

# The Expert Patients Programme Community Interest Company Response to the White Paper 'Equity and Excellence: Liberating the NHS'

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## Re EPP CIC consultation response to the governments white paper "Liberating the NHS"

I am pleased to enclose our response to your request for views on the principles set out in the governments White Paper.

Our response is based on our extensive experience of working with people with long-term health conditions who are the greatest users of health related services.

We also base it on our experience of working with commissioners as a not for profit social enterprise.

We are grateful for this opportunity to respond and would be happy to provide further insights into the extensive consultations that we have done amongst our client groups and other stakeholders.

Our principal contact for further information is our Policy Director, Jim Phillips.  
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Yours sincerely

Simon Knighton

Chief Executive

# The Expert Patients Programme Community Interest Company Response to the White Paper 'Equity and Excellence: Liberating the NHS'

## WHO WE ARE

The main aim of Expert Patients Programme Community Interest Company (EPP CIC) is to improve the lives of people living with long-term health conditions (LTCs). This is done by supporting them to develop the skills and confidence needed to manage their condition better on a daily basis.

EPP CIC was established in 2007 as a not for profit social enterprise. A mixture of volunteers, contracted staff and bank staff are used to deliver its range of services. We work in all communities, particularly those thought of as "hard to reach".

EPP CIC has proven success in improving health outcomes, reducing the costs and burden of disease on the NHS and improving services through the engagement of patients and clinicians. Further details are available on our website, [www.expertpatients.co.uk](http://www.expertpatients.co.uk)

EPP CIC courses are provided by over 50% of primary care trusts (PCTs) in England, across all local health boards in Wales and is a key part of Scottish health policy.

The underpinning concepts have been applied to health care systems in the USA, Australia, Denmark and Hong Kong and form a major part of the Kaiser Permanente approach to the management of long-term conditions and service development

EPP CIC is an internationally recognised organisation and is currently working with the World Health Organisation (WHO) on a European wide strategy on patient empowerment and involvement in health care.

EPP CIC has leading edge thinking and experience in the wider application of patient centred supported self-management principles to service redesign and commissioning frameworks.

EPP CIC is the leading UK trainer of volunteer lay tutors whose "health coaching" expertise extends the reach of clinicians and other providers of health services.

To date, in Britain over 100,000 people have used EPP services and we have trained over 2000 volunteer lay tutors nationwide.

In responding to this consultation, EPP CIC has engaged with volunteers, tutors and course participants via a web based survey as well as drawing on the organisation's knowledge and expertise of best practice for provision of care for LTCs. This survey is described in Appendix 1.

This paper is a response to the general principles laid out in the white paper. We will respond to the specific questions and issues in the further four consultation documents separately.

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## GENERAL POINTS

**EPP CIC generally welcomes the direction of travel set out in the white paper and can envisage a number of ways in which major patient focussed improvements can be achieved.**

### **Big Society and Health:**

- Volunteers play a key role in many areas of health services. EPP CIC believes that, with training, this lay role can be significantly expanded to compliment clinical relationships. Trained "health literate" volunteers can:
  - Tutor and lead group sessions amongst peers
  - Promote health information and support lifestyle and behaviour change amongst peers
  - Be exemplars to others
  - Aid patient centred service design
- Supported self-care provides people with the tools to be more self-confident and self-reliant and has a major role in all areas of health provision. People who self care are better able to:
  - Actively engage with health providers
  - Make discerning choices about their own care
  - Participate in healthier relationships with peers, friends and family
- EPP CIC can demonstrate that patients from the most "at risk" community groups who self care are:
  - More likely to slow the onset of deterioration of condition (thus saving cost)
  - More likely to make better rehabilitation (thus saving cost)
  - Able to increase social capital through greater engagement with the local community
- Self-care support, increasing health literacy and shared decision making are all key factors and drivers in ensuring the proposed changes keep patient needs at the centre of the NHS.

## **DEVOLVING COMMISSIONING - GPs AS COMMISSIONERS**

EPP CIC survey results indicate

- An ambivalence to commissioning structure
- A strong desire for more treatment in primary and community care settings
- The importance of accessibility and free at point of delivery
- A great desire to be more involved in decision making in respect of own care

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## EPP CIC response:

- The clinical leadership of commissioning is welcomed, but many clinicians need further development and expertise in supporting their patients to deal with the impact of the condition on their lives
- There is a significant risk that the transition will disrupt the current good progress of self care commissioning, while the practical risks of TUPE, pension and other cost barriers will inhibit social enterprises and locally based organisations from full participation
- There is major risk that the pursuit of “critical mass” detracts from local legitimacy; commissioning bodies should be small and close to the community, but able to easily access those services that require greater critical mass
- EPP CIC has partnered with a practice based commissioning group (IPCC) to produce a model which demonstrates how the integration of self-supported care principles into service deliver can produce
  - Better patient centred care
  - At lower cost than current service provision*This model is described in appendix 2*
- Services should be commissioned based upon a partnership between clinicians and patients: The NHS should be a patient **and** clinician centred service
- Lay people should have a central role in the commissioning consortia

## **COMPETITION - ANY WILLING PROVIDER**

### EPP CIC response:

#### **Payment by results and “risk and reward”**

- These schemes can have a major role to play in incentivising improved service provision. This can also be operated amongst the not for profit commissioning bodies where service delivery based on supported self care can produce significant cost savings. However it is our view that:
  - If any significant portion of savings are taken out of the service as dividends then this will create major negative perceptions, but on the other hand,
  - If local commissioning bodies can reinvest savings in local improvement then this will be welcomed

Appendix 2 describes a model in which a commissioning body will reinvest savings made to improve services that address health inequalities.

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## Overrun risk

Payment by results incentivises budget holders well when cost savings are achieved but commissioning bodies must also provide cover should budgets over run. A typical commercial response will be to insure against this risk and the model described in Appendix 2 envisages this route. However it should be noted that, on a national basis, market forces in the insurance field will not work to the best interest of the patient or the taxpayer. Alternatives that should be considered include:

- Provision of a "National Bond" into which commissioning bodies can participate and/or
- Provision of a capped level of overrun linked to population size that will protect commissioning bodies in the event of national epidemics or emergencies.

It is imperative that this matter is considered **before** budget "go live" in any of the commissioning bodies.

In the model described in Appendix 2 EPPCIC is providing "seed" or "pump priming" investment. It will not be possible for all of the new consortia to access this type of risk capital. It is imperative therefore that some form of set up capital is made available to early adopters.

We recognise that having a number of providers can help drive down cost and drive up quality.

However a balance needs to be achieved between the need for competition as a mechanism to reduce cost and the need for collaboration to solve complex care needs and seamless health services.

We therefore propose that incentives be linked to outcomes in a way that ensures collaboration to achieve long-term benefits - shared risk and shared reward across all providers and commissioners.

These may include quality of life and health literacy measures across a population group.

Consideration needs to be given to how contracting and tendering is carried out to ensure social enterprises, not for profits and smaller organisations are not disadvantaged in the tendering and contracting processes.

## OUTCOMES NOT TARGETS

**EPP CIC survey showed that the patients experience was rated as one of the most important ways to rate a service (rated higher than inspector or independent body with cleanliness being the current main issue.)**

The Wanless report in 2002 put forward the concept of the fully engaged NHS; one where people are responsible and engaged with their own health care. Without this, the NHS was deemed as unaffordable in the longer term.

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EPP CIC is of the view that there is currently a significant lack of service quality standards or measures for provisions of services to people with LTCs after they have gone through initial diagnosis and when they become a regular user of services.

EPP CIC survey results indicate:

- People want good, simple, high quality information
- Patients experience was one of the most important ways to rate a service (rated higher than inspector or independent body with cleanliness being the current main issue)
- People felt unsupported by the quality of information provided by the care teams when dealing with the daily issues of their condition. A key area raised was not just information on effectiveness but information on support available
- People reported issues around poor communication with health care teams including the lack of any care plan and the lack of shared decision making. It was also felt that clinicians did not take into account the goals of the person with the LTC. People have a very clear preference about the type of information, how it is accessed and how it is provided

EPP CIC response:

- Outcomes need to measure the extent health literacy and patient engagement is being improved in the population. We would therefore welcome a more central role for patient reported outcomes.
- Degenerating health is central feature of chronic illness so direct health outcomes can be misleading.

***A key outcome measure for long-term conditions needs to be around quality of life and support to manage a condition.***

We would like to see outcome measures that look at the following key areas all of which people have highlighted as vital in terms of managing their health. These relate to the extent the service and interaction with clinicians enables them to-

### **Change health related behaviour**

These activities may be aimed at either disease prevention and/or health promotion and relates to the support received to make changes in diet and exercise. There is significant evidence that lifestyle changes can dramatically affect the need for elective surgery especially in cardiac patients. Yet this is an area not reported on. Patients clearly stated that support with managing their health- self-management was a major component of the services they want.

### **Have a positive and active engagement in life**

The extent the service empowers rather than disempowers a person as a result of treatment- how good is the service at getting people back on their feet again or back to work?

### **Establish an emotional well-being**

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The extent the service provides support to deal with depression and anxiety and the emotional impact of ill health.

### **Acquire skills and technique**

The extent the service equips people with the training, knowledge and skills to effectively manage their health.

### **Receive support**

The provision of high quality rehabilitation, patient education and support groups and the outcomes these services achieve

### **Navigate easily around the health service**

How easy it was to access and apply information about services available and support in decision making and choosing treatments- how real was the choice available

### **To be involved with their own care plans**

Patient feedback on the quality of their care planning, their involvement with it, and its execution.

### **The ability to compare patient experience**

## **PUBLIC HEALTH**

- It is unclear from the proposals how public health in local authorities and the new NHS arrangements will work together. The boundary between public health, especially lifestyle management and early stages of chronic disease, are closely linked and we hope the public health white paper will clearly show how this will work to help reduce the burden of lifestyle related ill health
- We believe greater investment is needed to improve the health of communities and families
- Greater emphasis is needed on prevention by providing self care support to those with mild to moderate chronic illness or those classed as at risk (diabetes, vascular disease etc)

## **THE GP AS AN EXPERT GUIDE**

Survey results indicate

- People with LTCs did not view the GP as always the person most knowledgeable or best placed to be a guide to their care and treatment although all saw the GP as very important
- A concern about losing connection with their specialist consultant and the specialist nurse who they did see as key
- People want:
  - to be treated in a primary care setting

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- better access of their care record,
- better care planning and
- a single point of contact to help them navigate the system also ideally in primary care

### EPP CIC response:

- Consideration needs to be given to how this role is expressed and resourced. We also see the care planning process and the care plan record as fundamental to ensuring that the patient is a central to the process **“Nothing about me without me”**
- Make more secondary and acute services available in a primary care setting
- Provide GPs with access to secondary and acute “consultant” expertise to support local decision making

## THE INFORMATION REVOLUTION

Survey results indicate

- People struggle to find the right information
- People want information to be provided face to face and by a clinician, nurse or trained lay person
- **Telephone support came lowest in the ranking**

### EPP CIC response

- These findings demonstrate the importance people feel about getting the best expert advice; for quality of care, people want to hear about other people’s experiences and for information on treatment etc., they want to hear from the clinicians.
- This may explain why after phoning NHS direct people will still make a visit to the doctor.

Information needs to be made relevant to the individual’s circumstance- **“people like me”**

## CHOICE

- **83% of people surveyed said they would not change GP if they had the choice.** However there was significant support for GP choice. Many expressed this choice in the ability to stay with their GP if they move.

**“I want the choice to *keep* my GP”**

- True choice was of great importance; many felt that they were not given adequate information on options available or that their GP knew enough to be able to help them.

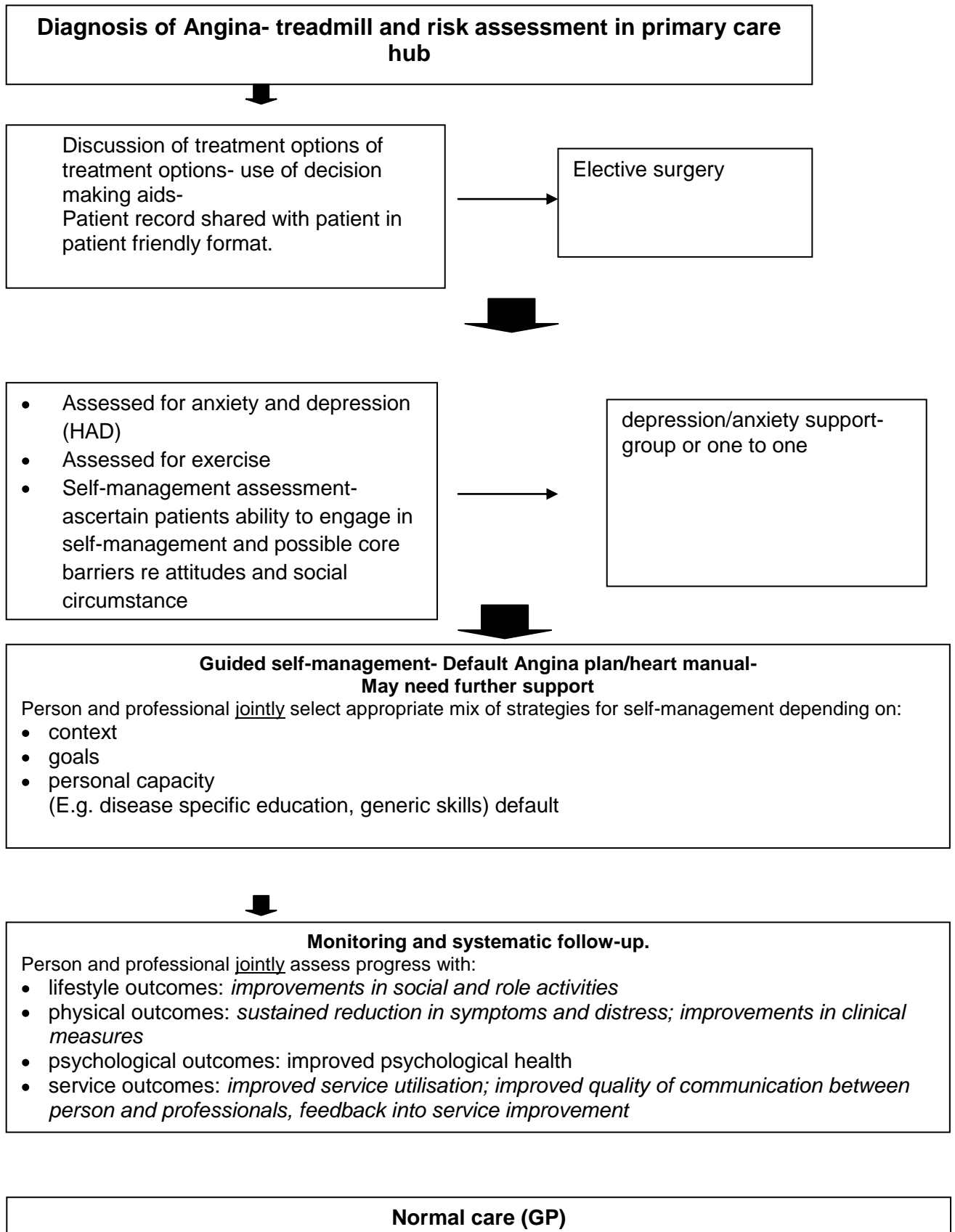
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- If choice is to be meaningful then there needs to be greater emphasis on support in making choices.
- EPP CIC welcomes a move to any suitable provider; however we are concerned about how a person is supported in making treatment and support choices and the additional time and resources that will be needed for this to be effective.
- We would also like to raise the issue of how a care pathway, designed with the full input of clinicians and the service user is commissioned to allow choice but does not fragment the pathway or increase the level of complexity.
- Feedback shows that for many, increased choice creates additional anxiety. Choice needs to be based on better decision making: for an individual, this often more about whether I eat this meal, or take a lifestyle decision or don't take a medication etc than about which GP or operating centre they choose.

### COMMISSIONING OF CARE PATHWAYS

- Emphasis needs to be placed on the role of the patient in commissioning. We are concerned that in the move to see the clinician as "expert" (which they are) the role of the patient as a manager of their care is not weakened.
- There is danger that some of the language used may indicate a shift to a more paternalistic pattern of care.
- Feedback from people with LTCs shows that most want to be active participants in their care. However, low health literacy, social background and other social factors can act as a barrier.
- The NHS needs to use this opportunity to ensure that care pathways are enabling pathways, particularly following an acute episode. Far more emphasis needs to be placed on the re-enablement of people following a hospital stay.
- Care pathways need to include the long-term management and support needs of patients, ideally in a primary care setting.
- In the integrated commissioning example shown in Appendix 2, EPP CIC and the PBC group have designed a stable angina pathway that incorporates opportunities for better supported self-care principle to be applied. An extract from this is shown

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### Appendix A. Survey results

Are you answering the questions as a		
Answer Options	Response Percent	Response Count
Carer	8.9%	14
Person living with a long-term health condition	93.6%	147
<i>answered question</i>		<b>157</b>
<i>skipped question</i>		<b>1</b>

Do you think that the support provided to you to deal with the impact of having a long-term condition has on your daily life and family has been		
Answer Options	Response Percent	Response Count
Too little	56.7%	89
Just right	39.5%	62

Does it matter who provides health services, private companies or NHS organisations, as long as it meets your needs and remains free?		
Answer Options	Response Percent	Response Count
Yes	43.9%	68
No	56.1%	87
<i>answered question</i>		<b>155</b>
<i>skipped question</i>		<b>3</b>

Do you agree or disagree with the proposal to move the control of NHS spending to GPs?		
Answer Options	Response Percent	Response Count
Agree	23.7%	37
Disagree	38.5%	60
Don't know	37.8%	59
<i>answered question</i>		<b>156</b>
<i>skipped question</i>		<b>2</b>

Would you say the amount of information you currently find out about your condition		
Answer Options	Response Percent	Response Count
Not enough	44.8%	69
About right	51.3%	79
<i>answered question</i>		<b>154</b>
<i>skipped question</i>		<b>4</b>

Would you say the quality of information is		
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Answer Options	Response Percent	Response Count
Very poor	3.2%	5
Poor	16.1%	25
Okay	44.5%	69
Good	30.3%	47
Very good	5.8%	9
<i>answered question</i>		<b>155</b>
<i>skipped question</i>		<b>3</b>

**Do you currently find getting the information you need**

Answer Options	Response Percent	Response Count
Very easy	5.2%	8
Easy	22.1%	34
Neither easy or hard	42.2%	65
Difficult	27.3%	42
Very difficult	3.2%	5
<i>answered question</i>		<b>154</b>
<i>skipped question</i>		<b>4</b>

**Do you use the internet for health information**

Answer Options	Response Percent	Response Count
All the time	26.0%	40
Sometimes	48.7%	75
Occasionally	14.3%	22
Hardly ever	7.1%	11
Not at all	3.9%	6
<i>answered question</i>		<b>154</b>
<i>skipped question</i>		<b>4</b>

**Does the information you find meet your needs?**

Answer Options	Response Percent	Response Count
Yes	60.5%	89
No	39.5%	58
<i>answered question</i>		<b>147</b>
<i>skipped question</i>		<b>11</b>

**Please state your preference against which format you would prefer to have information provided**

Answer Options	First choice	Second choice	Third choice	Fourth choice	Rating Average	Response Count
Website	25	51	45	28	2.51	149
Booklet	13	55	57	25	2.63	150

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Telephone information line	3	25	33	84	3.37	145
Face to face	111	21	14	6	1.44	152
Other						20
<i>answered question</i>						<b>154</b>
<i>skipped question</i>						<b>4</b>

### Please choose who you would prefer to receive information from

Answer Options	1st choice	2nd choice	3rd choice	4th choice	5th choice	6th choice
GP	100	22	7	14	5	4
Nurse	21	80	18	12	15	4
Telephone advisor	2	6	24	17	35	51
Trained patient/lay person	14	19	47	34	25	8
Patient group	11	17	32	50	23	12
Charity info line	3	4	18	18	38	59

### Have you ever wanted information on any of the following when choosing a hospital or treatment

Answer Options	Response Percent	Response Count
Infection rates	55.5%	66
What other patients think	64.7%	77
Re-admission rates	25.2%	30
Death rates	21.8%	26
Accidents- eg given wrong medication	33.6%	40
Information on the staff and doctors	61.3%	73
Information on how good your hospital is as rated by an inspector	54.6%	65
Information on how good your hospital is as rated by patients	67.2%	80
Information on how good a surgeon is	64.7%	77
Information on how clean your hospital is	71.4%	85
Information on how many people die each year at your hospital	16.8%	20
Other (please specify)		25
<i>answered question</i>		<b>119</b>
<i>skipped question</i>		<b>39</b>

### When choosing which hospital to use would you rather

Answer Options	Response Percent	Response Count
Spend time looking at information on different hospitals and choose one based on that information?	27.6%	42
Go to the hospital your GP recommends	43.4%	66
Use the hospital closest to you	11.8%	18
Use the hospital who can treat you quickest	17.1%	26
<i>answered question</i>		<b>152</b>
<i>skipped question</i>		<b>6</b>

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How important is it to you that you are able to choose:

Answer Options	Very important	Important	Somewhat important	Not important
The time and date of your hospital appointment	72	41	38	2
The hospital where you are treated	86	50	13	0
The Consultant who treats you in hospital	79	54	16	4
The type of treatment you receive	102	42	8	0
Your GP practice	108	37	8	1

Would you prefer more treatment to take place

Answer Options	Response Percent	Response Count
At the hospital	33.8%	49
At your GP surgery	66.2%	96
<i>answered question</i>		<b>145</b>
<i>skipped question</i>		<b>13</b>

Do you agree, neither agree nor disagree or disagree with the following statements

Answer Options	Agree	Neither agree or disagree	Disagree
My GP is the person who knows the most about what treatment I need	59	53	42
My GP is the person best placed to understand my support needs	62	55	35

The Government is proposing to allow you to register with any GP. How likely are you to change GPs if you have the choice

Answer Options	Response Percent	Response Count
Very likely	6.0%	9
Likely	3.3%	5
Somewhat likely	8.6%	13
Not likely	82.1%	124
<i>answered question</i>		<b>151</b>
<i>skipped question</i>		<b>7</b>

Do you have a care plan?

Answer Options	Response Percent	Response Count
Yes	22.2%	34
No	60.8%	93
I don't know what a care plan is	17.0%	26
<i>answered question</i>		<b>153</b>
<i>skipped question</i>		<b>5</b>

## Appendix 2

### Example: Merton Health Alliance - Aims

- Cost effectively improve quality of care amongst PBC 27000 patient population.
- To be a commissioner with delegated (per capita) budgets for all health related services on behalf of the patient pop.
- Reduce demand for acute/ services through enabling better clinician supported self management amongst patient pop.
- A sustainable joint venture social enterprise between IPPC and EPPCIC and other partners as required

### Service description

- The ICO will provide high quality and cost effective Pathway's in the following clinical area's:
  - Complex patients
  - Mental Health
  - Long Term conditions
  - Specialities such as Musculo-skeletal, Cardiology, Urology
  - Health inequality areas: Sexual health, Obesity, Substance misuse

## Delivery

- Integrated health care pathways will comprise of the following Clinical Skills Mix:
  - GP's
  - Medical Specialists
  - (Specialist) nurses/Physician assistants
  - Other specialists (such as psychiatrists, physiotherapists, dietitians, etc)
  - Management (to liaise and coordinate the ICO)

## An innovative partnership

- IPPC – committed GP's willing to engage and work as enablers
- EPPCIC – specialist in self management strategies and able to "seed" fund.
- In discussion –
  - Data handling, analysis and commercial risk insurance (Dr Foster, MCCI, Health Dialogue etc)
  - Pathway redesign – leading clinician advisers

## Benefits

The ICO will improve services and reduce costs by:

- Reducing GP referral rates for acute hospital out patient appointments
- Reducing A&E attendance rate
- Increasing patient self-efficacy (self confidence, managing conditions and exercise)
- Improving Health-related Quality of life of patients
- More informed and active patients coping better with long term health condition
- Better prepared and proactive clinical teams
- More effective and reliable delivery of rehabilitation services
- To return savings to the community where possible

## Cost avoidance

Cost avoidance opportunities for the SMPCT will include:

- Fewer ad hoc presentations at local A&E's, since patients will be able to more readily access primary care
- Lower Acute costs because bed occupancy times will be shorter with patients treated through primary care resources in their own homes
- Lower acute costs arising from fewer readmissions
- Lower call volumes and patients treated and transported by the London Ambulance Service treated with correspondingly lower funding required from the PCT