

## PPI - The Nails in the Rural Coffin?

First, this exchange:

Helen Jones: “Does my right hon. Friend accept that if we are to strengthen the voice of communities and patients in the health service, we have actively to seek to involve people from communities that are currently under-represented in the NHS's decision-making process? Will he give us an assurance that the commission will actively seek the involvement of people from deprived communities not only on advisory bodies, but in the NHS's decision-making process?”

Alan Milburn: “Unless we improve the NHS's governance **and make it more representative of the local communities that it serves**, we shall never reach the position at which local services are responding to the needs of local communities..... We need to ensure that the patients forums are not only representative of the local community but can express expertise on behalf of that local community.” (Commons Hansard, 2nd reading Health and Social Care Bill, 10.01.01.)

From the start then the Government considered it fundamentally important that there is a need to: “**....ensure that the patients forums are not only representative of the local community but can express expertise on behalf of that local community.**”

But the results of the ALB review brought a crucial decision: “Many workshop participants believe it would be logical to remove the distinction between PCT and NHS trust forums. Participants believed this would enable forums to look more effectively at the whole patients' journey.

After considering a number of ways we could reconfigure forums, we believe that this can best be achieved through combining forums within each Primary Care Trust (PCT) area. These forums would retain a specific focus on every NHS trust and NHS foundation trust in that PCT area. This would provide a coherent structure focused on the PCT which has responsibilities relating to both provision and commissioning of services. This approach will involve the minimum amount of disruption for forums, will provide continuity for NHS organisations and enable forums to track the patients' journey more closely.”

(Government response to the consultation exercise about the future support arrangements for patient and public involvement in health 15th March 2005)

This proposed change appears to be welcomed by many Forum members who have been unhappy with the arrangements so far and it can certainly be seen how in urban communities with relatively tight geographical areas and distances, and, usually, good public transport, it will be an improvement. The benefits are obvious: an increased number of volunteers for each PPI Forum; less duplication of effort; shorter lines of communication; and better awareness of the whole patient route.

The problem lies though, in the one-size-fits-all approach; for the many PPIFs in rural communities will find varying degrees of increased difficulty with unworkability at the extreme end. I'll describe my own area of Norfolk with the note that is not atypical: Norfolk is only the fifth largest county in England.

Spread over an area of over 2000 square miles we have three large general hospital trusts; one huge mental health trust which covers the whole of the county plus a section of north Suffolk; one ambulance trust which covers the massive geographical area of three counties; six PCT trusts and one PCT trust in north Suffolk which is involved because in that part of Suffolk mental health services are provided by the Norfolk and Waveney Mental Health Partnership NHS Trust.

Zooming in to more local communities, in the area covered by Southern Norfolk PCT - about 400+ square miles - the PCT PPI Forum has, since 01.12.03., yet to hold a public meeting in the eastern segment of that area and it has no plans, as yet, to do so. To get to the nearest public meeting of that forum so far (in Wymondham) a patient or member of the public from, say, Burgh St Peter, would have had to make a journey by car (there is no viable public transport connecting the two) of fifty six miles.

Circumstances and conditions in the county also reflect the national position, as I suspect is prevalent in other large counties: When I was in healthcare practice, I and some my colleagues used to routinely refer to "Norwich County Council", for all the services were centred in Norwich and its surrounds with a serious dearth of services in other areas of the county. Even now organisations such as ISU (Involving Service Users) purporting to represent Norfolk service users in reality ignores most users outside Norwich. That is just one example of the norm; even though 83% of Norfolk's population live outside Norwich. So take away the relatively local PPIFs and PPI is in real trouble.

In a recent mental health internet discussion about PPIF accessibility, having been asked why distance mattered at all, as most forum members have cars. I wrote:

"..... there is a large and very significant proportion of the service user/carer population who, for many reasons, cannot travel. Some are prevented physically - those people wheelchair bound; those with MS; those with ME; those with cerebral palsy; those with diabetes who have serious peripheral neuropathies or amputations; those with sensory deprivations; those with Meniere's disease; those with arthritis; those with problems of incontinence; those with epilepsy; those with autistic spectrum disorders; those with spinal disorders; etc, etc.... And all of these can have mental health problems in addition.

And then there are those who are prevented by mental impairments: those with agoraphobias; and a whole spectrum of phobias; those with certain kinds of schizophrenia; those whose depressive inertia chains them inside their homes; those with obsessive/compulsive disorder; those with anxiety disorders; those with certain kinds of personality disorder; those with Tourette's Syndrome; those whose self image is so fragile it is impossible for them to relate to other people; those with drug induced psychoses; those suffering from PTSD; etc, etc.....

And then there are those for whom travelling or participating is difficult by the fact of their conditions rendering them social pariahs: those with HIV/AIDS; those with sexually transmitted diseases; those with opiate addiction; etc, etc.....

And there are those for whom travelling is so difficult it is a barrier - by reason of social and financial deficits and complexities: those living on welfare benefits; young people who are seen as deviant and who take on those roles; people from previous generations and social classes for whom travel was never a facile thing ( I have a good friend - a very able person - who worked on the land all his life and who has lived contentedly inside the same three square miles all his life and wouldn't dream of trying to travel the 15 miles into Norwich, even though he has his own car); people who have never learned to drive; people who live in places where the bus arrives once or maybe twice a week; people who can't read or write; people who are afraid to travel because of what they perceive as ever present criminal activity; people with language problems; people with cultural misconceptions; people who live in fear of discrimination; etc, etc.....

These are all real first line service users and carers - people who should be in the forefront of PPI Forum membership, but people, especially in rural areas, who are neglected and excluded. And they are people who seem to be invisible to the usual worthies, retired healthcare professionals; OBE seekers, businessmen looking for the main chance to make a profit out of the NHS, and middle class suits who appear to constitute the core membership of the hospital and PCT trust PPI Forums around here.”

The Government, via Alan Milburn's Commons statement quoted above agrees with me: **“We need to ensure that the patients forums are not only representative of the local community but can express expertise on behalf of that local community.”!!**

Looking at things from another angle, The Norfolk and Waveney Mental Health Partnership NHS Trust PPI Forum currently has eight members. There are six PCT trusts in Norfolk and one in Waveney. Eight into seven? Just how marginalised will mental health be in these circumstances? Further to this, the MH PPIF is presently fortunately atypical in that its membership has a majority of genuine service users and carers. Those members, some of whom are vulnerable, now seem to be confident enough in themselves, via the support of the group, to participate fully in the work of the group contributing valuable expertise. It would seem a share out must be inevitable. Transfer one or two of those valuable experts to a large PCT and some will find it impossible to make themselves heard in a large unfamiliar group where other priorities are being fought for. And some will find the prospect too daunting full stop. Some of these factors apply, in varying degrees to the other PPIFs to be amalgamated. They will all be diluted in one way or another. And learning disabilities/difficulties which have yet to find PPI representation here will be relegated further.

And so it seems that the Government decision “...combining forums within each Primary Care Trust (PCT) area.” has probably been made by metropolitan people with metropolitan mindsets and urban imaginations withered by exhaust fumes. That decision undoubtedly sets up a continuum of difficulty with, at one end, clusters of advantages accruing to large cities with compact geographical areas and excellent (sometimes free) public transport through increasing problems for large towns and suburban conurbations to high impossibility for Helen Jones’ **vulnerable people from deprived communities that are currently under-represented in the NHS’s decision-making process** - country people in counties like Norfolk.

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