were seen to properly. Very clean, always good to get appointment, very friendly.

Used this service last week, very good.
• **Negative**
  My dentist went private, I haven’t found another one that has an open NHS list that I can get to. So no dental healthcare at the moment.

**GPs**

• **Positive**
  Sometimes very good – but not always aware of mental health issues or community services.

  In a group practice, [there was] one doctor who was good at picking up mental health problems.

• **Negative**
  I don’t like my GP. He seems afraid of me because of my mental health problem. When I applied for DLA (Disabled Living Allowance) he tore up the application and put it in the bin while I was there.

  Might not recognise what is going on. Also [GPs need to] give more than pills. Also do not need to have people checking [whilst you’re in appointment] – not all mental health people harm. (this participant had experience of being checked up on frequently whilst in appointments with her GP, apparently in case she tried to harm him, and she had to ask them to stop doing this)

  Not a lot of support now my doctor has left (this participant had been receiving good support from her previous GP)

**Health Visitor**

• **Positive**
  Very helpful

  Good at information sharing

  Need to find a good health visitor to get what you need, but good information regarding services and child welfare.

  Can be excellent for communication and links, signposting to community health service, social services, etc.

**Peace Outreach Project** (Voluntary sector outreach support for women who have experienced mental health difficulties who have dependent children)

• **Positive**
  This project has been good because it shows you the way to move forward in your life and to give help to other people in the project. .
Very positive. Would not have got through without it. Great for self esteem and building up courage. Made me love my kids even more. Taught me now to take care of myself as I am quite vulnerable.

Very helpful. Supported me while my daughter was at home. Would have liked to have this service when my children were smaller.

- Negative
  Needs more funding.

**Platform Penge (Creche service)**

- Positive
  This service is good but only helps people under 25

**Social Workers**

- Positive
  As a young mum, would need the extra help.
- Negative
  Do not always deliver what they promise
  Clients do no feel they can trust them.
  Afraid of children being taken into care.

**Sure Start**

- Negative
  Need someone to rally work within the area to see where really the money should go
  Strict criteria
  [Access] Depends on postcode
  Did nothing much for me

**Young carers groups**

- Positive
  Give me a break as I am single. But they could do more.

- Youth Clubs
  Not enough staff, need to take more control
Services which have been most helpful
1. Peace Outreach Project (Voluntary sector project which provides outreach support to women who experience mental health difficulties who have dependent children)
2. Connexions
3. CPNs

Services which have been least helpful
1. Social Workers
2. Sure Start
3. GPs and CMHTs.

Question 3: When you and your family need help and support, how, when, where and from whom do you want to get it?
The participants prioritised the options as follows:
a. 2
b. 4
c. 1 Top priority
d. 3
e. not felt relevant

Participants’ comments on each of the options are outlined below.

a) Providing convenient services which fit round people's lives, for example by extending opening hours.
Participants felt that this suggestion was good in theory, although not likely to work in practice due to cash restraints. One participant said hours were currently more restricted than previously, as her GP surgery used to be open on Saturday morning, but was not any longer.
It was felt it would be more helpful if appointments could be made outside working hours. For example, if someone works full time it is difficult to arrange times for a Community Psychiatric Nurse to visit, especially as the person may not wish to tell employers or work colleagues that they are seeing one. Having evening appointments would help.
It can also be difficult to arrange appointments with CPNs, counsellors etc if you have young children, and so some flexibility is needed.
It was felt it would be helpful if pharmacists could be open later in the evening, and information about emergency pharmacists should be easier to obtain.

Participants had found it difficult to get access to GP services out of hours, even in an emergency.

b) Providing care in convenient locations eg NHS Walk-In Centres, or allowing people to register with any family doctor, not just one where you live

Participants did not feel it was a priority to be able to register with more than one doctor. They commented that it can be difficult to be accepted even on to one doctor’s list if your medical records show a history of mental health problems. It was felt that increasing the hours GPs surgeries were open would remove the need to register with more than one doctor.

Participants felt people should register with only one doctor, as it is important that a doctor understands their medical history and builds up a relationship with them.

It was felt that Walk-in centres in an increased range of places, for example in railway stations may be of benefit.

c) Developing and providing more services in the local community rather than only in hospitals.

It was felt that it would be positive to be able to have blood tests, scans, x-rays, minor surgery etc carried out in community settings as it can currently be difficult to travel to hospitals for this, and waiting times can be long. Removing the need to travel long distances and then find parking would be positive.

d. Developing new services for people who don’t always currently access care.

This should be developed and may be useful for people with disabilities. People may not access services because they don’t know what is available. It was felt that people who know their way round the system get better access to care than those who don’t, and this is unfair. Some therapies can be difficult to access (eg talking therapies). People need to know what’s there, and should know what they entitled to receive as the system can be confusing, particularly in relation to benefits etc.

e) Allowing people to choose how to receive services at the end of life.

This option was not felt to be relevant by the group.

Other suggestions

1. There should be drop-in centres with crèches where people can make appointments to see counsellors etc.

2. Health and care services need to listen more to teenagers and their concerns, for example in relation to smoking and stress. Teenagers get
bombarded with information. Better sex education is also important for this group and there should be more work done with teenagers, for example about what it’s like to have a baby.

3. Benefits forms should be improved. There should be specific forms for mental health, as the current forms focus on physical health too much. There should be more access to benefits advice and help in filling in forms. Medical assessments for benefits should be more flexible as these can be difficult to attend eg if you have childcare responsibilities.

The views expressed are those of the participants and are not necessarily the policy position of Mind.

Moira Fraser
Policy Officer
Mind
m.fraser@mind.org.uk
5 Nov 2005
YOUR HEALTH, YOUR CARE, YOUR SAY

FEEDBACK FORM FOR LOCAL LISTENING EXERCISES
Thank you for your help with *your health, your care, your say*.

This feedback form is intended for both local and national organisations or groups to report on the findings their own devolved listening exercise as part *your health, your care, your say*.

Can I check, are you responding to this questionnaire as:

- A local organisation or group
- A national organisation or group
- Other (record details below) [x]

**National organisation reporting outcomes of local listening exercise**

All the information you submit will be analysed alongside the public’s response and the views obtained from other local and national organisations and groups and will feed in to the development of plans for improving community health and care services.

Please note the feedback form is in three parts:

- Section A: Thinking about the community health and social care services people use, what currently works less well?
- Section B: what do you think of the suggestions for improving health and social care services?
- Section C: details about your organisation and your listening exercise

If you haven’t covered Section A or all of the options under Section B, please just leave those questions blank.

Please make sure that you give us this feedback by 4th November, or earlier if possible. You can find out where to return this feedback by referring to the resource pack website, [www.yoursayresources.nhs.uk](http://www.yoursayresources.nhs.uk)

As you will see, most questions ask you to tick a box like this:

*Tick one box only*
Other questions give you space to record how you reached your decisions:

Please feel free to write as much, or as little, as you like.
Section A: Thinking about the community health and social care services people use, what currently works well, and what currently works less well?

**We want to make community-based health and social care services better for everyone. To help us reach the right decisions, we want to know what the people at the listening exercises you ran thought about community-based health and social care services at the moment.**

Q1. **What were the three key elements of community health and social care services that people though worked well?**

(Record below in priority order)

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Counselling</td>
</tr>
<tr>
<td>2</td>
<td>Voluntary sector</td>
</tr>
<tr>
<td>3</td>
<td></td>
</tr>
</tbody>
</table>

**Record below why people thought these worked well:**

Positive comments people gave about local services were as follows:

**Aftercare in the community**

- **Positive comments**
  
  Was good when I was really bad six years ago.

**Counselling**

- **Positive comments**
  
  Counselling in this area is to a high standard both in delivery and training - largely offered in all its diverse forms in the voluntary sector. Recognition is needed of this fact and more use made of it.
  
  Very good for friend (Bohemia Trust)
  
  Counselling in the NHS is the clinical model. The voluntary sector offers diverse types of counselling, well trained with better access suited to individual need for as long as needed - six weeks +.
  
  Counselling should be available on the NHS. It should have national standards and open to anyone who may need a variety of types of counselling.

**CPNs**

- **Positive comments**
  
  Coping despite excessive workload

**Community Mental Health Teams**

- **Positive comments**
  
  Very good when in crisis - really in crisis. Cannot get help before one is in crisis.
Day services

- **Positive comments**
  Good when they were there.
  Day services could be more flexible and be open to a drop in element.

GPs

- **Positive comments**
  All GPs should be able to have pharmacy in the same building.
  Gateway workers (positive development)
  Some very good and understanding, knowing more aspects of the person.

Voluntary sector

- **Positive comments**
  Takes on the roles that other people will not. Gives people chance to put their points of view.
  Funding needed for a development worker in some towns where there is no Mind development worker.

What were the three key elements of community health and social care services that people though worked less well?

(Record below in priority order)

1. Day Services
2. Community Mental Health Teams
3. GP services

Record below why people thought these worked less well:

Negative comments about community services are given below

**Aftercare in the community**

- **Negative comments**
  Takes a long time to get help - even when still "on the books".
  Long term support being taken away, loss of services and support, no "safe" centres for learning, training, fun, in places that are stress free, where there is no stigma and no people who do not accept us.

- **Negative comments**
  Too long waiting list. Cost sometimes too high.

**CPNs**

- **Negative comments**
Invaluable support for long term illness, but they have huge lists. We need more CPNs. Please do not discharge us to primary care or the voluntary sector. They are not well enough trained to support us.

Being asked to reduce case load.
Being redeployed to crisis and home treatment teams.
Reducing numbers.
Lack of CPNs.

**Community Mental Health Teams**
- **Negative comments**

People falling into a gap between being discharged by CPN but not being supported by CMHT.

People being discharged into primary care, whereas had long term support from CMHT. Who is going to support me and prevent me from getting ill?

If not in real/terrible crisis, help takes too long or no help.

Being reorganised with significant disruption. Being just accepted.

**Day Services**
- **Negative comments**

Hastings seems to have stopped them.

Our day service has been closed. No one is doing these activities. People are supposed to go to the voluntary sector but they are not trained adequately. Day service did provide important support to get well.

Concerns about local community mental health services in Hastings as a result of the proposed merger of mental health services into East/West Sussex, Brighton and Hove which could leave Hastings more deprived and isolated than at present.

**GPs**
- **Negative comments**

Family doctor model is good. Difficult to see GP. Refers on. No continuity.

GPs need to recognise the range of services they can use and not just resort to clinical treatment/prescriptions.

Started up a health walk in my area last year and then pulled out leaving it floundering.

Too short a time allocated to a patient. If you have a mental illness you need more than seven minutes.

GPs do not have adequate training in looking after people with mental illness, yet we are being discharged back to the GP. Who is going to provide support?

More flexible booking appointments. My GPs will only give same day appointments.

Worry that people will be sent back to GP before time/money is given to them.
Social Services

- **Negative comments**

Services need to be provided all round the clock and not 9 am to 5 pm.

Many Protection of Vulnerable Adults guidelines are not considered as basic standards. People are being neglected.

Voluntary sector

- **Negative comments**

Not sufficient funding. Look after very ill people who would be in asylum. But volunteers are not trained to work like this - risk; dangerous.

The voluntary sector provides services which bridge gaps in those provided by statutory agencies. However, this is often under-funded and resourced. If these voluntary services are to continue their needs must be considered.

What other issues did people mention? Please record any personal stories here if possible

As above.

In addition, participants wanted to have it noted that they felt the timescale for the consultation was too short. If more notice had been given, they would have been able to attract more people to the meeting, and the views of a wider group of people could have been included. They wanted to stress the importance of this to the Department of Health so that this can be taken into account when planning any future consultations.
Section B: what did people think of the suggestions for improving health and social care services?

HOW CAN PEOPLE LOOK AFTER THEMSELVES? HOW CAN WE HELP YOU TAKE CARE OF YOURSELF AND SUPPORT YOU AND YOUR FAMILY IN YOUR DAILY LIVES?

We are committed to helping people take better care of themselves, but big questions remain about how it can best do this.

...Thinking about how the NHS, Social Care and other services might help people to look after themselves more...

Q2. Which of the following did people at the listening exercises you ran think should be the top three priorities? (Please rank by writing 1, 2 or 3 in the boxes)

Encouraging and supporting better health, for example through routine check ups, advice on healthy lifestyles and promoting self-care and self-assessment.

Ensuring a range of health professionals, such as nurses and pharmacists, can provide people with information and support about how to take better care of themselves and their families. For instance pharmacists could give advice on getting the best out of the medicines you take or they could run clinics for people with high blood pressure.

Tackling the things that cause ill health and disadvantage, such as poverty and poor housing, by developing new services in the community and by expanding the range of services available in doctors’ surgeries (eg advisors to help with housing, employment and training and benefits), children’s centres and other locations.

Ensuring older people and those with disabilities can get the practical help and support they need to remain independent and active for longer

None of the above
Don’t know
PLEASE SUMMARISE WHY PEOPLE SELECTED THESE PRIORITIES:

Comments on the four options are given below

a) **Encouraging better health eg through regular check ups, advice on healthy lifestyles, promoting self care.**

**Advice on health**
Those giving advice need to listen to people. They shouldn’t pre-empt or assume what is best for people, eg medication, smoking. Advice only goes so far and sometimes does not deal with the realities of life – practical solutions are also needed.

**Healthy eating**
Participants felt that advice on healthy eating was fine, but it often wasn’t practical. Healthy food is often too expensive. At the time of the meeting, a farmer’s market was taking place in the town, but participants said they couldn’t afford to buy the produce on offer.

**Smoking cessation**
Participants commented that stopping smoking isn’t always realistic, and many people with mental health problems use it as a way of dealing with stress. General advice on stopping smoking is not likely to be useful, and other ways of dealing with stress are also needed.

**Mental well-being should be introduced in schools.**
This would need follow up, as it can’t just be covered once. It needs to be revisited throughout the school curriculum. Priorities need to be sustained as initiatives seem to come and go.

**More help from GPs**
Participants felt GPs should do more to encourage good mental health and should ask about emotional health as standard. This would ensure people who are experiencing depression have more chance of having their symptoms noticed and receiving help. It was felt that there is not enough GP time for people to be able to have regular check-ups.

**Mental health at work**
Work and employment should help with mental well-being. Employers should have responsibility to reduce stress.

b) **Ensuring a range of health professionals such as nurses and pharmacists can provide people with information and support about how to take care of themselves.**

**Pharmacists providing services**
Participants felt pharmacists could provide some advice and this would free up GP time, but this would need a private area in the pharmacy as there are already confidentiality issues about asking for medication or prescriptions in the main shop.
of a pharmacy where others can overhear. Pharmacists might be able to give some drugs advice, although it was felt strongly that GPs should retain responsibility for prescribing and monitoring drugs taken.

Participants were concerned that some people might go to a pharmacist instead of the doctor, and if they had a serious health problem, this might be overlooked and there could be a delay in getting necessary treatment.

**Mental healthcare**

Mental health training is needed for practice nurses, GPs and all healthcare workers, and mental health nurses should be employed in primary care practices as this would significantly improve the quality of mental healthcare provided in primary care.

The local Citizens Advice Bureau employed a mental health advisor, and this was found to be very helpful.

c) **Tackling the things that cause ill-health and disadvantage by developing new services in the community.**

Participants felt strongly that tackling things which cause ill-health eg poverty and housing were important and that services could be expanded in doctors surgeries, although simply improving communication between GPs and other services would also help a great deal.

It was felt it would be massive expense to adequately address issues such as housing, poverty etc. but that the cost would be worth it in the long run due to reduced need for health and other services later.

If there were multiple services available in GP practices, it was felt that initial assessment of needs and referral could be done by practice nurse, but mental health nurses are also needed in primary care. However, there is a shortage of nurses, and this would be a problem delivering this kind of service.

It was felt to be important that where an assessment has taken place, or a doctor has written a letter to another service on a patient’s behalf, this should be acted upon. There should not be multiple assessments eg for benefits as this is very stressful and time consuming.

Providing this kind of joined up service which properly addresses people’s needs constitutes civilisation, and this is what the government should aspire to.

**Other developments which would help if expanded**

Tackling social exclusion was seen as very important. Examples of good practice given were healthy walks and exercise organised by local groups or primary care trusts. The cost of this is minimal but has great benefit for physical and mental health as well as social inclusion.

Time banks were mentioned as an example of good practice, where individuals share skills within the community.

Special lodgers schemes had been tried in some places, matching up people in need with people willing to give some support. It had been found that this worked in some cases and not in others and needed further investigation.
d) Ensure older people and people with disabilities get practical help and support to stay healthy and independent.

It was felt that there is a great deal of age discrimination in services and older people do not get access to the same range of services as younger people, particularly in mental health. Older people’s mental health needs tend not to be taken seriously.

It was suggested that cheaper taxis should be provided for older people and disabled people as there is no transport in rural areas. There should also be allowances to buy in services which are wider than current direct payments.

Participants had experience of applying for direct payments, and said that they were not used in their area as they were told the money was all tied up already, and the service would not be viable if they were given direct payments. Participants wanted this situation to be addressed.
Q3. Did people think it would be enough for Government to only do these things to help people take better care of themselves? Why?

No. Much greater attention needs to be paid to improving mental health and mental health care, both in the general population and for people who already experience mental distress. Many of the options did not adequately address this.

Q4. What else would people like the Government to do to help people take better care of themselves?

This is outlined in the answers given above.
We want people to be able to use and find their way through health and social care services more easily. We also want these services to be ‘joined up’, even if several people or organisations are providing them.

...Thinking about how the NHS, Social Care and other services might help people find the services they need and improve the way these services are joined up ...

Q5. Which of the following did people at the listening exercises you ran think should be the top three priorities? (Please rank by writing 1, 2 or 3 in the boxes)

Providing effectively joined-up social care and health services to those that need them, for example through a single ‘needs assessment’. A ‘needs assessment’ would be a kind of one-stop-shop appointment instead of lots of appointments. A case manager would be someone who plans your care with you and then coordinates it.

Providing more help to people caring for others, for example with more respite care

Providing people with better information about what NHS, local authority and social care services are on offer

Improving the availability, quality and choice of services for long-term care users and people with long-term illnesses like diabetes e.g. support from people with similar conditions

None of the above

Don't know

PLEASE SUMMARISE WHY PEOPLE SELECTED THESE PRIORITIES:
Q6. Did people think it would be enough for Government to only do these things to help people manage their care and make decisions?

Q7. What else would people like the Government to do to help people manage their care and make decisions?
WHEN YOU AND YOUR FAMILY NEED HELP AND SUPPORT, HOW, WHEN, WHERE AND FROM WHOM DO YOU WANT IT?

We want to make sure people have access to the services they want, when they want them, where they want them and from whom they want them. But to do this there are some tough choices to be made.

...Thinking about how the NHS and Social Care and other services might improve how, when, where and from whom community-based services are delivered...

Q8. Which of the following did the people at the listening exercises you ran think should be top three priorities? (Please rank by writing 1, 2 or 3 in the boxes)

Providing convenient services which fit around people’s lives, for example by extending opening hours to evenings and weekends at the local GP practice, pharmacy and other community services, by enabling people who receive care at home to choose for example when the carer visits

Providing care in convenient locations (for example NHS Walk in Centres near train stations so people can get quick advice on problems and health issues on their way to work) or allowing people to register with any family Doctor, not just one where you live

Developing and providing more services in the local community, rather than only in hospitals, so they are more convenient for families and children to use. For example, blood tests, x-rays and some scans, minor surgery and physiotherapy could be provided locally. Also, hospital specialists could run clinics in the community.

Developing new services for people who don’t always currently access care, such as young men, teenagers, people from
different ethnic groups, people with disabilities.

Allowing people to choose how to receive services at the end of life and to die where they want with dignity. (This option is about the care people receive at the end of their lives, it is not about euthanasia)

None of the above
Don't know

PLEASE SUMMARISE WHY PEOPLE SELECTED THESE PRIORITIES:
Q9. Did people think it would be enough for Government to only do these things to help provide service how, where, when and from whom people want them? Why?

Q10. What else would people like the Government to do to help provide services how, where, when and from whom people want them?
Q11. Looking across all the options we have asked about, which of these did your group think was the most important thing to be done immediately?

- Encouraging and supporting better health, for example through routine check-ups, advice on healthy lifestyles and promoting self-care and self-assessment.

- Ensuring a range of health professionals, such as nurses and pharmacists, can provide people with information and support about how to take better care of themselves and their families. For instance pharmacists could give advice on getting the best out of the medicines you take or they could run clinics for people with high blood pressure.

- Tackling the things that cause ill health and disadvantage, such as poverty and poor housing, by developing new services in the community and by expanding the range of services available in doctors’ surgeries (eg advisors to help with housing, employment and training and benefits), children’s centres and other locations.

- Ensuring older people and those with disabilities can get the practical help and support they need to remain independent and active for longer.

- Providing effectively joined-up social care and health services to those that need them, for example through a single ‘needs assessment’. A ‘needs assessment’ would be a kind of one-stop-shop appointment instead of lots of appointments. A case manager would be someone who plans your care with you and then coordinates it.

- Providing more help to people caring for others, for example with more respite care.

- Providing people with better information about what NHS, local authority and social care services are on offer.
Improving the availability, quality and choice of services for long-term care users and people with long-term illnesses like diabetes e.g. support from people with similar conditions

Providing convenient services which fit around people’s lives, for example by extending opening hours to evenings and weekends at the local GP practice, pharmacy and other community services, by enabling people who receive care at home to choose for example when the carer visits

Providing care in convenient locations (for example NHS Walk in Centres near train stations so people can get quick advice on problems and health issues on their way to work) or allowing people to register with any family Doctor, not just one where you live

Developing and providing more services in the local community, rather than only in hospitals, so they are more convenient for families and children to use. For example, blood tests, x-rays and some scans, minor surgery and physiotherapy could be provided locally. Also, hospital specialists could run clinics in the community.

Developing new services for people who don’t always currently access care, such as young men, teenagers, people from different ethnic groups, people with disabilities.

Allowing people to choose how to receive services at the end of life and to die where they want with dignity. (This options is about the care people receive at the end of their lives, it is not about euthanasia)
Q12. Please summarise the main reasons why this option was chosen as the key priority?

Q13. Please summarise the main points from the discussion about whether these changes address the things that work less well at the moment, and maintain and support the things that work well at the moment.
Q14. Please summarise the main points from the discussion about what else the Department of Health should be doing to make sure that community-based health and social care services meet people’s needs in the 21st century?
Section C: details about your organisation and your listening exercises

To help us analyse the information you have given us, we need to find out a little bit more about your organisation and your listening exercise.

A. How many people took part in your devolved listening exercises?

   Write in below

   7

B. What sort of listening exercise was it?

   (Please tick one box only)

   A day long session (from 5 to 8 hours long)
   A half day session (from 3 to 5 hours long)
   Up to 3 hours long x
   Other (record below)

C. How many of each of the following types of people took part in your listening exercise?

   (Please put a number in each box even if it is zero)

   Members of the general public (i.e. with no specialist interest in health and social care) 5
   Members of the public who are involved with health and social care services e.g. PPI forum members
   Paid staff from your organisation
   Voluntary staff from your organisation
   Other (record below) 2

   Members of staff from other organisations
D. Please tell us how many of the people who took part – whether members of the public or staff - were from any of the specific sectors of the population listed below.

<table>
<thead>
<tr>
<th>Sector</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Children and young people</td>
<td></td>
</tr>
<tr>
<td>Older people</td>
<td>2</td>
</tr>
<tr>
<td>Pregnant women (and their partners)</td>
<td></td>
</tr>
<tr>
<td>Socially disadvantaged people</td>
<td></td>
</tr>
<tr>
<td>Disadvantaged children</td>
<td></td>
</tr>
<tr>
<td>Smokers</td>
<td></td>
</tr>
<tr>
<td>Excessive drinkers</td>
<td></td>
</tr>
<tr>
<td>Obese people</td>
<td></td>
</tr>
<tr>
<td>Substance misusers</td>
<td></td>
</tr>
<tr>
<td>Disabled people</td>
<td></td>
</tr>
<tr>
<td>People in prison</td>
<td></td>
</tr>
<tr>
<td>Black and minority ethnic groups</td>
<td></td>
</tr>
<tr>
<td>Travellers</td>
<td></td>
</tr>
<tr>
<td>Homeless people</td>
<td></td>
</tr>
<tr>
<td>People with mental health problems</td>
<td>6</td>
</tr>
<tr>
<td>People with learning disabilities</td>
<td></td>
</tr>
<tr>
<td>People in hospices/residential care</td>
<td></td>
</tr>
<tr>
<td>Asylum seekers</td>
<td></td>
</tr>
<tr>
<td>People with long term conditions</td>
<td></td>
</tr>
<tr>
<td>People with caring responsibilities</td>
<td>1</td>
</tr>
<tr>
<td>Other (record below)</td>
<td></td>
</tr>
</tbody>
</table>
E. Of the people that took part in your listening exercise, can you please tell us how many were from each of the ethnic groups listed below

<table>
<thead>
<tr>
<th>Ethnic Group</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>White British</td>
<td>7</td>
</tr>
<tr>
<td>White Irish</td>
<td></td>
</tr>
<tr>
<td>Any other white background</td>
<td></td>
</tr>
<tr>
<td>White and Black Caribbean</td>
<td></td>
</tr>
<tr>
<td>White and Black African</td>
<td></td>
</tr>
<tr>
<td>White and Asian</td>
<td></td>
</tr>
<tr>
<td>Any other mixed background</td>
<td></td>
</tr>
<tr>
<td>Indian</td>
<td></td>
</tr>
<tr>
<td>Pakistani</td>
<td></td>
</tr>
<tr>
<td>Bangladeshi</td>
<td></td>
</tr>
<tr>
<td>Any other Asian Background</td>
<td></td>
</tr>
<tr>
<td>Caribbean</td>
<td></td>
</tr>
<tr>
<td>African</td>
<td></td>
</tr>
<tr>
<td>Any other Black background</td>
<td></td>
</tr>
<tr>
<td>Chinese</td>
<td></td>
</tr>
<tr>
<td>Rather not say</td>
<td></td>
</tr>
</tbody>
</table>

F. Which of the following best describes the sector to which your organisation or group belongs / where you work:

(Please tick one box only)

- PPI forum or other patient group
- Community-based NHS services
G. If your listening exercises mostly involved staff rather than patients or service users please can you identify from the list below which groups they most often have contact with or provide services for:

(Please tick all relevant boxes)

- Children and young people
- Older people
- Pregnant women (and their partners)
- Socially disadvantaged people
- Disadvantaged children
- Smokers
- Excessive drinkers
- Obese people
- Substance misusers
- Disabled people
- People in prison
- Black and minority ethnic groups
- Travellers
- Homeless people
- People with mental health problems
- People with learning disabilities
- People in hospices/residential care
- Asylum seekers
| People with long term conditions |  |
| People with caring responsibilities |  |
| Do not deal with specific sectors of the community |  |
| Other (record below) |  |
If you work with specific ethnic groups, which of these groupings do you represent or work with?

<table>
<thead>
<tr>
<th>Grouping</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>White British</td>
<td></td>
</tr>
<tr>
<td>White Irish</td>
<td></td>
</tr>
<tr>
<td>Any other white background</td>
<td></td>
</tr>
<tr>
<td>White and Black Caribbean</td>
<td></td>
</tr>
<tr>
<td>White and Black African</td>
<td></td>
</tr>
<tr>
<td>White and Asian</td>
<td></td>
</tr>
<tr>
<td>Any other mixed background</td>
<td></td>
</tr>
<tr>
<td>Indian</td>
<td></td>
</tr>
<tr>
<td>Pakistani</td>
<td></td>
</tr>
<tr>
<td>Bangladeshi</td>
<td></td>
</tr>
<tr>
<td>Any other Asian Background</td>
<td></td>
</tr>
<tr>
<td>Caribbean</td>
<td></td>
</tr>
<tr>
<td>African</td>
<td></td>
</tr>
<tr>
<td>Any other Black background</td>
<td></td>
</tr>
<tr>
<td>Chinese</td>
<td></td>
</tr>
<tr>
<td>Do not deal with specific ethnic groups</td>
<td></td>
</tr>
<tr>
<td>Other (record below)</td>
<td></td>
</tr>
</tbody>
</table>
I. If you are a regional organisation, please tick the box below for the region you mainly work in
J. What is the name of your organisation?

Mind

K. What type of organisation are you responding as?

<table>
<thead>
<tr>
<th>A local organisation</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>A national organisation</td>
<td></td>
</tr>
<tr>
<td>Other (please record below)</td>
<td>x</td>
</tr>
<tr>
<td>National organisation reporting outcomes of local discussion group</td>
<td></td>
</tr>
</tbody>
</table>
L. Would like to be listed as a contributor to the consultation?

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>x</td>
</tr>
<tr>
<td>No</td>
<td></td>
</tr>
</tbody>
</table>

K. If you would like to receive a summary of our findings, please enter your contact details or email address in the box below:

Moira Fraser
Mind
15-19 Broadway
London
E15 4BQ
YOUR HEALTH, YOUR CARE, YOUR SAY
FEEDBACK FORM FOR LOCAL LISTENING EXERCISES
Thank you for your help with *your health, your care, your say*.

This feedback form is intended for both local and national organisations or groups to report on the findings their own devolved listening exercise as part *your health, your care, your say*.

Can I check, are you responding to this questionnaire as:

- A local organisation or group
- A national organisation or group
- Other (record details below)

National organisation reporting results of discussion held at local group

All the information you submit will be analysed alongside the public’s response and the views obtained from other local and national organisations and groups and will feed in to the development of plans for improving community health and care services.

Please note the feedback form is in three parts:

- Section A: Thinking about the community health and social care services people use, what currently works less well?
- Section B: what do you think of the suggestions for improving health and social care services?
- Section C: details about your organisation and your listening exercise

If you haven’t covered Section A or all of the options under Section B, please just leave those questions blank.

Please make sure that you give us this feedback by 4th November, or earlier if possible. You can find out where to return this feedback by referring to the resource pack website, [www.yoursayresources.nhs.uk](http://www.yoursayresources.nhs.uk)

As you will see, most questions ask you to tick a box like this:

*Tick one box only*
Other questions give you space to record how you reached your decisions:

Please feel free to write as much, or as little, as you like.
Section A: Thinking about the community health and social care services people use, what currently works well, and what currently works less well?

We want to make community-based health and social care services better for everyone. To help us reach the right decisions, we want to know what the people at the listening exercises you ran thought about community-based health and social care services at the moment.

Q1. What were the three key elements of community health and social care services that people though worked well?

(RECORD BELOW IN PRIORITY ORDER)

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Peace Outreach Project (Voluntary sector project which provides outreach support to women who experience mental health difficulties who have dependent children)</td>
</tr>
<tr>
<td>2</td>
<td>Connexions</td>
</tr>
<tr>
<td>3</td>
<td>CPNs</td>
</tr>
</tbody>
</table>

RECORD BELOW WHY PEOPLE THOUGHT THESE WORKED WELL:

Positive comments which participants gave about community health and care services were as follows:

**Adult Education services**
Helped to rebuild my confidence after becoming mentally ill. I intend to do more classes best year.
Have used adult education service, have gone on to do higher education,

**Citizens Advice Bureau**
Very useful for client referrals. [They do] visits to the local mental health hospital.
Benefits
I found the CAB very useful when having problems with work.

**Connexions**
Great for when kids grow older. Very popular set up. Very popular, loved by community

**Community options** (Voluntary sector, community mental health support)
How to find a good carer who helps, not boss you around.
**Community Psychiatric Nurses**

Very good, gives me the will to carry on and enough courage to become what I would like to be. Took great care of the kids and I.

Bossy and doesn’t really listen. However is reliable and efficient.

**Community Mental Health Team**

Usually helpful. No complaints generally but seem to want me to join activities that I don’t want to join, or to go back to work which I don’t think I could manage.

**Dentists**

[I have] The best dentist, first time my teeth were seen to properly. Very clean, always good to get appointment, very friendly.

Used this service last week, very good.

**GPs**

Sometimes very good – but not always aware of mental health issues or community services.

In a group practice, [there was] one doctor who was good at picking up mental health problems.

**Health Visitor**

Very helpful

Good at information sharing

Need to find a good health visitor to get what you need, but good information regarding services and child welfare.

Can be excellent for communication and links, sign-posting to community health service, social services, etc.

**Peace Outreach Project** (Voluntary sector outreach support for women who have experienced mental health difficulties who have dependent children)

This project has been good because it shows you the way to move forward in your life and to give help to other people in the project.

Very positive. Would not have got through without it. Great for self esteem and building up courage. Made me love my kids even more. Taught me now to take care of myself as I am quite vulnerable.

Very helpful. Supported me while my daughter was at home. Would have liked to have this service when my children were smaller.
Platform Penge (Creche service)
This service is good but only helps people under 25

Social Workers
As a young mum, would need the extra help.

Young carers groups
Give me a break as I am single. But they could do more.

What were the three key elements of community health and social care services that people thought worked less well?

(RECORD BELOW IN PRIORITY ORDER)

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Social Workers</td>
</tr>
<tr>
<td>2</td>
<td>Sure Start</td>
</tr>
<tr>
<td>3</td>
<td>GPs and Community Mental Health Teams.</td>
</tr>
</tbody>
</table>

RECORD BELOW WHY PEOPLE THOUGHT THESE WORKED LESS WELL:

Negative comments which participants gave about community health and care services were as follows:

Community Psychiatric Nurses
Used the service but did not find it really helpful.

Community Mental Health Team
They should give me time to listen to what they say not just act on their own accord. They should be careful how they label you.

Once you’re referred it takes a long time to have an assessment. Then takes a while to start seeing a CPN or shrink. After that they just always offer drugs. If you do you get sent away for a while before seeing them again. If you don’t take drugs, you see someone for like half and hour once a month. They don’t bother contacting you when they say they will. You get a CPN who doesn’t understand you or why you’re there you always go over everything that you don’t even need help with. You get the wrong CPN for whatever problems you have. You never get the right diagnosis. Get turned away because you didn’t do something years ago that they had suggested. Never really give you time and effort to even help.

They talk about you while you’re sitting there. It would be nicer if they talked with you

They don’t understand you’re a busy mum. They call you to give you an appointment over the phone and you soon forget and miss it if you can’t think when it was, then you receive a letter, like I was in the wrong for missing it. Just ain’t understanding.
**Counselling/Talking therapies**

I feel the time you get is about six weeks which is not long enough. I feel also that the services should have longer hours.

**Dentists**

My dentist went private, I haven’t found another one that has an open NHS list that I can get to. So no dental healthcare at the moment.

**GPs**

I don’t like my GP. He seems afraid of me because of my mental health problem. When I applied for DLA (Disabled Living Allowance) he tore up the application and put it in the bin while I was there.

Might not recognise what is going on. Also [GPs need to] give more than pills. Also do not need to have people checking [whilst you’re in appointment] – not all mental health people harm. (This participant had experience of being checked up on frequently whilst in appointments with her GP, apparently in case she tried to harm him, and she had to ask them to stop doing this)

Not a lot of support now my doctor has left (this participant had been receiving good support from her previous GP but now that doctor has left she feel little support is now available)

**Peace Outreach Project** (Voluntary sector outreach support for women who have experienced mental health difficulties who have dependent children)

Needs more funding.

**Social Workers**

Do not always deliver what they promise

Clients do no feel they can trust them.

Afraid of children being taken into care.

**Sure Start**

Need someone to really work within the area to see where really the money should go

Strict criteria

[Access] Depends on postcode

Did nothing much for me
Youth Clubs
Not enough staff, need to take more control

What other issues did people mention? Please record any personal stories here if possible

See above
Section B: what did people think of the suggestions for improving health and social care services?

### WHEN YOU AND YOUR FAMILY NEED HELP AND SUPPORT, HOW, WHEN, WHERE AND FROM WHOM DO YOU WANT IT?

We want to make sure people have access to the services they want, when they want them, where they want them and from whom they want them. But to do this there are some tough choices to be made.

...Thinking about how the NHS and Social Care and other services might improve how, when, where and from whom community-based services are delivered...

Q8. Which of the following did the people at the listening exercises you ran think should be top three priorities? (Please rank by writing 1, 2 or 3 in the boxes)

1. Providing convenient services which fit around people’s lives, for example by extending opening hours to evenings and weekends at the local GP practice, pharmacy and other community services, by enabling people who receive care at home to choose for example when the carer visits.

2. Providing care in convenient locations (for example NHS Walk in Centres near train stations so people can get quick advice on problems and health issues on their way to work) or allowing people to register with any family Doctor, not just one where you live.

3. Developing and providing more services in the local community, rather than only in hospitals, so they are more convenient for families and children to use. For example, blood tests, x-rays and some scans, minor surgery and physiotherapy could be provided locally. Also, hospital specialists could run clinics in the community.

4. Developing new services for people who don’t always currently access care, such as young men, teenagers, people from different ethnic groups, people with disabilities.

5. Allowing people to choose how to receive services at the end of life and to die where they want with dignity. (This options is
PLEASE SUMMARISE WHY PEOPLE SELECTED THESE PRIORITIES:

Participants’ comments on each of the options are outlined below.

a) Providing convenient services which fit round people’s lives, for example by extending opening hours.

Participants felt that this suggestion was good in theory, although not likely to work in practice due to cash restraints. One participant said hours were currently more restricted than previously, as her GP surgery used to be open on Saturday mornings, but was not any longer.

It was felt it would be more helpful if appointments could be made outside working hours. For example, if someone works full time it is difficult to arrange times for a Community Psychiatric Nurse to visit, especially as the person may not wish to tell employers or work colleagues that they are seeing one. Having evening appointments would help.

It can also be difficult to arrange appointments with CPNs, counsellors etc if you have young children, and so some flexibility is needed.

It was felt it would be helpful if pharmacists could be open later in the evening, and information about emergency pharmacists should be easier to obtain.

Participants had found it difficult to get access to GP services out of hours, even in an emergency.

b) Providing care in convenient locations eg NHS Walk-In Centres, or allowing people to register with any family doctor, not just one where you live

Participants did not feel it was a priority to be able to register with more than one doctor. They commented that it can be difficult to be accepted even on to one doctor’s list if your medical records show a history of mental health problems. It was felt that increasing the hours GPs surgeries were open would remove the need to register with more than one doctor.

Participants felt people should register with only one doctor, as it is important that a doctor understands their medical history and builds up a relationship with them.

It was felt that Walk-in centres, in an increased range of places, for example in railway stations may be of benefit.

c) Developing and providing more services in the local community rather than only in hospitals.
It was felt that it would be positive to be able to have blood tests, scans, x-rays, minor surgery carried out in community settings as it can currently be difficult to travel to hospitals for this, and waiting times can be long. Removing the need to travel long distances and then find parking would be positive.

d) Developing new services for people who don’t always currently access care.

This should be developed and may be useful for people with disabilities. People may not access services because they don’t know what is available, for example. It was felt that people who know their way round the system get better access to care than those who don’t, and this is unfair. Some therapies can be difficult to access (eg talking therapies). People need to know what’s there, and should know what they entitled to receive as the system can be confusing, particularly in relation to benefits etc.

e) Allowing people to choose how to receive services at the end of life.

This option was not felt to be relevant by the group

9. Did people think it would be enough for Government to only do these things to help provide service how, where, when and from whom people want them? Why?

Q10. What else would people like the Government to do to help provide services how, where, when and from whom people want them?

The group gave three further suggestions

1. There should be drop-in centres with crèches where people can make appointments to see counsellors etc.

2. Health and care services need to listen more to teenagers and their concerns, for example in relation to smoking and stress. Teenagers get bombarded with information. Better sex education is also important for this group and there should be more work done with teenagers, for example about what it’s like to have a baby.

3. Benefits forms should be improved. There should be specific forms for mental health, as the current forms focus on physical health too much. There should be more access to benefits advice and help in filling in forms,. Medical assessments for benefits should be more flexible as these can be difficult to attend eg if you have childcare responsibilities.
Section C: details about your organisation and your listening exercises

To help us analyse the information you have given us, we need to find out a little bit more about your organisation and your listening exercise.

A. How many people took part in your devolved listening exercises?  
   
   Write in below

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>6</td>
</tr>
</tbody>
</table>

B. What sort of listening exercise was it?  
   
   (Please tick one box only)

   A day long session (from 5 to 8 hours long)  
   A half day session (from 3 to 5 hours long)  
   Up to 3 hours long  x  
   Other (record below)

C. How many of each of the following types of people took part in your listening exercise?  
   
   (Please put a number in each box even if it is zero)

   Members of the general public (i.e. with no specialist interest in health and social care)  4  
   Members of the public who are involved with health and social care services e.g. PPI forum members  
   Paid staff from your organisation  2  
   Voluntary staff from your organisation  
   Other (record below)
D. Please tell us how many of the people who took part – whether members of the public or staff - were from any of the specific sectors of the population listed below.

<table>
<thead>
<tr>
<th>Sector</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Children and young people</td>
<td></td>
</tr>
<tr>
<td>Older people</td>
<td></td>
</tr>
<tr>
<td>Pregnant women (and their partners)</td>
<td></td>
</tr>
<tr>
<td>Socially disadvantaged people</td>
<td>4</td>
</tr>
<tr>
<td>Disadvantaged children</td>
<td></td>
</tr>
<tr>
<td>Smokers</td>
<td>2</td>
</tr>
<tr>
<td>Excessive drinkers</td>
<td></td>
</tr>
<tr>
<td>Obese people</td>
<td></td>
</tr>
<tr>
<td>Substance misusers</td>
<td></td>
</tr>
<tr>
<td>Disabled people</td>
<td></td>
</tr>
<tr>
<td>People in prison</td>
<td></td>
</tr>
<tr>
<td>Black and minority ethnic groups</td>
<td>1</td>
</tr>
<tr>
<td>Travellers</td>
<td></td>
</tr>
<tr>
<td>Homeless people</td>
<td></td>
</tr>
<tr>
<td>People with mental health problems</td>
<td>4</td>
</tr>
<tr>
<td>People with learning disabilities</td>
<td></td>
</tr>
<tr>
<td>People in hospices/residential care</td>
<td></td>
</tr>
<tr>
<td>Asylum seekers</td>
<td></td>
</tr>
<tr>
<td>People with long term conditions</td>
<td></td>
</tr>
<tr>
<td>People with caring responsibilities</td>
<td>4</td>
</tr>
</tbody>
</table>
E. Of the people that took part in your listening exercise, can you please tell us how many were from each of the ethnic groups listed below

<table>
<thead>
<tr>
<th>Ethnic Group</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>White British</td>
<td></td>
</tr>
<tr>
<td>White Irish</td>
<td></td>
</tr>
<tr>
<td>Any other white background</td>
<td></td>
</tr>
<tr>
<td>White and Black Caribbean</td>
<td></td>
</tr>
<tr>
<td>White and Black African</td>
<td></td>
</tr>
<tr>
<td>White and Asian</td>
<td></td>
</tr>
<tr>
<td>Any other mixed background</td>
<td></td>
</tr>
<tr>
<td>Indian</td>
<td></td>
</tr>
<tr>
<td>Pakistani</td>
<td></td>
</tr>
<tr>
<td>Bangladeshi</td>
<td></td>
</tr>
<tr>
<td>Any other Asian Background</td>
<td></td>
</tr>
<tr>
<td>Caribbean</td>
<td></td>
</tr>
<tr>
<td>African</td>
<td>1</td>
</tr>
<tr>
<td>Any other Black background</td>
<td></td>
</tr>
<tr>
<td>Chinese</td>
<td></td>
</tr>
<tr>
<td>Rather not say</td>
<td></td>
</tr>
</tbody>
</table>

F. Which of the following best describes the sector to which your organisation or group belongs / where you work:
(Please tick **one** box only)

- PPI forum or other patient group
- Community-based NHS services
- Local authority social care services
- Private sector health or social care services
- Voluntary sector health or social care services
- Other (record below)

G. If your listening exercises mostly involved staff rather than patients or service users please can you identify from the list below which groups they most often have contact with or provide services for:

(Please tick all relevant boxes)

- Children and young people
- Older people
- Pregnant women (and their partners)
- Socially disadvantaged people
- Disadvantaged children
- Smokers
- Excessive drinkers
- Obese people
- Substance misusers
- Disabled people
- People in prison
- Black and minority ethnic groups
- Travellers
- Homeless people
- People with mental health problems
- People with learning disabilities
<table>
<thead>
<tr>
<th>People in hospices/residential care</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Asylum seekers</td>
<td></td>
</tr>
<tr>
<td>People with long term conditions</td>
<td></td>
</tr>
<tr>
<td>People with caring responsibilities</td>
<td></td>
</tr>
<tr>
<td>Do not deal with specific sectors of the community</td>
<td></td>
</tr>
<tr>
<td>Other (record below)</td>
<td></td>
</tr>
</tbody>
</table>
H. If you work with specific ethnic groups, which of these groupings do you represent or work with?

<table>
<thead>
<tr>
<th>Grouping</th>
<th>Blank Space</th>
</tr>
</thead>
<tbody>
<tr>
<td>White British</td>
<td></td>
</tr>
<tr>
<td>White Irish</td>
<td></td>
</tr>
<tr>
<td>Any other white background</td>
<td></td>
</tr>
<tr>
<td>White and Black Caribbean</td>
<td></td>
</tr>
<tr>
<td>White and Black African</td>
<td></td>
</tr>
<tr>
<td>White and Asian</td>
<td></td>
</tr>
<tr>
<td>Any other mixed background</td>
<td></td>
</tr>
<tr>
<td>Indian</td>
<td></td>
</tr>
<tr>
<td>Pakistani</td>
<td></td>
</tr>
<tr>
<td>Bangladeshi</td>
<td></td>
</tr>
<tr>
<td>Any other Asian Background</td>
<td></td>
</tr>
<tr>
<td>Caribbean</td>
<td></td>
</tr>
<tr>
<td>African</td>
<td></td>
</tr>
<tr>
<td>Any other Black background</td>
<td></td>
</tr>
<tr>
<td>Chinese</td>
<td></td>
</tr>
<tr>
<td>Do not deal with specific ethnic groups</td>
<td></td>
</tr>
<tr>
<td>Other (record below)</td>
<td></td>
</tr>
</tbody>
</table>

I. If you are a regional organisation, please tick the box below for the region you mainly work in

<table>
<thead>
<tr>
<th>Region</th>
<th>Blank Space</th>
</tr>
</thead>
<tbody>
<tr>
<td>North East</td>
<td></td>
</tr>
<tr>
<td>North West</td>
<td></td>
</tr>
</tbody>
</table>
J. What is the name of your organisation?

Mind

K. What type of organisation are you responding as?

<table>
<thead>
<tr>
<th>Option</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>A local organisation</td>
<td></td>
</tr>
<tr>
<td>A national organisation</td>
<td></td>
</tr>
<tr>
<td>Other (please record below)</td>
<td></td>
</tr>
<tr>
<td>National organisation reporting outcomes of local event</td>
<td>x</td>
</tr>
</tbody>
</table>

L. Would like to be listed as a contributor to the consultation?
K. If you would like to receive a summary of our findings, please enter your contact details or email address in the box below:

Moira Fraser
Mind
15-19 Broadway
London
E15 4BQ
Discussion Event held at Hastings and Rother Mind, 13 October 2005

7 Participants attended, including mental health service users, carers and workers in health and social care.

Participants wanted to have it noted that they felt the timescale for the consultation was too short. If more notice had been given, they would have been able to attract more people to the meeting, and the views of a wider group of people could have been included. They wanted to stress the importance of this to the Department of Health so that this can be taken into account when planning any future consultations.

Activity 1:  
What’s working and what isn’t in current community health and care services?

Participants listed the services they wishes to comment on and described positive and negative aspects, which are directly reproduced below.

Aftercare in the community
- Positive comments
  Was good when I was really bad six years ago.
- Negative comments
  Takes a long time to get help - even when still "on the books".
  Long term support being taken away, loss of services and support, no "safe" centres for learning, training, fun, in places that are stress free, where there is no stigma and no people who do not accept us.

Counselling
- Positive comments
  Counselling in this area is to a high standard both in delivery and training - largely offered in all its diverse forms in the voluntary sector. Recognition is needed of this fact and more use made of it.
  Very good for friend (Bohemia Trust)
  Counselling in the NHS is the clinical model. The voluntary sector offers diverse types of counselling, well trained with better access suited to individual need for as long as needed - six weeks +.
  Counselling should be available on the NHS. It should have national standards and open to anyone who may need a variety of types of counselling.
- Negative comments
  Too long waiting list. Cost sometimes too high.
CPNs

- **Positive comments**
  Coping despite excessive workload

- **Negative comments**
  Invaluable support for long term illness, but they have huge lists. We need more CPNs. Please do not discharge us to primary care or the voluntary sector. They are not well enough trained to support us.
  Being asked to reduce case load.
  Being redeployed to crisis and home treatment teams.
  Reducing numbers.
  Lack of CPNs.

Community Mental Health Teams

- **Positive comments**
  Very good when in crisis - really in crisis. Cannot get help before one is in crisis.

- **Negative comments**
  People falling into a gap between being discharged by CPN but not being supported by CMHT.
  People being discharged into primary care, whereas had long term support from CMHT. Who is going to support me and prevent me from getting ill?
  If not in real/terrible crisis, help takes too long or no help.
  Being reorganised with significant disruption. Being just accepted.

Day services

- **Positive comments**
  Good when they were there.
  Day services could be more flexible and be open to a drop in element.

- **Negative comments**
  Hastings seems to have stopped them.
  Our day service has been closed. No one is doing these activities. People are supposed to go to the voluntary sector but they are not trained adequately.
  Day service did provide important support to get well.
  Concerns about local community mental health services in Hastings as a result of the proposed merger of mental health services into East/West Sussex, Brighton and Hove which could leave Hastings more deprived and isolated than at present.
GPs

- **Positive comments**
  All GPs should be able to have pharmacy in the same building.
  Gateway workers (positive development)
  Some very good and understanding, knowing more aspects of the person.

- **Negative comments**
  Family doctor model is good. Difficult to see GP. Refers on. No continuity.
  GPs need to recognise the range of services they can use and not just resort to clinical treatment/prescriptions.
  Started up a health walk in my area last year and then pulled out leaving it floundering.
  Too short a time allocated to a patient. If you have a mental illness you need more than seven minutes.
  GPs do not have adequate training in looking after people with mental illness, yet we are being discharged back to the GP. Who is going to provide support?
  More flexible booking appointments. My GPs will only give same day appointments.
  Worry that people will be sent back to GP before time/money is given to them.

Social Services

- **Negative comments**
  Services need to be provided all round the clock and not 9 am to 5 pm.
  Many Protection of Vulnerable Adults guidelines are not considered as basic standards. People are being neglected.

Voluntary sector

- **Positive comments**
  Takes on the roles that people will not. Gives people chance to put their points of view.
  Funding needed for a development worker in some towns where there is no Mind development worker.

- **Negative comments**
  Not sufficient funding. Look after very ill people who would be in asylum. But volunteers are not trained to work like this - risk; dangerous.
  The voluntary sector provides services which bridge gaps in those provided by statutory agencies. However, this is often under-funded and resourced. If these voluntary services are to continue their needs must be considered.
Activity 2:
How can people look after themselves? How can we help you to take care of yourself? Discussion of options

a) Encouraging better health eg through regular check ups, advice on healthy lifestyles, promoting self care.

Advice on health
Those giving advice need to listen to people. They shouldn’t pre-empt or assume what is best for people, eg medication, smoking. Advice only goes so far and sometimes does not deal with the realities of life – practical solutions are also needed.

Healthy eating
Participants felt that advice on healthy eating was fine, but it often wasn’t practical. Healthy food is often too expensive. At the time of the meeting, a farmer’s market was taking place in the town, but participants said they couldn’t afford to buy the produce on offer.

Smoking cessation
Participants commented that stopping smoking isn’t always realistic, and many people with mental health problems use it as a way of dealing with stress. General advice on stopping smoking is not likely to be useful, and other ways of dealing with stress are also needed.

Mental well-being should be introduced in schools.
This would need follow up, as it can’t just be covered once. It needs to be revisited throughout the school curriculum. Priorities need to be sustained as initiatives seem to come and go.

More help from GPs
Participants felt GPs should do more to encourage good mental health and should ask about emotional health as standard. This would ensure people who are experiencing depression have more chance of having their symptoms noticed and receiving help. It was felt that there is not enough GP time for people to be able to have regular check-ups.

Mental health at work
Work and employment should help with mental well-being. Employers should have responsibility to reduce stress.

b) Ensuring a range of health professionals such as nurses and pharmacists can provide people with information and support about how to take care of themselves.
Pharmacists providing services

Participants felt pharmacists could provide some advice and this would free up GP time, but this would need a private area in the pharmacy as there are already confidentiality issues about asking for medication or prescriptions in the main shop of a pharmacy where others can overhear. Pharmacists might be able to give some drugs advice, although it was felt strongly that GPs should retain responsibility for prescribing and monitoring drugs taken.

Participants were concerned that some people might go to a pharmacist instead of the doctor, and if they had a serious health problem, this might be overlooked and there could be a delay in getting necessary treatment.

Mental healthcare

Mental health training is needed for practice nurses, GPs and all healthcare workers, and mental health nurses should be employed in primary care practices as this would significantly improve the quality of mental healthcare provided in primary care.

The local Citizens Advice Bureau employed a mental health advisor, and this was found to be very helpful.

c) Tackling the things that cause ill-health and disadvantage by developing new services in the community.

Participants felt strongly that tackling things which cause ill-health eg poverty and housing were important and that services could be expanded in doctors surgeries, although simply improving communication between GPs and other services would also help a great deal.

It was felt it would be massive expense to adequately address issues such as housing, poverty etc. but that the cost would be worth it in the long run due to reduced need for health and other services later.

If there were multiple services available in GP practices, it was felt that initial assessment of needs and referral could be done by practice nurse, but mental health nurses are also needed in primary care. However, there is a shortage of nurses, and this would be a problem delivering this kind of service.

It was felt to be important that where an assessment has taken place, or a doctor has written a letter to another service on a patient’s behalf, this should be acted upon. There should not be multiple assessments eg for benefits as this is very stressful and time consuming.

Providing this kind of joined up service which properly addresses people’s needs constitutes civilisation, and this is what the government should aspire to.

Other developments which would help if expanded

Tackling social exclusion was seen as very important. Examples of good practice given were healthy walks and exercise organised by local groups or primary care trusts. The cost of this is minimal but has great benefit for physical and mental health as well as social inclusion.
Time banks were mentioned as an example of good practice, where individuals share skills within the community.

Special lodgers schemes had been tried in some places, matching up people in need with people willing to give some support. It had been found that this worked in some cases and not in others and needed further investigation.

d) Ensure older people and people with disabilities get practical help and support to stay healthy and independent.

It was felt that there is a great deal of age discrimination in services and older people do not get access to the same range of services as younger people, particularly in mental health. Older people’s mental health needs tend not to be taken seriously.

It was suggested that cheaper taxis should be provided for older people and disabled people as there is no transport in rural areas. There should also be allowances to buy in services which are wider than current direct payments.

Participants had experience of applying for direct payments, and said that they were not used in their area as they were told the money was all tied up already, and the service would not be viable if they were given direct payments. Participants wanted this situation to be addressed.

Activity 3: Voting on options

The participants at the session opted to distribute their 10 votes as follows:

Option a – 1 Lowest priority
Option b - 3
Option c – 4 Top priority
Option d - 2

The views expressed in this document are those of the participants at the session and have not been altered in any way by Mind. Views expressed are not necessarily the policy position of Mind.
YOUR HEALTH, YOUR CARE, YOUR SAY
FEEDBACK FORM FOR LOCAL LISTENING EXERCISES
Thank you for your help with *your health, your care, your say*.

This feedback form is intended for both local and national organisations or groups to report on the findings their own devolved listening exercise as part *your health, your care, your say*.

Can I check, are you responding to this questionnaire as:

- A local organisation or group ✔
- A national organisation or group
- Other (record details below)

All the information you submit will be analysed alongside the public’s response and the views obtained from other local and national organisations and groups and will feed in to the development of plans for improving community health and care services.

Please note the feedback form is in three parts:

- Section A: Why do community health and social care services matter to the nation as a whole?
- Section B: what do you think of the suggestions for improving health and social care services?
- Section C: details about your organisation and your listening exercise

If you haven’t covered Section A or all of the options under Section B, please just leave those questions blank.

Please make sure that you give us this feedback by 4th November, or earlier if possible. You can find out where to return this feedback by referring to the resource pack website, [www.yoursayresources.nhs.uk](http://www.yoursayresources.nhs.uk).

As you will see, most questions ask you to tick a box like this:

*Tick one box only* 

Other questions give you space to record how you reached your decisions:

Please feel free to write as much, or as little, as you like.
Section A: Why do community health and social care services matter to the nation as a whole?

We want to make community-based health and social care services better for everyone. To help us reach the right decisions, we want to know what the people at the listening exercises you ran thought about community-based health and social care services at the moment.

Q1. What did people think were the five main reasons why community health and social care matter to the nation as a whole?

(RECORD BELOW IN PRIORITY ORDER)

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td></td>
</tr>
<tr>
<td>2</td>
<td></td>
</tr>
<tr>
<td>3</td>
<td></td>
</tr>
<tr>
<td>4</td>
<td></td>
</tr>
<tr>
<td>5</td>
<td></td>
</tr>
</tbody>
</table>

RECORD BELOW WHY PEOPLE THOUGHT THESE WERE IMPORTANT:
We are committed to helping people take better care of themselves, but big questions remain about how it can best do this.

...Thinking about how the NHS, Social Care and other services might help people to look after themselves more...

Q2. Which of the following did people at the listening exercises you ran think should be the top three priorities? (Please rank by writing 1, 2 or 3 in the boxes)

- Promoting and supporting better health, for example through routine check ups, advice on healthy lifestyles and promoting self-care and self-assessment.

- Ensuring a range of health professionals, such as nurses and pharmacists, can provide people with information and support about how to take better care of themselves and their families.

- Tackling the things that cause ill health and disadvantage, such as poverty and poor housing, by developing new services in the community and by expanding the range of services available in doctors’ surgeries (eg providing jobs and skills advice), children’s centres and other locations.

- Ensuring older people and those with disabilities can get the practical help and support they need to remain independent and active for longer

- None of the above

- Don’t know

PLEASE SUMMARISE WHY PEOPLE SELECTED THESE PRIORITIES:

See Question 8
Q3. What else would people like the NHS, Social Care and other services to do to help people take better care of themselves?

<table>
<thead>
<tr>
<th>Long term conditions</th>
</tr>
</thead>
<tbody>
<tr>
<td>From MS patient: more as and when support from specialist team, ability to self refer, day care (not elderly care) and appropriate respite care (home or hospice) when needed.</td>
</tr>
<tr>
<td>From Parkinson’s Disease Society (9): need help with wide range of everyday needs, ie cooking, cleaning, help to get in and out of bed; only some get enough Home Care Service help and opportunities to attend day centre; more help needed to give carers a break.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Physical disability</th>
</tr>
</thead>
<tbody>
<tr>
<td>Help to maintain independence by supplying relevant information; help with finding a suitable, affordable place to live.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Sensory disability</th>
</tr>
</thead>
<tbody>
<tr>
<td>RNID: routine medical examinations on request; for GPs and nurses to have more time to spend with patients; access to ‘Alternative Therapies’.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Learning disability</th>
</tr>
</thead>
<tbody>
<tr>
<td>From outreach day service users: more support with everyday life, cleaning, shopping, laundry; more information through workshops, speakers on how to stay healthy.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>General public</th>
</tr>
</thead>
<tbody>
<tr>
<td>Plenty of information available after cardiac treatment in the way of literature, but there should be more preventative education. A need for more cholesterol, blood pressure and diabetes checks. Call for walk in clinics in convenient locations in towns and villages. Existing services need better advertising.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Residents Group, Care Home</th>
</tr>
</thead>
<tbody>
<tr>
<td>Would like routine check-ups to be regularly available and properly promoted. Also would like some talks about keeping healthy.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Prisoners &amp; Prisoners’ Families</th>
</tr>
</thead>
<tbody>
<tr>
<td>Improve preventative health care, better promotion and marketing of the help that is available.</td>
</tr>
<tr>
<td>Improved training for staff to deal with people with long-term illnesses.</td>
</tr>
<tr>
<td>Regular check ups and advice to be made available.</td>
</tr>
</tbody>
</table>

NB: A Health Fair was held in one of the prisons where an adapted questionnaire was used to seek prisoners’ views. Prisons want more information on how to keep themselves healthy and receive more advice and support on exercise and physical activity. They are keen to receive regular check ups to monitor cholesterol, blood pressure etc. At the health fair prisoners took advantage of the testing that was on offer.

A number of prisoners commented that access to medication is very restrictive and waiting times in queues can be frustrating.
We want to make sure people have access to the services they want, when they want them, where they want them and from whom they want them. But to do this there are some tough choices to be made.

**...Thinking about how the NHS and Social Care and other services might improve how, when, where and from whom community-based services are delivered...**

Q4. Which of the following did the people at the listening exercises you ran think should be top three priorities? (Please rank by writing 1, 2 or 3 in the boxes)

- Providing convenient services which fit around people’s lives, for example by extending opening hours to evenings and weekends at the local GP practice, pharmacy and other community services

- Providing care in convenient locations (for example NHS Walk in Centres near train stations so people can get quick advice on problems and health issues on their way to work) or allowing people to register with any family Doctor, not just one where you live

- Developing and providing more services in the local community, rather than only in hospitals, so they are more convenient for families and children to use

- Developing new services for people who don’t always currently access care, such as people from black and minority ethnic groups and teenagers

- Allowing people to choose how to receive services at the end of life and to die where they want with dignity.

- None of the above

- Don’t know

PLEASE SUMMARISE WHY PEOPLE SELECTED THESE PRIORITIES:

See Question 8
Q5. What else would people like the NHS, Social Care and other services to do in terms of how, when, where and from whom community-based services are delivered?

<table>
<thead>
<tr>
<th>Long-Term Conditions</th>
</tr>
</thead>
<tbody>
<tr>
<td>From MS sufferer: would like services provided by an MS specialist; needed at home or as near to home as possible; easily accessible information from GP, NHS clinics, health &amp; social care, libraries and other outlets.</td>
</tr>
<tr>
<td>From Parkinson’s Disease Society: wide range of specialists needed to meet all needs; night-time respite care is needed, but carers fear the temporary carer which might be used do not understand the needs of the patient.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Physical disability</th>
</tr>
</thead>
<tbody>
<tr>
<td>Make more arrangements for carers to have a break; often no support provided and can’t afford agencies; generally good help received from social services in providing lots of aids to enable independence.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Sensory disability</th>
</tr>
</thead>
<tbody>
<tr>
<td>RNID: greatest need is seeing the GP of choice and GPs to be available on Saturdays; outsource some services to private companies such as audiology and physiotherapy; provide loop systems in all surgeries and hospital consultation rooms.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Learning disability</th>
</tr>
</thead>
<tbody>
<tr>
<td>From outreach day service users: would like support in own homes to maintain independence; provide transport for hospital visits; introduce a free careline service for the disabled and elderly living alone; more local respite care services.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>General public</th>
</tr>
</thead>
<tbody>
<tr>
<td>Better and quicker liaison between GP and hospital following treatment in hospital. More thorough follow-up by the GP.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Residents Group/Care Home</th>
</tr>
</thead>
<tbody>
<tr>
<td>A reduction in waiting times for outpatients is needed.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Prisoners &amp; prisoners families</th>
</tr>
</thead>
<tbody>
<tr>
<td>One point of contact for all services and ongoing personal health care advisers needed.</td>
</tr>
<tr>
<td>Better co-ordination between health care and social services. Health care should be advising social services of potential problems to help get more help, faster.</td>
</tr>
<tr>
<td>Services need to be provided by appropriately trained staff.</td>
</tr>
<tr>
<td>NB: A Health Fair was held in one of the prisons where an adapted questionnaire was used to seek prisoners’ views. Generally prisoners felt access to the healthcare centre was good but would like access to a GP in 24 hours and extended times for access, for example on a Saturday.</td>
</tr>
</tbody>
</table>
We want people to be able to use and find their way through health and social care services more easily. We also want these services to be ‘joined up’, even if several people or organisations are providing them.

...Thinking about how the NHS, Social Care and other services might help people find the services they need and improve the way these services are joined up ...

Q6. Which of the following did people at the listening exercises you ran think should be the top three priorities? (Please rank by writing 1, 2 or 3 in the boxes)

- Providing effectively joined-up social care and health services to those that need them, for example through a single ‘needs assessment’. A ‘needs assessment’ would be one appointment to discuss a whole range of services instead of lots of individual appointments.

- Providing people with better information about what NHS, local authority and social care services are on offer

- Improving the availability, quality and choice of services for long-term care users and people with long-term illnesses like diabetes.

- None of the above

- Don’t know

PLEASE SUMMARISE WHY PEOPLE SELECTED THESE PRIORITIES:

See Question 8.
Q7. What else would people like the NHS, Social Care and other services to do to help people find the services they need and improve the way these services are joined up?

**Long Term Condition**

MS sufferer: automatic single assessment for all patients and carers; services located in one place ‘one stop shop’ and preferably in a non-clinical setting; a specialist professional eg a MS specialist nurse to co-ordinate services; training and support for carers.

From Parkinson’s Disease Society: education to all levels of care staff about nature of Parkinsons; more advise on symptom control and latest medication is a high priority; only one Parkinson Nurse Specialist, no coverage when she is away, 2nd PDNS needed; more access to therapy services; respite care at home desperately needed by well-informed carer.

**Physical disability**

More information at GP surgery and on a website; easier access to relevant information; directions from GP surgery as to where to go to get necessary help.

**Sensory disability**

RNID: more follow up is need following consultation to see whether treatment or aids (provided by different agencies) are improving patient’s life.

**Learning disability**

From outreach day service users: need 24 hour contact numbers for emergencies; regular meetings should take place between all support providers to access individual needs are met; work across agencies to provide more social housing to allow those with learning disability to live more independently, ie self-contained flat with staff support; more information on who to ask for help; more as and when help across services.

**Residents Group/Care Home**

The group felt that choices about accessing health services were made by the home’s managers, rather than by themselves. This may be because the group is elderly, and therefore deferential, but may also be a problem in care homes generally.

**Prisoners & Prisoners’ Families**

Request for named personal health care manager who takes ownership of individual and families health care issues and provides information. Improved lines of communication needed.

Specialist advisers for disabled people to help bridge the gap between health care and social services.

Prisoner comments that when at home he receives very good service, regular monitoring and supervision from social services and district nurses but this care is not continued and he receives no support for his specific physical and mental disabilities whilst in prison.

NB: A Health Fair was held in one of the prisons where an adapted questionnaire was used to seek prisoners’ views. Two prisoners felt that there could be better continuity of care from health and social services between prison and return to the community.
Q8. Looking across all the options we have asked about what are the top five priorities for the people at the listening exercises you ran? (Please write 1, 2, 3, 4, 5 in the boxes)

**Analysis from Questionnaires**

Promoting and supporting better health, for example through routine check ups, advice on healthy lifestyles and promoting self-care and self-assessment.

Ensuring a range of health professionals, such as nurses and pharmacists, can provide people with information and support about how to take better care of themselves and their families.

Tackling the things that cause ill health and disadvantage, such as poverty and poor housing, by developing new services in the community and by expanding the range of services available in doctors’ surgeries (eg providing jobs and skills advice), children’s centres and other locations.

Ensuring older people and those with disabilities can get the practical help and support they need to remain independent and active for longer

Providing convenient services which fit around people’s lives, for example by extending opening hours to evenings and weekends at the local GP practice, pharmacy and other community services

Providing care in convenient locations (for example NHS Walk in Centres near train stations so people can get quick advice on problems and health issues on their way to work) or allowing people to register with any family Doctor, not just one where you live

Developing and providing more services in the local community, rather than only in hospitals, so they are more convenient for families and children to use

Developing new services for people who don’t always currently access care, such as people from black and minority ethnic groups and teenagers
Allowing people to choose how to receive services at the end of life and to die where they want with dignity.

Providing effectively joined-up social care and health services to those that need them, for example through a single 'needs assessment'. A 'needs assessment' would be one appointment to discuss a whole range of services instead of lots of individual appointments.

Providing people with better information about what NHS, local authority and social care services are on offer

Improving the availability, quality and choice of services for long-term care users and people with long-term illnesses like diabetes.

Please note that the above areas 1 – 4 were mentioned in almost equal numbers as a priority by those completing the questionnaire.
Q9. Why were these their five top priorities?

Analysis taken from questionnaires only.
E. WHAT ELSE SHOULD THE NHS, SOCIAL CARE AND OTHER SERVICES BE DOING?

Q10. Below we provide a space for you to tell us about anything else which came up in the listening exercises you ran which will help us understand what people think should be done to make health and social care services better for everyone?

**PLEASE WRITE IN:**

From discussion with prisoners

One of the main areas of concern is the reliance upon the prison service to ensure that prisoners can access health care without this adversely affecting other people in the prison eg if someone on a wing has to go to hospital the wing would be 'locked down' because of the staffing arrangements.

There is also, it appears, a perception amongst some health staff that the prison service can not resource prison staff to accompany people to hospital and this influences the decisions made about health care.

Prisoners in older prisons (applies to two in area) have no, or very limited, access to outside space, fresh air, exercise, green space restricting the ability of prisoners to help look after their own health.
Section C: details about your organisation and your listening exercises

To help us analyse the information you have given us, we need to find out a little bit more about your organisation and your listening exercise.

A. How many people took part in your devolved listening exercises?

<table>
<thead>
<tr>
<th></th>
<th>Write in below</th>
</tr>
</thead>
<tbody>
<tr>
<td>Care home residents group (notes of meeting)</td>
<td>2 groups from Outreach Day Centres (notes of meeting)</td>
</tr>
<tr>
<td>28 full questionnaire returns from RNID</td>
<td>Meeting of 9 Parkinson’s Disease Society Members (notes of meeting)</td>
</tr>
<tr>
<td>6 short style and 22 adapted questionnaires from prisoners or their families at two prisons, and notes from discussions.</td>
<td>8 short style questionnaires received (Long term conditions, physical disabilities and other)</td>
</tr>
</tbody>
</table>

B. What sort of listening exercise was it?

(Please tick one box only)

- A day long session (from 5 to 8 hours long)
- A half day session (from 3 to 5 hours long)
- Up to 3 hours long
- Other (record below) ✗

Discussions took place through existing meetings of organisations and groups
Distribution, collection and analysis of short and full questionnaires and adapted questionnaires for prison populations.

C. How many of each of the following types of people took part in your listening exercise?

(Please put a number in each box even if it is zero)

- Members of the general public (i.e. with no specialist interest in health and social care)
- Members of the public who are involved with health and social care services e.g. PPI forum members
- Paid staff from your organisation
- Voluntary staff from your organisation
- Other (record below)
D. And now please tell us how many of the people who took part – whether members of the public or staff - were from any of the specific sectors of the population listed below.

(Please put a number in each box even if it is zero)

<table>
<thead>
<tr>
<th>Sector</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Children and young people</td>
<td></td>
</tr>
<tr>
<td>Older people</td>
<td></td>
</tr>
<tr>
<td>Pregnant women (and their partners)</td>
<td></td>
</tr>
<tr>
<td>Socially disadvantaged people</td>
<td></td>
</tr>
<tr>
<td>Disadvantaged children</td>
<td></td>
</tr>
<tr>
<td>Smokers</td>
<td></td>
</tr>
<tr>
<td>Excessive drinkers</td>
<td></td>
</tr>
<tr>
<td>Obese people</td>
<td></td>
</tr>
<tr>
<td>Substance misusers</td>
<td></td>
</tr>
<tr>
<td>Disabled people</td>
<td>6</td>
</tr>
<tr>
<td>Prisoners</td>
<td>28</td>
</tr>
<tr>
<td>Black and minority ethnic groups (GO TO QE)</td>
<td></td>
</tr>
<tr>
<td>Travellers</td>
<td></td>
</tr>
<tr>
<td>Homeless people</td>
<td></td>
</tr>
<tr>
<td>People with mental health problems</td>
<td></td>
</tr>
<tr>
<td>People with learning disabilities</td>
<td></td>
</tr>
<tr>
<td>People in hospices/residential care</td>
<td></td>
</tr>
<tr>
<td>Asylum seekers</td>
<td></td>
</tr>
<tr>
<td>People with long term conditions</td>
<td>9 + 2</td>
</tr>
<tr>
<td>People with caring responsibilities</td>
<td></td>
</tr>
<tr>
<td>Other (record below)</td>
<td></td>
</tr>
<tr>
<td>RNID – 28</td>
<td></td>
</tr>
</tbody>
</table>
E. You said that some of the people who took part in your listening event were from a specific ethnic group. Please tell us how many were from each of the groups listed below:

(Please put a number in each box even if it is zero)

White British
White Irish
Any other white background
White and Black Caribbean
White and Black African
White and Asian
Any other mixed background
Indian
Pakistani
Bangladeshi
Any other Asian Background
Caribbean
African
Any other Black background
Chinese

Information not recorded

E. Which of the following best describes the sector to which your organisation or group belongs / where you work:

(Please tick one box only)

- PPI forum or other patient group
- Community-based NHS services ✓
- Local authority social care services
- Private sector health or social care services
- Voluntary sector health or social care services
- Other (record below)
If your listening exercises mostly involved staff rather than patients or service users please can you identify from the list below which groups they most often have contact with or provide services for: N/A

(Please tick all relevant boxes)

<table>
<thead>
<tr>
<th>Group</th>
<th>Box</th>
</tr>
</thead>
<tbody>
<tr>
<td>Children and young people</td>
<td></td>
</tr>
<tr>
<td>Older people</td>
<td></td>
</tr>
<tr>
<td>Pregnant women (and their partners)</td>
<td></td>
</tr>
<tr>
<td>Socially disadvantaged people</td>
<td></td>
</tr>
<tr>
<td>Disadvantaged children</td>
<td></td>
</tr>
<tr>
<td>Smokers</td>
<td></td>
</tr>
<tr>
<td>Excessive drinkers</td>
<td></td>
</tr>
<tr>
<td>Obese people</td>
<td></td>
</tr>
<tr>
<td>Substance misusers</td>
<td></td>
</tr>
<tr>
<td>Disabled people</td>
<td></td>
</tr>
<tr>
<td>Prisoners</td>
<td></td>
</tr>
<tr>
<td>Black and minority ethnic groups (GO TO QE)</td>
<td></td>
</tr>
<tr>
<td>Travellers</td>
<td></td>
</tr>
<tr>
<td>Homeless people</td>
<td></td>
</tr>
<tr>
<td>People with mental health problems</td>
<td></td>
</tr>
<tr>
<td>People with learning disabilities</td>
<td></td>
</tr>
<tr>
<td>People in hospices/residential care</td>
<td></td>
</tr>
<tr>
<td>Asylum seekers</td>
<td></td>
</tr>
<tr>
<td>People with long term conditions</td>
<td></td>
</tr>
<tr>
<td>People with caring responsibilities</td>
<td></td>
</tr>
<tr>
<td>Other (record below)</td>
<td></td>
</tr>
</tbody>
</table>
If you would like your organisation to be listed as a contributor to the consultation, please record its name below:

NAME OF ORGANISATION

South West Dorset Primary Care Trust

If you would like to receive a copy of the summary of our findings, please tell us what format you would like it and give us your contact details:

EMAIL
ADDRESS:
YOUR HEALTH, YOUR CARE, YOUR SAY
FEEDBACK FORM FOR LOCAL LISTENING EXERCISES
Thank you for your help with your health, your care, your say.

This feedback form is intended for both local and national organisations or groups to report on the findings their own devolved listening exercise as part your health, your care, your say.

Can I check, are you responding to this questionnaire as:

- A local organisation or group [X]
- A national organisation or group
- Other (record details below)

All the information you submit will be analysed alongside the public’s response and the views obtained from other local and national organisations and groups and will feed into the development of plans for improving community health and care services.

Please note the feedback form is in three parts:

- Section A: Thinking about the community health and social care services people use, what currently works less well?
- Section B: what do you think of the suggestions for improving health and social care services?
- Section C: details about your organisation and your listening exercise

If you haven’t covered Section A or all of the options under Section B, please just leave those questions blank.

Please make sure that you give us this feedback by 4th November, or earlier if possible. You can find out where to return this feedback by referring to the resource pack website, www.yoursayresources.nhs.uk

As you will see, most questions ask you to tick a box like this:

*Tick one box only*

Other questions give you space to record how you reached your decisions:

Please feel free to write as much, or as little, as you like.
Section A: Thinking about the community health and social care services people use, what currently works well, and what currently works less well?

We want to make community-based health and social care services better for everyone. To help us reach the right decisions, we want to know what the people at the listening exercises you ran thought about community-based health and social care services at the moment.

Q1. What were the three key elements of community health and social care services that people though worked well? 

(RECORD BELOW IN PRIORITY ORDER)

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Qualified specialists providing services in the community</td>
</tr>
<tr>
<td>2</td>
<td>Highly skilled and trained staff when available</td>
</tr>
<tr>
<td>3</td>
<td>Once through the system people felt that the service was generally good – especially from those in 1 and 2</td>
</tr>
</tbody>
</table>

(RECORD BELOW WHY PEOPLE THOUGHT THESE WORKED WELL:)

The three consultation events were not asked to work through the elements of services which are currently working well. The list above reflects information shared. However, the 2 learning disabilities groups said that having access to specialist services was good – not all health professionals understand the needs of people with learning disabilities. One of the learning disability groups also said that they liked the support and care they received from their Day Centre and wanted that to continue. They also thought the service they got from their Short breaks (Respite) service was good.

It was also felt that Case Managers who personally support individuals with long term and complex conditions and the Expert Patient Programme were good examples of new local services.
What were the three key elements of community health and social care services that people thought worked less well?

**RECORD BELOW IN PRIORITY ORDER**

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Appointment systems at GP Practices</td>
</tr>
<tr>
<td>2</td>
<td>Social Care and Health and South Birmingham PCT not working well together</td>
</tr>
<tr>
<td>3</td>
<td>NHS Direct – there were mixed views on experience but it was clear one stop shop approaches need to be local and personal.</td>
</tr>
</tbody>
</table>

**RECORD BELOW WHY PEOPLE THOUGHT THESE WORKED LESS WELL:**

We did not ask people attending to rank these issues in any order, but these are the three areas that generated the most discussion and where people raised the most concerns.

People found it difficult to make a GP appointment – the current system requires patients to telephone early in the morning to get an appointment. Many people said that by the time they get through to the Practice there are no appointments left for that day.

People said that because Social Care and Health and South Birmingham PCT don’t work well together, there are long waits for those patients who require a social worker. Others wanted help in filling in benefits forms etc and one suggestion included expanding the role of the Choose and Book Facilitator to include this.

Some people said that they found NHS Direct to be ineffective and felt that it could not replace personalised care. One person said ‘I see these sorts of services as leading to a private NHS’. Positive comments included ‘technology has its place, lives can be saved if its used properly’ ‘It's early days yet, I see it improving over the next few years’.

One of the learning disability groups said that they thought that hospital signage was not good enough, and that they want hospitals to have clearer signs with symbols/pictures to help people with learning disabilities find their way around hospitals easily.

There was an emphasis on local approaches to one-stop shops and any emerging new centres should not compromise existing local services. People still want access to a local GP although a range of services under one roof is a benefit, more personal care and continuity is required.
What other issues did people mention? Please record any personal stories here if possible

Many people talked about information that is available for patients. Information needs to be given to people in plain language so that it can be understood. The learning disabilities consultation group said that easy words and pictures are really important.

As well as links to Social Care there was a general view that health services needed to be more co-ordinated for the patient and that help was required to support people through the system.

A number of participants felt that particular attention needed to be paid to disabled people and older people.
Section B: what did people think of the suggestions for improving health and social care services?

We are committed to helping people take better care of themselves, but big questions remain about how it can best do this.

...Thinking about how the NHS, Social Care and other services might help people to look after themselves more...

Q2. Which of the following did people at the listening exercises you ran think should be the top three priorities? (Please rank by writing 1, 2 or 3 in the boxes)

Encouraging and supporting better health, for example through routine check ups, advice on healthy lifestyles and promoting self-care and self-assessment.

Ensuring a range of health professionals, such as nurses and pharmacists, can provide people with information and support about how to take better care of themselves and their families. For instance pharmacists could give advice on getting the best out of the medicines you take or they could run clinics for people with high blood pressure.

Tackling the things that cause ill health and disadvantage, such as poverty and poor housing, by developing new services in the community and by expanding the range of services available in doctors’ surgeries (eg advisors to help with housing, employment and training and benefits), children’s centres and other locations.

Ensuring older people and those with disabilities can get the practical help and support they need to remain independent and active for longer

None of the above

Don’t know
Participants were not asked to rank these specific issues as we tried to give people more of a free choice to select the issues they felt important. The issues listed on the previous page were mentioned by participants.

People said that routine check-ups would be beneficial, but some people expressed concern that GP surgeries are not as accountable to patients as they should be. People supported the idea of a single assessment, but said that they wanted local services, with more services being available in the GP Practice. There was broad support for X-rays and minor injury clinics being available outside of hospitals, as long as standards of care remain high and clinics are easily accessible.

There was discussion about who would assess health and many were open to other professionals providing this but with the proviso that they were well trained. Some raised concern at seeing someone other than their GP based on their experience.

Promoting health rather than simply treating sickness is a key change that many want to see in a modern NHS. A popular suggestion was to provide information about fitness, nutrition and advice on healthy lifestyle.

People said that ‘self management is fine but there are times when you need to get hold of a GP and they are not available over the weekend’

‘Drop-in centres are too far away and GP Practice opening times are not convenient’. The more opportunities there are for check-ups and screenings, the more cost – effective it will be in the long term’.

‘More practical help and advice would go a long way’.

‘Training for carers would be a good idea’.

‘Free health checks for everyone’.

‘Build more links with fitness centres to get the message across about exercise’.

‘Information should be targeted at young people in schools and youth centres and via informal links with education colleges’.

‘People in care homes have difficulty keeping fit. Most of the time they are immobile’.

Access to information was a priority for most people – too much use of jargon, and more information about health and nutrition and exercise would help people to recover from illness.

Concern was expressed about people with mental health problems. ‘People are falling through the net because of lack of support’, ‘more investment is needed in this areas’, ‘counselling services are very limited and waiting times for treatment are long’.
Q3. Did people think it would be enough for Government to only do these things to help people take better care of themselves? Why?

No, other matters were mentioned – see Q4

<table>
<thead>
<tr>
<th>Q4. What else would people like the Government to do to help people take better care of themselves?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Provide easier access to exercise</td>
</tr>
<tr>
<td>Keep services local – people said they don’t want to travel far to access services</td>
</tr>
<tr>
<td>Provide transport for those who need it</td>
</tr>
<tr>
<td>Services to be provided by ‘those who are best at doing it’ i.e. specialists.</td>
</tr>
<tr>
<td>‘More training for health professionals re learning disabilities’</td>
</tr>
<tr>
<td>The learning disabilities group said they wanted ‘more centres with a drop-in service to maintain contact with friends, do activities etc’, ’more staff in day centres’.</td>
</tr>
<tr>
<td>’24 hour support if it's needed’</td>
</tr>
<tr>
<td>The learning disabilities group said that they want more social workers and people who know about learning disabilities.</td>
</tr>
<tr>
<td>Targeted services for older people, because their health needs are different.</td>
</tr>
<tr>
<td>‘Incentives aren’t needed for people with long term conditions, but exercise on prescription is good’.</td>
</tr>
<tr>
<td>Learning disabled people want to have regular health checks and plans that tell them what to do to stay healthy.</td>
</tr>
<tr>
<td>More information about health and health services in the media and more information about treatments available.</td>
</tr>
<tr>
<td>More support for carers, and more staff in day services.</td>
</tr>
</tbody>
</table>
We want people to be able to use and find their way through health and social care services more easily. We also want these services to be ‘joined up’, even if several people or organisations are providing them.

...Thinking about how the NHS, Social Care and other services might help people find the services they need and improve the way these services are joined up ...

Q5. Which of the following did people at the listening exercises you ran think should be the top three priorities? (Please rank by writing 1, 2 or 3 in the boxes)

- Providing effectively joined-up social care and health services to those that need them, for example through a single ‘needs assessment’. A ‘needs assessment’ would be a kind of one-stop-shop appointment instead of lots of appointments. A case manager would be someone who plans your care with you and then coordinates it.

- Providing more help to people caring for others, for example with more respite care

- Providing people with better information about what NHS, local authority and social care services are on offer

- Improving the availability, quality and choice of services for long-term care users and people with long-term illnesses like diabetes e.g. support from people with similar conditions

Please summarise why people selected these priorities:

Participants were not asked to rank these specific issues as we tried to give people more of a free choice to select the issues they felt important.

All four of the above issues were felt to be important by participants

People said that problems were caused by health and social care and health not working together and by not having enough social workers.

People said there were not enough breaks for carers, and carers should be offered training so that they could care better.
People said information needed to be available in plain language, not full of jargon, and that forms needed to be easier to fill in and shorter.

Hospitals have a role for people with long-term conditions and disabilities, and people in nursing and care homes need access to services e.g. physiotherapy.

There need to be closer links between GP’s and Community Hospitals.
Q6. Did people think it would be enough for Government to only do these things to help people manage their care and make decisions?

No, they identified additional issues – see Q7

Q7. What else would people like the Government to do to help people manage their care and make decisions?

People said there was a fear about benefits – if you apply for one benefit then you lose another benefit you already receive. They said there was no clear advice about this.

WHEN YOU AND YOUR FAMILY NEED HELP AND SUPPORT, HOW, WHEN, WHERE AND FROM WHOM DO YOU WANT IT?

We want to make sure people have access to the services they want, when they want them, where they want them and from whom they want them. But to do this there are some tough choices to be made.

...Thinking about how the NHS and Social Care and other services might improve how, when, where and from whom community-based services are delivered...

Q8. Which of the following did the people at the listening exercises you ran think should be top three priorities? (Please rank by writing 1, 2 or 3 in the boxes)

Providing convenient services which fit around people’s lives, for example by extending opening hours to evenings and weekends at the local GP practice, pharmacy and other community services, by enabling people who receive care at home to choose for example when the carer visits

Providing care in convenient locations (for example NHS Walk in Centres near train stations so people can get quick advice on problems and health issues on their way to work) or allowing people to register with any family Doctor, not just one where you live
Developing and providing more services in the local community, rather than only in hospitals, so they are more convenient for families and children to use. For example, blood tests, x-rays and some scans, minor surgery and physiotherapy could be provided locally. Also, hospital specialists could run clinics in the community.

Developing new services for people who don’t always currently access care, such as young men, teenagers, people from different ethnic groups, people with disabilities.

Allowing people to choose how to receive services at the end of life and to die where they want with dignity. (This option is about the care people receive at the end of their lives, it is not about euthanasia)

None of the above
Don’t know

PLEASE SUMMARISE WHY PEOPLE SELECTED THESE PRIORITIES:

Participants were not asked to rank these specific issues as we tried to give people more of a free choice to select the issues they felt important.

Participants mentioned the issues on the previous page, except for the last one.
Some people raised the idea that GP and Dentist Practice hours are extended to evenings and weekends, but more were concerned with improving the appointment arrangements for the current opening hours. There was a range of experience of different appointment systems, but on balance that a mix of appointments and open Practice time.
There were some negative comments about NHS Direct and about NHS Walk-in Centres. See previous sections.

When discussing targeted services some felt that this was only appropriate to provide targeted services where we know there are issues regarding access. More work on ensuring the general service is available to all the population is required. It was also emphasised that services could be taken to specific groups – young people in schools and older people in care homes for example.
One idea was to offer health checks and assessments in varied settings to target specific groups. This is done but only through specific initiatives and events rather than part of planned services.

Providing scans and assessments in community locations was favoured in the discussion but only if the professionals have the right equipment and resources to provide the service. Those taking part did not want to lose specialism and expertise.
Q9. Did people think it would be enough for Government to only do these things to help provide service how, where, when and from whom people want them? Why?

No, they felt there were other issues as outlined in previous sections.

Q10. What else would people like the Government to do to help provide services how, where, when and from whom people want them?
Q11. Looking across all the options we have asked about, which of these did your group think was the most important thing to be done immediately?

Encouraging and supporting better health, for example through routine check ups, advice on healthy lifestyles and promoting self-care and self-assessment.

Ensuring a range of health professionals, such as nurses and pharmacists, can provide people with information and support about how to take better care of themselves and their families. For instance pharmacists could give advice on getting the best out of the medicines you take or they could run clinics for people with high blood pressure.

Tackling the things that cause ill health and disadvantage, such as poverty and poor housing, by developing new services in the community and by expanding the range of services available in doctors’ surgeries (eg advisors to help with housing, employment and training and benefits), children’s centres and other locations.

Ensuring older people and those with disabilities can get the practical help and support they need to remain independent and active for longer.

Providing effectively joined-up social care and health services to those that need them, for example through a single ‘needs assessment’. A ‘needs assessment’ would be a kind of one-stop-shop appointment instead of lots of appointments. A case manager would be someone who plans your care with you and then coordinates it.

Providing more help to people caring for others, for example with more respite care.

Providing people with better information about what NHS, local authority and social care services are on offer.
Improving the availability, quality and choice of services for long-term care users and people with long-term illnesses like diabetes e.g. support from people with similar conditions

Providing convenient services which fit around people’s lives, for example by extending opening hours to evenings and weekends at the local GP practice, pharmacy and other community services, by enabling people who receive care at home to choose for example when the carer visits

Providing care in convenient locations (for example NHS Walk in Centres near train stations so people can get quick advice on problems and health issues on their way to work) or allowing people to register with any family Doctor, not just one where you live

Developing and providing more services in the local community, rather than only in hospitals, so they are more convenient for families and children to use. For example, blood tests, x-rays and some scans, minor surgery and physiotherapy could be provided locally. Also, hospital specialists could run clinics in the community.

Developing new services for people who don’t always currently access care, such as young men, teenagers, people from different ethnic groups, people with disabilities.

Allowing people to choose how to receive services at the end of life and to die where they want with dignity. (This options is about the care people receive at the end of their lives, it is not about euthanasia)
Q12. Please summarise the main reasons why this option was chosen as the key priority?

There was no ranking given to the above and many felt they could not outline one thing. However, more convenient primary care services, joined up health and social care, supporting older people and people with disabilities and providing better information were repeatedly raised.

Q13. Please summarise the main points from the discussion about whether these changes address the things that work less well at the moment, and maintain and support the things that work well at the moment.

The points raised in Q12 are about improving the things that work less well at the moment. Changing access to GP surgeries through appointment booking and hours of opening was an important topic and the experiences shared were varied.
Q14. Please summarise the main points from the discussion about what else the Department of Health should be doing to make sure that community-based health and social care services meet people’s needs in the 21st century?

Key points

Better co-ordination of personal care from a patient view and with much more facilitation across services to ensure access to the right care at the right time. In particular closer working between health and social care.

More accessible transport for people with disabilities and those who find services remote. Ring and ride is not sufficient.

Improved appointment systems for seeing a local GP – flexible to allow people to book in advance and also to be seen quickly if necessary.
Section C: details about your organisation and your listening exercises

To help us analyse the information you have given us, we need to find out a little bit more about your organisation and your listening exercise.

A. How many people took part in your devolved listening exercises?

\[ \text{Write in below} \]

55

B. What sort of listening exercise was it?

(Please tick one box only)

- A day long session (from 5 to 8 hours long)
- A half day session (from 3 to 5 hours long)
- Up to 3 hours long
- Other (record below)

C. How many of each of the following types of people took part in your listening exercise?

(Please put a number in each box even if it is zero)

- Members of the general public (i.e. with no specialist interest in health and social care) 35
- Members of the public who are involved with health and social care services e.g. PPI forum members 10
- Paid staff from your organisation 10
- Voluntary staff from your organisation
- Other (record below)
Much of this information was not collected from participants

<table>
<thead>
<tr>
<th>Sector</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Children and young people</td>
<td></td>
</tr>
<tr>
<td>Older people</td>
<td>10</td>
</tr>
<tr>
<td>Pregnant women (and their partners)</td>
<td></td>
</tr>
<tr>
<td>Socially disadvantaged people</td>
<td></td>
</tr>
<tr>
<td>Disadvantaged children</td>
<td></td>
</tr>
<tr>
<td>Smokers</td>
<td></td>
</tr>
<tr>
<td>Excessive drinkers</td>
<td></td>
</tr>
<tr>
<td>Obese people</td>
<td></td>
</tr>
<tr>
<td>Substance misusers</td>
<td></td>
</tr>
<tr>
<td>Disabled people</td>
<td>25</td>
</tr>
<tr>
<td>People in prison</td>
<td></td>
</tr>
<tr>
<td>Black and minority ethnic groups</td>
<td></td>
</tr>
<tr>
<td>Travellers</td>
<td></td>
</tr>
<tr>
<td>Homeless people</td>
<td></td>
</tr>
<tr>
<td>People with mental health problems</td>
<td></td>
</tr>
<tr>
<td>People with learning disabilities</td>
<td>20</td>
</tr>
<tr>
<td>People in hospices/residential care</td>
<td></td>
</tr>
<tr>
<td>Asylum seekers</td>
<td></td>
</tr>
<tr>
<td>People with long term conditions</td>
<td></td>
</tr>
<tr>
<td>People with caring responsibilities</td>
<td>5</td>
</tr>
<tr>
<td>Other (record below)</td>
<td></td>
</tr>
</tbody>
</table>
E. Of the people that took part in your listening exercise, can you please tell us how many were from each of the ethnic groups listed below

Not recorded

White British
White Irish
Any other white background
White and Black Caribbean
White and Black African
White and Asian
Any other mixed background
Indian
Pakistani
Bangladeshi
Any other Asian Background
Caribbean
African
Any other Black background
Chinese
Rather not say

F. Which of the following best describes the sector to which your organisation or group belongs / where you work:

(Please tick one box only)

PPI forum or other patient group
Community-based NHS services ✔
Local authority social care services
Private sector health or social care services
Voluntary sector health or social care services
Joint event – Community based NHS & LA SSD

G. If your listening exercises mostly involved staff rather than patients or service users please can you identify from the list below which groups they most often have contact with or provide services for:

(Please tick all relevant boxes)

<table>
<thead>
<tr>
<th>Group</th>
<th>Ticked</th>
</tr>
</thead>
<tbody>
<tr>
<td>Children and young people</td>
<td></td>
</tr>
<tr>
<td>Older people</td>
<td></td>
</tr>
<tr>
<td>Pregnant women (and their partners)</td>
<td></td>
</tr>
<tr>
<td>Socially disadvantaged people</td>
<td></td>
</tr>
<tr>
<td>Disadvantaged children</td>
<td></td>
</tr>
<tr>
<td>Smokers</td>
<td></td>
</tr>
<tr>
<td>Excessive drinkers</td>
<td></td>
</tr>
<tr>
<td>Obese people</td>
<td></td>
</tr>
<tr>
<td>Substance misusers</td>
<td></td>
</tr>
<tr>
<td>Disabled people</td>
<td></td>
</tr>
<tr>
<td>People in prison</td>
<td></td>
</tr>
<tr>
<td>Black and minority ethnic groups</td>
<td></td>
</tr>
<tr>
<td>Travellers</td>
<td></td>
</tr>
<tr>
<td>Homeless people</td>
<td></td>
</tr>
<tr>
<td>People with mental health problems</td>
<td></td>
</tr>
<tr>
<td>People with learning disabilities</td>
<td></td>
</tr>
<tr>
<td>People in hospices/residential care</td>
<td></td>
</tr>
<tr>
<td>Asylum seekers</td>
<td></td>
</tr>
<tr>
<td>People with long term conditions</td>
<td></td>
</tr>
<tr>
<td>People with caring responsibilities</td>
<td></td>
</tr>
<tr>
<td>Do not deal with specific sectors of the community</td>
<td></td>
</tr>
</tbody>
</table>
Other (record below)
If you work with specific ethnic groups, which of these groupings do you represent or work with?

- White British
- White Irish
- Any other white background
- White and Black Caribbean
- White and Black African
- White and Asian
- Any other mixed background
- Indian
- Pakistani
- Bangladeshi
- Any other Asian Background
- Caribbean
- African
- Any other Black background
- Chinese
- Do not deal with specific ethnic groups
- Other (record below)
I. If you are a regional organisation, please tick the box below for the region you mainly work in

<table>
<thead>
<tr>
<th>Region</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>North East</td>
<td></td>
</tr>
<tr>
<td>North West</td>
<td></td>
</tr>
<tr>
<td>Yorkshire &amp; the Humber</td>
<td></td>
</tr>
<tr>
<td>East Midlands</td>
<td></td>
</tr>
<tr>
<td>East of England</td>
<td></td>
</tr>
<tr>
<td>South East</td>
<td></td>
</tr>
<tr>
<td>London</td>
<td></td>
</tr>
<tr>
<td>South West</td>
<td></td>
</tr>
<tr>
<td>National Organisation</td>
<td></td>
</tr>
<tr>
<td>Not applicable</td>
<td></td>
</tr>
</tbody>
</table>

J. What is the name of your organisation?

South Birmingham Primary Care Trust

K. What type of organisation are you responding as?

<table>
<thead>
<tr>
<th>Type of Organisation</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>A local organisation</td>
<td>✓</td>
</tr>
<tr>
<td>A national organisation</td>
<td></td>
</tr>
<tr>
<td>Other (please record below)</td>
<td></td>
</tr>
</tbody>
</table>
L. Would like to be listed as a contributor to the consultation?

<table>
<thead>
<tr>
<th>Yes</th>
<th>✓</th>
</tr>
</thead>
<tbody>
<tr>
<td>No</td>
<td></td>
</tr>
</tbody>
</table>

K. If you would like to receive a summary of our findings, please enter your contact details or email address in the box below:

Stephanie.Belgeonne@sbpct.nhs.uk
YOUR HEALTH, YOUR CARE, YOUR SAY
FEEDBACK FORM FOR LOCAL LISTENING EXERCISES
Thank you for your help with *your health, your care, your say*.

This feedback form is intended for both local and national organisations or groups to report on the findings their own devolved listening exercise as part *your health, your care, your say*.

Can I check, are you responding to this questionnaire as:

- A local organisation or group [√ ]
- A national organisation or group
- Other (record details below)

All the information you submit will be analysed alongside the public’s response and the views obtained from other local and national organisations and groups and will feed in to the development of plans for improving community health and care services.

Please note the feedback form is in three parts:

- Section A: Thinking about the community health and social care services people use, what currently works less well?
- Section B: what do you think of the suggestions for improving health and social care services?
- Section C: details about your organisation and your listening exercise

If you haven’t covered Section A or all of the options under Section B, please just leave those questions blank.

Please make sure that you give us this feedback by 4th November, or earlier if possible. You can find out where to return this feedback by referring to the resource pack website, [www.yoursayresources.nhs.uk](http://www.yoursayresources.nhs.uk)

As you will see, most questions ask you to tick a box like this:

*Tick one box only* [ ]

Other questions give you space to record how you reached your decisions:

Please feel free to write as much, or as little, as you like.
Section A: Thinking about the community health and social care services people use, what currently works well, and what currently works less well?

We want to make community-based health and social care services better for everyone. To help us reach the right decisions, we want to know what the people at the listening exercises you ran thought about community-based health and social care services at the moment.

Q1. What were the three key elements of community health and social care services that people though worked well?

(RECORD BELOW IN PRIORITY ORDER)

<table>
<thead>
<tr>
<th></th>
<th>Local community hospital/ minor injury unit / health services</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Family planning services</td>
</tr>
<tr>
<td>2</td>
<td>Voluntary sector support services (Red Cross/ WRVS)</td>
</tr>
</tbody>
</table>

RECORD BELOW WHY PEOPLE THOUGHT THESE WORKED WELL:

2) Family planning services because there is easy access to fit according to people’s life styles. For example morning appointments for mothers with school age children, evening appointments for those who work. Waiting times are short and the service is also accessible to different age groups from teenagers to younger people.

Other services that work well include
- Macmillan Service
- NHS Direct
- Kernowdoc- the out of hours GP service – if the patient can visit the primary care centre
- Services for Parkinson’s patients
- Services that provide immediate advice or telephone access to advice for patients with long term conditions
What were the three key elements of community health and social care services that people though worked less well?

(RECORD BELOW IN PRIORITY ORDER)

<table>
<thead>
<tr>
<th></th>
<th>Co-ordination for a non life threatening condition at home</th>
</tr>
</thead>
<tbody>
<tr>
<td>2</td>
<td>Lack of coordinated care for a patient with dementia</td>
</tr>
<tr>
<td>3</td>
<td>NHS Dentistry</td>
</tr>
</tbody>
</table>

RECORD BELOW WHY PEOPLE THOUGHT THESE WORKED LESS WELL:

Patient needs can fall through the gaps due to different organisational boundaries.

Patients may be particularly vulnerable out of hours and at weekends because of a lack of comprehensive cover at these times.

The system is designed to rely on the patient being well enough to instigate care whereas this might not be the case.

Lack of a joint caseworker or care coordinator on behalf of health and social services.

Lack of availability of NHS dentists.
What other issues did people mention? Please record any personal stories here if possible

1) Patient had a fall at home on Saturday lunchtime. Out of hours GP service said they would send a GP to visit - but not for up to five hours. In view of this response the caller contacted the Ambulance Service. This resulted in the GP visit being speeded up and GP arrived within an hour. The GP then made referral to Social Services. The caller used own networks to contact Social Services care manager out of hours. Had Social Services not been available (which is possible) - this situation could have resulted in an avoidable hospital admission to a community or acute hospital.

2) Care of patient at home who has dementia. A number of health and social care workers visit. However the patient’s own assessment of their need is taken at face value although the patient’s condition meant that the individual was not well placed to assess their own need for services. Health and Social Care workers visit and leave their phone numbers together with a request that the patient contacts them if they are needed. This does not recognise that the patient’s condition means that they are unlikely to initiate contact. The same patient fails to turn up for an appointment and is treated as a ‘did not attend’ and taken off list. Hence the patient falls through gaps in the system due to a lack of proactive care or a single key worker.

Other services that do not work well:
- Lack of home visits for out of hours medical care
- Lack of provision for nursing care at night
- Patient transport
- GP contract which protects interest of GPs rather than promoting the interests of patients
- Specialist diabetes services in the acute hospital due to lack of knowledge of other services
- GP signposting to non consultant care- too much information for GP to be aware of
Section B: what did people think of the suggestions for improving health and social care services?

<table>
<thead>
<tr>
<th>HOW CAN PEOPLE LOOK AFTER THEMSELVES? HOW CAN WE HELP YOU TAKE CARE OF YOURSELF AND SUPPORT YOU AND YOUR FAMILY IN YOUR DAILY LIVES?</th>
</tr>
</thead>
</table>

We are committed to helping people take better care of themselves, but big questions remain about how it can best do this.

...Thinking about how the NHS, Social Care and other services might help people to look after themselves more...

Q2. Which of the following did people at the listening exercises you ran think should be the top three priorities? (Please rank by writing 1, 2 or 3 in the boxes)

- **3** Encouraging and supporting better health, for example through routine check ups, advice on healthy lifestyles and promoting self-care and self-assessment.

- **2** Ensuring a range of health professionals, such as nurses and pharmacists, can provide people with information and support about how to take better care of themselves and their families. For instance pharmacists could give advice on getting the best out of the medicines you take or they could run clinics for people with high blood pressure.

- **1** Tackling the things that cause ill health and disadvantage, such as poverty and poor housing, by developing new services in the community and by expanding the range of services available in doctors’ surgeries (eg advisors to help with housing, employment and training and benefits), children’s centres and other locations.

- **4** Ensuring older people and those with disabilities can get the practical help and support they need to remain independent and active for longer

None of the above

Don’t know
PLEASE SUMMARISE WHY PEOPLE SELECTED THESE PRIORITIES:

Because it is necessary to tackle the underlying causes of ill health and inequalities in health. The gap in health status between different income groups remains a major concern and needs to be tackled before a significant improvement in the health of the population can be secured.
Q3. Did people think it would be enough for Government to only do these things to help people take better care of themselves? Why?

Not answered

Q4. What else would people like the Government to do to help people take better care of themselves?

Not answered
We want people to be able to use and find their way through health and social care services more easily. We also want these services to be ‘joined up’, even if several people or organisations are providing them.

...Thinking about how the NHS, Social Care and other services might help people find the services they need and improve the way these services are joined up ...

Q5. Which of the following did people at the listening exercises you ran think should be the top three priorities? (Please rank by writing 1, 2 or 3 in the boxes)

Providing effectively joined-up social care and health services to those that need them, for example through a single ‘needs assessment’. A ‘needs assessment’ would be a kind of one-stop-shop appointment instead of lots of appointments. A case manager would be someone who plans your care with you and then coordinates it.

Providing more help to people caring for others, for example with more respite care.

Providing people with better information about what NHS, local authority and social care services are on offer.

Improving the availability, quality and choice of services for long-term care users and people with long-term illnesses like diabetes e.g. support from people with similar conditions.

None of the above

Don’t know

PLEASE SUMMARISE WHY PEOPLE SELECTED THESE PRIORITIES:

To ensure effective coordination of care based on patients needs and to overcome organisational / system boundaries.
To ensure a named individual is responsible for a patient’s care.
Q6. Did people think it would be enough for Government to only do these things to help people manage their care and make decisions?

Not answered

Q7. What else would people like the Government to do to help people manage their care and make decisions?

Not answered
WHEN YOU AND YOUR FAMILY NEED HELP AND SUPPORT, HOW, WHEN, WHERE AND FROM WHOM DO YOU WANT IT?

We want to make sure people have access to the services they want, when they want them, where they want them and from whom they want them. But to do this there are some tough choices to be made.

...Thinking about how the NHS and Social Care and other services might improve how, when, where and from whom community-based services are delivered...

Q8. Which of the following did the people at the listening exercises you ran think should be top three priorities? (Please rank by writing 1, 2 or 3 in the boxes)

1. Providing convenient services which fit around people’s lives, for example by extending opening hours to evenings and weekends at the local GP practice, pharmacy and other community services, by enabling people who receive care at home to choose for example when the carer visits

2. Providing care in convenient locations (for example NHS Walk in Centres near train stations so people can get quick advice on problems and health issues on their way to work) or allowing people to register with any family Doctor, not just one where you live

3. Developing and providing more services in the local community, rather than only in hospitals, so they are more convenient for families and children to use. For example, blood tests, x-rays and some scans, minor surgery and physiotherapy could be provided locally. Also, hospital specialists could run clinics in the community.

- Developing new services for people who don’t always currently access care, such as young men, teenagers, people from different ethnic groups, people with disabilities.

- Allowing people to choose how to receive services at the end of life and to die where they want with dignity. (This options is about the care people receive at the end of their lives, it is not about euthanasia)

None of the above

Don’t know
PLEASE SUMMARISE WHY PEOPLE SELECTED THESE PRIORITIES:

Because transport and accessibility are major factors in this area – compounded by low incomes, poor quality public transport and people living in rural isolation
Q9. Did people think it would be enough for Government to only do these things to help provide service how, where, when and from whom people want them? Why?

Not answered

Q10. What else would people like the Government to do to help provide services how, where, when and from whom people want them?

Not answered
Q11. Looking across all the options we have asked about, which of these did your group think was the most important thing to be done immediately?

**Encouraging and supporting better health, for example through routine check ups, advice on healthy lifestyles and promoting self-care and self-assessment.**

**Ensuring a range of health professionals, such as nurses and pharmacists, can provide people with information and support about how to take better care of themselves and their families. For instance pharmacists could give advice on getting the best out of the medicines you take or they could run clinics for people with high blood pressure.**

**Tackling the things that cause ill health and disadvantage, such as poverty and poor housing, by developing new services in the community and by expanding the range of services available in doctors’ surgeries (eg advisors to help with housing, employment and training and benefits), children’s centres and other locations.**

**Ensuring older people and those with disabilities can get the practical help and support they need to remain independent and active for longer**

**Providing effectively joined-up social care and health services to those that need them, for example through a single ‘needs assessment’. A ‘needs assessment’ would be a kind of one-stop-shop appointment instead of lots of appointments. A case manager would be someone who plans your care with you and then coordinates it.**

**Providing more help to people caring for others, for example with more respite care**

**Providing people with better information about what NHS, local authority and social care services are on offer**
Improving the availability, quality and choice of services for long-term care users and people with long-term illnesses like diabetes e.g. support from people with similar conditions

Providing convenient services which fit around people’s lives, for example by extending opening hours to evenings and weekends at the local GP practice, pharmacy and other community services, by enabling people who receive care at home to choose for example when the carer visits

Providing care in convenient locations (for example NHS Walk in Centres near train stations so people can get quick advice on problems and health issues on their way to work) or allowing people to register with any family Doctor, not just one where you live

Developing and providing more services in the local community, rather than only in hospitals, so they are more convenient for families and children to use. For example, blood tests, x-rays and some scans, minor surgery and physiotherapy could be provided locally. Also, hospital specialists could run clinics in the community.

Developing new services for people who don’t always currently access care, such as young men, teenagers, people from different ethnic groups, people with disabilities.

Allowing people to choose how to receive services at the end of life and to die where they want with dignity. (This options is about the care people receive at the end of their lives, it is not about euthanasia)
Effectively joined up health and social care services were the top priority closely followed by tackling the causes of health and disadvantage such as poverty and poor housing.

The first was selected as it is essential that a patient’s needs are assessed holistically according to their particular circumstances and with seamless care provided by Health and Social Services.

In addition

This leads to individual more coordinated approach.

Saves resources both for the services in terms of finance and time, and also stress to the individual and carers

Makes the patient pathway more efficient and makes better use of NHS investment

Less fragmentation leads to better outcomes for patients and greater trust in the system.

Early and efficient intervention can reduce and prevent further health problems.

The second issue was also a high priority because only by tackling the root causes of ill health can the Health Service move towards promoting the health of the population rather than focusing on treatment of illness.
Q13. Please summarise the main points from the discussion about whether these changes address the things that work less well at the moment, and maintain and support the things that work well at the moment.

Yes since as key themes in the identification of the services that worked less well were a lack of coordination of care and the need for more proactive person focussed care.
Q14. Please summarise the main points from the discussion about what else the Department of Health should be doing to make sure that community-based health and social care services meet people’s needs in the 21st century?

Lack of resources was identified as an underlying theme for example in the provision of comprehensive 24 hour nursing and social care.
Section C: details about your organisation and your listening exercises

To help us analyse the information you have given us, we need to find out a little bit more about your organisation and your listening exercise.

A. How many people took part in your devolved listening exercises?

Write in below

<table>
<thead>
<tr>
<th>12</th>
</tr>
</thead>
</table>

B. What sort of listening exercise was it?

(Please tick one box only)

- A day long session (from 5 to 8 hours long)
- A half day session (from 3 to 5 hours long)
- Up to 3 hours long
- Other (record below)

√

C. How many of each of the following types of people took part in your listening exercise?

(Please put a number in each box even if it is zero)

| Members of the general public (i.e. with no specialist interest in health and social care) | 0 |
| Members of the public who are involved with health and social care services e.g. PPI forum members | 9 |
| Paid staff from your organisation | 3 |
| Voluntary staff from your organisation | 0 |
| Other (record below) | 0 |
D. Please tell us how many of the people who took part – whether members of the public or staff - were from any of the specific sectors of the population listed below.

<table>
<thead>
<tr>
<th>Category</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Children and young people</td>
<td>0</td>
</tr>
<tr>
<td>Older people</td>
<td>1</td>
</tr>
<tr>
<td>Pregnant women (and their partners)</td>
<td>0</td>
</tr>
<tr>
<td>Socially disadvantaged people</td>
<td>0</td>
</tr>
<tr>
<td>Disadvantaged children</td>
<td>0</td>
</tr>
<tr>
<td>Smokers</td>
<td>0</td>
</tr>
<tr>
<td>Excessive drinkers</td>
<td>0</td>
</tr>
<tr>
<td>Obese people</td>
<td>0</td>
</tr>
<tr>
<td>Substance misusers</td>
<td>0</td>
</tr>
<tr>
<td>Disabled people</td>
<td>1</td>
</tr>
<tr>
<td>People in prison</td>
<td>0</td>
</tr>
<tr>
<td>Black and minority ethnic groups</td>
<td>0</td>
</tr>
<tr>
<td>Travellers</td>
<td>0</td>
</tr>
<tr>
<td>Homeless people</td>
<td>0</td>
</tr>
<tr>
<td>People with mental health problems</td>
<td>0</td>
</tr>
<tr>
<td>People with learning disabilities</td>
<td>0</td>
</tr>
<tr>
<td>People in hospices/residential care</td>
<td>0</td>
</tr>
<tr>
<td>Asylum seekers</td>
<td>0</td>
</tr>
<tr>
<td>People with long term conditions</td>
<td>1</td>
</tr>
<tr>
<td>People with caring responsibilities</td>
<td>3</td>
</tr>
<tr>
<td>Other (record below)</td>
<td>0</td>
</tr>
</tbody>
</table>
E. Of the people that took part in your listening exercise, can you please tell us how many were from each of the ethnic groups listed below

- White British: 12
- White Irish
- Any other white background
- White and Black Caribbean
- White and Black African
- White and Asian
- Any other mixed background
- Indian
- Pakistani
- Bangladeshi
- Any other Asian Background
- Caribbean
- African
- Any other Black background
- Chinese
- Rather not say

F. Which of the following best describes the sector to which your organisation or group belongs / where you work:

(Please tick one box only)

- PPI forum or other patient group
- Community-based NHS services: √
- Local authority social care services
- Private sector health or social care services
- Voluntary sector health or social care services
- Other (record below)
G. If your listening exercises mostly involved staff rather than patients or service users please can you identify from the list below which groups they most often have contact with or provide services for:

*(Please tick all relevant boxes)*

<table>
<thead>
<tr>
<th>Children and young people</th>
<th>Older people</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pregnant women (and their partners)</td>
<td></td>
</tr>
<tr>
<td>Socially disadvantaged people</td>
<td></td>
</tr>
<tr>
<td>Disadvantaged children</td>
<td></td>
</tr>
<tr>
<td>Smokers</td>
<td></td>
</tr>
<tr>
<td>Excessive drinkers</td>
<td></td>
</tr>
<tr>
<td>Obese people</td>
<td></td>
</tr>
<tr>
<td>Substance misusers</td>
<td></td>
</tr>
<tr>
<td>Disabled people</td>
<td></td>
</tr>
<tr>
<td>People in prison</td>
<td></td>
</tr>
<tr>
<td>Black and minority ethnic groups</td>
<td></td>
</tr>
<tr>
<td>Travellers</td>
<td></td>
</tr>
<tr>
<td>Homeless people</td>
<td></td>
</tr>
<tr>
<td>People with mental health problems</td>
<td></td>
</tr>
<tr>
<td>People with learning disabilities</td>
<td></td>
</tr>
<tr>
<td>People in hospices/residential care</td>
<td></td>
</tr>
<tr>
<td>Asylum seekers</td>
<td></td>
</tr>
<tr>
<td>People with long term conditions</td>
<td></td>
</tr>
<tr>
<td>People with caring responsibilities</td>
<td></td>
</tr>
<tr>
<td>Do not deal with specific sectors of the community</td>
<td></td>
</tr>
<tr>
<td>Other (record below)</td>
<td></td>
</tr>
</tbody>
</table>
If you work with specific ethnic groups, which of these groupings do you represent or work with?

<table>
<thead>
<tr>
<th>Ethnic Group</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>White British</td>
<td></td>
</tr>
<tr>
<td>White Irish</td>
<td></td>
</tr>
<tr>
<td>Any other white background</td>
<td></td>
</tr>
<tr>
<td>White and Black Caribbean</td>
<td></td>
</tr>
<tr>
<td>White and Black African</td>
<td></td>
</tr>
<tr>
<td>White and Asian</td>
<td></td>
</tr>
<tr>
<td>Any other mixed background</td>
<td></td>
</tr>
<tr>
<td>Indian</td>
<td></td>
</tr>
<tr>
<td>Pakistani</td>
<td></td>
</tr>
<tr>
<td>Bangladeshi</td>
<td></td>
</tr>
<tr>
<td>Any other Asian Background</td>
<td></td>
</tr>
<tr>
<td>Caribbean</td>
<td></td>
</tr>
<tr>
<td>African</td>
<td></td>
</tr>
<tr>
<td>Any other Black background</td>
<td></td>
</tr>
<tr>
<td>Chinese</td>
<td></td>
</tr>
<tr>
<td>Do not deal with specific ethnic groups</td>
<td></td>
</tr>
<tr>
<td>Other (record below)</td>
<td></td>
</tr>
</tbody>
</table>
I. If you are a regional organisation, please tick the box below for the region you mainly work in

<table>
<thead>
<tr>
<th>Region</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>North East</td>
<td></td>
</tr>
<tr>
<td>North West</td>
<td></td>
</tr>
<tr>
<td>Yorkshire &amp; the Humber</td>
<td></td>
</tr>
<tr>
<td>East Midlands</td>
<td></td>
</tr>
<tr>
<td>East of England</td>
<td></td>
</tr>
<tr>
<td>South East</td>
<td></td>
</tr>
<tr>
<td>London</td>
<td></td>
</tr>
<tr>
<td>South West</td>
<td>√</td>
</tr>
<tr>
<td>National Organisation</td>
<td></td>
</tr>
<tr>
<td>Not applicable</td>
<td></td>
</tr>
</tbody>
</table>

J. What is the name of your organisation?

West of Cornwall Primary Care Trust

K. What type of organisation are you responding as?

<table>
<thead>
<tr>
<th>Type of Organisation</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>A local organisation</td>
<td>√</td>
</tr>
<tr>
<td>A national organisation</td>
<td></td>
</tr>
<tr>
<td>Other (please record below)</td>
<td></td>
</tr>
</tbody>
</table>
L. Would like to be listed as a contributor to the consultation?

<table>
<thead>
<tr>
<th>Yes</th>
<th>√</th>
</tr>
</thead>
<tbody>
<tr>
<td>No</td>
<td></td>
</tr>
</tbody>
</table>

K. If you would like to receive a summary of our findings, please enter your contact details or email address in the box below:

Jane.Goldsworthy@westprimcare.cornwall.nhs.uk
FEEDBACK FROM MARIE CURIE CANCER CARE

IRIS
DAY CARE PATIENT
MARIE CURIE HOSPICE
CATERHAM
Thank you for your help with your health, your care, your say.

This feedback form is intended for both local and national organisations or groups to report on the findings their own devolved listening exercise as part your health, your care, your say.

Can I check, are you responding to this questionnaire as:

- A local organisation or group
- A national organisation or group
- Other (record details below)

On behalf of Marie Curie Cancer Care

All the information you submit will be analysed alongside the public’s response and the views obtained from other local and national organisations and groups and will feed in to the development of plans for improving community health and care services.

Please note the feedback form is in three parts:

- Section A: Thinking about the community health and social care services people use, what currently works less well?
- Section B: what do you think of the suggestions for improving health and social care services?
- Section C: details about your organisation and your listening exercise

If you haven’t covered Section A or all of the options under Section B, please just leave those questions blank.

Please make sure that you give us this feedback by 4th November, or earlier if possible. You can find out where to return this feedback by referring to the resource pack website, www.yoursayresources.nhs.uk

As you will see, most questions ask you to tick a box like this:

Tick one box only

Other questions give you space to record how you reached your decisions:

Please feel free to write as much, or as little, as you like.
Section A: Thinking about the community health and social care services people use, what currently works well, and what currently works less well?

We want to make community-based health and social care services better for everyone. To help us reach the right decisions, we want to know what the people at the listening exercises you ran thought about community-based health and social care services at the moment.

Q1. What were the three key elements of community health and social care services that people thought worked well?

(RECORD BELOW IN PRIORITY ORDER)

1. Home nursing to help terminally ill people and their carers
2. The hospice movement
3. Small personal expert teams e.g. when a District Nurse co-ordinates for all your needs under the supervision of your GP

RECORD BELOW WHY PEOPLE THOUGHT THESE WORKED WELL:

1. Home Nursing

People generally want to be in their own home at end of life if circumstances allow.

There is the positive pull of:

- Being in your own environment and with your loved ones
- Your dog, your garden, your food, your TV, your music
- Your own regime
- A sense of being in the ‘right’ place – your own homely space

There is also the push of trying to get out of hospital – an experience which many find terrible. “When I came out I vowed I wouldn’t go back”. They spoke about:

- Being moved from bed to bed
- The indignity of mixed wards
- Poor cleanliness with dirty toilets etc.
- Cold food or not being fed if a relative is not there to help. Your tray is just whisked away
- Not being washed unless your relatives help
- Terrible noise and disturbance at night with lights on, people rushing around
- Unfriendly ‘agency’ night staff
- Hustle and bustle all day and the absence of a calm environment
- Drug rounds being late
- Young nurses chatting across the bed to each other and being less mindful of your needs
- Endless waiting for things to happen, adding to your stress

Those who are at home with well organised care provided by District Nurses, Marie Curie nursing at nights and a good local GP were really appreciative of how things have worked out.

The night help for some was invaluable – ‘we couldn’t manage without it.’ This being important for care of the patient and support for the relative so that they can get rest and respite. Carers we encountered were devoted to making things as good as possible for their loved ones but the strain on them to provide 24 hour cover care shows. They need time off and to be able to sleep without thinking they have to answer a ringing bell to aid the patient etc.
2. The hospice movement

Those who had contact with a Marie Curie hospice either as a day patient or in-patient could not praise it highly enough.

“You get the care you need and you are being monitored all the time. They do more than care, they really look after you. It’s the bee’s knees.”

Day care is really appreciated for:

- the company/people to talk to
- support/help and advice if required
- Marie Curie gets things sorted for you and fast
- a break/ a respite
- confidence building
- respect and care for the individual and the carer provided by the doctor and nurses
- access to counsellors and people to help with depression
- free transport – a simple but important factor

Hospice in-patient care is also appreciated for all the previous points plus pain relief on demand

“It’s wonderful I get a lot of pain but as soon as I do I tell them and I get the drugs instantly”

“That’s why I’m in here. I was at home but my pain got out of control. I come in here and they sort it all out”

“I’ve said to the hospice manager – please God don’t let me die in East Surrey hospital. That is my real nightmare. I had such a bad time there”

People spoke highly of the hospice environment but, interestingly, most still long to get home.

“It’s OK here; the food’s not bad, the nurses are OK but if I could wave a magic wand I would just get out of here and go home… I want to be able to lounge in my own bed and do my own thing”

3. Small personal expert teams e.g. when a District Nurse co-ordinates for all your needs under the supervision of your GP

This was highly variable across the country. When it works well it is excellent. A terminally ill cancer patient would far prefer to be cared for by a couple of familiar faces than by a whole raft of impersonal names. There was cynicism about the use of the word team.

“At hospital they tell you ‘there will be a team looking after you’ but in reality it doesn’t work out like that”

But in instances e.g. in Lincolnshire when your care – health and social - had all been organised and co-ordinated by a District Nurse who is able and available regularly to visit you at home there is high satisfaction.

Good instances were cited of practical help being offered with bath aids, hospital beds for the home, commodes, carer bed chairs, disabled badges etc. When these things are offered and made easily available it’s a great help.

Equally well, some were highly satisfied that there was excellent liaison between their GP and the Marie Curie hospice doctor.

People feel safe under these circumstances. They feel that 24 hours a day they have a contact point (they believe they can call the hospice and if necessary have an emergency admission). What they dread is an emergency hospital admission. If the care in the community is good enough and their pain control is well supervised they hope that the ‘horrible’ hospital experience will be able to be avoided.
Quality at home care makes a huge difference to the carer. They can concentrate on making things as good as possible for their loved one and are saved from the exhaustion and expense of repeated long journeys to make hospital visits.

Inevitably, many carers are themselves elderly and not in perfect health. Hence, they cannot manage on their own. Support in the community both tangible, practical help and the sense that back up is there 24/7 in the event of a ‘crisis’ is essential so that they can have the confidence to accept the challenge of caring for someone with advanced cancer at home.

The nights are often the worst so help then is fantastic but many would ideally like more respite for themselves and help for their patient during the day too.

**GPs**

Many praised their GPs. People do, of course, ideally like to see the same face and the one who best knows your story.

In Lincolnshire there seemed to be a particularly good liaison between a GP and a District Nurse benefiting all.

Elsewhere one man complained that to get a repeat prescription for his morphine he had to give 48 hours notice. The only alternative was to take a same day appointment. He thought this was wasteful of the GPs time

“Surely they could have a better system than this?”

**Pharmacies**

One person spoke about how their pharmacy had made up a blister ‘cocktail’ pack of drugs for a patient. This made it so much easier to take the right thing at the right time. This was felt to be a practical and helpful innovation.
What were the three key elements of community health and social care services that people thought worked less well? *(RECORD BELOW IN PRIORITY ORDER)*

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>1</strong></td>
<td>Information provision</td>
</tr>
<tr>
<td><strong>2</strong></td>
<td>Out of hours cover</td>
</tr>
<tr>
<td><strong>3</strong></td>
<td>Dignity and respect</td>
</tr>
</tbody>
</table>

RECORD BELOW WHY PEOPLE THOUGHT THESE WORKED LESS WELL:

### 1. Information provision

Most people admit that they started out knowing terribly little about what care in the community is available and how you source it.

When you are in hospital and there is talk about being discharged this is a real concern. How will we (me and my carer) cope? It is a daunting prospect. You dislike the hospital but broadly feel safe there. There are hospital beds, the required drugs, doctors on tap etc.

Several people admitted to feeling vulnerable at this stage. Others were confused. There was talk about how things were going to be organised but they were not certain about the practicalities of how things would work out.

“We’ve heard that things will be organised by a District Nurse, but I don’t know what they do”

“We didn’t know we were going to get care in the community – what is that? I know nothing about it. There’s been vague discussion but nothing concrete”

“It is not at all obvious who you speak to about what. It makes my head ache just thinking about it. “

Those people needing social assistance with allowances, cleaners, carers or practical alterations to make their housing suitable had particular frustrations with contacting social service and local authority departments. They disliked:

- The lack of clarity about who you contact about what
- The forms that need to be filled in
- Lack of assistance with form completion
- Lack of clarity about entitlements
- Lack of explanation about refused applications
- Insensitive and poorly explained means testing. A cleaner that was free one week costs £15 the next
- Inability to contact these departments out of hours
- Phones not being answered, calls not being returned

### 2. Out of Hours Cover

There is general anxiety about accessing care in the community outside of 9 – 5 Monday to Friday.

Most people know that your GP is not available beyond these hours and that you will be dealing with an unknown doctor who does not have your notes.

In fairness our patients did not feel ‘abandoned’.

- They commented ‘if you mention cancer you tend to get their attention’. There was a sense that they were likely to be given priority and not dismissed as time wasters
- Those in touch with a Marie Curie hospice took great comfort from the perception that they could call and get help 24/7
Those with a good District Nurse felt they had emergency options if necessary

Even so there is concern that ‘things could fall apart’ at weekends/at night and that this is when you are most vulnerable.

People felt that trying to get any social assistance out of hours was ‘a joke’. They felt this was really antiquated and that there should be straight-forward help lines and access to information 24/7.

“I like to think that in the future there will be one number you can call, tell them your postcode and your condition and they will tell you quite simply what you can get, how you get it and ‘order it for you on the spot’. The current system is a shambles. There needs to be progress like there has been with NHS Direct”

3. Dignity and Respect

Although we have ranked this third, for some this was a top priority. In hospital several felt they had lost dignity. Importantly, this was recovered if they were ‘lucky’ enough to get quality care in the community or via a hospice

Our patients were seriously ill, often in pain and generally incredibly grateful for the care and treatment they had received from the NHS.

Specifically, they could not fault Marie Curie and spoke glowingly of it. The care, kindness and compassion that Marie Curie staff extend to people, who in many cases have really lost their confidence having endured horrible chemotherapy and other treatment, transforms their lives.

“If the cancer doesn’t kill me the kindness will”

“Talking to people here has saved me. I was suicidal before”

Sadly, however, many could report other instances during their health and social care treatment of feeling really overlooked or treated with no respect.

Lack of Respect  Not being treated as an Individual

“In hospital you feel as if you are just a lump of meat on a bed. Here (at the Marie Curie hospice) they speak to you as a person. It makes an enormous difference”

“When I was in hospital I hated the mixed wards. Whilst I was there I had to put up with 12 different men in my bay. It was terrible”

“I felt as if the doctors had given up on me…”

“I was so keen to leave the hospital I would have gone even if they had discharged me to a pub and I don’t drink”

Poor Communication

Several instances of poor communication from hospital doctors were cited:

“They dropped the bombshell that my wife had cancer. They were talking about benign and malignant and I didn’t know what they were talking about. It was Thursday and we couldn’t see a specialist until Monday. They told us the bad news and then just left us to our own devices”

This ‘inhumane’ approach was contrasted with the gentle and sympathetic approach of Marie Curie. People felt their nurses and doctors had time to talk, to explain things to you, to answer any of your questions and to reassure you about your concerns and anxieties. They commented that Marie Curie treated the whole person.
“Marie Curie will call the hospital and sort out things that you don’t understand about your situation. They will decode it for you. They really take time to ensure that you are less confused and feel more cared for”

Specific Criticism of Social Care Providers Not Listening to My Needs

Poor communication and apparent lack of respect from social care providers was also cited.

“I’ve no real complaints about my medical care but I do have complaints about Islington Social Services”

“They weren’t just bad they were rude. They employ the wrong people”

“No-one listened to my needs or explained things to me. They just came in and said this is what you are getting. It was atrocious”

“I get the impression they feel I’ve lived too long. They are just biding their time and waiting for me to die – so that they don’t have to pay out the allowance.”

What other issues did people mention? Please record any personal stories here if possible

POSITIVE STORIES AND QUOTES

Hospice experiences

“They have been excellent here (Marie Curie Caterham), very good. They would do anything for you … you don’t get all the dashing rush, not all the rush and tear. It’s a calmer environment”

“They really built up my confidence to fight the cancer and I dress up when I come in, for them now. I want to see the nurses’ faces when I look nice, I’ve done it for them as they were so good when I needed them, they say ‘you look nice’ and it’s a kind of family thing”.

“They’re very genuine, no pretending, no back biting, everyone is equal, there’s no history. You look forward to mixing with other people. You feel as if you are wanted it’s the atmosphere and it’s confidence to fight the cancer and then you don’t get so frightened, a lot of people do get frightened but even if it’s only a couple of weeks you can still put up a fight and try.”

“I’ve never heard an argument here. Everyone is treated with respect. Everyone is on first name terms; I’d recommend this hospice to anyone.”

“At Marie Curie they are such a lovely crowd … I get transport there – they have lovely volunteer drivers”

“A year ago I was suicidal I got over that bad patch …. the local GP said why not go to the Marie Curie day centre, it’s local and they are good with old people. Marie Curie was the turning point.”

“The hospice has been the best thing that has happened. There are nurses there and people you can talk to, people who can explain things. My confidence was very low with the chemotherapy. I used to stay in the house 24 hours a day. The mental health nurse and the hospice helped build my confidence; otherwise I don’t know what would have happened.”

“At the hospice you get support from the nurses and doctors, and everyone there… It’s so sad they have to rely on charity”
NEGATIVE STORIES AND QUOTES

Social Services

“Social services have been very lax, very disappointing, they are employing the wrong people..... I do have complaints about social services.”

“My gripe is with the social services. They are not very polite; in fact they can be abrupt and rude.”

“You contact somebody for assistance and they say they’ll help but they never come back to you.”

Hospitals

“Terrible, the toilets were dirty, the medication was never on time, nobody helped you wash, nobody seemed to care.”

“The food was always cold... why couldn’t they have a microwave in the ward? I like porridge but I can’t eat cold porridge!”

“Whilst I was there 11 different men came and went (in my bay). One lady was moved 9 times we were told it was the way the bed managers massage the figures”

“When you go into hospital these days it doesn’t seem to be a happy place. No-one is smiling. The atmosphere is very low as if all the staff are low...I especially dislike the nights and the agency nurses they use then”

“In hospitals everyone’s milling around waiting for someone else to do something”

“Different departments don’t talk to each other at East Surrey never mind at different hospitals”

“Chemotherapy and Haematology departments are not properly linked – we would get conflicting reports and advice from each”

“I hate the terminology they use at hospital when my wife had to go back into hospital they were talking across us saying to each other ‘this is a failed discharge’. It really annoyed me and I thought it was very disrespectful”

“The atmosphere at the Whittington is not so good...there are prisoners in chains being marched up and down the corridors!”

Inability to get same day prescriptions form GP

“If I run out of drugs like morphine, I need them the same day, I don’t need them tomorrow, or the day after, I need them the same day. And I can’t always say that I’m going to run out of morphine, because I’ve had trouble with my ribs and I’m having trouble sleeping, I also take oral morphine as well and that has been helping me sleep. So I’ve been running out of that and immediately I run out of that I needed it the same day sort of thing and then all you get is a load of cheek off the receptionist and really, honestly and truthfully all I want is something to control my pain.”

Problems with Cleaners!

“I had a young lady come in to do my cleaning; she used to come twice a week. If I had any cleaning to do she’d do it and if I had any washing she’d go and do the washing for me. Well the cleaning she used to just flit around with the Hoover, I used to say, well just do the hall and the kitchen and the bathroom and I’ll be happy with that, but I didn’t know what else she was supposed to do, because nobody ever explained it to me. So then I eventually, the other week, a couple of weeks ago I had some woman come, Islington Social Services, somebody or other, I don’t know what her name is, she phoned me up and said, to do an assessment on my care, so I said, yeah fair enough you can come and sit and talk to me. And then she didn’t bother explaining what care I
should be getting, or anything. Then I had somebody me up from, I don’t know where, from somewhere in Goswell Road where they assess your means, then all of a sudden I get a letter telling me that I’m going to have to pay £15 a week for something, which I was getting for free the week before. And unfortunately I lost my rag with them, because what I was having Mary do for me wasn’t worth £15. So since then I cancelled it, I said, right I’ll cancel all the care, but I said I’m not saying I’m not willing to pay for the care, but I’m willing to pay for it as long as he explained to me what I’m going to get for my £15. As long as I get £15 worth of care then I am perfectly happy about the situation”.

It’s Not Joined Up

“Well, I think if the social services was run by somebody with any, what I call savvy up top, a brain in between two ears, then you might get somewhere, but when you’ve got people that I really don’t think they know what they’re talking about, running the service, then I don’t think you’ve got a lot of chance. And I can’t see it improving, because I personally feel that they’re employing the wrong the type of people to do the job. ………..

My GP is my main point of contact basically and obviously my GP doesn’t know my circumstances all the time, or what sort of care I need at home. But having recommended me for care to the social service, there should be somebody in the social services who is responsible for saying, well you will need this sort of care and you will need it X times a week and all the rest of it. But I don’t think that they’ve got anybody qualified enough to say what sort of care you need. Had they got somebody qualified enough to say what sort of care that I personally need, then it would be different, but they haven’t got anybody like that and I don’t think they’ve got any plans to do anything about it. If they had, with putting somebody like, you need somebody with nursing experience and who knows what it’s like, it’s like for people suffer pain and all the rest of it, then you get the type of care that you need in the community. You don’t get it from somebody saying, well so and so can call in and do your cleaning once a week … we need my conversation to you and your conversation to me and then we can work out between myself and you what sort of care I need. No, just coming in and saying, oh we’re going to give you this and we’re going to give you that is no good.”

Can’t see My Very Own GP for 10 Days

“To see my GP I might have to wait ten days, but I can see a GP that day, but it won’t be my GP and I’ve got to go through all the rigmarole of explaining what’s wrong with me and why I’m on morphine and what pains I’m getting and it just goes on for an hour, whereas to see my GP, my GP knows what’s wrong with me, so I’m in and out in five minutes and somebody else could get seen.”

For Effective Needs Assessment You Require A High Calibre Person

“It needs to be a qualified person, who’s in contact with the patient, the GP, the Macmillan Nurses and also the hospices and the hospitals in turn and so that when you go to hospital for an operation you’re going to come out and it’s somebody that actually knows what care you need. Instead of going to this person, who comes from the social services department, who ain’t got a clue. She’s never going to have a clue and my gripe is with the social services, because I find them to be not very polite at times, they can be rather abrupt and rude and I don’t think that that is the way to treat anybody, regardless of colour, creed, or wherever they come from. They should be treated with politeness and all the rest”

“But I think if you had somebody as a middle man between, who knows what they’re talking about, which has got to be very, very important, who can liaise between you being a patient in hospital and you coming out into the community and knowing exactly what care you’re going to need. In other words they’ve got to go and visit your house and they’ve got to say, well can you manage them steps, if you can’t well then the council have got to re-house you somewhere else, it’s got to be like that, but there’s nobody doing that sort of job”.

10
Section B: what did people think of the suggestions for improving health and social care services?

<table>
<thead>
<tr>
<th>HOW CAN PEOPLE LOOK AFTER THEMSELVES? HOW CAN WE HELP YOU TAKE CARE OF YOURSELF AND SUPPORT YOU AND YOUR FAMILY IN YOUR DAILY LIVES?</th>
</tr>
</thead>
</table>

We are committed to helping people take better care of themselves, but big questions remain about how it can best do this.

...Thinking about how the NHS, Social Care and other services might help people to look after themselves more...

Q2. Which of the following did people at the listening exercises you ran think should be the top three priorities? (Please rank by writing 1, 2 or 3 in the boxes)

- Encouraging and supporting better health, for example through routine check-ups, advice on healthy lifestyles and promoting self-care and self-assessment.
- Ensuring a range of health professionals, such as nurses and pharmacists, can provide people with information and support about how to take better care of themselves and their families. For instance pharmacists could give advice on getting the best out of the medicines you take or they could run clinics for people with high blood pressure.
- Tackling the things that cause ill health and disadvantage, such as poverty and poor housing, by developing new services in the community and by expanding the range of services available in doctors' surgeries (eg advisors to help with housing, employment and training and benefits), children's centres and other locations.
- Ensuring older people and those with disabilities can get the practical help and support they need to remain independent and active for longer

<table>
<thead>
<tr>
<th>None of the above</th>
</tr>
</thead>
<tbody>
<tr>
<td>Don’t know</td>
</tr>
</tbody>
</table>

PLEASE SUMMARISE WHY PEOPLE SELECTED THESE PRIORITIES:

| NOT RANKED PLEASE SEE COMMENTS OVER PAGE |
THE ABOVE PRIORITIES WERE NOT THAT APPROPRIATE FOR US TO DISCUSS WITH OUR ‘END OF LIFE’ PEOPLE

HOWEVER THE GENERAL PRINCIPLE OF MORE INFORMATION AND ADVICE BEING AVAILABLE LOCALLY WITH HOME NURSING AND MORE AT GP SURGERIES WAS LIKED

PRACTICAL HELP WITH HOUSING WAS VERY IMPORTANT TO SOME

“You shouldn’t have to fight to get a hand rail outside your house when you are really ill”

Practical help and support and new expanded services available at GP’s surgeries would be welcomed by those fit enough to make use of them. Our patients, however, given a choice might prefer the specialist, caring atmosphere of a hospice or similar environment.

They like the calm, kind, happy atmosphere of the hospice.

“I hated the hospital. The morale was terrible. All the nurses had low morale. It was such a miserable experience. Here, it seems funny to say it, but there is a happy atmosphere”

They take great comfort from speaking to others ‘in the same boat’.

NB End of life patients need extremely sensitive handling. Some are ignorant of their condition or in denial about it. All communication with them needs to be personally tailored to their level of knowledge and acceptance about their condition. It is imperative that all involved in contact with them are well trained in communication skills for palliative care.

In general GPs and District Nurses were said to be good in this respect. Marie Curie were found to be excellent. There was also praise for Macmillan nurses and specialist staff at chemotherapy units. But some hospital staff were said to be “blunt and insensitive” and some social care staff said to be “downright rude”

There was repeated criticism of the “rush and bustle and noisiness” of hospitals and other clinics. If there are going to be more services for the terminally ill available in the future via GP surgeries we suggest this needs to be in the context of designated clinics with extra emphasis on a slower, quieter, calmer approach. People want to be given time, to have things explained at their pace and to be treated as an individual.

Home visits are also really relevant when people are at this end of life stage. They may be too weak to travel and they far prefer the calmer, more personal encounter that is possible at home.

As well as medical assistance people do need help with Disability Allowance claims and with adapting their home to make it as safe and comfortable as possible. They do not want to have to struggle with social services in this respect. Many need someone to fill in forms for them and help them through the maze.

“Macmillan helped me fill in the form – I couldn’t do it”

Many spoke about financial anxieties and related stress

“Will I be charged for carers? How much will it cost and will I be able to afford it?”

People were also bothered about “the person down the road gets x benefit and other people tell me I should be getting it too…I feel it’s not at all clear and it niggles me”
Q3. Did people think it would be enough for Government to only do these things to help people take better care of themselves? Why?

WE CANNOT ANSWER THIS SIMPLY!
NO EXTRA COMMENT

Q4. What else would people like the Government to do to help people take better care of themselves?

NO EXTRA COMMENT HERE
We want people to be able to use and find their way through health and social care services more easily. We also want these services to be ‘joined up’, even if several people or organisations are providing them.

...Thinking about how the NHS, Social Care and other services might help people find the services they need and improve the way these services are joined up ...

Q5. Which of the following did people at the listening exercises you ran think should be the top three priorities? (Please rank by writing 1, 2 or 3 in the boxes)

Providing effectively joined-up social care and health services to those that need them, for example through a single ‘needs assessment’. A ‘needs assessment’ would be a kind of one-stop-shop appointment instead of lots of appointments. A case manager would be someone who plans your care with you and then coordinates it.

Providing more help to people caring for others, for example with more respite care

Providing people with better information about what NHS, local authority and social care services are on offer

Improving the availability, quality and choice of services for long-term care users and people with long-term illnesses like diabetes e.g. support from people with similar conditions

None of the above

Don’t know

PLEASE SUMMARISE WHY PEOPLE SELECTED THESE PRIORITIES:

WE DID NOT RANK THE ABOVE PRIORITIES WITH OUR END OF LIFE PATIENTS
THEIR OVERRIDING PRIORITIES ARE PAIN CONTROL, BEING AT HOME IF AT ALL POSSIBLE AND CARE FOR THEIR CARERS. IN ADDITION TO THEIR OWN WORRIES AND ANXIETIES THEY ARE ANXIOUS ABOUT THEIR CARERS

However, learning emerged on these topics as follows:

JOINED-UP SOCIAL CARE AND HEALTH SERVICES

Yes, joined up care is the ideal.

- Only have to tell your story once
- Someone really understands your predicament and can tailor care to your specific needs
- One point of contact for problem solution. Advanced cancer patients have lots to worry about and if they feel reassured and secure this alleviates some of their stress
For people to be able to manage at home – which is their ideal – they need to be given the confidence that there is back up and practical support to help them.

PROVIDING MORE HELP TO PEOPLE CARING FOR OTHERS, FOR EXAMPLE MORE RESPITE CARE

The importance of care for carers was recognised both by patients and carers.

- Without the carer there will be readmission to hospital and many dread this
- Carers suffer stress and damage to their own health if they don’t sleep
- Carers need personal time for basics like shopping, getting your hair done – unless home nursing is provided they can’t leave the house. Ideally, they need day time respite as well as some night time cover too.

One carer when asked if she got out at all answered “Yes I did go out for lunch last month with my sister”. This suggested that any time for herself was very limited.

A 40 year old man who had given up work to care for his 40 year old wife was evidently stressed and worried. He had been contacted by a local carers’ organisation and told that he should be claiming a Carers allowance in addition to his wife’s disability allowance.

“Now I’m getting a Carers allowance but I’d feel better if they paid me a wage. I can’t work because I’m looking after my wife and now we have real financial worries. It is work and you should be getting paid for the work you do”

Understandably, some people feel that being ‘on benefits’ is demeaning. This couple felt particularly hard done by as they had also used £3,500 of their own savings for private tests at a stage when they felt they could not wait for NHS appointments to come through.

We spoke to several male carers and it became apparent that male carers can feel very isolated. More traditionally women are carers and in society in general women are more likely to share worries and concerns with each other. Hence they have stronger support networks. However, when a man stops work and takes on a caring role he may have the added burden of isolation and lack of obvious support networks.

A few spoke about holidays that had been funded by local agencies to give the patient and carer a break. This type of initiative is really valued.

PROVIDING PEOPLE WITH BETTER INFORMATION ABOUT WHAT NHS, LOCAL AUTHORITY AND SOCIAL CARE SERVICES ARE ON OFFER

See before information is important.

However, at the end of life stage people need things sorted not just information about what you can get. In a few instances comments were made about being overwhelmed with discussion about choice and options.

“The palliative care team came and talked to us about all sorts of choices. They were very nice but it was almost overwhelming. I wanted someone to make a decision. I was too tired to start weighing up choices”

When you are terminally ill you need swift action by someone who can judge and appraise your situation and do the best for you.

In some instances where there is excellent District Nurse provision she takes on this role of sorting everything out in a one stop provision.

Inevitably, there is dissatisfaction when services are discussed then found not to be available.

“When I left hospital I was told we would have back up from Macmillan. When I called the number they gave me the woman was on leave and there was no-one to cover for her. I felt deflated”
The importance of social care services should not be under-estimated. Several of our patients were angry about what they felt were failed or inadequate arrangements to do with household services and cleaning. This relates back to issues about dignity and respect. They are trying to manage independently at home having had major cancer surgery. They wish as much as possible to lead a normal life and simple help in the home is vital.

“I was told that Age Concern could get me a cleaner but when I rang the number there was no reply”

“The tiles on my floor were lifting up and I was scared of tripping up but no-one from the council would treat me seriously. And I needed my cupboards lowered because I can’t reach up because of my breast operation”

“I needed a socket moved because the wire to my special bed trails across the floor and I’m worried about falling over it”

“If I was in a wheelchair they would take me seriously but because I make a point of trying to look nice and be cheerful people thing I’m being too demanding and trying to jump the queue”

“Surely it would help if priority cases were flagged up in some way to social services – you get the impression that the people who visit have no idea of the seriousness of your condition”

IMPROVING THINGS FOR LONG TERM CARE USERS AND SUPPORT FROM PEOPLE WITH SIMILAR CONDITIONS

There was a lot of positive comment about the value of hospice day care in terms of contact with people with similar conditions. People benefit from the care of the staff but they also greatly like the company of other patients.

“The Thursday lunch club is a really nice group”

“I really look forward to coming up here (Hampstead Marie Curie hospice). I live on my own and there’s always people here to talk to, you can have a coffee and a chat”
Q6. Did people think it would be enough for Government to only do these things to help people manage their care and make decisions?

NO EXTRA COMMENT

Q7. What else would people like the Government to do to help people manage their care and make decisions?

NO EXTRA COMMENT

WHEN YOU AND YOUR FAMILY NEED HELP AND SUPPORT, HOW, WHEN, WHERE AND FROM WHOM DO YOU WANT IT?

We want to make sure people have access to the services they want, when they want them, where they want them and from whom they want them. But to do this there are some tough choices to be made.

...Thinking about how the NHS and Social Care and other services might improve how, when, where and from whom community-based services are delivered...

Q8. Which of the following did the people at the listening exercises you ran think should be top three priorities? (Please rank by writing 1, 2 or 3 in the boxes)

Providing convenient services which fit around people’s lives, for example by extending opening hours to evenings and weekends at the local GP practice, pharmacy and other community services, by enabling people who receive care at home to choose for example when the carer visits

Providing care in convenient locations (for example NHS Walk in Centres near train stations so people can get quick advice on problems and health issues on their way to work) or allowing people to register with any family Doctor, not just one where you live

Developing and providing more services in the local community, rather than only in hospitals, so they are more convenient for families and children to use. For example, blood tests, x-rays and some scans, minor surgery and physiotherapy could be provided locally. Also, hospital specialists could run clinics in the community.

Developing new services for people who don’t always currently access care, such as young men, teenagers, people from different ethnic groups, people with disabilities.

Allowing people to choose how to receive services at the end of life and to die where they want with dignity. (This options is about the care people receive at the end of their lives, it is not about euthanasia)

None of the above

Don’t know

NOT RANKED SEE OVER
PLEASE SUMMARISE WHY PEOPLE SELECTED THESE PRIORITIES:

DID NOT RANK BUT COMMENTS AS FOLLOWS

Enabling people who receive care at home to choose for example when the carer visits
Ideally people would like choice about carer visits.

“They just told me the cleaner was coming twice a week in the afternoon. My hospital appointments were then so I would have liked the morning but there was no consideration for what was good for me”

Providing care in convenient locations/in the local community
More local services would be appreciated. Travelling long distances is a real struggle for patients and carers and costly too.
But in the final stages care in the home is what is really important.

Allowing people to choose how to receive services at the end of life and to die where they want with dignity
This is a tricky conversation to have with people who may or may not want to face the reality of dying. Taboos talking about death abound. Quite clearly, however, people want to be able have their say about how and where they are in their final days. In most cases the preference is ‘my home’ for reasons as previously discussed.

Choice please but not overwhelming
Again we need to repeat the point that at this stage people should be guided and helped rather than presented with overwhelming choices. Unfortunately, a few people (usually women) are experienced carers having had to look after several dying relatives.

“It’s no problem for me caring for my husband because I looked after my mother, then my mother in law and then my sister. I know how to care”

Support for Carers
However, for the majority the first significant family death is a totally new experience. Hence, the important role of community people like District Nurses and Marie Curie nurses and care assistants who can gently talk people through it.

However, there is the stark fact that the carers of elderly cancer patients are likely to be elderly and possibly infirm or disabled themselves. Hence, for many ‘going home’ is not an option. Hospices are really appreciated for providing respite and flexibility.

“I’d like to be at home but it’s not possible. I’ve passed out 20 times and been on the floor. My wife has Parkinsons and just couldn’t cope… but I go home for the weekends which is lovely”

“I’m here (at the hospice) because my husband has got Alzheimer’s. I’ve got six boys and one of them used to live in Canada but got divorced and now he cares for my husband. The other boys have organised a rota and they take it in turns to come over on a Saturday night, stay the night and bring my husband to see me on a Sunday.”

Dignity is a major issue.
Again we need to emphasise the importance of ensuring that all who deal with the terminally ill master appropriate communication skills.
Q9. Did people think it would be enough for Government to only do these things to help provide service how, where, when and from whom people want them? Why?

NO EXTRA COMMENT

Q10. What else would people like the Government to do to help provide services how, where, when and from whom people want them?

NO EXTRA COMMENT
Q11. Looking across all the options we have asked about, which of these did your group think was the most important thing to be done immediately?

- Encouraging and supporting better health, for example through routine check ups, advice on healthy lifestyles and promoting self-care and self-assessment.

- Ensuring a range of health professionals, such as nurses and pharmacists, can provide people with information and support about how to take better care of themselves and their families. For instance pharmacists could give advice on getting the best out of the medicines you take or they could run clinics for people with high blood pressure.

- Tackling the things that cause ill health and disadvantage, such as poverty and poor housing, by developing new services in the community and by expanding the range of services available in doctors’ surgeries (e.g., advisors to help with housing, employment and training and benefits), children’s centres and other locations.

- Ensuring older people and those with disabilities can get the practical help and support they need to remain independent and active for longer.

- Providing effectively joined-up social care and health services to those that need them, for example through a single ‘needs assessment’. A ‘needs assessment’ would be a kind of one-stop-shop appointment instead of lots of appointments. A case manager would be someone who plans your care with you and then coordinates it.

- Providing more help to people caring for others, for example with more respite care.

- Providing people with better information about what NHS, local authority and social care services are on offer.

- Improving the availability, quality and choice of services for long-term care users and people with long-term illnesses like diabetes e.g. support from people with similar conditions.

- Providing convenient services which fit around people’s lives, for example by extending opening hours to evenings and weekends at the local GP practice, pharmacy and other community services, by enabling people who receive care at home to choose for example when the carer visits.

- Providing care in convenient locations (for example NHS Walk in Centres near train stations so people can get quick advice on problems and health issues on their way to work) or allowing people to register with any family Doctor, not just one where you live.
Developing and providing more services in the local community, rather than only in hospitals, so they are more convenient for families and children to use. For example, blood tests, x-rays and some scans, minor surgery and physiotherapy could be provided locally. Also, hospital specialists could run clinics in the community.

Developing new services for people who don’t always currently access care, such as young men, teenagers, people from different ethnic groups, people with disabilities.

Allowing people to choose how to receive services at the end of life and to die where they want with dignity. (This option is about the care people receive at the end of their lives, it is not about euthanasia)
Q12. Please summarise the main reasons why this option was chosen as the key priority?

WE DID NOT RANK THESE THINGS

Clearly for our audience quality care at end of life is paramount as aforesaid.

Q13. Please summarise the main points from the discussion about whether these changes address the things that work less well at the moment, and maintain and support the things that work well at the moment.

NO EXTRA COMMENT
Q14. Please summarise the main points from the discussion about what else the Department of Health should be doing to make sure that community-based health and social care services meet people's needs in the 21st century?

From our conversations the top 5 basic priorities are

- Effective pain control
- More home nursing,
- More hospice provision,
- More information and
- Improved communication skills for all who deal with the terminally ill

In addition people would like:

- Effective integration of health and social care services as aforementioned to reduce the struggle to 'sort everything out'
- More links between mental health and welfare and terminal care
- Care for carers. The terminally ill worry about the strain they put on their nearest and dearest. Carers are typically very uncomplaining and therefore 'put upon'. It is unjust that more men die at home because women accept the mantle of caring for them. A lot more support needs to be given to men to enable them to become carers too.
- Many elderly patients said that they had children and that 'in theory they are a help but in practice they are not'. This is a reflection of the breakdown of the nuclear family, children living far away, working full time and for long hours and being over-stretched with their own work and family life etc.
- There is a need for a significant initiative to improve both the status of being a carer and recognition of its practical value.
- More equitable provision regarding availability and quality of home and hospice care for the terminally ill
- Transparent and open access regarding entitlements for allowances

The ideal is that all who are terminally ill feel as secure and loved as the following two cases.

"Coming here to the Marie Curie hospice is the most wonderful thing that has happened to me… the nurses must be picked because they are all gorgeous, they treat me like royalty. I love being here"

"We know if we ask we will get, nurses will be organised by the GP and out of hours we can call the hospice or the hospital. The most important thing for me is being one to one with my wife, she’s my rock and she does everything for me so I feel safe. I’m in my own environment, at home. We are making the best of the situation ….. we watch all the quiz shows on TV and our treat is having a £2 bet on the horses. You’ve got to keep positive".
Section C: details about your organisation and your listening exercises

To help us analyse the information you have given us, we need to find out a little bit more about your organisation and your listening exercise.

A. How many people took part in your devolved listening exercises?

Write in below

| 21 |

B. What sort of listening exercise was it?

(Please tick one box only)

| A day long session (from 5 to 8 hours long) |
| A half day session (from 3 to 5 hours long) |
| Up to 3 hours long |
| Other (record below) |

21 one to one depth interviews of one hour in length with terminally ill cancer patients and their carers

C. How many of each of the following types of people took part in your listening exercise?

(Please put a number in each box even if it is zero)

| Members of the general public (i.e. with no specialist interest in health and social care) | 0 |
| Members of the public who are involved with health and social care services e.g. PPI forum members | 0 |
| Paid staff from your organisation | 0 |
| Voluntary staff from your organisation | 0 |
| Other (record below) | 21 |

15 terminally ill cancer patients and 6 carers

D. Please tell us how many of the people who took part – whether members of the public or staff - were from any of the specific sectors of the population listed below.

| Children and young people |
| Older people | 17 |
| Pregnant women (and their partners) |
| Socially disadvantaged people |
| Disadvantaged children |
| Smokers |
| Excessive drinkers |
E. Of the people that took part in your listening exercise, can you please tell us how many were from each of the ethnic groups listed below

<table>
<thead>
<tr>
<th>Ethnic Group</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>White British</td>
<td>17</td>
</tr>
<tr>
<td>White Irish</td>
<td>2</td>
</tr>
<tr>
<td>Any other white background</td>
<td>1</td>
</tr>
<tr>
<td>White and Black Caribbean</td>
<td></td>
</tr>
<tr>
<td>White and Black African</td>
<td></td>
</tr>
<tr>
<td>White and Asian</td>
<td></td>
</tr>
<tr>
<td>Any other mixed background</td>
<td></td>
</tr>
</tbody>
</table>
F. Which of the following best describes the sector to which your organisation or group belongs / where you work:

(Please tick one box only)

- PPI forum or other patient group
- Community-based NHS services
- Local authority social care services
- Private sector health or social care services
- Voluntary sector health or social care services
- Other (record below)

[ ] yes

Marie Curie Cancer Care

G. If your listening exercises mostly involved staff rather than patients or service users please can you identify from the list below which groups they most often have contact with or provide services for:

(Please tick all relevant boxes)

- Children and young people
- Older people
- Pregnant women (and their partners)
- Socially disadvantaged people
- Disadvantaged children
- Smokers
- Excessive drinkers
- Obese people
<table>
<thead>
<tr>
<th>Category</th>
<th>Check Box</th>
</tr>
</thead>
<tbody>
<tr>
<td>Substance misusers</td>
<td></td>
</tr>
<tr>
<td>Disabled people</td>
<td></td>
</tr>
<tr>
<td>People in prison</td>
<td></td>
</tr>
<tr>
<td>Black and minority ethnic groups</td>
<td></td>
</tr>
<tr>
<td>Travellers</td>
<td></td>
</tr>
<tr>
<td>Homeless people</td>
<td></td>
</tr>
<tr>
<td>People with mental health problems</td>
<td></td>
</tr>
<tr>
<td>People with learning disabilities</td>
<td></td>
</tr>
<tr>
<td>People in hospices/residential care</td>
<td></td>
</tr>
<tr>
<td>Asylum seekers</td>
<td></td>
</tr>
<tr>
<td>People with long term conditions</td>
<td></td>
</tr>
<tr>
<td>People with caring responsibilities</td>
<td></td>
</tr>
<tr>
<td>Do not deal with specific sectors of the community</td>
<td></td>
</tr>
<tr>
<td>Other (record below)</td>
<td></td>
</tr>
</tbody>
</table>
If you work with specific ethnic groups, which of these groupings do you represent or work with?

- White British
- White Irish
- Any other white background
- White and Black Caribbean
- White and Black African
- White and Asian
- Any other mixed background
  - Indian
  - Pakistani
  - Bangladeshi
- Any other Asian Background
  - Caribbean
  - African
- Any other Black background
  - Chinese
- Do not deal with specific ethnic groups
- Other (record below)

I. If you are a regional organisation, please tick the box below for the region you mainly work in

- North East
- North West
- Yorkshire & the Humber
- East Midlands
- East of England
- South East
J. What is the name of your organisation?

Marie Curie Cancer Care

K. What type of organisation are you responding as?

<table>
<thead>
<tr>
<th>A local organisation</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>A national organisation</td>
<td>yes</td>
</tr>
<tr>
<td>Other (please record below)</td>
<td></td>
</tr>
</tbody>
</table>

L. Would like to be listed as a contributor to the consultation?

<table>
<thead>
<tr>
<th>Yes</th>
<th>yes</th>
</tr>
</thead>
<tbody>
<tr>
<td>No</td>
<td></td>
</tr>
</tbody>
</table>

K. If you would like to receive a summary of our findings, please enter your contact details or email address in the box below:

Maeve.Hully@mariecurie.org.uk
Lucinda@elucidationresearch.co.uk
Tel 0207 419 1565
Mob 07973 502 180
14 Langbourne Avenue
London N6 6AL
Thank you for your help with your health, your care, your say.

This feedback form is intended for both local and national organisations or groups to report on the findings their own devolved listening exercise as part your health, your care, your say.

Can I check, are you responding to this questionnaire as:

- A local organisation or group
- A national organisation or group
- Other (record details below)

All the information you submit will be analysed alongside the public’s response and the views obtained from other local and national organisations and groups and will feed in to the development of plans for improving community health and care services.

Please note the feedback form is in three parts:

- Section A: Thinking about the community health and social care services people use, what currently works less well?
- Section B: what do you think of the suggestions for improving health and social care services?
- Section C: details about your organisation and your listening exercise
If you haven’t covered Section A or all of the options under Section B, please just leave those questions blank.

Please make sure that you give us this feedback by 4th November, or earlier if possible. You can find out where to return this feedback by referring to the resource pack website, www.yoursayresources.nhs.uk

As you will see, most questions ask you to tick a box like this:

*Tick one box only*

Other questions give you space to record how you reached your decisions:

Please feel free to write as much, or as little, as you like.

Section A: Thinking about the community health and social care services people use, what currently works well, and what currently works less well?

We want to make community-based health and social care services better for everyone. To help us reach the right decisions, we want to know what the people at the listening exercises you ran thought about community-based health and social care services at the moment.

Q1. What were the three key elements of community health and social care services that people though worked well?

(RECORD BELOW IN PRIORITY ORDER)

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Availability of most drugs and explanation of descriptions</td>
</tr>
<tr>
<td>2</td>
<td>Good relations with most NHS staff</td>
</tr>
<tr>
<td>3</td>
<td>Health monitoring of those at risks i.e. aged by GPs</td>
</tr>
</tbody>
</table>

RECORD BELOW WHY PEOPLE THOUGHT THESE WORKED WELL:

The majority of our focus group thought that the drugs their GPs prescribed for them were always available and the staff at the GPs and also the GPs themselves gave them satisfactory explanation of the way to use the drugs and the risks involved in not doing so. They agreed this helps them to use the drugs with care
and in a mature way. The same applied to the drugs they collect for their children and aged parents.

On the relations with the staff many thought the staff was good and very friendly especially once you come to know them well. And good relationship is developed individual GPs and nurses go out of their way to help and encourage their patients. This was seen as a positive step especially by the women in the focus group since they said it encouraged them to articulate their situation with confidence and trust.

On the health monitoring, they said there are many particularly those from the developing countries who had no idea they were suffering from serious diseases like blood pressure and diabetes and are now receiving treatment thanks to the random monitoring exercises conducted at the GP level. An early warning system is what this monitoring is doing.

What were the three key elements of community health and social care services that people thought worked less well?

(RECORD BELOW IN PRIORITY ORDER)

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Emergencies</td>
</tr>
<tr>
<td>2</td>
<td>Home visits</td>
</tr>
<tr>
<td>3</td>
<td>Referral to hospitals/waiting time</td>
</tr>
</tbody>
</table>

RECORD BELOW WHY PEOPLE THOUGHT THESE WORKED LESS WELL:
The participants thought that the worst of all is the emergency service. The problem has nothing to do with the Ambulance or its staff but the nightmare begins once you arrive at the hospital. The following remarks were given:

- You sit there on benches for hours
- No one seems to care
- You are blamed for coming the emergency
- You may end up with few tabs of paracetamol

It appears they said the ambulance service and the hospital have nothing to do with each other. The ambulance keep on damping people in the hospital while nothing is happening to the previous deliveries.

Home visit is another area they thought needed to be looked into. This provision they said currently is non-existent. Many patients would have been helped and treated at home without causing congestion at the hospital.

Most of the participants felt that GPs try their level best to deny patients referral to NHS Hospitals where they can be able to receive more substantial checkups. Some thought this was a deliberate action by the GPs to save themselves from extra paper work. They said it took them ages to get through the GPs and spent unnecessary time explaining their needs when GPs could simply give them proper checkups and refer them straight away.
The current waiting time is also damaging they said. It is too long and frustrating they said.

What other issues did people mention? Please record any personal stories here if possible

Participants strongly suggested that there should be more doctors practising as GPs. They said there is need to training more doctors especially from the ethnic minority and the refugee communities.
Participants from the Somali community raised particular concern about the lack of Somali doctors in the UK and expressed their frustration on why ‘their qualified’ doctors from home were denied the licence to practice.

Participants also deliberated on the lack of provision in the NHS of simple surgery operations that many migrate to mainland Europe to receive them freely or cheaply.

Section B: what did people think of the suggestions for improving health and social care services?

We are committed to helping people take better care of themselves, but big questions remain about how it can best do this.

...Thinking about how the NHS, Social Care and other services might help people to look after themselves more...

Q2. Which of the following did people at the listening exercises you ran think should be the top three priorities? (Please rank by writing 1, 2 or 3 in the boxes)

Encouraging and supporting better health, for example through routine check ups, advice on healthy lifestyles and promoting self-care and self-assessment.

Ensuring a range of health professionals, such as nurses and pharmacists, can provide people with information and support about how to take better care of themselves and their families. For instance pharmacists could give advice on getting the best out of the medicines you take or they could run clinics for people with high blood pressure.

Tackling the things that cause ill health and disadvantage, such as poverty and poor housing, by developing new services in the community and by expanding the range of services available in doctors’ surgeries (eg advisors to help with housing, employment and training and benefits), children’s centres and
other locations.

Ensuring older people and those with disabilities can get the practical help and support they need to remain independent and active for longer

- None of the above
- Don’t know

PLEASE SUMMARISE WHY PEOPLE SELECTED THESE PRIORITIES:

The participants were of the opinion that the living condition of an individual heavily impacted on their health condition. The chances of contracting diseases are more likely and in many cases obvious for those residing in rundown districts with derelict accommodation. Congestion is another strong factor because in that case spread of diseases in the household is faster and uncontrollable. This was their line of argument.

The speed with which one can access medical service works marvellously against the spread of diseases and their treatment. The more health facilities available within the neighbourhood the better, particularly in the eradication of diseases.

The direct involvement of frontline health staff like nurses and pharmacist in the campaign to educate the masses about health issues and personal health is invaluable. All participants thought this was a wonderful idea.
Q3. Did people think it would be enough for Government to only do these things to help people take better care of themselves? Why?

Many thought that the provision of health facilities will not be enough without the right people to manage them. They thought that all the Government was doing was to give the money ask for numbers – how many benefited and not how they benefited. They said people have been reduced to statistics and fed into a database.

They said doctors and nurses must be empathetic and deal with human emotions rather than dealing with objects.

Doctors and other health staff should be made to take guidance and counselling courses to help the deal more humanly and at the same time professionally with their patients.

Q4. What else would people like the Government to do to help people take better care of themselves?

Health leaflets written in their own language would be very helpful.
We want people to be able to use and find their way through health and social care services more easily. We also want these services to be ‘joined up’, even if several people or organisations are providing them.

...Thinking about how the NHS, Social Care and other services might help people find the services they need and improve the way these services are joined up ...

Q5. Which of the following did people at the listening exercises you ran think should be the top three priorities? (Please rank by writing 1, 2 or 3 in the boxes)

Providing effectively joined-up social care and health services to those that need them, for example through a single ‘needs assessment’. A ‘needs assessment’ would be a kind of one-stop-shop appointment instead of lots of appointments. A case manager would be someone who plans your care with you and then coordinates it.

Providing more help to people caring for others, for example with more respite care

Providing people with better information about what NHS, local authority and social care services are on offer

Improving the availability, quality and choice of services for long-term care users and people with long-term illnesses like diabetes e.g. support from people with similar conditions

None of the above

Don’t know

PLEASE SUMMARISE WHY PEOPLE SELECTED THESE PRIORITIES:

The participants were impressed by the first choice. They thought a one stop for everything is the best for them. All their needs could be addressed at one stop. But they added the choice of the case manager must be on the user and should be able to terminate it whenever he deems necessary.
Q6. Did people think it would be enough for Government to only do these things to help people manage their care and make decisions?

No

Q7. What else would people like the Government to do to help people manage their care and make decisions?

The participants thought that the best carers are those in the neighbourhood. So they should be identified and trained from the neighbourhood.
WHEN YOU AND YOUR FAMILY NEED HELP AND SUPPORT, HOW, WHEN, WHERE AND FROM WHOM DO YOU WANT IT?

We want to make sure people have access to the services they want, when they want them, where they want them and from whom they want them. But to do this there are some tough choices to be made.

...Thinking about how the NHS and Social Care and other services might improve how, when, where and from whom community-based services are delivered...

Q8. Which of the following did the people at the listening exercises you ran think should be top three priorities? (Please rank by writing 1, 2 or 3 in the boxes)

1. Providing convenient services which fit around people’s lives, for example by extending opening hours to evenings and weekends at the local GP practice, pharmacy and other community services, by enabling people who receive care at home to choose for example when the carer visits.

2. Providing care in convenient locations (for example NHS Walk in Centres near train stations so people can get quick advice on problems and health issues on their way to work) or allowing people to register with any family Doctor, not just one where you live.

3. Developing and providing more services in the local community, rather than only in hospitals, so they are more convenient for families and children to use. For example, blood tests, x-rays and some scans, minor surgery and physiotherapy could be provided locally. Also, hospital specialists could run clinics in the community.

4. Developing new services for people who don’t always currently access care, such as young men, teenagers, people from different ethnic groups, people with disabilities.

5. Allowing people to choose how to receive services at the end of life and to die where they want with dignity. (This options is about the care people receive at the end of their lives, it is not about euthanasia)

None of the above

Don't know
If GPs and the Pharmacists open longer hours and on daily basis it would help people access help whenever need be. Flu doesn't give you the choice of when to contract it! And when services are within the neighbourhood, it is something to celebrate about. It saves you the time and energy to drag yourself to a hospital. Hospitals will then be left to deal with serious ailments only. Participants were impressed by these ideas.
Q9. Did people think it would be enough for Government to only do these things to help provide service how, where, when and from whom people want them? Why?

Participants were of the idea that all sectors of the society should be involved in its setting up and then represented. More information and targeted education should be carried out.

Q10. What else would people like the Government to do to help provide services how, where, when and from whom people want them?

As mentioned earlier routine home visits should be included. Telephone booking service should be included.
Q11. Looking across all the options we have asked about, which of these did your group think was the most important thing to be done immediately?

Encouraging and supporting better health, for example through routine check-ups, advice on healthy lifestyles and promoting self-care and self-assessment.

Ensuring a range of health professionals, such as nurses and pharmacists, can provide people with information and support about how to take better care of themselves and their families. For instance pharmacists could give advice on getting the best out of the medicines you take or they could run clinics for people with high blood pressure.

Tackling the things that cause ill health and disadvantage, such as poverty and poor housing, by developing new services in the community and by expanding the range of services available in doctors’ surgeries (eg advisors to help with housing, employment and training and benefits), children’s centres and other locations.

Ensuring older people and those with disabilities can get the practical help and support they need to remain independent and active for longer.

Providing effectively joined-up social care and health services to those that need them, for example through a single ‘needs assessment’. A ‘needs assessment’ would be a kind of one-stop-shop appointment instead of lots of appointments. A case manager would be someone who plans your care with you and then coordinates it.

Providing more help to people caring for others, for example with more respite care.

Providing people with better information about what NHS, local authority and social care services are on offer.
Improving the availability, quality and choice of services for long-term care users and people with long-term illnesses like diabetes e.g. support from people with similar conditions

Providing convenient services which fit around people’s lives, for example by extending opening hours to evenings and weekends at the local GP practice, pharmacy and other community services, by enabling people who receive care at home to choose for example when the carer visits

Providing care in convenient locations (for example NHS Walk in Centres near train stations so people can get quick advice on problems and health issues on their way to work) or allowing people to register with any family Doctor, not just one where you live

Developing and providing more services in the local community, rather than only in hospitals, so they are more convenient for families and children to use. For example, blood tests, x-rays and some scans, minor surgery and physiotherapy could be provided locally. Also, hospital specialists could run clinics in the community.

Developing new services for people who don’t always currently access care, such as young men, teenagers, people from different ethnic groups, people with disabilities.

Allowing people to choose how to receive services at the end of life and to die where they want with dignity. (This options is about the care people receive at the end of their lives, it is not about euthanasia)
Q12. Please summarise the main reasons why this option was chosen as the key priority?

Please see above

Q13. Please summarise the main points from the discussion about whether these changes address the things that work less well at the moment, and maintain and support the things that work well at the moment.

Participants distinctly separated what they perceived as working well and what were not. In the discussion improvement of what were working well and what were not were both summed up. The crunch of the matter was ‘what was good for us?’
Q14. Please summarise the main points from the discussion about what else the Department of Health should be doing to make sure that community-based health and social care services meet people’s needs in the 21st century?

The discussion went around the following:
- Improvement of the existing services
- More community based services
- Modernisation of the services
- Better training of the staff
- Involvement of the beneficiaries
- Reaching out to all
- More days and hours of accessibility to services
- Community representatives in the NHS
- Decentralised services
- User friendly approach in the department
Section C: details about your organisation and your listening exercises

To help us analyse the information you have given us, we need to find out a little bit more about your organisation and your listening exercise.

A. How many people took part in your devolved listening exercises?

\[
\begin{array}{|c|c|}
\hline
\text{Write in below} & 15 \\
\hline
\end{array}
\]

B. What sort of listening exercise was it?

(Please tick one box only)

- A day long session (from 5 to 8 hours long) \(\sqrt{}\)
- A half day session (from 3 to 5 hours long)
- Up to 3 hours long
- Other (record below)

C. How many of each of the following types of people took part in your listening exercise?

(Please put a number in each box even if it is zero)

- Members of the general public (i.e. with no specialist interest in health and social care) \(\sqrt{}\)
- Members of the public who are involved with health and social care services e.g. PPI forum members
- Paid staff from your organisation
- Voluntary staff from your organisation \(\sqrt{}\)
- Other (record below)
D. Please tell us how many of the people who took part – whether members of the public or staff - were from any of the specific sectors of the population listed below.

<table>
<thead>
<tr>
<th>Sector</th>
<th>Yes/No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Children and young people</td>
<td>✓</td>
</tr>
<tr>
<td>Older people</td>
<td></td>
</tr>
<tr>
<td>Pregnant women (and their partners)</td>
<td></td>
</tr>
<tr>
<td>Socially disadvantaged people</td>
<td>✓</td>
</tr>
<tr>
<td>Disadvantaged children</td>
<td></td>
</tr>
<tr>
<td>Smokers</td>
<td></td>
</tr>
<tr>
<td>Excessive drinkers</td>
<td></td>
</tr>
<tr>
<td>Obese people</td>
<td></td>
</tr>
<tr>
<td>Substance misusers</td>
<td></td>
</tr>
<tr>
<td>Disabled people</td>
<td></td>
</tr>
<tr>
<td>People in prison</td>
<td></td>
</tr>
<tr>
<td>Black and minority ethnic groups</td>
<td>✓</td>
</tr>
<tr>
<td>Travellers</td>
<td></td>
</tr>
<tr>
<td>Homeless people</td>
<td></td>
</tr>
<tr>
<td>People with mental health problems</td>
<td></td>
</tr>
<tr>
<td>People with learning disabilities</td>
<td></td>
</tr>
<tr>
<td>People in hospices/residential care</td>
<td></td>
</tr>
<tr>
<td>Asylum seekers</td>
<td>✓</td>
</tr>
<tr>
<td>People with long term conditions</td>
<td></td>
</tr>
<tr>
<td>People with caring responsibilities</td>
<td></td>
</tr>
<tr>
<td>Other (record below)</td>
<td></td>
</tr>
</tbody>
</table>
E. Of the people that took part in your listening exercise, can you please tell us how many were from each of the ethnic groups listed below

- White British
- White Irish
- Any other white background
- White and Black Caribbean
- White and Black African
- White and Asian
- Any other mixed background
- Indian
- Pakistani
- Bangladeshi
- Any other Asian Background
- Caribbean
- African
- Any other Black background
- Chinese
- Rather not say

F. Which of the following best describes the sector to which your organisation or group belongs / where you work:

(Please tick one box only)

- PPI forum or other patient group
- Community-based NHS services
- Local authority social care services
- Private sector health or social care services
- Voluntary sector health or social care services
G. If your listening exercises mostly involved staff rather than patients or service users please can you identify from the list below which groups they most often have contact with or provide services for:

*(Please tick all relevant boxes)*

<table>
<thead>
<tr>
<th>Group</th>
<th>Ticked</th>
</tr>
</thead>
<tbody>
<tr>
<td>Children and young people</td>
<td></td>
</tr>
<tr>
<td>Older people</td>
<td></td>
</tr>
<tr>
<td>Pregnant women (and their partners)</td>
<td></td>
</tr>
<tr>
<td>Socially disadvantaged people</td>
<td></td>
</tr>
<tr>
<td>Disadvantaged children</td>
<td></td>
</tr>
<tr>
<td>Smokers</td>
<td></td>
</tr>
<tr>
<td>Excessive drinkers</td>
<td></td>
</tr>
<tr>
<td>Obese people</td>
<td></td>
</tr>
<tr>
<td>Substance misusers</td>
<td></td>
</tr>
<tr>
<td>Disabled people</td>
<td></td>
</tr>
<tr>
<td>People in prison</td>
<td></td>
</tr>
<tr>
<td>Black and minority ethnic groups</td>
<td></td>
</tr>
<tr>
<td>Travellers</td>
<td></td>
</tr>
<tr>
<td>Homeless people</td>
<td></td>
</tr>
<tr>
<td>People with mental health problems</td>
<td></td>
</tr>
<tr>
<td>People with learning disabilities</td>
<td></td>
</tr>
<tr>
<td>People in hospices/residential care</td>
<td></td>
</tr>
<tr>
<td>Asylum seekers</td>
<td></td>
</tr>
<tr>
<td>People with long term conditions</td>
<td></td>
</tr>
<tr>
<td>People with caring responsibilities</td>
<td></td>
</tr>
<tr>
<td>Do not deal with specific sectors of the community</td>
<td></td>
</tr>
</tbody>
</table>
If you work with specific ethnic groups, which of these groupings do you represent or work with?

- White British
- White Irish
- Any other white background
- White and Black Caribbean
- White and Black African
- White and Asian
- Any other mixed background
- Indian
- Pakistani
- Bangladeshi
- Any other Asian Background
- Caribbean
- African
- Any other Black background
- Chinese

Do not deal with specific ethnic groups

Other (record below)
I. If you are a regional organisation, please tick the box below for the region you mainly work in

<table>
<thead>
<tr>
<th>Region</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>North East</td>
<td></td>
</tr>
<tr>
<td>North West</td>
<td></td>
</tr>
<tr>
<td>Yorkshire &amp; the Humber</td>
<td></td>
</tr>
<tr>
<td>East Midlands</td>
<td></td>
</tr>
<tr>
<td>East of England</td>
<td></td>
</tr>
<tr>
<td>South East</td>
<td></td>
</tr>
<tr>
<td>London</td>
<td></td>
</tr>
<tr>
<td>South West</td>
<td></td>
</tr>
<tr>
<td>National Organisation</td>
<td></td>
</tr>
<tr>
<td>Not applicable</td>
<td></td>
</tr>
</tbody>
</table>

J. What is the name of your organisation?

Appropriate Support & Training – (ASAT)

K. What type of organisation are you responding as?

<table>
<thead>
<tr>
<th>Type of Organisation</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>A local organisation</td>
<td>✓</td>
</tr>
<tr>
<td>A national organisation</td>
<td></td>
</tr>
<tr>
<td>Other (please record below)</td>
<td></td>
</tr>
</tbody>
</table>
L. Would like to be listed as a contributor to the consultation?

<table>
<thead>
<tr>
<th>Yes</th>
<th>√</th>
</tr>
</thead>
<tbody>
<tr>
<td>No</td>
<td></td>
</tr>
</tbody>
</table>

K. If you would like to receive a summary of our findings, please enter your contact details or email address in the box below:

H H Hassan  
Appropriate Support & Training  
Wamo Trading Centre, Unit 9,  
97 Western Road, Southall, Middx  
UB2 5HN  
Tel. 0208 574 5600  
Email: HssH698@aol.com
YOUR HEALTH, YOUR CARE, YOUR SAY
FEEDBACK FORM FOR LOCAL LISTENING EXERCISES
Thank you for your help with your health, your care, your say.

This feedback form is intended for both local and national organisations or groups to report on the findings their own devolved listening exercise as part your health, your care, your say.

Can I check, are you responding to this questionnaire as:

- A local organisation or group
- A national organisation or group
- Other (record details below)

NHS end of life care programme

All the information you submit will be analysed alongside the public's response and the views obtained from other local and national organisations and groups and will feed in to the development of plans for improving community health and care services.

Please note the feedback form is in three parts:

- Section A: Why do community health and social care services matter to the nation as a whole?
- Section B: what do you think of the suggestions for improving health and social care services?
- Section C: details about your organisation and your listening exercise

If you haven't covered Section A or all of the options under Section B, please just leave those questions blank.

Please make sure that you give us this feedback by 4th November, or earlier if possible. You can find out where to return this feedback by referring to the resource pack website, www.yoursayresources.nhs.uk.

As you will see, most questions ask you to tick a box like this:

*Tick one box only*

Other questions give you space to record how you reached your decisions:

Please feel free to write as much, or as little, as you like.
Section A: Why do community health and social care services matter to the nation as a whole?

We want to make community-based health and social care services better for everyone. To help us reach the right decisions, we want to know what the people at the listening exercises you ran thought about community-based health and social care services at the moment.

Q1. What did people think were the five main reasons why community health and social care matter to the nation as a whole? *(RECORD BELOW IN PRIORITY ORDER)*

<table>
<thead>
<tr>
<th>1</th>
</tr>
</thead>
<tbody>
<tr>
<td>2</td>
</tr>
<tr>
<td>3</td>
</tr>
<tr>
<td>4</td>
</tr>
<tr>
<td>5</td>
</tr>
</tbody>
</table>

RECORD BELOW WHY PEOPLE THOUGHT THESE WERE IMPORTANT:
Section B: what did people think of the suggestions for improving health and social care services?

We are committed to helping people take better care of themselves, but big questions remain about how it can best do this.

...Thinking about how the NHS, Social Care and other services might help people to look after themselves more...

Q2. Which of the following did people at the listening exercises you ran think should be the top three priorities? (Please rank by writing 1, 2 or 3 in the boxes)

Promoting and supporting better health, for example through routine check ups, advice on healthy lifestyles and promoting self-care and self-assessment.

Ensuring a range of health professionals, such as nurses and pharmacists, can provide people with information and support about how to take better care of themselves and their families.

Tackling the things that cause ill health and disadvantage, such as poverty and poor housing, by developing new services in the community and by expanding the range of services available in doctors’ surgeries (eg providing jobs and skills advice), children’s centres and other locations.

Ensuring older people and those with disabilities can get the practical help and support they need to remain independent and active for longer

None of the above
Don’t know

PLEASE SUMMARISE WHY PEOPLE SELECTED THESE PRIORITIES:
Q3. What else would people like the NHS, Social Care and other services to do to help people take better care of themselves?
When you and your family need help and support, how, when, where and from whom do you want it?

We want to make sure people have access to the services they want, when they want them, where they want them and from whom they want them. But to do this there are some tough choices to be made.

...Thinking about how the NHS and Social Care and other services might improve how, when, where and from whom community-based services are delivered ...

Q4. Which of the following did the people at the listening exercises you ran think should be top three priorities? (Please rank by writing 1, 2 or 3 in the boxes)

<table>
<thead>
<tr>
<th>Providing convenient services which fit around people’s lives, for example by extending opening hours to evenings and weekends at the local GP practice, pharmacy and other community services</th>
</tr>
</thead>
<tbody>
<tr>
<td>Providing care in convenient locations (for example NHS Walk in Centres near train stations so people can get quick advice on problems and health issues on their way to work) or allowing people to register with any family Doctor, not just one where you live</td>
</tr>
<tr>
<td>Developing and providing more services in the local community, rather than only in hospitals, so they are more convenient for families and children to use</td>
</tr>
<tr>
<td>Developing new services for people who don't always currently access care, such as people from black and minority ethnic groups and teenagers</td>
</tr>
<tr>
<td>Allowing people to choose how to receive services at the end of life and to die where they want with dignity.</td>
</tr>
<tr>
<td>None of the above</td>
</tr>
<tr>
<td>Don’t know</td>
</tr>
</tbody>
</table>

Please summarise why people selected these priorities:
Q5. What else would people like the NHS, Social Care and other services to do in terms of how, when, where and from whom community-based services are delivered?
We want people to be able to use and find their way through health and social care services more easily. We also want these services to be ‘joined up’, even if several people or organisations are providing them.

...Thinking about how the NHS, Social Care and other services might help people find the services they need and improve the way these services are joined up ...

Q6. Which of the following did people at the listening exercises you ran think should be the top three priorities? (Please rank by writing 1, 2 or 3 in the boxes)

- Providing effectively joined-up social care and health services to those that need them, for example through a single ‘needs assessment’. A ‘needs assessment’ would be a kind of one-stop-shop appointment instead of lots of appointments.
- Providing people with better information about what NHS, local authority and social care services are on offer
- Improving the availability, quality and choice of services for long-term care users and people with long-term illnesses like diabetes.
- None of the above
- Don’t know

PLEASE SUMMARISE WHY PEOPLE SELECTED THESE PRIORITIES:
Q7. What else would people like the NHS, Social Care and other services to do to help people find the services they need and improve the way these services are joined up?
MAKING HEALTH AND SOCIAL CARE BETTER FOR EVERYONE

Q8. Looking across all the options we have asked about what are the top five priorities for the people at the listening exercises you ran? (Please write 1, 2, 3, 4, 5 in the boxes)

Promoting and supporting better health, for example through routine check ups, advice on healthy lifestyles and promoting self-care and self-assessment.

Ensuring a range of health professionals, such as nurses and pharmacists, can provide people with information and support about how to take better care of themselves and their families.

Tackling the things that cause ill health and disadvantage, such as poverty and poor housing, by developing new services in the community and by expanding the range of services available in doctors’ surgeries (eg providing jobs and skills advice), children’s centres and other locations.

Ensuring older people and those with disabilities can get the practical help and support they need to remain independent and active for longer.

Providing convenient services which fit around people’s lives, for example by extending opening hours to evenings and weekends at the local GP practice, pharmacy and other community services.

Providing care in convenient locations (for example NHS Walk in Centres near train stations so people can get quick advice on problems and health issues on their way to work) or allowing people to register with any family Doctor, not just one where you live.

Developing and providing more services in the local community, rather than only in hospitals, so they are more convenient for families and children to use.

Developing new services for people who don’t always currently access care, such as people from black and minority ethnic groups and teenagers.
Allowing people to choose how to receive services at the end of life and to die where they want with dignity.

Providing effectively joined-up social care and health services to those that need them, for example through a single ‘needs assessment’. A ‘needs assessment’ would be a kind of one-stop-shop appointment instead of lots of appointments.

Providing people with better information about what NHS, local authority and social care services are on offer

Improving the availability, quality and choice of services for long-term care users and people with long-term illnesses like diabetes.
Q9. Why were these are their five top priorities?
E. WHAT ELSE SHOULD THE NHS, SOCIAL CARE AND OTHER SERVICES BE DOING?

Q10. Below we provide a space for you to tell us about anything else which came up in the listening exercises you ran which will help us understand what people think should be done to make health and social care services better for everyone?

**PLEASE WRITE IN:**

We looked at the points set out at Q8 above, in the context of “what would be needed for an individual if they were dying?” Also we have included suggestions associated with organisational and service delivery that would support individual needs:

All present thought that it was vital that signposting and navigation was available on how to get into the system e.g. GP practices, drop-in centres

Single needs assessment process for the patient and their family/carer which needs to be flexible and ongoing. There is also a great need to develop advanced care planning an example being that of Preferred Place of Care

Patients and carers want to be treated as individuals and as partners with care providers.

The importance of caring for the carer and addressing their needs. Many carers have conflicting priorities e.g. family, parents and jobs

Co-ordination of services between health, social care, private and voluntary organisations. A key worker/navigator would be invaluable so that individuals know where to go for further help and support. Other aspects to aid coordination include IT programme integration, patients flagged on the electronic system and this information is available to out of hours and NHS Direct.

It is vital that health and social care work more in partnership and the cultural differences are addressed, e.g. access to resources needs to be equitable such as health and social services agreeing shared protocols for equipment stores and agreement on swift response to those at the end of life.

Patients want honest, open and timely discussion with either health or social care professionals about end of life care and what choices they have. Patients also need to understand when they are nearing the end of their lives. They may also wish to discuss resuscitation.

In order for this to happen all health and social care workers need to improve communications skills. It is of paramount importance that patients and their families irrespective of their disease are communicated with in a sensitive, informative and confident manner. This requires health and social care workers feeling able to cope with reactions and providing initial support to the patient and their family.
Joint commissioning of end of life care service between health and social care. A range of models are needed as one size will not fit all. Health and social care budgets should be unified and personalised for patients.

Death should be seen as part of life and a natural process and necessarily an acute medicalised event. This requires awareness raising for the general public and should be included in school and college education.

The importance of using the experience and reflections of older people from organisations such as Help the Aged and Age Concern to inform service development and delivery to ensure services stays responsive to need.

There are three end of life care tools which are currently being rolled out and adapted for a variety of care settings encompasses many of these issues. They are:

Gold Standards Framework - This is used when people are likely to be in the last year of life. It was started to help GPs to plan care for these patients and to make sure that information about their 'likely needs' was shared with others involved in their care. In the care home it works in the same way, keeping a list of these residents ensuring that their care plans discussed by the whole team responsible for providing care. This helps with managing symptoms and with giving the patient and their family confidence in their care, especially by planning ahead for what might happen.

Liverpool Care Pathway for the Dying Patient (LCP) - was developed to take the best of hospice care into care for people in hospital and other settings including care homes. It is used to care for patients in the last days or hours of life once it is known that they are dying. The LCP involves prompting good communication with the patient and family, anticipatory planning including psychosocial and spiritual needs, symptom control and care after death. The LCP has accompanying symptom control guidelines and information for relatives.

The Preferred Place of Care Plan (PPC) - is a document that the patient holds for themselves and takes with them if they get care in different places. It has space for the patients’ thoughts about their care and the choices they would like to make, including saying where they would want to be when they die. Information about the family can also be recorded so that any new care staff can read about who’s who and what matters to them too. If anything changes, this can be written in the plan so it stays up to date. It is never too early to start a PPC plan.

Voluntary hospices currently provide two thirds of the funding for specialist palliative care provision. This needs to be addressed if hospices are to be able to develop palliative care models for supporting or providing advice for patients with non cancer diagnosis.

There should be ‘target drivers’ to improve end of life care. In order to achieve a 5% reduction in hospital admissions priority needs to be given to developing quality measures around deaths at home.

The importance of linking up urgent care networks and rapid response teams to incorporate end of life care would also enable patients to live and die in the place of their choice.
In summary the National End of Life Care Steering Group consider the following as priorities

a) Education and training in communication skills – increasing confidence and competence
b) Continue to roll out the end of life care tools to cover the whole country – skilling up generalists
c) Address organisational cultural barriers between health and social services – begin with joint commissioning
d) Ensure that end of life care, particularly services provided by the VCS are linked with ‘Connect for Health’
e) Funding for voluntary hospices should be addressed.
f) Navigation/case management approaches should be utilised
g) ‘talking about death’ should be ‘normalised’ and introduced into education curriculums
h) The experience of Older people should utilised.
i) End of life care should be recognised as ‘urgent care’ and where urgent care centres are being developed end of life care should be an integral component.
Section C: details about your organisation and your listening exercises

To help us analyse the information you have given us, we need to find out a little bit more about your organisation and your listening exercise.

A. How many people took part in your devolved listening exercises?  
   Write in below  

   [ ] [ ] [ ]

B. What sort of listening exercise was it?  
   (Please tick one box only)  
   A day long session (from 5 to 8 hours long)  
   A half day session (from 3 to 5 hours long)  
   Up to 3 hours long  
   Other (record below)  

C. How many of each of the following types of people took part in your listening exercise?  
   (Please put a number in each box even if it is zero)  
   Members of the general public (i.e. with no specialist interest in health and social care)  
   Members of the public who are involved with health and social care services e.g. PPI forum members (i.e. patients/carers)  
   Paid staff from your organisation (i.e. NHS staff)  
   Voluntary staff from your organisation (National Council/Macmillan)  
   Other (record below) (DH/CAT)  

D. And now please tell us how many of the people who took part – whether members of the public or staff - were from any of the specific sectors of the population listed below.  
   (Please put a number in each box even if it is zero)  

   [ ]
E. You said that some of the people who took part in your listening event were from a specific ethnic group. Please tell us how many were from each of the groups listed below:

(Please put a number in each box even if it is zero)
White British
White Irish
Any other white background
White and Black Caribbean
White and Black African
White and Asian
Any other mixed background
Indian
Pakistani
Bangladeshi
Any other Asian Background
Caribbean
African
Any other Black background
Chinese

E. Which of the following best describes the sector to which your organisation or group belongs / where you work:

(Please tick one box only)
- PPI forum or other patient group
- Community-based NHS services
- Local authority social care services
- Private sector health or social care services
- Voluntary sector health or social care services
- Other (record below)

F. If your listening exercises mostly involved staff rather than patients or service users please can you identify from the list below which groups they most often have contact with or provide services for:
(Please tick all relevant boxes)

<table>
<thead>
<tr>
<th>Category</th>
<th>Box</th>
</tr>
</thead>
<tbody>
<tr>
<td>Children and young people</td>
<td></td>
</tr>
<tr>
<td>Older people</td>
<td></td>
</tr>
<tr>
<td>Pregnant women (and their partners)</td>
<td></td>
</tr>
<tr>
<td>Socially disadvantaged people</td>
<td></td>
</tr>
<tr>
<td>Disadvantaged children</td>
<td></td>
</tr>
<tr>
<td>Smokers</td>
<td></td>
</tr>
<tr>
<td>Excessive drinkers</td>
<td></td>
</tr>
<tr>
<td>Obese people</td>
<td></td>
</tr>
<tr>
<td>Substance misusers</td>
<td></td>
</tr>
<tr>
<td>Disabled people</td>
<td></td>
</tr>
<tr>
<td>Prisoners</td>
<td></td>
</tr>
<tr>
<td>Black and minority ethnic groups (GO TO QE)</td>
<td></td>
</tr>
<tr>
<td>Travellers</td>
<td></td>
</tr>
<tr>
<td>Homeless people</td>
<td></td>
</tr>
<tr>
<td>People with mental health problems</td>
<td></td>
</tr>
<tr>
<td>People with learning disabilities</td>
<td></td>
</tr>
<tr>
<td>People in hospices/residential care</td>
<td></td>
</tr>
<tr>
<td>Asylum seekers</td>
<td></td>
</tr>
<tr>
<td>People with long term conditions</td>
<td></td>
</tr>
<tr>
<td>People with caring responsibilities</td>
<td></td>
</tr>
<tr>
<td>Other (record below)</td>
<td></td>
</tr>
</tbody>
</table>
If you would like your organisation to be listed as a contributor to the consultation, please record its name below:

NAME OF ORGANISATION

NHS End of life care programme

If you would like to receive a copy of the summary of our findings, please tell us what format you would like it and give us your contact details:

EMAIL Claire.henry@eolc.nhs.uk
ADDRESS: 3rd floor St Johns House East Street Leicester LE1 6NB
Feedback to Department of Health on the outcome of consultation events held within the community represented by Mendip Primary Care Trust Somerset.

Background

Mendip Primary Care Trust was invited by the strategic health authority on behalf of the Department of Health to contribute to the national consultation Your health, your care, your say.

Specifically the Trust was asked to discuss with two specific groups and, in partnership with the local authority, with the general public three open questions relating to the community’s views around non hospital care.

The detailed action plan is appendix 1

The outcomes of these discussions are available to the Trust CEO and to the DSSHA by 21st October and to the Department of Health by 4th November 2005.

Purpose

Below is a summarised verbatim report of the responses made to three open questions identifying consensual themes. The prioritisation is also given by participants of the identified issues.

Outcome:

General Public & Staff

Number of participants: 45

QUESTION 1: How can people look after themselves? How can we help you take care of yourself and support you and your family in your daily lives?

This question aims to determine what the NHS, social care and other services can do to help people take better care of themselves and support them in their daily lives. Issues include self-care support, disease prevention, and keeping people healthy and independent.

Response.

Four themes were identified:

- **The role of early and life long education** – helping people to understand how lifestyle choices impact on their long term health. Creative, innovative approaches required to attract young people. Knowing where & how to get good quality information.

- **Personal Responsibility** – NHS (and society) to encourage people to take more responsibility for their own health rather than expecting the NHS to solve problems at a later stage through medical interventions. Less paternalism by professionals.

- **Access** – to healthy choices needed to be made easier and more cheaply, gym membership, cycle lanes, healthy foods, contraception. Some people felt easy fast
access to GP appointments led people to be less self reliant –if they had to wait to be
seen they got on with managing for themselves. (In relation to minor ailments)

- **Partnership** – other organisations had a part to contribute, education, local authority,
supermarkets.

Prioritisation

1. **Promoting better health**
2. Ensuring older people & those with disability get support to remain
   independent
3. = Ensuring professionals provide a range of information on self care
3. = Tackling things that cause ill health e.g. housing poverty, unemployment

**QUESTION 2: When you and your family need help and support, how, when, where and from whom do you want to get it?**

This question aims to work out how to provide health and social care services that are
right for everybody.

Response

Seven main themes identified.

- **Better access to other healthcare services**, such as Mental Health and Social
  Services. The right help and advice at the right time from the right person.

- **Consultation times need to be flexible / variable** to meet the needs of the patient. A
  longer time may be needed particularly if life changing information or news is to be
  given or if there is a need for greater understanding or clarity.

- **All services need better links and to communicate effectively**. The delay and
  frustration of not knowing who should be approached or involved or who should be
told and when. People wanted to access care via their **GP practice** and felt that
social care, etc. should be instigated through this route. NHS Direct was criticised for
long wait times for response from clinically trained staff.

- **More support for carers** and perhaps education opportunities. Particularly for those
  carers of patients who have long term conditions or for education / support
  specifically for the carer and from their point of view.

- **Better access to dentistry**. More availability over longer periods. Unplanned
  appointments on a daily basis.

- **Same level of service outside of normal working hours**. As many people are at
  work and may work a significant distance from their practice early morning or evening
availability or even routine appointments available alongside the GP out of hours
service.

- **Wider choice of therapies and other available options**. The palliative care option
  is not always appropriate and individuals may request alternative options or solutions
  such as managing a condition rather than treating them.

Prioritisation:

1. Providing effectively joined up social care and health services to those that need
   them for example through a single needs assessment this would be a kind of one
   stop shop appointment instead of lots of appointments
2. Providing people with better information and the NHS local authority and social care
   services that are available.
3. Improving the availability quality and choice of services for long term users and people with long term conditions such as COPD and diabetes.

QUESTION 3: How can we help you get the right services, when you need them, and ensure your care and support is properly coordinated?

This question aims to work out what can be done to help people use and find their way through health and social care services more effectively. It also aims to work out how to join up care in a better way, for example between hospitals and patients’ GPs.

Three themes were identified.

- **Need to increase understanding about who did what.** This was relevant to both staff and members of the public. It related to partnership agencies as well as those roles internal to the NHS. People generally felt that there could be more cooperation and team work if individuals understood the perspective and motivations of each other. It would also reduce the gaps in services when sometimes there was a misconception that areas of work were covered by another’s brief when this was not the case. Joint training would improve insights.

- **Removal or softening of organisational boundaries.** Co-ordinated care would evolve more easily if Joint budgets, common aspirations, goals and drivers were developed, managed under one organisation. Roles such as the new community matrons which will work across boundaries will help.

- **Sharing of records.** This needs to be increased across organisational boundaries. At times professional anxieties in relation to breaching of confidentiality get in the ways of this happening so more training in this area. This applied to data collection and analysis too.

- **Patient centred care – the cultural shift to people as participants in their own care rather than passive recipients needed further movement to support organisations developing services and processes that worked for people rather than the host organisation or the professional identity.**

**Prioritisation**

1. Providing effectively joined up social care and health services to those that need them for example through a single needs assessment this would be a kind of one stop shop appointment instead of lots of appointments.

2. Providing people with better information and the NHS local authority and social care services that is available.

3. Improving the availability quality and choice of services for long term users and people with long term conditions such as COPD and diabetes.
Travellers

Number of participants: 15

NB. This group comprised of people who define themselves as new age travellers as well as several people who are homeless. No Romany gypsies were part of the cohort.

For travellers their specific concerns are around the culture of the NHS which largely they feel does not respond to their particular approach to life. They have a sound grasp of the wider determinates of health and the impact that their social circumstances can have upon their physical and mental well being.

Prioritisation
Travellers did not prioritise from the list for any question.

QUESTION 1: How can people look after themselves? How can we help you take care of yourself and support you and your family in your daily lives?

- Having the chance to be treated quickly (sometimes surgery) before things got worse – letting people get on with their lives and not need more help
- We need fundamental change to the way society is organised.
- More help for the homeless
- Having the choice to go to the doctor for health checks, screening and preventive medicine is not something we do – it’s a really middle class thing - we have so much to think of we can only manage to get there if we’re really ill.
- For all sorts of reasons (sic cultural, upbringing as well as attitude of staff) people often feel they might be wasting the doctors time and don’t like to go for this reason.

QUESTION 2: When you and your family need help and support, how, when, where and from whom do you want to get it?

- Better access to local NHS dentistry
- More natural and complimentary health provision both a wider choice of therapies as well as more appointments for existing services
- Its good having the choice to see a local GP with homeopathy training – more doctors offering this would be even better.
- Registering as a permanent patient with a GP is not usually offered if you have no home – we’re only offered temporary status
- Choices around appointment times are fine for most people – if you turn up early in the morning it’s usually easy to be seen. What is hard is to book an appointment in advance, over the phone, as access to the telephone is difficult and expensive.
- Also urgent appointments can be hard to get to if you don’t have transport so a choice of times to come would help.
- Like the choice of who to see, doctor, or nurse, health visitor but not always sure who does what
- Many people don’t know what’s on offer what other agencies (sic voluntary) could help – little access to phone so don’t know about NHS Direct/Signposts/Care Direct
- Need it in a number of formats but some people can’t read and it’s difficult for them to say so – offering literacy skills at the centre will be great.
- General feeling was that group would like specialist service configured to their needs. A practitioner who had the skills to treat their particular problems, plus advice on keeping well.
- Out reach services that came to the drop in centre – where they felt safe and comfortable
- More time to talk with a professional – especially GPs 10 minutes is not long enough
We need services to talk to each other – for instance between health and social security, (medical assessments for disability benefits) health and housing - why can’t they communicate better?

QUESTION 3: How can we help you get the right services, when you need them, and ensure your care and support is properly coordinated?

- More information on what skills different professionals have. Who does what?
- Information about complimentary therapies and who is skilled/trained difficult to come by this would be really useful
- Don’t visit surgeries often to see leaflets/posters speak to people
- Libraries are good sources of information - Often hear about things word to mouth
- Drop in centre very good source of information – could use it more for health information –closer relationship with the Trust –i.e. health information in non NHS places
- Providing first aid training so we can help ourselves
- More preventative health care –
- Should people who smoke or don’t exercise be denied treatment until they change these things – it sounds fascist but I think it’s the right thing
- Taxes (and profits) from damaging products – cigarettes, alcohol, environmental hazard should go into the health service to help treat the outcomes.

Offenders

Number of participants: 6

NB The prison within Mendip has a population defined by its categorisation. The inmates are all male with the majority over age 40. All are within the final stage of long sentences. They have therefore had very little exposure to health services outside the prison for, in most cases over twenty years. This context impacts on their perspective and experience.

QUESTION 1: How can people look after themselves? How can we help you take care of yourself and support you and your family in your daily lives?

- Professionals being honest about the impact of lifestyle choices and their long term consequences. 'A doctor made it clear to me that there was little point in him treating me if I didn't give up smoking. It was a kick in the teeth it really helped.'
- Making sure good support is available. Easy access to the gym, need to ensure that activities are available that are suitable for the older men. Walking up all the stairs in the compound keeps you fit (although this is a problem for the frail and elderly inmates. Help to stop smoking including NRT. Little else to do in prison so using these facilities is made easier. Prison food always provides healthy eating options and information about what is good for you to eat. Limited access to unhealthy options which is a positive thing.
- Media influence can be very effective helps people to understand the benefits of exercise and diet.
- Written information is widely available on the many notice boards but a large minority of prisoners have low literacy levels so radio and TV is better. More consideration needs to be given in a sensitive way to those who can’t read and write and often don’t feel comfortable to acknowledge this.
- Help with healthcare costs.Whilst you are in prison all your health costs are met but there is a concern that on discharge this will not be the case and ex offenders may have difficulty affording to stay well. Anxious that they may not receive the information they need on the outside about how to access the support they need.
Prioritisation

1. Tackling things that cause ill health e.g. housing poverty, unemployment
2. Ensuring older people & those with disability get support to remain independent
3. Ensuring professionals provide a range of information on self care
4. Promoting better health

QUESTION 2: When you and your family need help and support, how, when, where and from whom do you want to get it?

- **People you trust other than healthcare professionals.** ‘I would go to the gym instructor because I know him well - especially about muscular aches and pains or back problems. I might ask another inmate if he had the same condition but only if I thought he was well informed.’
- **Equally okay about seeing a nurse or a doctor.**
- **Easy access to services is important.** In the prison it is always possible to seek advice from a healthcare professional at anytime of the day or night. Health centre is open three times a week for routine work and this is plenty.
- **Dentistry is not a problem for us** the dentist comes to the prison.
- **If we require help it comes to us unless we have to go to the acute hospital to see a specialist.** There could be a problem for elderly frail people who are not sick enough for transfer to prison hospital but need some help with personal care- nursing care in the cells would be very limited too.

Prioritisation.

1. Developing and providing more services in the local community rather than only in hospitals so that they are more convenient for families and children to use.
2. Providing convenient services which fit around people’s lives, for example by extending opening hours to evenings and weekends at the local GP practice pharmacy and other community services.
3. Providing care in convenient locations( for example NHS walk-in centre near work places or allowing people to register with any family doctor not just the one where they live.
4. Developing services for people who don’t currently access care e.g. teenagers and people from black & minority ethnic groups.
5. Allowing people to choose how to receive services at the end of life and to die where they want in dignity.

QUESTION 3: How can we help you get the right services, when you need them, and ensure your care and support is properly coordinated?

- **Prisons are small communities generally we don’t like the fact that there is no hiding place but it does mean that if you are unwell it’ll be noticed you wont be left with no support.**
- **Information from hospital to primary care is very slow in coming – discharge summaries too some times we have been moved before we’ve heard the outcome of tests etc this delays us getting help/treatment**
- Because we have less to think about illness can become the focus of our lives we have few distractions this means it becomes more important to us to get it right and we can be asking for more help than is available.
- **One stop shops seem a very good idea** - this would be especially helpful on discharge when services will look very confusing to us and we are likely to need help from a number of different places all at once.
Prioritisation

1. Improving the availability quality and choice of services for long term users and people with long term conditions such as COPD and diabetes.

2. Providing effectively joined up social care and health services to those that need them for example through a single needs assessment this would be a kind of one stop shop appointment instead of lots of appointments.

3. Providing people with better information and the NHS local authority and social care services that is available.
Appendix 1

‘YOUR HEALTH, YOUR CARE, YOUR SAY’ – IMPROVING COMMUNITY HEALTH AND CARE SERVICES

CONSULTATION PLAN

BACKGROUND

1. In July 2005 the Government announced a public consultation – ‘Your Health, Your Care, Your Say’ to help the Department of Health find out what people want from community-based health and social care services (or services provided outside of hospitals).

2. The findings from this consultation will help to develop a White Paper that sets out improvements to how these services are provided.

WHAT DO WE WANT TO KNOW?

3. Patients will be asked:

- What can you do for yourself? How can we help you take care of yourself and support you and our family in your daily lives?

- When you and your family need help and support, how, when, where and from who do you want to get it?

- How can we help you get the right services, when you need them and ensure your care and support is properly co-ordinated?

WHO ARE WE GOING TO ASK?

4. The groups identified for Mendip Primary Care Trust are:

- Travellers
- Offenders

These consultations will take the form of focus groups and will cover the three questions within the consultation.

General public

Concurrent events will be utilised as opportunities for consultation. To enable these groups to absorb this added work into their set programmes each group will only tackle one question. This methodology allows for the PCT to involve a diverse population in the process without overstretching the resources of community groups.

This consultation is to be carried out collaboratively with the local authority and other stakeholders.

Contact Jill Ord Somerset County Council 01823 355640

5. USE OF MEDIA/RESOURCES

- Supporting information will also be placed on the Trust website and a link established to the questionnaire.

- The PALS service will take telephone enquiries (an answer phone will be in use out of hours).

- Outcomes from previous consultation exercise regarding Choice, Responsiveness and Equity will contribute to the information as a relevant and appropriate resource as
will the work undertaken by the Trust in relation to the development of our local delivery plan.

**Schedule of proposed consultation and promotion for ‘your health, your care, your say’**

<table>
<thead>
<tr>
<th>Consultation</th>
<th>Specific Interest Group</th>
<th>How Many</th>
<th>When</th>
<th>Methodology</th>
</tr>
</thead>
<tbody>
<tr>
<td>Prisoners</td>
<td>6</td>
<td>20/10/05</td>
<td>Focus Group</td>
<td></td>
</tr>
<tr>
<td>Travellers</td>
<td>15</td>
<td>20/10/03</td>
<td>Focus Group</td>
<td></td>
</tr>
<tr>
<td>Public</td>
<td>RNID Information Day</td>
<td>10</td>
<td>08/10/05</td>
<td>Focus Group (Q1)</td>
</tr>
<tr>
<td></td>
<td>AGM</td>
<td>13</td>
<td>28/09/05</td>
<td>Semi-formal interviews (Q3)</td>
</tr>
<tr>
<td>Staff</td>
<td>Practice managers</td>
<td>14</td>
<td>14/10/05</td>
<td>Discussion group (Q3)</td>
</tr>
<tr>
<td></td>
<td>Meeting</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Joint Management Staff Committee</td>
<td>8</td>
<td>27/09/05</td>
<td>Discussion group (Q1)</td>
</tr>
<tr>
<td>Promotion</td>
<td>Staff</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Joint Management Staff Committee</td>
<td></td>
<td>27/09/05</td>
<td>Information and signposting to complete website questionnaire</td>
</tr>
<tr>
<td></td>
<td>Practice Managers Forum</td>
<td></td>
<td>30/09/05</td>
<td>Information to cascade to practice staff and signposting to complete website questionnaire</td>
</tr>
<tr>
<td>Partner Organisations</td>
<td>Mendip Strategic Partnership</td>
<td></td>
<td>04/09/05</td>
<td>Information and signposting to complete website questionnaire</td>
</tr>
<tr>
<td>Public</td>
<td>Patient &amp; Public Involvement Forum</td>
<td></td>
<td>05/10/05</td>
<td>Information and signposting to complete website questionnaire – hard copies of questionnaire distributed for central return</td>
</tr>
<tr>
<td></td>
<td>Mendip PCT AGM</td>
<td></td>
<td>28/09/05</td>
<td>Information and signposting to complete website questionnaire – hard copies of questionnaire distributed for central return</td>
</tr>
<tr>
<td>Feedback</td>
<td>SHA</td>
<td></td>
<td>21/10/05</td>
<td></td>
</tr>
<tr>
<td></td>
<td>National website</td>
<td></td>
<td>04/11/05</td>
<td></td>
</tr>
<tr>
<td></td>
<td>To contributors</td>
<td></td>
<td>31/11/05</td>
<td></td>
</tr>
</tbody>
</table>
YOUR HEALTH, YOUR CARE, YOUR SAY
FEEDBACK FORM FOR LOCAL LISTENING EXERCISES
Thank you for your help with *your health, your care, your say*.

This feedback form is intended for both local and national organisations or groups to report on the findings their own devolved listening exercise as part *your health, your care, your say*.

Can I check, are you responding to this questionnaire as:

- A local organisation or group
- A national organisation or group
- Other (record details below)

All the information you submit will be analysed alongside the public’s response and the views obtained from other local and national organisations and groups and will feed in to the development of plans for improving community health and care services.

Please note the feedback form is in three parts:

- Section A: Thinking about the community health and social care services people use, what currently works less well?
- Section B: what do you think of the suggestions for improving health and social care services?
- Section C: details about your organisation and your listening exercise

If you haven’t covered Section A or all of the options under Section B, please just leave those questions blank.

Please make sure that you give us this feedback by 4th November, or earlier if possible. You can find out where to return this feedback by referring to the resource pack website, [www.yoursayresources.nhs.uk](http://www.yoursayresources.nhs.uk)

As you will see, most questions ask you to tick a box like this:

*Tick one box only*

Other questions give you space to record how you reached your decisions:

Please feel free to write as much, or as little, as you like.
Section A: Thinking about the community health and social care services people use, what currently works well, and what currently works less well?

We want to make community-based health and social care services better for everyone. To help us reach the right decisions, we want to know what the people at the listening exercises you ran thought about community-based health and social care services at the moment.

Q1. What were the three key elements of community health and social care services that people thought worked well?  

(RECORD BELOW IN PRIORITY ORDER)

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Relationship between patient &amp; professional</td>
</tr>
<tr>
<td>2</td>
<td>Pharmacy services and prescriptions</td>
</tr>
<tr>
<td>3</td>
<td>Walk-In Centres where they exist</td>
</tr>
<tr>
<td>4</td>
<td>Comprehensive &amp; effective support in crisis situations</td>
</tr>
<tr>
<td>5</td>
<td>Range of services available in GP surgeries</td>
</tr>
</tbody>
</table>

RECORD BELOW WHY PEOPLE THOUGHT THESE WORKED WELL:

Priority 1
Relationships were felt to be very good on a one to one basis

Priority 2
Good range of services available from community pharmacies. Delivery of prescriptions. Time taken to explain about medication.

Priority 3
Working well. All services in the same place. Could provide 24 hour access. No appointment required. Instant access for high numbers of people. Need to be more widespread.

Priority 4
In emergency situations provision of services works well.

Priority 5
People felt generally happy with the range of services provided from GP surgeries, including complementary therapies to help with long term conditions, taking blood samples, dietician, physiotherapy
What were the three key elements of community health and social care services that people though worked less well?

(RECORD BELOW IN PRIORITY ORDER)

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Access to services</td>
</tr>
<tr>
<td>2</td>
<td>Information about services in different formats</td>
</tr>
<tr>
<td>3</td>
<td>Joined up working</td>
</tr>
<tr>
<td>4</td>
<td>Taking proper account of physical disabilities</td>
</tr>
<tr>
<td>5</td>
<td>The constant re-organisation of the NHS</td>
</tr>
</tbody>
</table>

RECORD BELOW WHY PEOPLE THOUGHT THESE WORKED LESS WELL:

Priority 1
This included barriers to getting a GP appointment, access issues in rural areas, access to respite care, out-of-hours services, children & family services, lack of services for adolescents and there was a big issue about access to dental services. GP access systems not working – having to ring for appointment on same day and not being able to make appointments in advance.

Priority 2
Communication can be poor between health and social care services and also sometimes between different parts of the NHS. This can result in people ‘falling through the net’. Failure to share records and information. There exists a health v social care divide

Priority 3
There should be more options available for accessing information about health and social care services..

Priority 4
Not enough preventative help especially regarding waiting lists for OT assessments. Would be good to get everything from one place.

Priority 5
Staff morale low because of constant changes and reorganisation can get in the way of getting the job done. Endless and repeated reorganisations undermine services.
What other issues did people mention? Please record any personal stories here if possible

**Other things that were thought to work well:**

PALS  
Mental Health partnership working between health & social care  
Patient Transport service  
Some specific services – eg ‘Falls service’  
Some outreach services  
The way in which the NHS consults  
Self-management of chronic conditions  
‘LIFT’schemes

**Other things that were thought to work less well:**

Early intervention  
NHSD – poor quality information  
Education on looking after yourself and healthy living from birth onwards
Section B: what did people think of the suggestions for improving health and social care services?

We are committed to helping people take better care of themselves, but big questions remain about how it can best do this. 

...Thinking about how the NHS, Social Care and other services might help people to look after themselves more...

Q2. Which of the following did people at the listening exercises you ran think should be the top three priorities? (Please rank by writing 1, 2 or 3 in the boxes)

- Encouraging and supporting better health, for example through routine check ups, advice on healthy lifestyles and promoting self-care and self-assessment.  
  - 1 
  - 32%

- Ensuring a range of health professionals, such as nurses and pharmacists, can provide people with information and support about how to take better care of themselves and their families. For instance pharmacists could give advice on getting the best out of the medicines you take or they could run clinics for people with high blood pressure.
  - 4
  - 19%

- Tackling the things that cause ill health and disadvantage, such as poverty and poor housing, by developing new services in the community and by expanding the range of services available in doctors’ surgeries (eg advisors to help with housing, employment and training and benefits), children’s centres and other locations.
  - 2
  - 25%

- Ensuring older people and those with disabilities can get the practical help and support they need to remain independent and active for longer
  - 3
  - 24%

- None of the above

- Don’t know
PLEASE SUMMARISE WHY PEOPLE SELECTED THESE PRIORITIES:

Priority 1
It would encourage & support people to become experts in looking after themselves and would move away from a ‘disease service’ to a ‘health service’
It would empower people to make informed lifestyle decisions & take responsibility for their own health
The NHS would become more proactive rather than reactive
There would be a long-term improvement in health and a better quality of life for the population
It would save money in the long term

Priority 2
Combined with effective health promotion, it would provide empowered, confident people who are able to make informed choices about their health and lifestyle
There would be a gradual reduction in health inequalities although progress would be slow and it may be difficult to show the link between action and impact

Priority 3
If this is not addressed, it will become a bigger problem in future years due to the ageing population.
It will enable older people and those with disabilities to have an improved quality of life and retain dignity, self-respect and independence
There would be a reduction in hospital bed days and less hospital admissions
Better home care would enable more people to remain in their own homes and to die at home
Q3. Did people think it would be enough for Government to only do these things to help people take better care of themselves? Why?

Q4. What else would people like the Government to do to help people take better care of themselves?

Thought the integration of health, social care and EDUCATION is important as it is essential that services work together to deliver person-centred services from birth onwards.

A full health check for everyone at age 21 to give an initial record to monitor against.

Involve local recreation and leisure facilities to promote fitness and provide free exercise facilities.

Need modern facilities in a range of locations with 24/7 access.

Make first aid and healthy living part of the national curriculum and provide advice on all health issues in schools.

Schools are a crucial area for action.

Work with the voluntary and community sector as an equal partner.
HOW CAN WE HELP GET THE RIGHT SERVICES, WHEN YOU NEED THEM, AND ENSURE YOUR CARE AND SUPPORT IS PROPERLY COORDINATED?

We want people to be able to use and find their way through health and social care services more easily. We also want these services to be ‘joined up’, even if several people or organisations are providing them.

...Thinking about how the NHS, Social Care and other services might help people find the services they need and improve the way these services are joined up ...

Q5. Which of the following did people at the listening exercises you ran think should be the top three priorities? (Please rank by writing 1, 2 or 3 in the boxes)

Providing effectively joined-up social care and health services to those that need them, for example through a single ‘needs assessment’. A ‘needs assessment’ would be a kind of one-stop-shop appointment instead of lots of appointments. A case manager would be someone who plans your care with you and then coordinates it.

1 38%

Providing more help to people caring for others, for example with more respite care

2 25%

Providing people with better information about what NHS, local authority and social care services are on offer

3 23%

Improving the availability, quality and choice of services for long-term care users and people with long-term illnesses like diabetes e.g. support from people with similar conditions

None of the above

Don't know
PLEASE SUMMARISE WHY PEOPLE SELECTED THESE PRIORITIES:

Priority 1
A case manager would help people to navigate their way through the system
Less people would ‘fall through the net’
It would provide a service tailored to individual needs
It would enable more effective use of resources
Reviews, care planning and shared information systems also need to be included and there would need to be continuity in the provision of case managers

Priority 2
Carers are key to making the system work and are often unfairly neglected, under-valued and isolated
If not properly supported, this can add to the ill-health burden and the cost to health and social care
Need to consult carers about what they need in the way of services/support, but also need to recognise that the patient has a voice and that not all carers act in the best interest of the patient

Priority 3
Choice must be meaningful with respect to availability and quality
Choice will be informed by clinical advice
If patients are more in control of their condition, they are likely to spend less time in hospital.
People with long-term conditions often feel their issues are ‘put to one side’ or delayed
Poor quality of services for long-term sufferers can lead to depression and deterioration in their condition
Patients should be educated to take responsibility for their own health and only access services when they really need to
Q6. Did people think it would be enough for Government to only do these things to help people manage their care and make decisions?

Q7. What else would people like the Government to do to help people manage their care and make decisions?

Health and social care services should be fully integrated with the same lines of accountability and reporting and should work to an agreed set of principles and guidelines.

There should be a shared care record.

There needs to be regular, accessible, good quality respite care and there should be routine re-assessment during respite care to ensure the patient is getting the most appropriate services/care.

Need to audit the quality of the care services provided.

The benefits system should be simplified and made more accessible. There were concerns around the ‘means testing’ arrangements.

There should be 24/7 emergency access to care and support.

There should be a greater investment in OT to improve the quality of life and independence.

Introduce a dedicated help line for carers.

Needs to be greater investment in education to allow people to make their own decisions.
When you and your family need help and support, how, when, where and from whom do you want it?

We want to make sure people have access to the services they want, when they want them, where they want them and from whom they want them. But to do this there are some tough choices to be made.

...Thinking about how the NHS and Social Care and other services might improve how, when, where and from whom community-based services are delivered...

Q8. Which of the following did the people at the listening exercises you ran think should be top three priorities? (Please rank by writing 1, 2 or 3 in the boxes)

Providing convenient services which fit around people’s lives, for example by extending opening hours to evenings and weekends at the local GP practice, pharmacy and other community services, by enabling people who receive care at home to choose for example when the carer visits

Providing care in convenient locations (for example NHS Walk in Centres near train stations so people can get quick advice on problems and health issues on their way to work) or allowing people to register with any family Doctor, not just one where you live

Developing and providing more services in the local community, rather than only in hospitals, so they are more convenient for families and children to use. For example, blood tests, x-rays and some scans, minor surgery and physiotherapy could be provided locally. Also, hospital specialists could run clinics in the community.

Developing new services for people who don’t always currently access care, such as young men, teenagers, people from different ethnic groups, people with disabilities.

Allowing people to choose how to receive services at the end of life and to die where they want with dignity. (This options is about the care people receive at the end of their lives, it is not about euthanasia)

1

29%

2

22%

3

18%

None of the above
Don’t know
**PLEASE SUMMARISE WHY PEOPLE SELECTED THESE PRIORITIES:**

<table>
<thead>
<tr>
<th>Priority 1</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>It would provide flexible working for staff and provide more flexible access for service users</td>
<td></td>
</tr>
<tr>
<td>It would enable people to access services that fit around their work and other commitments. However, there was some concern around the willingness of GPs to take this on and recognition that they also had personal lives outside of work. There were also concerns around cost, safety and security issues</td>
<td></td>
</tr>
<tr>
<td>It could help to relieve pressure on A&amp;E and other out-of-hours services</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Priority 2</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>It would be better suited to meet the needs of modern lifestyles</td>
<td></td>
</tr>
<tr>
<td>It could help to reduce waiting lists and cut down the demand for hospital services</td>
<td></td>
</tr>
<tr>
<td>Concerns around the number of consultants available to provide specialist services in the community</td>
<td></td>
</tr>
<tr>
<td>It would enable hospitals to be used for more specialist procedures/services</td>
<td></td>
</tr>
<tr>
<td>It would reinforce the value of community services</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Priority 3</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Would be very useful for people who are working</td>
<td></td>
</tr>
<tr>
<td>It may help to reduce time absent from work</td>
<td></td>
</tr>
<tr>
<td>It may assist with earlier diagnosis</td>
<td></td>
</tr>
<tr>
<td>Could enable ‘sensitive’ services to become less obvious</td>
<td></td>
</tr>
<tr>
<td>Concerns that popular GPs would be inundated so there would have to be some control measures</td>
<td></td>
</tr>
</tbody>
</table>
Q9. Did people think it would be enough for Government to only do these things to help provide service how, where, when and from whom people want them? Why?

Q10. What else would people like the Government to do to help provide services how, where, when and from whom people want them?

Need to ensure the right mix of professionals so that you don’t always have to see a GP
 Should be increased use of pharmacy services for routine health problems
 Introduce more ‘mobile clinics’ especially in rural areas
 Provide services in more informal settings rather than traditional healthcare settings
 Provide more walk-in centres in accessible locations
 Re-introduce community hospitals
 Better use of telemedicine facilities
 Provide some outreach services in schools
Q11. Looking across all the options we have asked about, which of these did your group think was the most important thing to be done immediately?

- Encouraging and supporting better health, for example through routine check ups, advice on healthy lifestyles and promoting self-care and self-assessment.
  
  - Ensuring a range of health professionals, such as nurses and pharmacists, can provide people with information and support about how to take better care of themselves and their families. For instance pharmacists could give advice on getting the best out of the medicines you take or they could run clinics for people with high blood pressure.
  
  - Tackling the things that cause ill health and disadvantage, such as poverty and poor housing, by developing new services in the community and by expanding the range of services available in doctors’ surgeries (eg advisors to help with housing, employment and training and benefits), children’s centres and other locations.
  
  - Ensuring older people and those with disabilities can get the practical help and support they need to remain independent and active for longer
  
  - Providing effectively joined-up social care and health services to those that need them, for example through a single ‘needs assessment’. A ‘needs assessment’ would be a kind of one-stop-shop appointment instead of lots of appointments. A case manager would be someone who plans your care with you and then coordinates it.
  
  - Providing more help to people caring for others, for example with more respite care
  
  - Providing people with better information about what NHS, local authority and social care services are on offer
Improving the availability, quality and choice of services for long-term care users and people with long-term illnesses like diabetes e.g. support from people with similar conditions

Providing convenient services which fit around people’s lives, for example by extending opening hours to evenings and weekends at the local GP practice, pharmacy and other community services, by enabling people who receive care at home to choose for example when the carer visits

Providing care in convenient locations (for example NHS Walk in Centres near train stations so people can get quick advice on problems and health issues on their way to work) or allowing people to register with any family Doctor, not just one where you live

Developing and providing more services in the local community, rather than only in hospitals, so they are more convenient for families and children to use. For example, blood tests, x-rays and some scans, minor surgery and physiotherapy could be provided locally. Also, hospital specialists could run clinics in the community.

Developing new services for people who don’t always currently access care, such as young men, teenagers, people from different ethnic groups, people with disabilities.

Allowing people to choose how to receive services at the end of life and to die where they want with dignity. (This options is about the care people receive at the end of their lives, it is not about euthanasia)
Q12. Please summarise the main reasons why this option was chosen as the key priority?

If everyone were given the knowledge and support to implement a healthy lifestyle, and take more active involvement in their own health care, then the demands on the service would be less, yet a healthier more empowered population achieved. This could be started right away and some results would be seen relatively quickly.

It would be good to have help navigating our way through the system, but there needs to be integration of health and social care and also the involvement of education for this to be effective and make more effective use of resources.

Q13. Please summarise the main points from the discussion about whether these changes address the things that work less well at the moment, and maintain and support the things that work well at the moment.
Q14. Please summarise the main points from the discussion about what else the Department of Health should be doing to make sure that community-based health and social care services meet people’s needs in the 21st century?
Section C: details about your organisation and your listening exercises

To help us analyse the information you have given us, we need to find out a little bit more about your organisation and your listening exercise.

A. How many people took part in your devolved listening exercises?

Write in below

| 33 |  |

B. What sort of listening exercise was it?

(Please tick one box only)

- A day long session (from 5 to 8 hours long) [√]
- A half day session (from 3 to 5 hours long)
- Up to 3 hours long
- Other (record below)

C. How many of each of the following types of people took part in your listening exercise?

(Please put a number in each box even if it is zero)

| Members of the general public (i.e. with no specialist interest in health and social care) |  |
| Members of the public who are involved with health and social care services e.g. PPI forum members | 33* |
| Paid staff from your organisation |  |
| Voluntary staff from your organisation |  |
| Other (record below) |  |

* Included members of Local Authority Health Overview & Scrutiny Committees
D. Please tell us how many of the people who took part – whether members of the public or staff - were from any of the specific sectors of the population listed below.

<table>
<thead>
<tr>
<th>Sector</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Children and young people</td>
<td></td>
</tr>
<tr>
<td>Older people</td>
<td>23</td>
</tr>
<tr>
<td>Pregnant women (and their partners)</td>
<td></td>
</tr>
<tr>
<td>Socially disadvantaged people</td>
<td></td>
</tr>
<tr>
<td>Disadvantaged children</td>
<td></td>
</tr>
<tr>
<td>Smokers</td>
<td>4</td>
</tr>
<tr>
<td>Excessive drinkers</td>
<td></td>
</tr>
<tr>
<td>Obese people</td>
<td>1</td>
</tr>
<tr>
<td>Substance misusers</td>
<td></td>
</tr>
<tr>
<td>Disabled people</td>
<td>5</td>
</tr>
<tr>
<td>People in prison</td>
<td></td>
</tr>
<tr>
<td>Black and minority ethnic groups</td>
<td>1</td>
</tr>
<tr>
<td>Travellers</td>
<td></td>
</tr>
<tr>
<td>Homeless people</td>
<td></td>
</tr>
<tr>
<td>People with mental health problems</td>
<td>3</td>
</tr>
<tr>
<td>People with learning disabilities</td>
<td></td>
</tr>
<tr>
<td>People in hospices/residential care</td>
<td></td>
</tr>
<tr>
<td>Asylum seekers</td>
<td></td>
</tr>
<tr>
<td>People with long term conditions</td>
<td>19</td>
</tr>
<tr>
<td>People with caring responsibilities</td>
<td>8</td>
</tr>
<tr>
<td>Other (record below)</td>
<td></td>
</tr>
</tbody>
</table>
E. Of the people that took part in your listening exercise, can you please tell us how many were from each of the ethnic groups listed below

- White British: 31
- White Irish
- Any other white background
- White and Black Caribbean
- White and Black African
- White and Asian
- Any other mixed background: 1
- Indian: 1
- Pakistani
- Bangladeshi
- Any other Asian Background
- Caribbean
- African
- Any other Black background
- Chinese
- Rather not say

F. Which of the following best describes the sector to which your organisation or group belongs / where you work:

(Please tick one box only)

- PPI forum or other patient group
- Community-based NHS services
- Local authority social care services
- Private sector health or social care services
- Voluntary sector health or social care services
- Other (record below) √
- Strategic Health Authority
G. If your listening exercises mostly involved staff rather than patients or service users please can you identify from the list below which groups they most often have contact with or provide services for:

*(Please tick all relevant boxes)*

<table>
<thead>
<tr>
<th>Children and young people</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Older people</td>
<td></td>
</tr>
<tr>
<td>Pregnant women (and their partners)</td>
<td></td>
</tr>
<tr>
<td>Socially disadvantaged people</td>
<td></td>
</tr>
<tr>
<td>Disadvantaged children</td>
<td></td>
</tr>
<tr>
<td>Smokers</td>
<td></td>
</tr>
<tr>
<td>Excessive drinkers</td>
<td></td>
</tr>
<tr>
<td>Obese people</td>
<td></td>
</tr>
<tr>
<td>Substance misusers</td>
<td></td>
</tr>
<tr>
<td>Disabled people</td>
<td></td>
</tr>
<tr>
<td>People in prison</td>
<td></td>
</tr>
<tr>
<td>Black and minority ethnic groups</td>
<td></td>
</tr>
<tr>
<td>Travellers</td>
<td></td>
</tr>
<tr>
<td>Homeless people</td>
<td></td>
</tr>
<tr>
<td>People with mental health problems</td>
<td></td>
</tr>
<tr>
<td>People with learning disabilities</td>
<td></td>
</tr>
<tr>
<td>People in hospices/residential care</td>
<td></td>
</tr>
<tr>
<td>Asylum seekers</td>
<td></td>
</tr>
<tr>
<td>People with long term conditions</td>
<td></td>
</tr>
<tr>
<td>People with caring responsibilities</td>
<td></td>
</tr>
<tr>
<td>Do not deal with specific sectors of the community</td>
<td></td>
</tr>
<tr>
<td>Other (record below)</td>
<td></td>
</tr>
</tbody>
</table>
H If you work with specific ethnic groups, which of these groupings do you represent or work with?

- White British
- White Irish
- Any other white background
- White and Black Caribbean
- White and Black African
- White and Asian
- Any other mixed background
- Indian
- Pakistani
- Bangladeshi
- Any other Asian Background
- Caribbean
- African
- Any other Black background
- Chinese
- Do not deal with specific ethnic groups
- Other (record below)
I. If you are a regional organisation, please tick the box below for the region you mainly work in

<table>
<thead>
<tr>
<th>Region</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>North East</td>
<td></td>
</tr>
<tr>
<td>North West</td>
<td></td>
</tr>
<tr>
<td>Yorkshire &amp; the Humber</td>
<td></td>
</tr>
<tr>
<td>East Midlands</td>
<td></td>
</tr>
<tr>
<td>East of England</td>
<td></td>
</tr>
<tr>
<td>South East</td>
<td></td>
</tr>
<tr>
<td>London</td>
<td></td>
</tr>
<tr>
<td>South West</td>
<td></td>
</tr>
<tr>
<td>National Organisation</td>
<td></td>
</tr>
<tr>
<td>Not applicable</td>
<td></td>
</tr>
</tbody>
</table>

J. What is the name of your organisation?

   Cumbria & Lancashire Strategic Health Authority

K. What type of organisation are you responding as?

<table>
<thead>
<tr>
<th>Organisation Type</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>A local organisation</td>
<td>√</td>
</tr>
<tr>
<td>A national organisation</td>
<td></td>
</tr>
<tr>
<td>Other (please record below)</td>
<td></td>
</tr>
</tbody>
</table>
L. Would like to be listed as a contributor to the consultation?

<table>
<thead>
<tr>
<th>Yes</th>
<th>√</th>
</tr>
</thead>
<tbody>
<tr>
<td>No</td>
<td></td>
</tr>
</tbody>
</table>

K. If you would like to receive a summary of our findings, please enter your contact details or email address in the box below:

liz.holt@clha.nhs.uk
Thank you for your help with *your health, your care, your say.*

This feedback form is intended for both local and national organisations or groups to report on the findings their own devolved listening exercise as part *your health, your care, your say.*

Can I check, are you responding to this questionnaire as:

- A local organisation or group
- A national organisation or group
- Other (record details below)

North Kirklees Primary Care Trust ✓

All the information you submit will be analysed alongside the public's response and the views obtained from other local and national organisations and groups and will feed into the development of plans for improving community health and care services.

Please note the feedback form is in three parts:

- Section A: Thinking about the community health and social care services people use, what currently works less well?
- Section B: what do you think of the suggestions for improving health and social care services?
- Section C: details about your organisation and your listening exercise

If you haven't covered Section A or all of the options under Section B, please just leave those questions blank.

Please make sure that you give us this feedback by 4th November, or earlier if possible. You can find out where to return this feedback by referring to the resource pack website, [www.yoursayresources.nhs.uk](http://www.yoursayresources.nhs.uk)

As you will see, most questions ask you to tick a box like this:

*Tick one box only*

Other questions give you space to record how you reached your decisions:

Please feel free to write as much, or as little, as you like.
Section A: Thinking about the community health and social care services people use, what currently works well, and what currently works less well?

We want to make community-based health and social care services better for everyone. To help us reach the right decisions, we want to know what the people at the listening exercises you ran thought about community-based health and social care services at the moment.

Q1. What were the three key elements of community health and social care services that people thought worked well?

(RECORD BELOW IN PRIORITY ORDER)

<table>
<thead>
<tr>
<th></th>
<th>Services provided by GP practices</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Services provided by our local authority (Kirklees Council) especially social and leisure services</td>
</tr>
<tr>
<td>3</td>
<td>Support provided by local voluntary organisations</td>
</tr>
</tbody>
</table>

RECORD BELOW WHY PEOPLE THOUGHT THESE WORKED WELL:

1. **Services provided by GP practices:**
   During our listening events it was clear that generally people living in North Kirklees are happy with the wide range of services provided by the staff who work in their GP practices. Patients feel that as far as health is concerned, they would turn to their GP practice in the first instance for help. Generally, the public think that services provided in the practices are easily accessible. Overall the staff are well trained, give good advice, patients have trust in them and that is why it works well. There are always some elements of the service that do not quite work as well as they should do and these are listed elsewhere in this report.

2. **Services provided by our local authority (Kirklees Council), especially social and leisure services.**
   Our local community generally feel that services provided by the local authority are good and are easily accessible. They feel that there is help available when it is needed and local authority access points are very easy to find and are in every locality. Local people generally feel that the local authority is good at promoting their services and encouraging people to keep fit and healthy. As with the GP services, sometimes things do not quite work out as people would expect and these are listed elsewhere in this report.

3. **Support provided by local voluntary organisations**
   There is a wide range of well established voluntary, community, church and self-help groups in the district all providing a vital life-line for people, many of whom live...
alone. These groups offer a variety of activities and are often the only opportunity for some people to socialise with others. The network of groups keep people motivated and in touch with others and do a tremendous job in complementing the role of local health and social services.

What were the three key elements of community health and social care services that people thought worked less well?

**RECORD BELOW IN PRIORITY ORDER**

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Access to NHS dentists</td>
</tr>
<tr>
<td>2</td>
<td>Unable to register with a GP</td>
</tr>
<tr>
<td>3</td>
<td>Waiting times for some services and treatments</td>
</tr>
</tbody>
</table>

**RECORD BELOW WHY PEOPLE THOUGHT THESE WORKED LESS WELL:**

1. **Access to NHS dentists**
   Access to an NHS dentist is a high priority for many people in North Kirklees. At present we do not have any dentists taking on NHS patients. As our area is designated as one or the worst for child dental care in the country the public feel that this is compounded by the lack of access to NHS dentistry.

   Evidence of this situation is borne out by the high number of calls to our PALS service from people trying to access NHS dentistry.

2. **Unable to register with a GP**
   For people without a GP or wanting to change their GP, registering can prove very difficult across North Kirklees. This is borne out by the high number of calls received by our PALS service. People, when trying to register with a GP, are informed that some lists are full. It is at this time that members of the public contact PALS for help and assistance with the process.

3. **Waiting times for some services and treatments**
   This applies to both health and social services. Many patients have told us that the problem is not getting an appointment to find out what treatment they need, but getting the treatment afterwards can involve a long wait, specialist podiatry, hearing aids.

   The waiting time between being assessed and receiving the appropriate equipment/service from Social Services is regularly raised as an issue.
What other issues did people mention? Please record any personal stories here if possible

<table>
<thead>
<tr>
<th>Walk In Centre: several positive comments received about our new Walk In Centre –</th>
</tr>
</thead>
<tbody>
<tr>
<td>“quick and efficient service - much better than waiting in A&amp;E”</td>
</tr>
<tr>
<td>“should be open 24/7”</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Repeat Prescriptions: public would like process for repeat prescriptions consistent.</th>
</tr>
</thead>
<tbody>
<tr>
<td>“make all systems the same for repeat prescriptions surgery to surgery. Streamline the system so that all patients have the same opportunity to get them easily”</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Attitude of some GPs and dentists toward patients:</th>
</tr>
</thead>
<tbody>
<tr>
<td>“better training for GPs/dentists to help them to improve their listening skills and improve their attitude and help them to be more caring”</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Expert Patient Programme:</th>
</tr>
</thead>
<tbody>
<tr>
<td>“there should be more funding for more Expert Patient courses”. “I did an Expert Patient course and it has changed my life”</td>
</tr>
</tbody>
</table>
Section B: what did people think of the suggestions for improving health and social care services?

We are committed to helping people take better care of themselves, but big questions remain about how it can best do this.

...Thinking about how the NHS, Social Care and other services might help people to look after themselves more...

Q2. Which of the following did people at the listening exercises you ran think should be the top three priorities? (Please rank by writing 1, 2 or 3 in the boxes)

1. Encouraging and supporting better health, for example through routine check ups, advice on healthy lifestyles and promoting self-care and self-assessment.

2. Ensuring a range of health professionals, such as nurses and pharmacists, can provide people with information and support about how to take better care of themselves and their families. For instance pharmacists could give advice on getting the best out of the medicines you take or they could run clinics for people with high blood pressure.

3. Tackling the things that cause ill health and disadvantage, such as poverty and poor housing, by developing new services in the community and by expanding the range of services available in doctors’ surgeries (eg advisors to help with housing, employment and training and benefits), children’s centres and other locations.

4. Ensuring older people and those with disabilities can get the practical help and support they need to remain independent and active for longer.

None of the above
Don’t know
PLEASE SUMMARISE WHY PEOPLE SELECTED THESE PRIORITIES:

During our listening events, all of the above areas were brought up during our discussions. All these issues are priorities in North Kirklees.

**Statement 1**

People are happier to look after themselves as long as they have all the right information, support and resources to be able to cope. Family and friends play an important part in this process.

**Statement 2**

People have a great deal of respect for their health care professionals, especially nurses and nowadays more and more people are taking advice from their local pharmacy which is encouraged by the PCT.

**Statement 3**

North Kirklees is recognised as a deprived area and the people involved in our listening events felt that both the NHS and the Local Authority are working hard to improve the life of its local citizens. They feel however, that the self-care message should be more strongly emphasised.

**Statement 4**

What has come across very strongly during our discussions with our local groups is the need for more support for local groups who provide a wide range of activities for local people, many of them elderly. Many of the groups only survive on fund-raising which is really hard for older peoples’ groups. These groups realistically are keeping people out of hospital and people feel that proper funding should be provided. Without many of our local community and voluntary groups people feel that health and social services would be struggling to meet the needs of its population.
Q3. Did people think it would be enough for Government to only do these things to help people take better care of themselves? Why?

The people involved in our discussions felt that it was very important to keep services local. We have many families on low incomes and easy access to good local services is vital.

Q4. What else would people like the Government to do to help people take better care of themselves?

We had a lot of comments about opening hours and access to services:

- longer GP opening hours. People understand that GPs cannot work 24/7 but would appreciate being able to access their GP (or a GP in their practice) when they need one. People want a GP who they know, not a stranger. People involved in our discussions put great emphasis on the role of the GP and the quality of the services provided in the practice.

- provide more funding available to train physiotherapists, podiatrists, and other health care professionals. This would cut down the waiting times, once identified that a certain treatment is required e.g. specialist podiatry. One lady quoted an instance of seeing the podiatrist but being told she could not have the treatment she needed because of lack of funding.

- improve the help available to enable people to stay in their own homes e.g. help with shopping, bathing, dressing, meals
We want people to be able to use and find their way through health and social care services more easily. We also want these services to be ‘joined up’, even if several people or organisations are providing them.

...Thinking about how the NHS, Social Care and other services might help people find the services they need and improve the way these services are joined up ...

Q5. Which of the following did people at the listening exercises you ran think should be the top three priorities? (Please rank by writing 1, 2 or 3 in the boxes)

1. Providing effectively joined-up social care and health services to those that need them, for example through a single ‘needs assessment’. A ‘needs assessment’ would be a kind of one-stop-shop appointment instead of lots of appointments. A case manager would be someone who plans your care with you and then coordinates it.

2. Providing more help to people caring for others, for example with more respite care.

3. Providing people with better information about what NHS, local authority and social care services are on offer.

4. Improving the availability, quality and choice of services for long-term care users and people with long-term illnesses like diabetes e.g. support from people with similar conditions.

5. None of the above

6. Don’t know

PLEASE SUMMARISE WHY PEOPLE SELECTED THESE PRIORITIES:

**Priority 1**

Time and time again during our listening events we heard the same comment “why is it necessary for us to give our details every time we have an appointment with someone in health or social services”. NKPCT does have a single assessment process in operation which when embedded into the system should overcome this situation.

There needs to be an improvement in the communication between health/social services neighbours when dealing with patients who cross boundaries for services.
This was highlighted by a lady who had her operation outside the district but when discharged home the help she expected from our local social services did not happen. They didn't know anything about her.

**Priority 2**

Many comments were received about keeping services local. It was felt that people with long term medical conditions have enough to cope with at the best of times and they should not have to travel great distances to get services. People do like choice but asked what they would like and they will reply – to go to my local hospital or my local health centre.

We have an active Expert Patient Programme and it was commented upon that long term funding should be made available to give more patients with LTMCs the opportunity of taking part in the programme.

**Priority 3**

During our discussions people said that if they needed help and support for a family member their first point of call would be their GP and Social Services to find out what was available. They would then expect to take care of their family member themselves with help. They said that people caring for a loved one should expect as much help as was needed e.g. help with bathing, cleaning, shopping, finance, transport. People would expect local respite care in cases where they were not able to cope at home.
Q6. Did people think it would be enough for Government to only do these things to help people manage their care and make decisions?

It came across very strongly during our discussions that people would prefer to help themselves by having all the necessary information to make their own decisions. However, once they have made those decisions it is important to people to have confidence in the services to provide what is necessary for the family to have a good quality of life.

Q7. What else would people like the Government to do to help people manage their care and make decisions?

Provide more funding to support local voluntary and community groups because this is where many people go for a social life and friendship. People share experiences and the specialists groups (eg. Parkinsons Disease, Diabetic, Heart) are excellent at keeping up to date with the latest information and are able to give advice to members.
WHEN YOU AND YOUR FAMILY NEED HELP AND SUPPORT, HOW, WHEN, WHERE AND FROM WHOM DO YOU WANT IT?

We want to make sure people have access to the services they want, when they want them, where they want them and from whom they want them. But to do this there are some tough choices to be made.

...Thinking about how the NHS and Social Care and other services might improve how, when, where and from whom community-based services are delivered...

Q8. Which of the following did the people at the listening exercises you ran think should be top three priorities? (Please rank by writing 1, 2 or 3 in the boxes)

1. Providing convenient services which fit around people’s lives, for example by extending opening hours to evenings and weekends at the local GP practice, pharmacy and other community services, by enabling people who receive care at home to choose for example when the carer visits

2. Providing care in convenient locations (for example NHS Walk in Centres near train stations so people can get quick advice on problems and health issues on their way to work) or allowing people to register with any family doctor, not just one where you live

3. Developing and providing more services in the local community, rather than only in hospitals, so they are more convenient for families and children to use. For example, blood tests, X-rays and some scans, minor surgery and physiotherapy could be provided locally. Also, hospital specialists could run clinics in the community.

4. Developing new services for people who don’t always currently access care, such as young men, teenagers, people from different ethnic groups, people with disabilities.

5. Allowing people to choose how to receive services at the end of life and to die where they want with dignity. (This option is about the care people receive at the end of their lives, it is not about euthanasia)

None of the above

Don't know
PLEASE SUMMARISE WHY PEOPLE SELECTED THESE PRIORITIES:

**Priority 1**
During all our listening events, the subject of longer GP opening hours was brought up. As mentioned before in this submission, people put a high priority on being able to access their GP services quickly. It’s the safety and trust aspect – they feel comfortable. People have very busy lives and they need to know that when they need services they are available promptly and in most instances the first port of call is the GP practice.

**Priority 2**
The innovation of Walk In Centres is new to our district and the recent opening of our own centre has been well received and people have accepted very quickly that there is an alternative to A&E.

As mentioned before in this submission – the choice of GP is a high priority as borne out in the number of calls to our PALS service.

**Priority 3**
The theme emerging from our listening events has been local services for local people.
Q9. Did people think it would be enough for Government to only do these things to help provide service how, where, when and from whom people want them? Why?

No – people would like the Government to provide long term funding for voluntary and community groups to help sustain the valuable work they carry out for vulnerable people.

Q10. What else would people like the Government to do to help provide services how, where, when and from whom people want them?

People want access to all services to be made easier e.g. provision of very recognisable helpline number so that they can ring one number similar to 999 and 0845 4647 and get a human response. People find systems very complicated.
Q11. Looking across all the options we have asked about, which of these did your group think was the most important thing to be done immediately?

*Encouraging and supporting better health, for example through routine check ups, advice on healthy lifestyles and promoting self-care and self-assessment.*

*Ensuring a range of health professionals, such as nurses and pharmacists, can provide people with information and support about how to take better care of themselves and their families. For instance pharmacists could give advice on getting the best out of the medicines you take or they could run clinics for people with high blood pressure.*

*Tackling the things that cause ill health and disadvantage, such as poverty and poor housing, by developing new services in the community and by expanding the range of services available in doctors’ surgeries (eg advisors to help with housing, employment and training and benefits), children’s centres and other locations.*

*Ensuring older people and those with disabilities can get the practical help and support they need to remain independent and active for longer*

*Providing effectively joined-up social care and health services to those that need them, for example through a single ‘needs assessment’. A ‘needs assessment’ would be a kind of one-stop-shop appointment instead of lots of appointments. A case manager would be someone who plans your care with you and then coordinates it.*

*Providing more help to people caring for others, for example with more respite care*

*Providing people with better information about what NHS, local authority and social care services are on offer*
Improving the availability, quality and choice of services for long-term care users and people with long-term illnesses like diabetes e.g. support from people with similar conditions

Providing convenient services which fit around people’s lives, for example by extending opening hours to evenings and weekends at the local GP practice, pharmacy and other community services, by enabling people who receive care at home to choose for example when the carer visits

Providing care in convenient locations (for example NHS Walk in Centres near train stations so people can get quick advice on problems and health issues on their way to work) or allowing people to register with any family Doctor, not just one where you live

Developing and providing more services in the local community, rather than only in hospitals, so they are more convenient for families and children to use. For example, blood tests, x-rays and some scans, minor surgery and physiotherapy could be provided locally. Also, hospital specialists could run clinics in the community.

Developing new services for people who don’t always currently access care, such as young men, teenagers, people from different ethnic groups, people with disabilities.

Allowing people to choose how to receive services at the end of life and to die where they want with dignity. (This options is about the care people receive at the end of their lives, it is not about euthanasia)
Q12. Please summarise the main reasons why this option was chosen as the key priority?

The four listening groups involved highlighted the following reasons for this priority:

- High quality local services for local people – keep services local. If kept local more likely that people will attend. Transport is an issue in our district – not everyone has access to a car.
- want a GP of ‘my’ choice – want to be able to choose
- opening times and services available to fit in with work and family commitments
- easy access to services, therefore cutting down the time and preventing wasting time (both patients and staff).
- if community groups receive funding and support, they will be able to carry on providing a life-line to hundreds of people who take part in their activities. This type of community support is vital to the very fabric of the well-being of the people of North Kirklees.

Q13. Please summarise the main points from the discussion about whether these changes address the things that work less well at the moment, and maintain and support the things that work well at the moment.
Q14. Please summarise the main points from the discussion about what else the Department of Health should be doing to make sure that community-based health and social care services meet people’s needs in the 21st century?

These are topics raised during our four listening events (not in any priority or order):

**Medication**
- put a stop to postcode prescribing

**Information**
- information about local services delivered by direct mail shot to every household
- NHS Direct – overall a valuable service, but some issues have arisen around the number of people a patient may have to talk to before getting some action – in one instance the patient spoke to 6 people.
- keeping people informed - improved communication by health and social services e.g. letting people know they are still on a waiting list. Very often people think they have been forgotten and wonder if they are still ‘in the loop’

**Older People**
- Age discrimination – why is it necessary to put a patient’s age on a referral form. It is felt that sometimes this will lead to a delay in a patient being seen because of age.
- better performance management of ‘tradesmen’ employed by Social Services. Quality of work is sometimes not up to standard. Who is responsible for checking the quality of the work carried out in peoples’ homes
- better access to quality housing for older people
- equality throughout the country - in some parts of the country transport is free to certain sections of the community.
- MOTs for people 60+

**Car Parking**
- national standards for providing car parking for health service premises
GPs
- encourage GPs to carry out home visits when appropriate.
- The rule should be changed regarding the fact that GPs do not have to give a reason why they have removed a patient from their list. Patients want to know why they have been removed.

Dental
- when dental students qualify, there should be a commitment to work within the NHS to improve access to NHS Dentistry

Funding
- provide long term funding for special services such as Air Ambulance – they should not have to fund raise for this vital service.
Section C: details about your organisation and your listening exercises

To help us analyse the information you have given us, we need to find out a little bit more about your organisation and your listening exercise.

A. How many people took part in your devolved listening exercises?

<table>
<thead>
<tr>
<th>Group</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Expert Patient Group</td>
<td>25</td>
</tr>
<tr>
<td>Luncheon Club</td>
<td>22</td>
</tr>
<tr>
<td>Pensioners Group</td>
<td>32</td>
</tr>
<tr>
<td>Church Group</td>
<td>10</td>
</tr>
</tbody>
</table>

**Write in below**

B. What sort of listening exercise was it?

(Please tick one box only)

- A day long session (from 5 to 8 hours long)
- A half day session (from 3 to 5 hours long)
- Up to 3 hours long
- Other (record below)

†

C. How many of each of the following types of people took part in your listening exercise?

(Please put a number in each box even if it is zero)

<table>
<thead>
<tr>
<th>Category</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Members of the general public (i.e. with no specialist interest in health and social care)</td>
<td>64</td>
</tr>
<tr>
<td>Members of the public who are involved with health and social care services e.g. PPI forum members</td>
<td>25</td>
</tr>
<tr>
<td>Paid staff from your organisation</td>
<td></td>
</tr>
<tr>
<td>Voluntary staff from your organisation</td>
<td></td>
</tr>
<tr>
<td>Other (record below)</td>
<td></td>
</tr>
</tbody>
</table>
D. Please tell us how many of the people who took part – whether members of the public or staff - were from any of the specific sectors of the population listed below.

<table>
<thead>
<tr>
<th>Sector</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Children and young people</td>
<td></td>
</tr>
<tr>
<td>Older people</td>
<td>√</td>
</tr>
<tr>
<td>Pregnant women (and their partners)</td>
<td></td>
</tr>
<tr>
<td>Socially disadvantaged people</td>
<td>√</td>
</tr>
<tr>
<td>Disadvantaged children</td>
<td></td>
</tr>
<tr>
<td>Smokers</td>
<td>√</td>
</tr>
<tr>
<td>Excessive drinkers</td>
<td></td>
</tr>
<tr>
<td>Obese people</td>
<td>√</td>
</tr>
<tr>
<td>Substance misusers</td>
<td></td>
</tr>
<tr>
<td>Disabled people</td>
<td>√</td>
</tr>
<tr>
<td>People in prison</td>
<td></td>
</tr>
<tr>
<td>Black and minority ethnic groups</td>
<td>√</td>
</tr>
<tr>
<td>Travellers</td>
<td></td>
</tr>
<tr>
<td>Homeless people</td>
<td></td>
</tr>
<tr>
<td>People with mental health problems</td>
<td>√</td>
</tr>
<tr>
<td>People with learning disabilities</td>
<td></td>
</tr>
<tr>
<td>People in hospices/residential care</td>
<td></td>
</tr>
<tr>
<td>Asylum seekers</td>
<td></td>
</tr>
<tr>
<td>People with long term conditions</td>
<td>√</td>
</tr>
<tr>
<td>People with caring responsibilities</td>
<td>√</td>
</tr>
<tr>
<td>Other (record below)</td>
<td>23</td>
</tr>
</tbody>
</table>
E. Of the people that took part in your listening exercise, can you please tell us how many were from each of the ethnic groups listed below

<table>
<thead>
<tr>
<th>Ethnic Group</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>White British</td>
<td>88</td>
</tr>
<tr>
<td>White Irish</td>
<td></td>
</tr>
<tr>
<td>Any other white background</td>
<td></td>
</tr>
<tr>
<td>White and Black Caribbean</td>
<td></td>
</tr>
<tr>
<td>White and Black African</td>
<td></td>
</tr>
<tr>
<td>White and Asian</td>
<td></td>
</tr>
<tr>
<td>Any other mixed background</td>
<td></td>
</tr>
<tr>
<td>Indian</td>
<td></td>
</tr>
<tr>
<td>Pakistani</td>
<td>1</td>
</tr>
<tr>
<td>Bangladeshi</td>
<td></td>
</tr>
<tr>
<td>Any other Asian Background</td>
<td></td>
</tr>
<tr>
<td>Caribbean</td>
<td></td>
</tr>
<tr>
<td>African</td>
<td></td>
</tr>
<tr>
<td>Any other Black background</td>
<td></td>
</tr>
<tr>
<td>Chinese</td>
<td></td>
</tr>
<tr>
<td>Rather not say</td>
<td></td>
</tr>
</tbody>
</table>

F. Which of the following best describes the sector to which your organisation or group belongs / where you work:

(Please tick one box only)

- PPI forum or other patient group
- Community-based NHS services ✓
- Local authority social care services
- Private sector health or social care services
- Voluntary sector health or social care services
G. If your listening exercises mostly involved staff rather than patients or service users please can you identify from the list below which groups they most often have contact with or provide services for:

(Please tick all relevant boxes)

- Children and young people
- Older people
- Pregnant women (and their partners)
- Socially disadvantaged people
- Disadvantaged children
- Smokers
- Excessive drinkers
- Obese people
- Substance misusers
- Disabled people
- People in prison
- Black and minority ethnic groups
- Travellers
- Homeless people
- People with mental health problems
- People with learning disabilities
- People in hospices/residential care
- Asylum seekers
- People with long term conditions
- People with caring responsibilities
- Do not deal with specific sectors of the community
Other (record below)
H If you work with specific ethnic groups, which of these groupings do you represent or work with?

- White British
- White Irish
- Any other white background
- White and Black Caribbean
- White and Black African
- White and Asian
- Any other mixed background
- Indian
- Pakistani
- Bangladeshi
- Any other Asian Background
- Caribbean
- African
- Any other Black background
- Chinese
- Do not deal with specific ethnic groups
- Other (record below)

North Kirklees has a mixed population consisting of 83% White British, 17% South Asian origin. We work with a whole range of groups across the patch.
I. If you are a regional organisation, please tick the box below for the region you mainly work in

<table>
<thead>
<tr>
<th>Region</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>North East</td>
<td></td>
</tr>
<tr>
<td>North West</td>
<td></td>
</tr>
<tr>
<td>Yorkshire &amp; the Humber</td>
<td>√</td>
</tr>
<tr>
<td>East Midlands</td>
<td></td>
</tr>
<tr>
<td>East of England</td>
<td></td>
</tr>
<tr>
<td>South East</td>
<td></td>
</tr>
<tr>
<td>London</td>
<td></td>
</tr>
<tr>
<td>South West</td>
<td></td>
</tr>
<tr>
<td>National Organisation</td>
<td></td>
</tr>
<tr>
<td>Not applicable</td>
<td></td>
</tr>
</tbody>
</table>

J. What is the name of your organisation?

North Kirklees Primary Care Trust

K. What type of organisation are you responding as?

<table>
<thead>
<tr>
<th>Type</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>A local organisation</td>
<td></td>
</tr>
<tr>
<td>A national organisation</td>
<td></td>
</tr>
<tr>
<td>Other (please record below)</td>
<td></td>
</tr>
<tr>
<td>NHS Trust</td>
<td>√</td>
</tr>
</tbody>
</table>
L. Would like to be listed as a contributor to the consultation?

<table>
<thead>
<tr>
<th>Yes</th>
<th>✓</th>
</tr>
</thead>
<tbody>
<tr>
<td>No</td>
<td></td>
</tr>
</tbody>
</table>

K. If you would like to receive a summary of our findings, please enter your contact details or email address in the box below:

Marilyn Horton – PPI Manager
Marilyn.horton@nkpct.nhs.uk

Comments:

Our process of consultation:

- Forwarded the ‘Your Say’ Internet Link details to all our South Asian community leaders to encourage them to take part. This has been particularly difficult because the consultation was running at the same time as Ramhadan which started on the 3 October. I would question the timing of the consultation because of the Muslim festival. I feel it is important that before the dates of any future DOH consultation periods are decided that care should be taken to avoid similar situations happening in the future. I know that our South Asian population have not been as involved as I would have liked because of the timing of the consultation.

- 2,000 ‘Your Say’ paper questionnaires were circulated together with freepost envelopes to make it easy for members of the public to complete and return direct to DOH. These were sent to:
  - voluntary and community groups
  - expert patients
  - ‘interested people’ on our database
  - a supply sent to all GP and dental practices, pharmacies and
Opticians for their patients to complete
- Walk In Centre for patients to complete

- E-mail sent to all PCT staff with ‘Your Say’ Internet Link with an message to complete the questionnaire on line and then pass on the information to family and friends.

- ‘Your Say’ weblink included in PCT’s website home page

- ‘Your Say’ article and weblink details included in October edition of in house staff magazine

- Articles in all local newspapers across the district

- Discussions held with PPIF about their involvement in the process
Your Health Care, Your Say!

The questions were discussed by the Wednesday Service User Committee for Rushcliffe Day Services. The Committee is an opportunity for people with moderate to severe learning disabilities within the Rushcliffe locality to have their voices heard. The service users discuss various aspects of their lives and invite people along who may impact these aspects.

The group decided to consider the following services when thinking about the questions:

- Specialised hearing facilities
- Dentists
- Hospitals
- Doctors
- Pharmacist
- Health Visitors
- Community or specialised nurses
- Chiropodists
- Paramedics
- Social Workers
• Care workers
• Opticians
• Speech and Language Therapists
• Councillors

Why do community health and social care services matter to the nation as a whole?
• They look after us
• They make sure that we are healthy
• They help us to make changes and move on
• They protect us from illness
• They visit us and talk to us
• They help with benefits
• They help with paperwork
• They work with each other
• They protect vulnerable people and assist with personal matters
• They advice on health issues
• They monitor our health and specialise in specific conditions
• They arrange other services for us
What Can You Do For Yourself?

• Access Health Services with Support
• Tell staff when requiring access to Health Services
• Maintain a good diet and healthy eating
• Exercise - walking, gym, swimming, gardening, climbing stairs, aerobics, housework
• Take medication
• Personal hygiene and cleanliness

How can we help you take care of yourself and support you and your family in your daily life?

• Promote and advertise healthy eating on T.V and posters etc.
• Promote exercise
• Cleaner hospitals
• Lower prices of local gyms
• Promote 'Learning Disabilities' to increase acceptance in local health services
• Regular visits to people who can't access local services
• Make health services more accessible to people with learning disabilities
• Share your knowledge with people with learning disabilities

When you and your family need support:

How would you get it?
• Talking to people
• Various communication methods - Makaton etc
• Go to various health services

When would you get it?
• When poorly
• If something happens or significant changes in your life such as moving house or your parents splitting up
• To monitor health - check ups

Where would you get it?
• At Home
• Day Centre
• Hospitals
• Medical centre
From whom would you get it?

- Social Workers
- Community Nurses
- Community Learning Disability Teams
- Day Services
- Supported Living
- Carers
- Family
- Staff
- General Practitioner

How can we help you get the right services, when you need them and ensure your care and support is properly co-ordinated?

- Care Co-ordinator allocated to each person with regular visits and checks
- Regular check ups
- Reminder letters or phone calls for check ups and appointments
- Assistance with transport and support to access health venues
- Provide advocates to explain procedures
- Informed choice
During October 2005, the PCT has undertaken a number of consultations within Eastern Leicester including with individuals and groups within its Black and Ethnic Minority population. These have included a two-day Health promotion event on 15th and 16th October organised by the Leicester Islamic Medical Association to which over one thousand people attended, visits to blind and visually impaired BME groups at VISTA, the Leicester City Council’s Older Persons Forum on 26th October, Eastern Leicester’s Public & Patient Involvement Forum and some of Eastern Leicester’s Practice Patient Groups. A presentation was also made to the City Council’s Overview & Scrutiny Committee.

In addition the PCT also devoted one of its staff seminars to the topic; asking staff to reflect their view as patients and carers. As expected this group was more knowledgeable about current service developments than the wider public but nonetheless made a very valuable contribution to the consultation exercise.

Groups and organisations representing BME patients expressed concerns to us that the nationally organised consultation process would not adequately reflect either the range of health deprivation experienced by BME populations nor their voice in how these should be addressed. It might be added that professionals working with the Homeless, Travellers and Asylum Seekers share these views.

This report seeks to reflect the comments and views expressed at these different events. Wherever possible copies of the Your Health, Your Care, Your Say Questionnaires were distributed. A common theme at BME gatherings was that this Questionnaire was quite daunting to complete and not very user friendly for those whose first language was not English. Interpreters were available to assist with this process but on average completion took 30 minutes. The PCT offered to facilitate the submission of the questionnaire and have returned approximately 50 completed forms to the survey team.

The PPI Forum members expressed great disappointment at being excluded from the regional event organised in Leicester in September.
Members of the Older Persons Forum had a number of helpful suggestions about how they [and others] could be enabled to stay healthy:

- Regular health checks (with GP or Nurse)
- Advice about diet and exercise
- Giving Pensioners an adequate income
- Attending adult learning classes [but these are being cut back]
- Providing easy to understand information in as many places as possible
- Disease specific support groups e.g. diabetes
- Expert Patient programmes
- Flu jabs at place of need not only surgeries

There was strong support for as many services as possible being under the same roof. Although they are not yet open, the proposal for the City to have a number of Health & Social Care Centres was welcomed.

Members of staff provided a slightly different set of suggestions:

- Free access to leisure facilities for certain groups
- Introduction of a healthy food ‘Kite Mark’
- Multiple access points and methods for health education
- Better use of the PALS service to provide quality information on what services offer and how to access them.
- Promotion of the local pharmacy as a point of advice and access to healthcare.

**Getting Help**

Generally speaking white people of all ages were much more positive about NHS Direct than were those whose English was poor or non-existent. If the latter could not find anyone to telephone on their behalf some said they go direct to A&E. Even though white people found staff at NHS Direct helpful and courteous the most common outcome was to consult a doctor or go to A&E.
NB Whilst these outcomes are positive from the patient’s point of view they run contrary to deflecting all but the most serious cases from attending A&E.

Locally, people had mixed experiences with Prime Care [the organisation that provides the Out of Hours GP service in Leicester and Leicestershire.] There was particular criticism of Locums who were not familiar with the local health community or the geography.

Most people were very satisfied with the service they received from their GPs – this was especially so of BME patients who were with single practitioners *— but there was universal criticism of aspects of the appointments system(s). Many complained of never being able to get through on the telephone, of not being able to make an appointment in person or of being able to make an appointment some days ahead. The role of receptionists as "gate-keepers" was mentioned several times. Almost everyone confirmed that if they needed an urgent appointment one could be made available that day or the following one. There was very little reluctance to see a Nurse rather than a GP and a (surprising?) number of people were already making greater use of pharmacists.

* Patients in larger practices missed not being able to see “their GP”.

Participants would like greater flexibility in practice opening times – the occasional early evening surgery and a return to Saturday mornings.

For participants who live in one area but work in another; the flexibility of being able to access GP services more convenient to them was important.

Some people’s experience of social care services were very good but a minority were concerned about the number of different agencies involved and a lack of continuity.

The Older Persons Forum felt strongly that home care services were much better when they had been provided directly by the local authority.
An across the board observation was the number of times people reported having to give the same information about themselves to different professionals and "couldn’t public bodies get their act together?"

There was a request for a single access point for health and social care services; possibly the introduction of a non-emergency help line for social care.

For people with long-term conditions who need to attend specialist services regularly, such as diabetes and the complaints associated with the disease, the provision of such a service in the local community would be welcomed.

**Right services when needed**

Almost everyone would prefer to remain in his or her own homes for as long as possible. They want care and support to enable them to do so. Appropriate housing was felt to be key along with the provision of much better and timely information.

A number of people felt that if discharge from hospital took place too soon or without adequate preparation long term independence could be jeopardised with people re-admitted or admitted inappropriately to residential or nursing care.

The introduction of Community Matrons was considered a very positive development [if very few people knew what they might actually do!] especially if this brought effective case management, less unnecessary admissions to hospital and care in localities near to home.

There was a strong desire for health and social care organisations to listen [really listen!] to the views and opinions of the service users.

There is now a clear expectation that the comments made will be reflected in the white paper; even if they are not Eastern Leicester PCT has recorded the suggestions and will endeavour to implement many of them as opportunities arise.
YOUR HEALTH, YOUR CARE, YOUR SAY
FEEDBACK FORM FOR LOCAL LISTENING EXERCISES
Thank you for your help with your health, your care, your say.

This feedback form is intended for both local and national organisations or groups to report on the findings their own devolved listening exercise as part your health, your care, your say.

Can I check, are you responding to this questionnaire as:

A local organisation or group  x
A national organisation or group
Other (record details below)

All the information you submit will be analysed alongside the public’s response and the views obtained from other local and national organisations and groups and will feed in to the development of plans for improving community health and care services.

Please note the feedback form is in three parts:

- Section A: Thinking about the community health and social care services people use, what currently works less well?
- Section B: what do you think of the suggestions for improving health and social care services?
- Section C: details about your organisation and your listening exercise

If you haven’t covered Section A or all of the options under Section B, please just leave those questions blank.

Please make sure that you give us this feedback by 4th November, or earlier if possible. You can find out where to return this feedback by referring to the resource pack website, www.yoursayresources.nhs.uk

As you will see, most questions ask you to tick a box like this:

Tick one box only

Other questions give you space to record how you reached your decisions:

Please feel free to write as much, or as little, as you like.
Section A: Thinking about the community health and social care services people use, what currently works well, and what currently works less well?

We want to make community-based health and social care services better for everyone. To help us reach the right decisions, we want to know what the people at the listening exercises you ran thought about community-based health and social care services at the moment.

Q1. What were the three key elements of community health and social care services that people thought worked well?

(RECORD BELOW IN PRIORITY ORDER)

1
2
3

RECORD BELOW WHY PEOPLE THOUGHT THESE WORKED WELL:
What were the three key elements of community health and social care services that people though worked less well? 

(RECORD BELOW IN PRIORITY ORDER)

1 
2 
3 

RECORD BELOW WHY PEOPLE THOUGHT THESE WORKED LESS WELL:

What other issues did people mention? Please record any personal stories here if possible


Section B: what did people think of the suggestions for improving health and social care services?

We are committed to helping people take better care of themselves, but big questions remain about how it can best do this.

...Thinking about how the NHS, Social Care and other services might help people to look after themselves more...

Q2. Which of the following did people at the listening exercises you ran think should be the top three priorities? (Please rank by writing 1, 2 or 3 in the boxes)

Encouraging and supporting better health, for example through routine check ups, advice on healthy lifestyles and promoting self-care and self-assessment.

Ensuring a range of health professionals, such as nurses and pharmacists, can provide people with information and support about how to take better care of themselves and their families. For instance pharmacists could give advice on getting the best out of the medicines you take or they could run clinics for people with high blood pressure.

Tackling the things that cause ill health and disadvantage, such as poverty and poor housing, by developing new services in the community and by expanding the range of services available in doctors’ surgeries (eg advisors to help with housing, employment and training and benefits), children’s centres and other locations.

Ensuring older people and those with disabilities can get the practical help and support they need to remain independent and active for longer

None of the above

Don’t know
PLEASE SUMMARISE WHY PEOPLE SELECTED THESE PRIORITIES:
Q3. Did people think it would be enough for Government to only do these things to help people take better care of themselves? Why?

Q4. What else would people like the Government to do to help people take better care of themselves?
We want people to be able to use and find their way through health and social care services more easily. We also want these services to be ‘joined up’, even if several people or organisations are providing them.

...Thinking about how the NHS, Social Care and other services might help people find the services they need and improve the way these services are joined up ...

Q5. Which of the following did people at the listening exercises you ran think should be the top three priorities? (Please rank by writing 1, 2 or 3 in the boxes)

- Providing effectively joined-up social care and health services to those that need them, for example through a single ‘needs assessment’. A ‘needs assessment’ would be a kind of one-stop-shop appointment instead of lots of appointments. A case manager would be someone who plans your care with you and then coordinates it.

- Providing more help to people caring for others, for example with more respite care

- Providing people with better information about what NHS, local authority and social care services are on offer

- Improving the availability, quality and choice of services for long-term care users and people with long-term illnesses like diabetes e.g. support from people with similar conditions

- None of the above

- Don’t know

PLEASE SUMMARISE WHY PEOPLE SELECTED THESE PRIORITIES:
Q6. Did people think it would be enough for Government to only do these things to help people manage their care and make decisions?

Q7. What else would people like the Government to do to help people manage their care and make decisions?
**WHEN YOU AND YOUR FAMILY NEED HELP AND SUPPORT, HOW, WHEN, WHERE AND FROM WHOM DO YOU WANT IT?**

We want to make sure people have access to the services they want, when they want them, where they want them and from whom they want them. But to do this there are some tough choices to be made.

...**Thinking about how the NHS and Social Care and other services might improve how, when, where and from whom community-based services are delivered...**

**Q8. Which of the following did the people at the listening exercises you ran think should be top three priorities? (Please rank by writing 1, 2 or 3 in the boxes)**

- **Providing convenient services which fit around people’s lives, for example by extending opening hours to evenings and weekends at the local GP practice, pharmacy and other community services, by enabling people who receive care at home to choose for example when the carer visits**  (1)

- **Providing care in convenient locations (for example NHS Walk in Centres near train stations so people can get quick advice on problems and health issues on their way to work) or allowing people to register with any family Doctor, not just one where you live**  (2)

- **Developing and providing more services in the local community, rather than only in hospitals, so they are more convenient for families and children to use. For example, blood tests, x-rays and some scans, minor surgery and physiotherapy could be provided locally. Also, hospital specialists could run clinics in the community.**  (3)

- **Developing new services for people who don’t always currently access care, such as young men, teenagers, people from different ethnic groups, people with disabilities.**

- **Allowing people to choose how to receive services at the end of life and to die where they want with dignity.***(This options is about the care people receive at the end of their lives, it is not about euthanasia)*

- **None of the above**

- **Don’t know**
PLEASE SUMMARISE WHY PEOPLE SELECTED THESE PRIORITIES:

**Issue 3a** Group decided that this issue was the most relevant from their own PCT perspective/point of view and should definitely be centred on the population of Harrow.

Key words: Demographic, Serving all members of the community

GPs - Hours needed to extend to help those working who are unable to take time off work or travel from work.

GPs to communicate more effectively contact numbers for others for other services provided by PCT and signpost patients to the appropriate places proactively rather than as a direct consequence of a patient asking questions initially or patients having to research issues themselves.

Blood Test Clinics - extension of the length of time of these so that it will attract more people and thus help the community as a whole in the long term. Facilities should be made available for blood tests to be done outside normal working hours. For example being able to have these done in purpose built areas in Supermarkets, Pharmacies and such like.

Mobile Blood Transfusion vans: - more should be made available to help with both the perceived local and National shortage of donors.

Timed Visits for those in house-bound care: - This was discussed and the group felt that such a service would be excellent for the patient/carer and would help reduce the stress and inconvenience suffered by many patients who are not totally housebound but need remedial help every now and then in their home. The timed visit would not have to be precise but would fall within a 2-3 hour time window so that the patient could be allowed to do other things during the day.

Overall summary: - The general feeling was that whilst having more sites would be more convenient for the public, it was still important that the core places (such as the GP Surgery, Hospital and Health Clinics) were further invested in and maintained so that they were still the mainstay for the majority of the services provided by the PCT.

**Issue 3c** Keywords: Investing money into the local community, Relocating existing services, Lack of quality

Developing services - Group felt that investing money into the community would have a cascade affect i.e the more money coming in, the more choice the patient would have.

Overall summary - Group stated that convenience does not necessarily equate to quality and that there was a danger that localisation of too many services could lead to degradation in quality or treatment and the overall service offered to the public.

The driver behind the group’s sentiments was that the access to actually be receipt of the services such as Physiotherapy was more of a major issue rather than the issue of convenience. They explained that waiting 4-5 months for Physio treatment was far more concerning and stressful than having to travel a little further to go the appointment.
Q9. Did people think it would be enough for Government to only do these things to help provide service how, where, when and from whom people want them? Why?

No – not enough options to choose from. Other issues brought up included mental health, in particular young people; getting dentists/opticians etc more involved; more scope for voluntary groups

Q10. What else would people like the Government to do to help provide services how, where, when and from whom people want them?
Q11. Looking across all the options we have asked about, which of these did your group think was the most important thing to be done immediately?

Encouraging and supporting better health, for example through routine check ups, advice on healthy lifestyles and promoting self-care and self-assessment.

Ensuring a range of health professionals, such as nurses and pharmacists, can provide people with information and support about how to take better care of themselves and their families. For instance pharmacists could give advice on getting the best out of the medicines you take or they could run clinics for people with high blood pressure.

Tackling the things that cause ill health and disadvantage, such as poverty and poor housing, by developing new services in the community and by expanding the range of services available in doctors’ surgeries (eg advisors to help with housing, employment and training and benefits), children’s centres and other locations.

Ensuring older people and those with disabilities can get the practical help and support they need to remain independent and active for longer

Providing effectively joined-up social care and health services to those that need them, for example through a single ‘needs assessment’. A ‘needs assessment’ would be a kind of one-stop-shop appointment instead of lots of appointments. A case manager would be someone who plans your care with you and then coordinates it.

Providing more help to people caring for others, for example with more respite care

Providing people with better information about what NHS, local authority and social care services are on offer
Improving the availability, quality and choice of services for long-term care users and people with long-term illnesses like diabetes e.g. support from people with similar conditions

Providing convenient services which fit around people’s lives, for example by extending opening hours to evenings and weekends at the local GP practice, pharmacy and other community services, by enabling people who receive care at home to choose for example when the carer visits

Providing care in convenient locations (for example NHS Walk in Centres near train stations so people can get quick advice on problems and health issues on their way to work) or allowing people to register with any family Doctor, not just one where you live

Developing and providing more services in the local community, rather than only in hospitals, so they are more convenient for families and children to use. For example, blood tests, x-rays and some scans, minor surgery and physiotherapy could be provided locally. Also, hospital specialists could run clinics in the community.

Developing new services for people who don’t always currently access care, such as young men, teenagers, people from different ethnic groups, people with disabilities.

Allowing people to choose how to receive services at the end of life and to die where they want with dignity. (This option is about the care people receive at the end of their lives, it is not about euthanasia)
Q12. Please summarise the main reasons why this option was chosen as the key priority?

Q13. Please summarise the main points from the discussion about whether these changes address the things that work less well at the moment, and maintain and support the things that work well at the moment.
Q14. Please summarise the main points from the discussion about what else the Department of Health should be doing to make sure that community-based health and social care services meet people’s needs in the 21st century?
Section C: details about your organisation and your listening exercises

To help us analyse the information you have given us, we need to find out a little bit more about your organisation and your listening exercise.

A. How many people took part in your devolved listening exercises?

Write in below

<p>| | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>23</td>
</tr>
</tbody>
</table>

B. What sort of listening exercise was it?

(Please tick one box only)

- A day long session (from 5 to 8 hours long)
- A half day session (from 3 to 5 hours long)
- Up to 3 hours long
- Other (record below)

X

C. How many of each of the following types of people took part in your listening exercise?

(Please put a number in each box even if it is zero)

<table>
<thead>
<tr>
<th>Category</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Members of the general public (i.e. with no specialist interest in health and social care)</td>
<td>7</td>
</tr>
<tr>
<td>Members of the public who are involved with health and social care services e.g. PPI forum members</td>
<td>9</td>
</tr>
<tr>
<td>Paid staff from your organisation</td>
<td>4</td>
</tr>
<tr>
<td>Voluntary staff from your organisation</td>
<td>1</td>
</tr>
<tr>
<td>Other (record below)</td>
<td>2</td>
</tr>
</tbody>
</table>
D. Please tell us how many of the people who took part – whether members of the public or staff - were from any of the specific sectors of the population listed below.

<table>
<thead>
<tr>
<th>Sector</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Children and young people</td>
<td></td>
</tr>
<tr>
<td>Older people</td>
<td>6</td>
</tr>
<tr>
<td>Pregnant women (and their partners)</td>
<td></td>
</tr>
<tr>
<td>Socially disadvantaged people</td>
<td>2</td>
</tr>
<tr>
<td>Disadvantaged children</td>
<td></td>
</tr>
<tr>
<td>Smokers</td>
<td></td>
</tr>
<tr>
<td>Excessive drinkers</td>
<td></td>
</tr>
<tr>
<td>Obese people</td>
<td></td>
</tr>
<tr>
<td>Substance misusers</td>
<td></td>
</tr>
<tr>
<td>Disabled people</td>
<td>2</td>
</tr>
<tr>
<td>People in prison</td>
<td></td>
</tr>
<tr>
<td>Black and minority ethnic groups</td>
<td>7</td>
</tr>
<tr>
<td>Travellers</td>
<td></td>
</tr>
<tr>
<td>Homeless people</td>
<td></td>
</tr>
<tr>
<td>People with mental health problems</td>
<td></td>
</tr>
<tr>
<td>People with learning disabilities</td>
<td></td>
</tr>
<tr>
<td>People in hospices/residential care</td>
<td></td>
</tr>
<tr>
<td>Asylum seekers</td>
<td></td>
</tr>
<tr>
<td>People with long term conditions</td>
<td>2</td>
</tr>
<tr>
<td>People with caring responsibilities</td>
<td>2</td>
</tr>
<tr>
<td>Other (record below)</td>
<td>2</td>
</tr>
</tbody>
</table>
E. Of the people that took part in your listening exercise, can you please tell us how many were from each of the ethnic groups listed below

<table>
<thead>
<tr>
<th>Ethnic Group</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>White British</td>
<td>13</td>
</tr>
<tr>
<td>White Irish</td>
<td>1</td>
</tr>
<tr>
<td>Any other white background</td>
<td></td>
</tr>
<tr>
<td>White and Black Caribbean</td>
<td>1</td>
</tr>
<tr>
<td>White and Black African</td>
<td></td>
</tr>
<tr>
<td>White and Asian</td>
<td>1</td>
</tr>
<tr>
<td>Any other mixed background</td>
<td>1</td>
</tr>
<tr>
<td>Indian</td>
<td>4</td>
</tr>
<tr>
<td>Pakistani</td>
<td></td>
</tr>
<tr>
<td>Bangladeshi</td>
<td>1</td>
</tr>
<tr>
<td>Any other Asian Background</td>
<td></td>
</tr>
<tr>
<td>Caribbean</td>
<td></td>
</tr>
<tr>
<td>African</td>
<td></td>
</tr>
<tr>
<td>Any other Black background</td>
<td>1</td>
</tr>
<tr>
<td>Chinese</td>
<td></td>
</tr>
<tr>
<td>Rather not say</td>
<td></td>
</tr>
</tbody>
</table>

F. Which of the following best describes the sector to which your organisation or group belongs / where you work:

(Please tick one box only)

- PPI forum or other patient group
- Community-based NHS services [x]
- Local authority social care services
- Private sector health or social care services
- Voluntary sector health or social care services
- Other (record below)
G. If your listening exercises mostly involved staff rather than patients or service users please can you identify from the list below which groups they most often have contact with or provide services for:

(Please tick all relevant boxes)

- Children and young people
- Older people
- Pregnant women (and their partners)
- Socially disadvantaged people
- Disadvantaged children
- Smokers
- Excessive drinkers
- Obese people
- Substance misusers
- Disabled people
- People in prison
- Black and minority ethnic groups
- Travellers
- Homeless people
- People with mental health problems
- People with learning disabilities
- People in hospices/residential care
- Asylum seekers
- People with long term conditions
- People with caring responsibilities
- Do not deal with specific sectors of the community
- Other (record below)
If you work with specific ethnic groups, which of these groupings do you represent or work with?

- White British
- White Irish
- Any other white background
- White and Black Caribbean
- White and Black African
- White and Asian
- Any other mixed background
- Indian
- Pakistani
- Bangladeshi
- Any other Asian Background
- Caribbean
- African
- Any other Black background
- Chinese
- Do not deal with specific ethnic groups
- Other (record below)
I. If you are a regional organisation, please tick the box below for the region you mainly work in

<table>
<thead>
<tr>
<th>Region</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>North East</td>
<td></td>
</tr>
<tr>
<td>North West</td>
<td></td>
</tr>
<tr>
<td>Yorkshire &amp; the Humber</td>
<td></td>
</tr>
<tr>
<td>East Midlands</td>
<td></td>
</tr>
<tr>
<td>East of England</td>
<td></td>
</tr>
<tr>
<td>South East</td>
<td></td>
</tr>
<tr>
<td>London</td>
<td>x</td>
</tr>
<tr>
<td>South West</td>
<td></td>
</tr>
<tr>
<td>National Organisation</td>
<td></td>
</tr>
<tr>
<td>Not applicable</td>
<td></td>
</tr>
</tbody>
</table>

J. What is the name of your organisation?

Harrow Primary Care Trust

K. What type of organisation are you responding as?

<table>
<thead>
<tr>
<th>Type of Organisation</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>A local organisation</td>
<td>x</td>
</tr>
<tr>
<td>A national organisation</td>
<td></td>
</tr>
<tr>
<td>Other (please record below)</td>
<td></td>
</tr>
</tbody>
</table>
L. Would like to be listed as a contributor to the consultation?

<table>
<thead>
<tr>
<th>Yes</th>
<th>x</th>
</tr>
</thead>
<tbody>
<tr>
<td>No</td>
<td></td>
</tr>
</tbody>
</table>

K. If you would like to receive a summary of our findings, please enter your contact details or email address in the box below:

anne.hurst@harrowpct.nhs.uk
YOUR HEALTH, YOUR CARE, YOUR SAY
FEEDBACK FORM FOR LOCAL LISTENING EXERCISES
Thank you for your help with your health, your care, your say.

This feedback form is intended for both local and national organisations or groups to report on the findings their own devolved listening exercise as part your health, your care, your say.

Can I check, are you responding to this questionnaire as:

- A local organisation or group [X]
- A national organisation or group
- Other (record details below)

All the information you submit will be analysed alongside the public’s response and the views obtained from other local and national organisations and groups and will feed in to the development of plans for improving community health and care services.

Please note the feedback form is in three parts:

- Section A: Why do community health and social care services matter to the nation as a whole?
- Section B: what do you think of the suggestions for improving health and social care services?
- Section C: details about your organisation and your listening exercise

If you haven’t covered Section A or all of the options under Section B, please just leave those questions blank.

Please make sure that you give us this feedback by 4th November, or earlier if possible. You can find out where to return this feedback by referring to the resource pack website, www.yoursayresources.nhs.uk.

As you will see, most questions ask you to tick a box like this:

Tick one box only

Other questions give you space to record how you reached your decisions:

Please feel free to write as much, or as little, as you like.
Section A: Why do community health and social care services matter to the nation as a whole?

We want to make community-based health and social care services better for everyone. To help us reach the right decisions, we want to know what the people at the listening exercises you ran thought about community-based health and social care services at the moment.

Q1. What did people think were the five main reasons why community health and social care matter to the nation as a whole? (Record below in priority order)

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td></td>
</tr>
<tr>
<td>2</td>
<td></td>
</tr>
<tr>
<td>3</td>
<td></td>
</tr>
<tr>
<td>4</td>
<td></td>
</tr>
<tr>
<td>5</td>
<td></td>
</tr>
</tbody>
</table>

Record below why people thought these were important:
Section B: what did people think of the suggestions for improving health and social care services?

We are committed to helping people take better care of themselves, but big questions remain about how it can best do this.

...Thinking about how the NHS, Social Care and other services might help people to look after themselves more...

Q2. Which of the following did people at the listening exercises you ran think should be the top three priorities? (Please rank by writing 1, 2 or 3 in the boxes)

Promoting and supporting better health, for example through routine check ups, advice on healthy lifestyles and promoting self-care and self-assessment.

Ensuring a range of health professionals, such as nurses and pharmacists, can provide people with information and support about how to take better care of themselves and their families.

Tackling the things that cause ill health and disadvantage, such as poverty and poor housing, by developing new services in the community and by expanding the range of services available in doctors’ surgeries (eg providing jobs and skills advice), children’s centres and other locations.

Ensuring older people and those with disabilities can get the practical help and support they need to remain independent and active for longer

PLEASE SUMMARISE WHY PEOPLE SELECTED THESE PRIORITIES:

The strongest message was that it is important to focus on preventing ill health and addressing the root causes of ill health rather than focusing on health care. Local people were very clear that the main influences on their health are elements such as housing,
community safety, access to affordable healthy food and exercise opportunities. Local people were able to make connections between not feeling safe on the streets or not having green open spaces and therefore not being able to get enough physical activity. Local people were also supportive of providing treatment arrangements in the community rather than in hospital. Respondents were also in favour of receiving health care from health professionals other than GPs e.g. a practice nurse or a community pharmacist.
Q3. What else would people like the NHS, Social Care and other services to do to help people take better care of themselves?

Participants did not always distinguish between the role of the NHS and the role of Local Authorities particularly in connection with health promotion/health improvement and Public Health. Local people wanted support for healthy choices to be easy choices e.g. a ban on smoking in public places. Many people expressed concern about the cost associated with being healthy e.g. healthy food or gym membership. Local people were particularly supportive of more being done to support children to be healthy.
WHEN YOU AND YOUR FAMILY NEED HELP AND SUPPORT, HOW, WHEN, WHERE AND FROM WHOM DO YOU WANT IT?

We want to make sure people have access to the services they want, when they want them, where they want them and from whom they want them. But to do this there are some tough choices to be made.

...Thinking about how the NHS and Social Care and other services might improve how, when, where and from whom community-based services are delivered...

Q4. Which of the following did the people at the listening exercises you ran think should be top three priorities? (Please rank by writing 1, 2 or 3 in the boxes)

1. Providing convenient services which fit around people’s lives, for example by extending opening hours to evenings and weekends at the local GP practice, pharmacy and other community services

2. Providing care in convenient locations (for example NHS Walk in Centres near train stations so people can get quick advice on problems and health issues on their way to work) or allowing people to register with any family Doctor, not just one where you live

3. Developing and providing more services in the local community, rather than only in hospitals, so they are more convenient for families and children to use

4. Developing new services for people who don’t always currently access care, such as people from black and minority ethnic groups and teenagers

5. Allowing people to choose how to receive services at the end of life and to die where they want with dignity.

PLEASE SUMMARISE WHY PEOPLE SELECTED THESE PRIORITIES:

The need to provide accessible, convenient and good quality services was an issue which was important to all participants. The negative attitudes of receptionists and the lack of suitable GP premises in this area have been mentioned as significant issues e.g. ‘houses are for families – not doctors’ and ‘receptionists need to remember they are only receptionists’. Kensington and Chelsea is a diverse area and many of the people participating in community health activities are from black and minority ethnic groups or people who themselves live in diverse areas, therefore, people are aware of the difficulties
people can face in navigating their way around the NHS. As stated above people were supportive of the idea of receiving health care from health professionals other than GPs.
Q5. What else would people like the NHS, Social Care and other services to do in terms of how, when, where and from whom community-based services are delivered?

There was support for ‘new’ types of services in community settings which are both accessible in terms of travel and more user friendly. There was a lot of support for preventative measures rather than just treating illness. There was support for the voluntary and community sector to be able to provide some services either in partnership with statutory service or independently. This reflects the fact that several participants were involved in community or voluntary sector organisations. Community approaches were favoured because 1) closer to the community and are therefore able to be more responsive to needs, 2) community locations are easier for people to get to, 3) community locations are not necessarily associated with illness (unlike hospitals) and may also be seen as less ‘official’ and therefore less intimidating, 4) new services could contain elements of community health development such as engaging communities in action to improve their own health and be a resource for the local community.
We want people to be able to use and find their way through health and social care services more easily. We also want these services to be ‘joined up’, even if several people or organisations are providing them.

...Thinking about how the NHS, Social Care and other services might help people find the services they need and improve the way these services are joined up ...

Q6. Which of the following did people at the listening exercises you ran think should be the top three priorities? (Please rank by writing 1, 2 or 3 in the boxes)

- Providing effectively joined-up social care and health services to those that need them, for example through a single ‘needs assessment’. A ‘needs assessment’ would be a kind of one-stop-shop appointment instead of lots of appointments.

- Providing people with better information about what NHS, local authority and social care services are on offer

- Improving the availability, quality and choice of services for long-term care users and people with long-term illnesses like diabetes.

- None of the above X

- Don’t know

PLEASE SUMMARISE WHY PEOPLE SELECTED THESE PRIORITIES:

Residents completing a Royal Borough of Kensington and Chelsea Residents Survey indicated the following as priorities:

- 87.3% thought that patients should be involved in decisions about their own health care/treatment
- 83.5% thought that everyone should get access to the health care services they need
- 68.6% thought that there should be more alternatives to hospital based treatment provided in the community
- 67.9% of people wanted to receive healthcare from health professionals such as pharmacists or specialist nurses rather than GPs
- 66.7% thought that there should be more co-ordination between health and social care services

819 people completed the questionnaire out to a sample of 1,800 residents of RBKC
Q7. What else would people like the NHS, Social Care and other services to do to help people find the services they need and improve the way these services are joined up?

See above. It is worth reiterating that local people do not always distinguish between or organisational boundaries or, indeed, understand them.
Q8. Looking across all the options we have asked about what are the top five priorities for the people at the listening exercises you ran? (Please write 1, 2, 3, 4, 5 in the boxes)

Promoting and supporting better health, for example through routine check ups, advice on healthy lifestyles and promoting self-care and self-assessment.

Ensuring a range of health professionals, such as nurses and pharmacists, can provide people with information and support about how to take better care of themselves and their families.

Tackling the things that cause ill health and disadvantage, such as poverty and poor housing, by developing new services in the community and by expanding the range of services available in doctors’ surgeries (e.g. providing jobs and skills advice), children’s centres and other locations.

Ensuring older people and those with disabilities can get the practical help and support they need to remain independent and active for longer.

Providing convenient services which fit around people’s lives, for example by extending opening hours to evenings and weekends at the local GP practice, pharmacy and other community services.

Providing care in convenient locations (for example NHS Walk in Centres near train stations so people can get quick advice on problems and health issues on their way to work) or allowing people to register with any family Doctor, not just one where you live.

Developing and providing more services in the local community, rather than only in hospitals, so they are more convenient for families and children to use.

Developing new services for people who don’t always currently access care, such as people from black and minority ethnic groups and teenagers.
Allowing people to choose how to receive services at the end of life and to die where they want with dignity.

Providing effectively joined-up social care and health services to those that need them, for example through a single ‘needs assessment’. A ‘needs assessment’ would be a kind of one-stop-shop appointment instead of lots of appointments.

Providing people with better information about what NHS, local authority and social care services are on offer

Improving the availability, quality and choice of services for long-term care users and people with long-term illnesses like diabetes.
Q9. Why were these their five top priorities?

The most support was for preventing ill health by tackling the root causes e.g. addressing the reasons why people smoke rather than setting up smoking cessation classes and ensuring people can have access to affordable healthy food. Treatment was seen as being better than cure and respondents had a sophisticated understanding of the influences on health e.g. having a job/enough money.

Most people wanted health care services which were appropriate to them; which provided opportunities for them to participate in decisions about their health care; which are high quality; provided at convenient times for them and in convenient locations. Being treated within the community was perceived as being easier (in terms of transport) and less threatening or intimidating.

Most people were supportive of receiving healthcare from health professionals other than GPs and most people were supportive of being offered alternatives to going into hospital and being treated in the local community. Being treated in the local community and being treated by health professionals other than GPs were sometimes seen as interchangeable.

The main theme running through all answers is that services and public health/health improvement initiatives need to be genuinely based on the needs of the whole community.
E. WHAT ELSE SHOULD THE NHS, SOCIAL CARE AND OTHER SERVICES BE DOING?

Q10. Below we provide a space for you to tell us about anything else which came up in the listening exercises you ran which will help us understand what people think should be done to make health and social care services better for everyone?

**PLEASE WRITE IN:**

People were concerned that this is being done to simply save money rather than because of any genuine desire to improve the health of the population. Generally people knew what they should do to be ‘healthier’ but wanted more assistance to help/enable/facilitate them to do it.

There was suspicion that professionals (and the Government) seldom listen to (or take seriously) what communities say and rarely act upon information which communities provide.
Section C: details about your organisation and your listening exercises

To help us analyse the information you have given us, we need to find out a little bit more about your organisation and your listening exercise.

A. How many people took part in your devolved listening exercises?

*Write in below*

- 140 people
- Choosing Health Consultation
- 819 people answered the residents questionnaire
- 40 people in total attended focus groups to discuss health
- 14 local people participated in discussions as part of the community health theory & practice course

B. What sort of listening exercise was it?

*(Please tick one box only)*

- A day long session (from 5 to 8 hours long)
- A half day session (from 3 to 5 hours long)
- Up to 3 hours long
- Other (record below) X

Combination of approaches including focus groups to inform the local community strategy, residents panel questionnaire to inform local community strategy, information from Choosing Health consultation, discussions with community members participating in a community health development theory and practice course

C. How many of each of the following types of people took part in your listening exercise?

*(Please put a number in each box even if it is zero)*

- Members of the general public (i.e. with no specialist interest in health and social care) 1013
- Members of the public who are involved with health and social care services e.g. PPI forum members 0
- Paid staff from your organisation 0
Voluntary staff from your organisation 0
Other (record below)

D. And now please tell us how many of the people who took part – whether members of the public or staff - were from any of the specific sectors of the population listed below.

(Please put a number in each box even if it is zero)

<table>
<thead>
<tr>
<th>Sector</th>
<th>Box</th>
</tr>
</thead>
<tbody>
<tr>
<td>Children and young people</td>
<td></td>
</tr>
<tr>
<td>Older people</td>
<td></td>
</tr>
<tr>
<td>Pregnant women (and their partners)</td>
<td></td>
</tr>
<tr>
<td>Socially disadvantaged people</td>
<td></td>
</tr>
<tr>
<td>Disadvantaged children</td>
<td></td>
</tr>
<tr>
<td>Smokers</td>
<td></td>
</tr>
<tr>
<td>Excessive drinkers</td>
<td></td>
</tr>
<tr>
<td>Obese people</td>
<td></td>
</tr>
<tr>
<td>Substance misusers</td>
<td></td>
</tr>
<tr>
<td>Disabled people</td>
<td></td>
</tr>
<tr>
<td>Prisoners</td>
<td></td>
</tr>
<tr>
<td>Black and minority ethnic groups (GO TO QE)</td>
<td></td>
</tr>
<tr>
<td>Travellers</td>
<td></td>
</tr>
<tr>
<td>Homeless people</td>
<td></td>
</tr>
<tr>
<td>People with mental health problems</td>
<td></td>
</tr>
<tr>
<td>People with learning disabilities</td>
<td></td>
</tr>
<tr>
<td>People in hospices/residential care</td>
<td></td>
</tr>
<tr>
<td>Asylum seekers</td>
<td></td>
</tr>
<tr>
<td>People with long term conditions</td>
<td></td>
</tr>
</tbody>
</table>
E. You said that some of the people who took part in your listening event were from a specific ethnic group. Please tell us how many were from each of the groups listed below:

(Please put a number in each box even if it is zero)

White British
White Irish
Any other white background
White and Black Caribbean
White and Black African
White and Asian
Any other mixed background
Indian
Pakistani
Bangladeshi
Any other Asian Background
Caribbean
African
Any other Black background
Chinese

E. Which of the following best describes the sector to which your organisation or group belongs / where you work:

(Please tick one box only)

PPI forum or other patient group
### Community Services Involved

- Community-based NHS services
- Local authority social care services
- Private sector health or social care services
- Voluntary sector health or social care services
- Other (record below)

If your listening exercises mostly involved staff rather than patients or service users please can you identify from the list below which groups they most often have contact with or provide services for:

**Please tick all relevant boxes**

- Children and young people
- Older people
- Pregnant women (and their partners)
- Socially disadvantaged people
- Disadvantaged children
- Smokers
- Excessive drinkers
- Obese people
- Substance misusers
- Disabled people
- Prisoners
- Black and minority ethnic groups (GO TO QE)
- Travellers
- Homeless people
- People with mental health problems
- People with learning disabilities
- People in hospices/residential care
<table>
<thead>
<tr>
<th>Category</th>
</tr>
</thead>
<tbody>
<tr>
<td>Asylum seekers</td>
</tr>
<tr>
<td>People with long term conditions</td>
</tr>
<tr>
<td>People with caring responsibilities</td>
</tr>
<tr>
<td>Other (record below)</td>
</tr>
</tbody>
</table>
If you would like your organisation to be listed as a contributor to the consultation, please record its name below:

**NAME OF ORGANISATION**

| Kensington and Chelsea PCT |

If you would like to receive a copy of the summary of our findings, please tell us what format you would like it and give us your contact details:

**EMAIL** janine.jolly@kc-pct.nhs.uk

**ADDRESS:** 125, Old Brompton Road, London, SW7 3RP