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Plymouth LINK's response to proposals contained in the Consultation *Liberating the NHS: Greater Choice and Control*

Plymouth LINK strongly supports the ethos of patients having greater choice and control over their care. This response is based on feedback themes of the Plymouth LINK and individual responses (the latter are shown in yellow boxes).

Question 1: How should people have greater choice and control over their care?

How can we make this as personalised as possible?

Feedback to Plymouth LINK shows that people are not always able to get the service they would like, for reasons such as location, access, information or just not knowing what is available. There seem to be barriers to choice and control. Giving people choice and control needs to try to remove these barriers, which needs to start before first contact with a service. Personalised care will require individual involvement in their treatment pathway at every stage and will have a significant impact on resources.

The ultimate aim must be to satisfy the three 'W's demand. Who someone can see; where they can see them; and When they can see them. To facilitate this people need to know what and who is available to them and thus there must be explicit use of all means of communication ranging from notices in public buildings, to I.T solutions.

IN ADDITION the government needs to accept and acknowledge that 'care' as stated in the above question covers not just clinical healthcare but also social welfare care and thus any information made available must be specific as to exactly what 'care' needs are being addressed.

Question 2: Which healthcare services should be our priorities for introducing choice of any willing provider?

Plymouth LINK has received much feedback about difficulties in getting a service from primary care providers and would recommend that improving choice should begin here. Often, as the gatekeepers to further services and follow-up, GPs are the first point of contact. Many people who have contacted Plymouth LINK have not been able to register at a surgery they would like,

or are unable to find a new GP or find that they cannot remain with a trusted GP due to a house move. Removing GP boundaries will allow patients to exercise choice and control and highlight the professionals who offer a better service – patients will vote with their feet.

Based on the above answer, the logical priorities must be for those services that can be delivered by a broad range of suppliers, i.e. only brain surgeons can perform intricate brain surgery, but as per the quoted example of frequent changes of a wound dressing, then the skill required is less intense and thus in theory service providers should find it easier to meet the demand.

Thus those demands which can currently, in theory, be dealt with by more than one source should be the priority.

Question 3: How can we offer greater choice of provider in unplanned care?

Plymouth LINK is aware and supportive of the developments in the South Western Ambulance Service Trust to be able to instigate and offer more suitable alternatives to Accident & Emergency departments. We are also aware that a service directory will enable the ambulance trust to have relevant information about services, providing choice. Plymouth LINK would recommend that this new opportunity for unplanned care is made in partnership with the patient and not a completely clinician led decision. Up to date information about treatment options can be shared by the emergency services to ensure choice and control for the patient.

This is partly dependent on how the government sees the future role of local HealthWatch's. If HealthWatch is to be an enabling organisation, which logically it must be in the first instance, then this is the group to actively promote choice to local communities and signpost them to care providers. Hence it follows that care providers should be encouraged to establish a dialogue with local HealthWatch's.

If on the other hand the government sees HealthWatch as being a one stop shop and delivering services then it is difficult to see, how other than signposting, HealthWatch can possibly offer any choice to users and patients.

Question 4: What would help more people to have more choice over where they are referred?

Plymouth LINK has worked closely with our GP community interest company, Sentinel Healthcare, that runs the Choose & Book system. Feedback shows this is working well and we have recommended improvements to support the patient's choice – for example, clarity that all follow-up treatment will occur with the chosen provider, information on travel, access to be available on pot's providers to help the patient make a decision.

Currently most people are aware of the reputation and effectiveness of various Hospitals, Consultants etc through word of mouth and the experiences of others. No system will ever totally replace this as people will always talk about extremes of experience. Other than that the current bar for most people is travel. Whilst the reputation of one particular Hospital etc might be far better than others, if individuals cannot see how they and their families can get to the Hospital it will remain an option they cannot and will not access. Thus wherever possible service provision needs to be geographically widespread, as many people would probably prefer to wait and be seen locally, than travel many miles just to be seen sooner.

Question 5: Which choices would you like to see in maternity services and which are the most important

Plymouth LINK has received limited feedback about maternity services and locally there are currently limited choices of where to give birth.

This is totally dependent on whether it is a first pregnancy or not, and whether there are any (expected or unexpected) problems. For first time mothers (and fathers) ante-natal and then Labour care are extremely relevant, and as stated before their choice will almost certainly be based on word of mouth, from peers and other family members. For those having a second or third child etc, their choices will be based on previous experience and they are far more likely to have a clear idea as to what level of support they need.

Question 6: Are these the right choices for users of mental health services, and if not why not?

Plymouth LINK is receiving increasing feedback about mental health services, with lack of information about what is available and how you can access it a key issue. Improving choice of mental health service provider will be determined by the information available to inform choice. As a possible future role for LINKs (as HealthWatch) an information point will play a key role to achieving this. Feedback also highlights issues returning to services and availability of mental health services. Improved choice will allow patients to re-access services after discharge and work with those services that offer a more patient-centred approach. This in turn will put added pressure on some services. Plymouth LINK also works closely with a mental health service user and carer forum (PIPS – Plymouth Involvement & Participation Service). PIPS response to Question 6 is as follows:

Access to therapies seems to be opening up for people under the care of primary care – for those with lower level needs (moderate anxiety & Depression) – What is going to happen or be available to individuals in secondary care? Is it going to open up in the same way – if it did I think that we would see clients pass through secondary services much quicker and relieve some of the financial burden on NHS over the long term. Is it opening up to primary care because that is where clinicians are most likely to get the best results? (SL)

I think there are some very positive ideas that look great in theory but not sure how they would work in practice. I think that patients should still have to access services through a GP initially because otherwise I think the system could be open to abuse.

I do think been given a choice between a mental health nurse and a psychiatrist assessing you is a good idea as I have often found it very intimidating to speak to a psychiatrist and wasted their time as I have not been able to talk to them. I also feel mental health nurses can be more open in the ideas they put forward rather than just going down the route of medication that I sometimes think psychiatrists concentrate too much on.

I think people should be made aware of what is available to them but how is the information going to be fed through as I don't think patients are always aware of what is available and there also doesn't seem to be a consistency about what health care professionals are aware of themselves. I know a directory has been put together but again do all health care professionals have access to it or are aware of it, let alone patients. (GR)

Personalised Care Plans

I definitely think more involvement in care plans is important and for them to be more focussed on what the patient expects to be the outcome and how this can be achieved, with more need to 'think outside the box' and with a focus on the person as a whole rather than just the mental health side. I think getting more involved in the community and having a routine can be just as helpful as taking pills but I don't think patients get enough help in achieving this. For someone with long term mental health problems I think it is important that the care plan and statement of wishes are looked at when a patient is feeling well as I

know when a patient becomes unwell they lose some control over their care and it would be nice to think that some of their wishes were still been taken into account. (GR)

The idea of a care plan is a good one and should give mental health care users and their carers/ supporters a better feeling of control over the direction and choices of their care. For this to work I feel there needs to be a means for all those involved in a user's care plan to communicate with one another in a way that avoids duplication and conflicting treatments/advice. Perhaps a single point of reference should be made for all of the possible options when formulating a care plan? The mental health user, care co-ordinator, and any others providing support, would then be able to see what was available when doing so. It seems to me to be also important that mental health users are made aware that entering into this process is their choice. It sounds obvious to me as I write this that if anyone felt, rightly or wrongly, that they were being coerced into this process then it would be likely to result in a negative response.

There might also be a means of all those involved (whether co-ordinator, user, etc.) for providing feedback on the process, allowing the opportunity for review of how it is working based on comments. There would then be the opportunity to introduce changes if necessary after the review (perhaps at either a 6 month or 12 month interval?).

I think that on the whole this appears to be a positive change to the way support is provided. A sense of control over a person's treatment would feel to a mental health user that their concerns were being responded and listened to. (DR)

Personalisation is a good thing; client directed and a valuing of the clients own expertise – balance of power – choice etc. My only concern is that clients do not always know what is best for them i.e. work and the like... There is still a need for them to be constructively challenged and led out of their comfort zones... Think this has to occur. Statement of wishes when deemed not in control of own house is a good thing a sort of advanced directive. (SL)

Personalised budgets – supposedly/potentially going to be there when under secondary care but what about when individuals move on? If the intervention that the personal budget pays for is keeping someone well than why should it stop as they begin to function at a higher level? A disincentive to get/cope better and perhaps the client will return to services if they lose the intervention. (SL)

Whilst it is very laudable to aspire to choice for mental health service users it is a double edged sword as is already being experienced over the issue of personal budgets. Many individuals and not just mental health users are not using their full quota of personal budget and saving some 'just in case' or are using the money for other needs.

Furthermore in the case of many elderly people, immediate family members may well have already registered a Lasting Power of Attorney or made a similar arrangement against the day the elderly person can no longer care for themselves. Thus the notion of yet potentially another additional 'statement of wishes and choices' document may cause confusion and even legal argument. There needs to be careful thought applied to such a document being introduced.

Question 7: When people are referred for healthcare, there are a number of stages when they might be offered a choice of where they want to go to have their diagnostic tests, measurements or samples taken. At the following stages, and provided it is clinically appropriate, should people be given a choice about where to go to have their tests or their measurements and samples taken:

- *At their initial appointment - for example, with a GP, dentist, optometrist or practice nurse?*
- *Following an outpatient appointment with a hospital consultant?*
- *Whilst in hospital receiving treatment?*
- *After being discharged from hospital but whilst still under the care of a hospital consultant?*

Plymouth LINK supports patient choice at any of the points indicated. It might be unlikely for a

patient in hospital to choose a different setting for tests, but choice may also reflect the practitioner as well. Patients should have the right to choose who performs tests, scans, measurements, etc. Plymouth LINK has received feedback from different cultural communities that a certain gender of professional has been requested and not available. Women often prefer women doctors and staff who are trained in working with learning disabilities may be the choice of patients with learning disabilities.

The obvious answer is YES to the first two points and the final point. It is more difficult to see any logic behind someone already in hospital then choosing to go to another location for tests, unless the hospital in which they are cannot perform the tests.

Question 8: *Are there any circumstances where choice of where to go for diagnostic testing would not be appropriate, and if so what are they?*

As part of specialised commissioning there are services regionally that offer specialist treatment for rare illnesses. Where tests are specialised enough, there may be limitations on who can provide these.

The main question the government will need to address is when there are differences in testing procedures between England, Scotland and Wales, and where an individual lives very close to the border and wishes to cross the border to have a testing procedure not available where they live.

Question 9: *Would you like the opportunity to choose your healthcare provider and named consultant-led team after you have been diagnosed with an illness or other condition?*

Plymouth LINK has received feedback where patients have been unhappy with the attitudes or responses of a doctor. In these situations opportunity to change provider after diagnosis will support those patients to change their provider to someone they prefer. Numbers of patients moving between services and reasons for this will help services to identify where and who need to make improvements.

Yes

Question 10: *What information and/or support would help you to make your choice in this situation and are there any barriers or obstacles that would need to be overcome to make this happen?*

Patients often tell the LINK that they worry about whether complaining will affect the treatment they receive. Patients are loyal to services if they have been helpful in the past and fear the consequences of making waves. If information about options are regularly available at admission, appointments, in discussions, etc., and discussed with patients, it will help to create an environment where choice is possible. This will have big implications for healthcare staff and how they embrace and promote this principle.

As mentioned before travel is the main barrier.

Question 11: *Is there anything that might discourage you from changing your healthcare provider or named consultant-led team - for example, if you had to repeat tests, wait longer or travel further?*

Information about the practicalities of changing provider should be made available to patients.

Again travel is the big issue, followed by waiting time.

Question 12: *What else needs to happen so that personalised care planning can best help people living with long term conditions have more choice and control over their healthcare?*

One of the main areas of LINK feedback relates to the need for improved, joined-up working for health and social care services. Services need to work together (on compatible systems for a central ??) to share information and allow a seamless transition between services. Care managers will need to access services from health and social care which, from feedback, are often at odds about funding. Staff will need training and support to facilitate this new way of working, as well as information sharing. Feedback often highlights that health professions are unaware of what other services are available and the directory which will enable emergency services to allow choice could be shared across all services.

This is another laudable intention, but in the issues quoted about individuals who need both medical and social care, all the time the government keeps the monetary and responsibility threads for medical care and social care separate there will always be two puppet masters. Renaming LINKs as Healthwatch when they will retain responsibility for social care issues as well is just a small example of the thinking that has gone into these consultation papers. If the intention is for true personalised care plans then one solitary authority must be in place, otherwise we will end up with two people with similar needs, one having their care plan overseen by a medical person and the other having their plan overseen by a social care worker, in other words, no consistency.

Question 13: *What choices are most important to people as they approach the end of their lives? What would best help to meet these?*

Plymouth LINK has received limited feedback about end of life care and some praise for local hospices. The LINK supports choices in as many areas as possible – venue, treatment and support.

Most important is maintaining dignity, and that means different things to different people. It is hard to envisage anyone wanting to die in hospital rather than in their own bed, but for many elderly they do not live at home but rather in some form of care home.

Question 14: *We need to strengthen and widen the range of end of life care services from which patients and carers can choose. How can we best enable this?*

People experiencing end of life care, their carers and families who have gone through a death, should be consulted about the range of services available and where the focus needs to be.

It is unlikely this is a subject people give much thought to, or discuss, until the issue becomes imminent. As such encouragement to plan earlier and learn about what options are available should be practised.

Question 15: *Carers may sometimes feel that they themselves have no choice when the person they care for chooses to die at home. How should the respective needs and wishes of patients and carers be balanced?*

Carers have given feedback that in front of the cared-for they cannot always be as honest as they would like. Carers' needs should be discussed in their own right and not as an add-on to the care-for treatment package. Feedback shows us that everyone is different and it is the responsibility of end of life care services to support each family to come to a decision.

This must form part of every Carers Assessment

Question 16: . *What sort of choices would you like to see about the NHS treatment that you have? Treatment could mean therapy, support for self management, medication or a procedure like surgery?*

Plymouth LINK supports the opportunity to extend as much choice as possible to patients. Most illnesses have a wide range of options for treatment (self-management, medication, holistic, invasive, alternative) and patients should be made aware of the range of options, even where they step outside the medical model, for example, we are aware of the success of local acupuncture services for pregnant women at the hospital.

As per question 1. The three big issues are; Who you see, Where you see them and When you see them.

Question 17: *How can we encourage people to take more responsibility for their health and treatment choices?*

Changing the culture of services will take time for both services and patients. Feedback to Plymouth LINK indicates that barriers to exercising choice and control are often:

- * Information;
- * Staff approach;
- * Fear of jeopardising treatment.

Patients need information and reassurance about their right to choice and control. Our contact with different communities shows that the accessibility of information, services, staff approach are key barriers for people for whom English is not their first language, asylum seekers and refugees for instance. Feedback from older people highlights an attitude that they need permission to speak out and don't want to make a fuss. A consistent and positive response to people making a choice will support them to make them again.

A local organisation such as HealthWatch could be key in engaging with local communities.

Question 18: *How do we make sure that everyone can have a say in their healthcare?*

We often hear that people are not asked what they want. This would seem like an obvious but simple way of encouraging people to share their views/issues, etc. Health services and staff should be asking this as a matter of course and be monitored for their involvement of patients and outcomes relating to patients.

If ever there was a strap-line for the future Healthwatches this is it!
The next series of questions effectively define what local Healthwatches could be all about.

Question 19: *How can we make sure that people's choices can reflect their different backgrounds - whether ethnic, religious or any other background that could affect their healthcare preferences?* Staff training in Equality & Diversity issues should be mandatory for all working in health and social care, to improve awareness of possible issues. Assessment, treatment and care planning should include discussion of patients' individual needs on this area and the impact on further healthcare. Information should be formatted to meet the needs of the patient (languages, audio, etc.). Patient needs should then be communicated to all services involved. Plymouth LINK has received quite a lot of feedback about difficulties accessing health services, despite the legal requirements of services under equal opportunities legislation.

Healthwatch

Question 20: *How can we make sure that carers and the families of patients and service users can have a say in decisions about the healthcare of the people they support, where appropriate?*

Where possible family and carers should be part of healthcare discussions and decision making. Carers often tell Plymouth LINK about issues of confidentiality preventing them from receiving information about the cared-for.

HealthWatch

Question 21: *How can we support the changing relationship between healthcare professionals and patients, service users, their families and carers?*

In any healthcare situation the professional has a duty of care to the patient. Plymouth LINK is aware through feedback that patients perceive a power imbalance in the professional/patient relationship. Therefore the responsibility to change the relationship and support a healthcare partnership has to be led by the professional. This can be supported by training, clear expectations, monitoring and even tying new responsibilities to funding.

HealthWatch – As an independent critical friend.

Question 22: *What needs to be done to ensure that shared decision making becomes the norm? What should we do first?*

Training is one way that professionals can begin to understand a new way of working. Incentives could encourage services to work in this way and penalties for not working in this way. Areas of good practice could be used to mentor areas of poor practice.

Firmly define the role of Healthwatch and champion that role.

Question 23: *Should healthcare professionals support the choices their patients make, even if they disagree with them?*

Healthcare professionals should give patients all the facts and then support patient choice (even if they disagree). Where the patient can make an informed choice.

Unless the decision is likely to be injurious to that person's health, then yes.

Question 24: *What sort of advice and information would help healthcare professionals to make sure that everyone can make choices about their healthcare?*

Work with local services and trusts highlight that they are not always aware of the demographics of local populations and their needs. Public health provides an important role informing services of the needs of local people. An understanding of the local population and the barriers they face is a good start.

Full knowledge of what locally is available in the broadest spectrum of care service providers and a good working knowledge of the culture of the user.

Question 25: *How can we encourage more people to engage in advance care planning about their preferences for the care and support they receive – for example, when they are approaching the end of their life?*

Again, Plymouth LINK has not received much feedback about end of life care and planning for this. However, we would support this to occur.

Many people who are 'in' the health care system have regular checks ups, even if it is only an annual eye sight test, or the annual Flu jab. An annual review of their care planning could be added to this list or become part of the annual flu jab session for example. Once it becomes an established procedure, word of mouth will ensure those 'not in' the health care system will become aware of what is being offered.

Question 26: *Would you welcome a chance to engage in advance care planning before you become ill – for example, when you go for your mid-life Health Check – rather than after a diagnosis of a life-threatening condition?*

As above.

Most people would say yes, but we have to acknowledge that for some cultures talking and planning around death might not be an acceptable thing to do.

Question 27: *How could training and education make choice and shared decision-making a part of healthcare professionals' working practices?*

Patient experiences should form part of the training and assessment of new professionals as they go through college/university etc. Modules or work streams on patient involvement/patient centred services should form part of mainstream training at all levels. Staff and service management should also cover this.

Surely the question is not How, but When should such training be given. For those not yet qualified it should be an integral part of the qualification process. For those already employed in the caring services it must be part of the annual training in the workplace program, and it must be targeted at those at the top first, so can they lead by example.

Question 28: *How can we help people to learn more about how to manage their health?*

Feedback shows us that people need different levels of information – training is not for everyone. Health professionals should include patient education as part of their involvement in someone's care, which could include – what level of information the patient would like, how they would prefer this delivered, when and by whom. Feedback also shows that professionals use a lot of jargon and terminology which can be confusing for patients.

HealthWatch

Question 29: *What help should be available to make sure that everyone is able to have a say in their healthcare?*

Plymouth LINK feedback highlights that people who have a disability, language barrier or are not from this country have particular difficulties knowing what services/options are available to them. Help for those groups needs to overcome their speech barriers to enable understanding and choice. Others need support from advocates to have their say. There are many service groups and support for these groups already in place and could be used as a channel for information. Plans for local HealthWatch to be appoint of information for services will also support this, and HealthWatch will have close knowledge and links with advocacy and

community organisations.

HealthWatch as an enabling / signposting organisation

Question 30: *Who would you like to go to for help with understanding information and making decisions and choices about your healthcare, or that of someone you support?*

Through discussions with local organisations we are aware that people trust and go to their local support services rather than an unknown healthcare provider (for example, in Plymouth asylum seekers and refugees will use agencies such as Refugee First and Refugee Action as a first point of contact for everything). It is through these people that help should be available.

HealthWatch

Question 31: *How can we make sure that carers' views are taken into account when the person they support makes a healthcare choice?*

See response to questions 15, 20 and 21.

The carer should have the right to ask for a new carer's assessment if they feel the choice being made impinges on their ability to be a carer.

Question 32: *What information and support do carers, parents, guardians and those with powers of attorney or deputyship need to help others to make choices or to make choices on others' behalf?* As already mentioned, carers need the same information as the cared for, to support their treatment and decision making. Carers also need to know the impact on their caring role for the choices available.

It is not What but Where do they go to get support, advice etc. And the answer is HealthWatch

Question 33: *What information and support do voluntary sector and patient-led support groups need so that they can continue to help people to make choices about their healthcare?*

The community and voluntary sector need to work more closely with health services in order to support choice and control for the people they work with. As opportunities and developments in health services occur this should be communicated to the wider community and voluntary sector as a matter of course. Commissioners should discuss organisations offering roles in supporting healthcare choices in the new system and the potential impact on service provision and on funding to support the community and voluntary sector to do this.

See answer to Question 32

Question 34: *How can people be encouraged to be more involved in decisions about their healthcare?* See responses to questions 17 and 18.

Another prime example of what a local HealthWatch could be tasked with.

Question 35: . *Would decision aids be a useful tool for healthcare professionals and their patients and service users? Are there any barriers to their use?*

Decision aids, alongside all information will need to reflect the accessibility needs of the individual. See responses to question 4, 17 etc.

Simplified, non-jargon flow charts that show at what points a choice may be available and then what those different choices and what their implications are. In some of the examples in the consultation paper you have used examples of choosing between a local service with a potential time delay, and a service further away but with no time delay. You have also used an example of a knee replacement operation and a lengthy recovery time as opposed to a non surgical option. If these choices were made available for all to see it might help, although the care professional might be concerned about the costs involved in the different options.

Question 36: *How should people be told about relevant research and how should their preferences be recorded?* Plymouth often hears about patients that are confused by jargon and terminology. Talking to patients about research needs to be done in a way that the patient can understand. If the patient is offered the opportunity to be involved then the risks/lack of clinical evidence needs clarity and this relies again on accessible communication targeted to meet individual patient needs.

Whatever method(s) are chosen they must be accompanied by means to control expectations. If a million people volunteer to be part of a research program that only wanted a few hundred there needs to be a way of managing the disappointment many will feel, particularly if they have been waiting a long time for a potential breakthrough. Also this is entering the realm of patient confidentiality, where in effect the government might be asking people to disclose their medical condition, 'for future reference' if a suitable research project becomes available. Conversation will be needed with civil liberties groups on this issue.

Question 37: *How can we encourage more healthcare professionals to use Choose and Book when they make a referral?* Potentially the use of incentives for using the choose and book service. It could form part of a service's contractual responsibilities.

Depends on whether the government prefers the stick or carrot method in reality.

Question 38: *How can we encourage more healthcare providers to list their services on Choose and Book?* Again use of incentives or contractual responsibilities

This won't be an issue if personal budgets are still concerned the way forward. Those who do not list their services will earn no revenue.

Question 39: *How else can we make sure that Choose and Book supports the choice commitments in chapter 2?*

See answers to questions in section 2

HealthWatch

Question 40: *Do you agree with the proposed approach to implementing choice of named consultant-led team? What else would you suggest needs to be done?*

Yes, Plymouth LINK supports the proposed approach.

Many official named lists are way out of date and turn-over of staff in some departments and at some hospitals can be quite prolific. Also many hospitals only have one consultant in any given discipline so exactly how much choice there will be is open to debate given previous questions about travel and time delays.

That aid this is a step in the right direction but may not be the most successful initiative.

Question 41: *Do you agree with proposed approach to establishing a provider's fitness to provide NHS services? What other criteria would you suggest?*

Plymouth LINK is aware locally that different providers offer different levels of service, which vary in terms of how patient centred the service is. A provider fitness for NHS services will help to ensure consistency. Based on LINK feedback, the criteria should focus on the accessibility of the service, how well it caters for the needs of potential patients, staff training in equality and diversity and patient focus, continual evaluation of patient experience and service response to patient feedback, monitoring of diversity of patients using the service and how the service meets the needs of the demographics of different patients.

There is currently a furore over the use of GP's from overseas to cover the out of hours GP surgery commitment. If the government is serious about licensing or registering service providers then as well as ensuring the standard is at least the NHS standard there **must** be criteria about the skills of the people they will employ and use to deliver these services.

Question 42: *Should this approach apply uniformly to all providers, no matter what size, sector and healthcare services that they provide? For example, should a small charity providing only one healthcare service to a very localised group of patients be subject to the same degree of rigour as a large acute hospital that delivers a range of services to a regional catchment of patients?*

Yes, every provider should be subject to and able to evidence that they are fit for purpose, strategically relevant and offer a patient centred service. In the Third sector, all sizes of organisations are subject to the same funding constraints, quality assurance and monitoring. This should also apply to providers of health and social care.

Making exceptions is the thin end of the wedge and must be resisted.

If in your example the small charity wishes to continue to provide that service, then as long as it clear to users that the service does not meet the standards the government requires for registration / licensing, in keeping with the spirit of this paper about enabling people to choose, people should still be free to choose the service provided by the small charity.

Question 43: *Do you agree that an "any willing provider" directory should be established to make it easier for commissioners to identify providers that are licensed and have agreed to the NHS standard contract terms and conditions?*

Yes, as this will encourage providers to be competitive and offer a good service.

Yes in principle, but the practicality may be very different. In one example in this paper a patient chose a hospital 50 miles away so as be near a relative. Thus is the suggestion one directory for the whole country or a series of more local directories? Is there any way in which a national provider can be distinguished from a small, local provider, who could otherwise be overrun with demand? Users may know about a service provider in another part of the country through family / friends but how are health / care specialists supposed to know whether that provider is a suitable choice?

In short with much more detail about what will be in the directory there are more questions than answers.

Question 44: *The White Paper indicates that the Government will explore the potential for introducing a right to a personal health budget in discrete areas. Which conditions or services should be included in this right?*

Personal health budgets will have a greater impact on people with long term conditions. Long term conditions should be included in this right.

As stated earlier the personal budgets already devolved in adult and child social care have not always been the success anticipated with many people not spending the full allocation. This is certainly the case for many people who have received budgets to allow for a certain number of hours care per week but have chosen to 'purchase' a reduced number of hours instead. This is therefore an area which the government needs to explore very carefully and slowly and would be advised to evaluate the success or otherwise of the personal budgets introduced in 2008.

Question 45: *How can we make sure that any limits on choice are fair, and do not have an unequal effect on some groups or communities?*

Discussions in Plymouth LINK about choose and book and specialised commissioning have highlighted possible inequalities where people have to travel to access a service. For people on a low income, travelling to a provider or being visited by family to support their treatment or recovery will be difficult. This impacts on a need to go out of area for a specialist service but also limits choice for people where the choice may require travel. In these circumstances, the process will not be a fair one; subsidising travel/accommodation or paying for families on low incomes may help to address this.

HealthWatch

Question 46: *What do you consider to be the main challenges to ensuring that people receive joined-up services, whatever choices they make, and how should we tackle these challenges?* Through feedback, the main challenges would seem to be lack of compatible systems for different service providers, and lack of understanding of other services. We are always surprised that even in one of our health trusts that services are not aware of each other. Services need a universal system that holds records on local people that can be accessed by all. Services also need to update knowledge of other services locally and the directory previously mentioned could help this. Joined up services requires a change in culture and should form part of a services contract, monitoring and registration to ensure a proactive approach.

Firstly there needs to be transparency and simplicity over funding streams for the different type of care services people want to access.

Secondly the system will not work effectively unless there is a robust organisation like Healthwatch to monitor check and raise awareness of issues both to health professional and service users.

Question 47: *What do you consider to be the main risks to the affordability of choice and how should we mitigate these risks?*

Based on issues that have come to Plymouth LINK, time spent sharing the same information with different healthcare professionals at different stages of treatment is a cost issue and accessibility of travelling to services will also rise if people are to have more choice. New IT systems and patient records that can be easily shared/travel with the patient will support the first point. Increased costs for travelling will require varying budgets but improvements may see savings which can be used in this area.

The cost of providing services in rural areas will clearly be more than in inner cities and major conurbations. Thus we risk repeating history whereby the typical cottage hospital was scrapped and all services gravitated to a main city based hospital with many people having to travel miles to receive treatment / undergo tests etc.

A city servicing a population of 250,000 will have little difficulty in attracting service providers to meet demand, but predominantly rural PCT's and local authorities will have a major headache.

Question 48: *How far should we extend entitlements to choice in legislation and hold organisations to account against these?*

Unless choice is written into the legislation, it will be difficult to enforce organisations to uphold the principles and hold them to account. Basic requirements should support a patient to choose the service they want and for that service to receive the patient where possible. Legislation should also expect services to make reasonable adjustments to be accessible to local people. (info etc.).

There needs to be a careful balance between creating a new raft of Human Rights type legislation and leaving it up to organisations good will. Quite simply if health and social care providers wish to remain on the government register / license then they must comply with the principle of shared decision making. Similarly if those who initiate the process GP's, social workers etc wish to remain registered as such they must also be able to demonstrate they actively support the principle.

Question 49: *Where no specific right to choice applies, how can the Board best encourage GP consortia to maintain and extend the choice offer?*

The commissioning board needs to ensure that choice is reflected in the terms of reference principles and set up of GP consortia and forms part of the tests of decision making for GP consortia. This can also be supported by the role of HealthWatch on the board.

HealthWatch

Question 50: *What is the right mix of measures to encourage GP consortia to offer appropriate choices to their populations?*

In order to encourage GP consortia to commission choices for patients, they need a clear picture of existing services (what is working well or not, including a picture of the area they are commissioning within/numbers, demographics, needs of local populations). Identifying new services to commission needs to be supported by patient/local feedback which can be provided by local HealthWatch.

An appropriate mix can only be developed over time after best practise has been identified. As such initially the issue must be subject to inspection by the Board and feedback from local HealthWatches to HealthWatch England. Once best practise has been identified then measures to ensure it is repeated everywhere, with allowance for local variances, can be put in place.

Question 51: *What is the best way to gather patient feedback about the extent to which commissioners have put in place choices?*

Feedback should come directly from patients using/recently used the services being considered. An overall picture can be gained from local HealthWatch and complaints/PALS can offer insight as well. As a matter of course services should ask patients to evaluate their services and questions about choice could form part of that evaluation, supporting a picture for GP commissioners.

HealthWatch

Question 52: *Are the responsibilities of organisations as outlined enough to:*

- *ensure that choices are offered to all patients and service users where choices are safe, appropriate and affordable?*
- *ensure that no-one is disadvantaged by the way choice is offered or by the choices they make?*

Yes

This totally depends on the way in which the government sees HealthWatch operating. As an enabling organisation with the ability to utilise the skills of other agencies and to signpost users then the answer is YES.

However under the section on Local Government it could be interpreted that there is an expectation that HealthWatch itself would be responsible complaints advocacy. This is a major issue for debate as there is a world of difference in assisting someone who has an issue with a process or policy; however it is entirely another world if someone has a complaint about medical negligence against a specific individual.

So until there is clarity about government thinking on this issue it is impossible to give a definitive answer to this question.

Question 53: *If you do not get a choice you are entitled to, what should you be able to do about it?*

Plymouth LINK highlights that people are often unaware of what to do when they do not receive a good service. It is a service's responsibility to promote routes for PALS/complaints/HealthWatch and check that patients are happy with their service and that they have received choice. This information should then go back to GP consortia/health and wellbeing boards/commissioning board to inform future provision. Patients who are able to voice their lack of choice should be offered choice.

See the answer to question 52 because again there is a complete world of difference between a service user who got no choice because of a policy or process as opposed to a service user who was denied a choice because of the deliberate or negligent actions of an individual.

Question 54: *What do you think are the main risks associated with choice and how should we best mitigate these risks?*

The ability for patients to vote with their feet will impact negatively on those providers not offering a good service and increase demand on those that do. In response to this failing services could be offered training, mentoring and support to improve, and demanded services increased funding to do more of what they do well.

The biggest risks must be: -

Firstly managing public expectation. Unless this whole concept is sold to the public in the right way, everybody will be expecting to see a Harley Street Specialist on the NHS as a matter of 'Human Rights'.

Secondly there must be a big risk around health and care specialists knowing or thinking they know what is right for an individual and the individual themselves disagreeing and exercising their right no matter what.

Addendum

One member of Plymouth LINK raised some views about accessing choice for different patients and the potential impact of this choice.

1. Hypothetical question:

Single parent-you know the ones we as a society are now to believe are the scourge of the benefit system; becomes ill.

G.P. (preferred) recommends best consultant is in Exeter!

Where does a single parent find the cost of the ticket from Plymouth: child care and lost income from low paid part time work?

Those who can pay will pay; those who cannot will not be in a fiscal position to engage best suited programmes of care. Two tier health-care; no longer care from cradle to grave; just demolition of Bevin's dream.

Mental Health is even more to become the poor relation; cuts in domestic care or increased costs; will slip through community care (if as there is not slippage already).

Restrictive choice is NOT progressive; health both physical and mental health suffer; with other cut-backs; Mental Health will become a serious issue;

Stress already accounts for more days sickness than skeletal illness.

Hypothetical question:

G.P. of choice decides that the drain on his budget of long term pharmaceutical intervention is prohibited what intervention can be made within the realms of person choice?

These are just two examples; who decides- the budget payer or the public?

2. If you are a single parent there is no way that options are reachable.

If the recommendation is say for Exeter- who pays transport costs, child care costs, extra prescription, lost wages?

Only those within society who have the means will access choice.