Genuine Partners Revisited



Older People's Involvement in the Implementation of the National Service Framework for Older People

A REVIEW OF CURRENT PRACTICE September 2007

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Commissioned by the Greater Manchester Older People's NSF Reference Group

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1: Background

The National Service Framework for Older People (NSFOP) is a ten year plan launched in 2001 which aims to improve health and social care services for older people (Department of Health, 2001). Local Implementation Teams (or LITs) bring together a wide range of people from the statutory and voluntary sector and are responsible for translating the plan into action. Central to the NSFOP is the belief that older people should be involved as 'genuine partners' in the implementation process.

This report describes how older people have been engaged in NSFOP implementation across twelve Local Implementation Teams in Greater Manchester. First, it revisits an earlier report of involvement practice completed in 2002 (NHS Executive North West Regional Office, 2002); and then follows this up through a review of current practice completed in 2007. The review was perceived to be timely because of the reorganisation of health and social services (now adult services) and the publication of two documents by the Department of Health ['A New Ambition for Old Age' (2006a) and 'A Recipe for Care', (2007)] which aim to give new direction and impetus to NSFOP implementation.

The review of current practice was commissioned by the Greater Manchester Older People's NSFOP Reference Group. This is a group run by older people for older people (aged 50 years plus); offering networking opportunities and support to enhance the effectiveness of 'lay representation' on Local Implementation Teams and their related task groups. Funding for the Reference Group is provided by the 'Greater Manchester Association of Primary Care Trusts' and in return the Reference Group acts in an advisory capacity on issues related to older persons' health and social care services. Administrative services and developmental support are provided to the Reference Group by a voluntary organisation called MACC ['Manchester Alliance for Community Care' <u>www.macc.org.uk</u>].

Review Aims:

- To gather evidence of older people's experiences of serving as 'lay representatives' on Local Implementation Teams and their associated subgroups across the Greater Manchester area.
- To gather evidence from older people on their experiences of being supported in the process and if they think their involvement has been effective.
- To audit new opportunities for involvement building on the NSFOP.
- To evaluate the effectiveness of the support services provided to the Greater Manchester Reference Group by Manchester Alliance for Community Care [MACC].

2: Method

In 2002, the former NHS Executive North West Regional Office commissioned research from the University of Manchester to identify good practice around the involvement and engagement of older people on NSFOP Local Implementation Teams and to design an audit tool against which future practices could be assessed. The *'Clear Voices'* audit tool was launched in 2005 (Scott *et al.*, 2005) and this forms the basis for the review of practice described in this report (see Figure 1 overleaf).

The review was small scale and completed during April to July 2007 on a limited budget (£2,500). The starting point was a documentary analysis of the reports and discussion papers which the Reference Group has produced. In terms of gathering older people's perspectives on involvement in NSFOP implementation, Reference Group members (n=16) were given the option of attending one of four focus groups or participating in a telephone interview. Many Reference Group members were involved in producing the earlier report on involvement practices published in 2002 and were able to provide a unique longitudinal perspective on NSFOP implementation. It is acknowledged, however, that further work is needed to ascertain the perspectives of older people who have not been involved through the Reference Group and who may have been involved in NSFOP implementation in other ways.

The review also included telephone interviews (n=11) with staff from the statutory or the voluntary sector who have lead responsibility for supporting or championing older people's involvement within the LIT or more broadly across various planning boards where the LIT is no longer operational. Finally, a telephone interview was carried out with a

representative from the 'Greater Manchester Association of Primary Care Trusts'.

Figure 1: Clear Voices Brief Audit Tool (Scott et al., 2005)

WW= Working Well IN=Improvement Needed

Questions	WW	IN	Action
Question 1 – Are older people and carers offered appropriate induction and training to assist maximum			
participation and clarify expectations on both sides?			
Question 2 – Is there an open access annual meeting with all older people and carers to review involvement work and its outcomes?			
Question 3 – Is dedicated staff time allocated to assist older people and carers to develop and coordinate their involvement activity?			
Question 4 – Are older people and carers with special conditions or experiences consulted as communities of interest?			
Question 5 – Does the Local Implementation Team use older people and carers' voices to influence decisions made above Local Implementation Team level to good effect?			
Question 6 – Are older people and carers regularly consulted about their experience of involvement so training and practice can be continuously improved?			
EVIDENCE/EXAMPLES/REASONS FOR SCORING ??			

3: Early Days of NSFOP Implementation

The first report of involvement practice in NSFOP implementation called *'Genuine Partners or Token Reps?'* (NHS Executive North West Regional Office, 2002; McNally *et al.* 2002) was instigated by older people who were members of the former 'NHS Executive North West Regional Office [NSFOP Task Force]'. The Task Force was responsible for supporting the implementation of the NSFOP across the northwest of England. In 2002, one year after the launch of the NSFOP, a conference was organised to find out what was happening locally as regards older people's involvement. Twenty-eight LITs were operating in the northwest at this time and each was asked to pass on an invitation to their older members. This served to put the issue of older people's involvement on the agenda. At this stage many of the LITs had not yet recruited older people into their midst.

The 'Genuine Partners or Token Reps' conference was held in Manchester and was attended by 25 older people. Delegates worked in small groups to share their experiences of sitting on the LITs. Most delegates felt that the process by which they had been recruited onto their LIT was not transparent. It appeared that most LITs had approached existing forums or other established groups of older people as a pool from which to recruit older members. As result, it was felt that the 'usual suspects' were over represented. One consequence of not having a clear and proactive policy on recruitment was that, almost without exception, the early LITs were excluding:

- Older people from black and ethnic minorities
- Older people who have disabilities
- Older People who live in care homes
- Older people who are not middle class.

Where people had been recruited onto the LIT, some were already considering dropping out because they did not feel sufficiently supported. Jargon was identified as a major problem as were the sheer length and complexity of the documents people were expected to read. As regards the payment of expenses, most LITs appeared to operate under the impression that it was the responsibility of local voluntary organisations 'to pick up the tab' for older people's participation.

Although the conference was held a year after the launch of the NSFOP delegates considered that action was very slow to take shape and that it was far too early to say if their involvement was making a difference. Overall, it was felt that while there was some evidence of good practice this was not consistently spread across the region.

In addition to producing a snap shot of current practices, the 'Genuine Partners' conference had a further outcome which was the establishment of a Northwest Regional Reference Group. This enabled older people sitting on the LITs to have the opportunity to continue to meet and to campaign for better involvement and engagement practices. When the NHS Executive North West Regional Office was replaced by three new Strategic Health Authorities in 2004, the Regional Reference Group divided into three to mirror these organisational changes. Reference Groups were established for Greater Manchester; Cheshire and Merseyside; and Cumbria and Lancashire. All three Reference Groups continue to operate today (mid 2007), but their rate of development has varied as each has not received the same amount of support and funding.

The Greater Manchester Older People's Reference Group received \pounds 6,000 in funding in 2005/6 and in 2007/8 from the Greater Manchester

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Association of Primary Care Trusts. The funding was made available to enable the Reference Group to continue to promote good practice around older people's involvement in NSFOP implementation and to act in an advisory capacity to older people's working groups linked to the Association of Primary Care Trusts: facilitating consultation on specific issues; assisting in monitoring and performance of the LITs; and providing a corporate voice for older people's perspectives (See Figure 2 for full Terms of Reference).

Figure 2: Terms of Reference for The Greater Manchester Older People's NSFOP Reference Group.

Overall Aim:

The Primary Purpose of the Greater Manchester Older People's Reference Group is to bring together older people (50 years plus) who are involved in the implementation of the NSFOP, to support their effective involvement in the work.

The group will:

- To support and enhance the effectiveness of older people serving as lay representatives on Local Implementation Teams and all older people working with related NSF task groups across the Greater Manchester Area
- Provide a Reference Group for the Manchester Association of Primary Care Trusts, on issues related to older persons' health and social care services.
- Establish links with parallel groups in the North West Strategic Health Authority Area and other relevant NW bodies (e.g. Better Government for Older People, Age Concern and Help the Aged)

Deliverables:

- Establish and facilitate meetings brining together older people sitting on the LITs.
- Be a means for older people to be informed and influence the planning and delivery of health and social care services.
- Identify and report on current mechanisms for involvement, reflecting good practice and barriers to involvement.
- Provide a forum to identify and share information on policy issues that impact on older people and carers.

In 2005, a local voluntary group called Manchester Alliance for Community Care (MACC) was appointed by the Greater Manchester Older People's Reference Group to provide support services. MACC is paid a 10% management fee for their work (which amounts to £600 per year) and is responsible for ensuring that members are provided with appropriate support to maximise their involvement in implementing the NSFOP. MACC organises suitable venues for meetings; prepares minutes; briefing papers and information sheets; organises the payment of expenses (for attending Reference Group meetings) and supports members' attendance at other relevant meetings and conferences locally and nationally. Significantly, where conferences and events do not offer concessions to older people, the Reference Group will meet the costs of the events so that members are not excluded or out of pocket. MACC also helps the Reference Group to identify and meet the training needs of its members.

The Greater Manchester Reference Group currently has 30 members most of whom are drawn from the 12 Greater Manchester NSFOP Local Implementation Teams. The majority of Reference Group members are also connected to many other older people's forums, local and national working groups and organisations such as Help the Aged, Age Concern and Better Government for Older People. A core group of 12 members meet on a monthly basis to plan and manage the work of the Reference Group.

The work of the Reference Group has been reviewed in a recent activity report (see Appendix 1). This demonstrates a wide and varied contribution to policy and practice development in health and social care across Greater Manchester and, indeed, nationally. Members have attended numerous meetings and events and also plan their own events, setting their own priorities and agenda for action. For example, the mental health and well-being of older people were identified as a priority area of work for the Reference Group for 2006/07:

'Through members' contacts and networks, we have been able to feed our views into a number of structures and use our collective influence to try and improve services and support for older people. The Reference Group has been a mechanism for older people to gather views and experiences, to feed into our own local, regional and national NSF implementation structures.'

> Chair of the Greater Manchester Reference Group Activity Report June 2004 – March 2007

4: Review Findings

According to the recent national review of NSFOP implementation (Healthcare Commission, 2006), there is still much to be achieved when it comes to improving practice around older people's involvement and engagement:

- In a survey of older people's views, 95% of respondents said they had not been consulted about NHS or council services in the last year. In addition around 80% of the older people surveyed felt that they had no influence in planning health and social care services or in monitoring their quality;
- There is little evidence that communities are building a shared vision based on the views and priorities of older people;
- Involvement is not always systematic or carried out routinely;
- Local councils have mechanisms that are better developed than those in the NHS for engaging with older people. Some local authorities deal with the wider concerns of older people as citizens rather than exclusively as users of care services;
- Most inspected communities are finding it a challenge to involve older people who are seldom reached, such as older people in black and minority ethnic groups.

In this section, we report the findings from the most recent review of older people's experiences of involvement and engagement across the 12 Local Implementation Teams (LITs) in Greater Manchester. Given the limitations of the study because of its focus on consultation with those older people most closely linked to NSFOP implementation rather than the general population of older people, it is nevertheless striking that they are in such contrast to those described above. Reference Group members described how great strides have been made since the early days of NSFOP implementation and how there is a resounding sense of having become 'genuine partners' rather than 'token reps':

'The thing for me is that when I first joined the LIT I was the only person there, the only lay person, now we have seven people from the public on the Reference Group... I feel really part of what is going on.'

'I think we are being listened to and we do have a voice which is something we didn't have'.

'It's totally different now - the atmosphere has changed - there is a lot more talk about older people having rights than was acknowledged before.'

'We have a voice and we are allowed to speak and they like the dialogue because we are as important to them as they are to us.'

The Views of Reference Group Members

In the remainder of this section, we draw on the review findings to describe the structures, practices and values which underpin this 'good practice'. The issues considered are: What is happening with the LITs? How are older people involved? What support is provided? And finally, what are the outcomes of this involvement? For reference purposes, a summary table of the review findings is presented in Appendix 2.

What is happening with the LITs?

In 6 out of the 12 areas contacted the LITs are continuing to meet on a regular basis (3 of the LITs are considering merging together). All are broadening the focus of their work from the original eight standards contained in the NSFOP to take on new work implicated in more recent policy documents such as 'A New Ambition for Old Age' (DH, 2006a) and 'Our Health, Our Care, Our Say' (DH, 2006):

'I feel very comfortable that the LIT is still going forward. We are looking at developing a new title but it will probably be the same team.'

Reference Group Member

In 6 of the areas, the LITs have disbanded. Here, work around older people's issues is now managed through various new planning groups and structures such as the boards linked to Local Strategic Partnerships, Valuing Older People and Opportunity Age [information about these initiatives is provided in the glossary]. As Vegaris *et al.* (2007) point out, public engagement in governance and public services, alongside democratic voting, constitute the core of the government's active citizenship and civil renewal agendas. These initiatives are often led by the local council, involve a wide range of stakeholders (including older people) and take a much broader view of older people's issues, encompassing not just health and social care but also 'community well-being' (Manthorpe *et al.*, 2006) and issues such as transport and community safety. Reference Group members broadly welcome this shift and the opportunity it affords to work on a wide range of issues that are important to older people:

Following changes within the NSFOP, the LIT team split in half. Half of it is to do with independence and the other half is health and

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well being. The independence group goes under the term "All Our Tomorrows Board" and the health and well being comes under the title of the "Health Improvement Partnership"... The "All Our Tomorrows Partnership Board" has retained responsibility for standard one [of the NSFOP] on age discrimination...'

Reference Group Member

Some Reference Groups members did however, caution that while it is important to see older people as *'active citizens'* and not just as just *'users'* of services, this should not permit health and social care issues to fall off the agenda. Some members felt that in taking a broader view of older people's issues there was a danger that social care in particular and issues affecting the most frail and vulnerable older people could easily be forgotten.

Within the Reference Group there are different perceptions as to how much progress has been made implementing the NSFOP. Some members believed that there was much work to do while others felt that their own LIT had made good progress in meeting the milestones and standards. A key issue identified for future discussion was the extent to which the Reference Group needs to *'move on'* or champion the reinvigoration of the NSFOP locally:

'At any given [LIT] meeting there is always quite a few of the [professionals] that should be there missing - so the meeting has to be adjourned... Actually last week we had to say to this person that hadn't been there for months that we need you to come and explain some of your work otherwise you are not keeping us in the picture'

Reference Group Member

How are older people involved on the LITs and in the new planning structures?

While things are perceived to be moving on from the NSFOP, an important finding of the audit is that there is much continuity of involvement:

'The world has moved on and we have tried to move with that without losing our commitment to the all the NSFOP issues. One thing we have done is kept the older representatives well and truly in the frame'.

Paid Officer

The LITs are perceived to have been a very important mechanism in *'opening doors'* for Reference Group members, allowing them to pursue what might be termed an *'involvement career:'*

'[From the LIT] *I went on to the Diverse Communities and then the Healthier Communities so varied things I do in the month... I was 85 at the weekend and for me* [it's about] *getting up every day and have something that I can put my mind to'.'*

Reference Group Member

'I [used to be involved with] *charities* – *fund raising etc, never anything for the PCT or the City Council …but this is my life now…'* Reference Group Member

The extent to which older people are involved directly on the LITs and the new planning boards varies from area to area. Most LITs/boards involve one or two older people at the level of access to key meetings and core business. Sometimes, though not always, older people invited to sit on the *'main groups'* are representing the views of a *'shadow group'* comprising

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all older people. The newer boards, especially, are increasingly adopting more sophisticated strategies for older people's involvement, for example, by arranging elections in order to promote older people from the shadow boards onto the main boards and on to other committees. In one area, there was a conscious strategy to ensure an appropriate balance between the number of older people and number of paid officers sitting on the main LIT. In their study of engagement practices across London Boroughs, Vegeris *et al.* (2007) identify three distinctive models which are helpful in understanding current practices across Greater Manchester (see Figure 3 overleaf).

The LITs in particular seem to be developing expertise in project or topic based involvement work. One LIT, for example, had recently completed research on the views of older people from ethnic minorities. Some of the LITs also see their role as more about championing and supporting involvement at the level of front line practice; encouraging and guiding practitioners and managers to put the necessary systems in place to undertake, for example, regular surveys of *'patients'* views of hospital care. Interestingly, the recent review of the NSFOP (Healthcare Commission, 2006) makes the point that while the NHS may have expertise in working with *'service users'*, local councils may be more adept at working with older people in their own groups and as *'citizens'*.

Figure 3: Most Common Engagement Models

- The independent forum: A separate organisation, typically led and administered by older people, that lends autonomy to older people's concerns. Individuals often engage directly with council staff. However, engagement can involve only a few core members and there are sustainability issues due to low funding and time pressures on key members. A sub-type of this model involves a forum of older people that is funded by the council and facilitated by a council officer. This helps to make the forum more sustainable but could also be seen to limit independence.
- The supported group: In this structure, engagement is organised and overseen by the partner, typically a voluntary sector agency specializing in older people issues, who is contracted by the council to act as intermediary between it and local older people. This facilitates engagement and ensures financial and administrative stability, yet engagement is often reactive and contact between older people and the council is sometimes indirect.
- The older citizens' panel: A large pool of older people who can be contacted on an ad hoc basis, allowing wide representation and the involvement of those who are not interested in traditional meeting structures. Individuals often engage directly with council staff but engagement tends to be reactive. Since the group does not exist as a separate entity it lacks independence and opportunity for older people to build a common cause is limited.

Engaging Older Citizens, a Study of London Boroughs (Vegeris et al., 2007) In terms of their own sense of identity, Reference Group members often make the distinction between those colleagues who are new to involvement activities and those who are <u>'leading activists'</u>. As Postle *et al.* (2005) point out in a study of independent older people's forums some older people are taking part in new forms of political activity, marking a shift of focus from self-help to campaigning:

'If we go back to our LITs or whatever organisation we are from, taking some of the things we have learned [from the Reference Group] back with us then to me that is a campaigning part because we are bringing things to their notice. I mean just recently I was at the Intermediate Care Day and I went back to my LIT and took them over the coals about it... and so they are now going to bring somebody to the next LIT meeting to explain what went wrong. We don't want to just sit there and let them think everything is hunky dory because it isn't.'

'We are not professionals we are the other people...It's right that we should be able to challenge some of these professionals because we find out through other people what is going on and what can be done, and what is available and what is out there.'

Views of Reference Group Members

Reference Group members felt strongly that the 'values' of the individual professionals concerned were crucial to ensuring that involvement was not tokenistic. Some paid staff were said to actively encourage older people to speak their mind and to provide constructive criticism, while others were known to be to be defensive, leading older people to hold back on their views and 'tread carefully':

'We have a true partnership of equals. The older people we have are not afraid to ask questions... Our culture is very open and trusting and we are big enough to cope with [criticism].'

Paid Officer

'I put my name down [for the LIT] because I knew that [the professional who invited me to join] would be trying his level best to do things and make things move in [this area]... It was a bit daunting when I first went to the LIT because I was the only lay person and these were all professional people who knew a whole lot about every subject than I did, but as time went on... you soon got to know the people - the professionals - who were really trying to do something and the others were just sitting there and doing their job and taking their pay every month... But I have to say that the majority of them were trying to do a good job so I felt well - I can go along with that.'

Reference Group Member

'[Reflecting on a presentation by a group of paid officers] They heard the voice of older people and they were surprised ... [Older] people expressed their reservations and they were non-plussed at the end.'

Reference Group Member

Among participants in the audit, the commonly held view is that Reference Group members hold places on the LITs/boards by virtue of their links into independent older people's forums and/or other community and voluntary groups which means they are representing a broader range of older people rather than just themselves as isolated individuals or *'service users':* 'I was involved in the older peoples' group and I also belong to the Community Centre which is a group of about 100 [older people] and I do voluntary work... So, any feedback, we try to dispense the information around you know.'

Reference Group Member

However, a weakness of this approach is that the mechanism for linking the views of the broader forum of older people to the older person acting in a representative capacity is rarely made explicit. Very often taking forward the views of *'other'* older people is based on an intuitive understanding of their experiences and needs rather than on the use of a specific methodological tool such as interviews or focus group (for a full discussion of the different tools see DH, 2003). This lack of transparency often causes paid staff to worry that they are involving only a very small number of older people who may not be *'truly representative'*. An argument which, according to literature on involvement, is invoked most frequently by professionals when the views of older people are negative or critical:

'When workers find what we [users] are saying challenging, the most usual strategy to discredit user voices is to suggest we are not to be listened to because we are too articulate, and not representative. Workers seem to be looking for someone, the 'typical' patient who is so passive and/or drugged that they comply with their plans.'

(Lindow 1999, p166 quoted in Glasby, 2007)

Perhaps reflecting broader good practices across the LITs/boards as regard recognition of the need to be inclusive and to reach out to groups of older people whose voices are seldom heard, older people from black and minority ethnic communities are well represented on the Reference Group as are older people with a range of long terms conditions and disabilities. For many Reference Group members a particular challenge is how to attract *'new blood'* (younger older people), especially those willing to take on leadership and committee roles.

In order to ensure that the LITs become 'more representative', officers described a range of approaches. One area was developing a 'hub and spoke' model looking at ways of linking its core group ('shadow board') of 15 older people with the wider community of older people. In another area moves were already underway to develop a 'pool' or 'bank of older people' who could be consulted on different topics as and when required. In one area there was even a well-intentioned move away from involving older people at committee level:

'Sitting down with [older people] as partners and trying to make things better that's our emphasis... We are not thinking a lot of the time about OK - we've got this new group - we need to get an older person on that committee. That isn't really our approach... We take our ideas out to a group of older people genuinely interested in that issue, whether it be road safety or what ever, and get feedback... and then crucially we feedback to them what has happened as a result'

Paid Officer

However, by restricting involvement and engagement to consultation and feedback there is the risk of excluding older people from decision-making. Indeed, opening-up the LIT and other key decision making arenas to older people, especially at the highest strategic levels, was the rationale for setting up of the former North West Regional Reference Group. Among paid officers the difficulty of getting to grips with the different models and concepts which underpin involvement is highlighted as a particular challenge:

'It would be great if someone could come up with the easy solution to getting older people's involvement in the right way'.

Paid Officer

What support is provided to 'lay representatives'?

The support provided by the LITs and the various new boards to support older people's participation varies considerably from place to place. Reference Group Members said that they generally felt very well supported. This was especially the case where there is the support of a dedicated 'involvement officer'. Longer-term relationships with key officers were thought to be most effective in achieving positive outcomes:

'We have had lots and lots of support from our LIT without any doubt.'

Reference Group Member

'Our success is mainly due to our Support Officer... She is wonderful, caring and committed.'

Reference Group Members

There is evidence that Reference Group Members are being asked for their views on how involvement is working. 'Pre-meetings' (where older people are given the opportunity to meet and talk through an agenda before the meeting) and annual involvement days were also described:

'I am working on the LITs and it is very good. In the beginning they gave me all the jargon busters... You can phone up if there is anything you don't understand and they always give you the opportunity to say what you feel and I think that is very important, that means that they are listening to what you have to say.' 'Usually we meet about half an hour before the official meeting time... We have seven [older] people [on the LIT] and we go through the Agenda and we have this person who explains what will take place during that Agenda so that you don't have someone getting up and you have no idea what they are talking about because they are inclined to speak in this language....terminology and things'

'A good example of partnership working with LIT Officers was the Annual Involvement Day. This year the focus was on Dignity in Care. The morning activities commenced with an interactive market place providing information and advice from local services. Following lunch there were several presentations, a guest speaker and workshops. LIT members, guests and a diverse section of older people including older Asian ladies (who provided an assortment of sweet meats) divided into groups, LIT members sitting and participating with older people as equal partners to help influence the local agenda - particularly in terms of health and social care services. Concluding activities included a Tai Chi demonstration and a display of classical Indian Dance.'

The Views of Reference Group Members

None of the LITs had developed an explicit strategy to identify and meet the training requirements of older people. Individually tailored inductions were offered to new members by LIT Chairs and/or involvement officers and more established members were encouraged to access the same training events and resources as other LIT members: 'We do not offer any support and training to our older representatives as such as they have a fair amount of expertise already... We fund them to attend conferences or workshops in the same way as the other LIT members'.

Paid Officer

One identifiable area for improvement, however, relates to reimbursement and the payment of expenses (for good practice see DH, 2006c). Only one LIT was reimbursing older people for sharing their expertise and time (paying £10 per meeting). Many interviewees were unclear if a policy existed on the payment of expenses and older people were not actively encouraged and supported to make a claim. While free transport meant that travel did not always need to be claimed for, there was the issue of stamps, telephone use and other resources which might be used in the course of LIT business.

The practice of the Reference Group itself as regards its own meetings and events was to actively encourage members to claim expenses, for example, to make use of a taxi rather than the bus if someone had been unwell. With the advent of free local transport, funds had been diverted to enable members to attend more conferences and events. Expenses were paid in cash on the day so that members were never out of pocket and refreshments were always provided. However, among Reference Group members the issue of reimbursement was particularly contentious. Some members were happy to act as volunteers on the LIT while some felt there was an important principle around valuing the expertise of older people in the same way as any other 'professional expertise' which usually incurs either a wage or a consultancy fee:

'[Researcher: And do they pay for your time?] No - Just your pension, that's your wage... I think most of us volunteer we don't expect to be paid - we wouldn't be doing it if we did.'

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Reference Group Member

In supporting older people's participation on the LITs, the Greater Manchester Older People's Reference Group is perceived by its members to play an invaluable role which is qualitatively different from the support provided locally. Key benefits of membership include access to specially tailored information and events which offer opportunities for networking and '*peer mentoring.*' Having somewhere to develop and test out your ideas and thoughts before putting them to the LIT was thought to be especially important as was having an arena for older people to set their own agenda and priorities for action:

'During this first twelve months of the Reference Group being funded [by the Association of Primary Care Trusts] and supported [by MACC], members were able to increase their knowledge and understanding of specific areas in health and social care by attending relevant meetings and conferences. Examples during the first year were: the Northern Lights event on mental health, the Connecting for Health conference and the conference on Elder Abuse in Warwick. These opportunities have been a positive experience for individual members by developing their knowledge base, but also of benefit to the group as a whole'.

> Chair of the Greater Manchester Reference Group Activity Report June 2004 – March 2007

'[The Reference Group] provides information about what is going on really.... A clearing house for information'

'It educates us and encourages us to speak about things and provide a better service'.

'[The Reference Group] organises a small conference or work shop relating to issues like mental health – dementia... I think that's a very useful part of the Reference Group - I feel as quite comfortable with the fact that we do a lot of work like that in [my area], but it's also good to know what other areas are doing and I think that is the beauty of the Reference Group - that we try to learn from one another and if it is good pinch it and I think that benefits all older people'

'I think it's so important what we learn from one another - to take it back from the network to the wider field'.

'We can pick from what we have seen or hear from other authorities to push the point'.

'Some areas are superb and if we didn't have [the Reference Group] we wouldn't have known that we have pockets of good experience in some areas and not in others. I think this Reference Group fills that purpose.'

'[With the Reference Group] You have got this big back up... All these professionals coming back at you, but with the support of the information that you get from the [group] then you feel that you have some support at the back of you and you can say exactly what you want to say.'

'Within the group they are supportive, very supportive and I feel also that it encourages people to voice opinions and you can almost test it out in that environment before you go and test it in your own'

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'Another thing that this reference group does is it allows you to have an agenda, so it's not professionals coming in and saying we are going to do this and that'

The Views of Reference Group Members

In accounting for the perceived success of the Reference Group, members were particularly appreciative of support provided by their 'support agency' (MACC):

> 'I feel that strive as we may - we are all volunteers - we are superbly lead and supported by the secretariat in the form of [the MACC Officer]. My punch is that without her we would flounder and that is both praise and a criticism'

> > Reference Group Member

The fact that MACC provides the Reference Group with a 'home' is considered especially important:

'[The MACC Office] is a focus so that we can meet somewhere regularly. It provides the support that is needed... so it has given us stability'.

'[MACC] allows us to come and see all the stuff that is here in this office ... all this information. Whereas in our Authority we don't seem to get into people's offices anymore to see the real thing - we are at 'arms length'.

Views of Reference Group Members

The terms of reference between MACC and the Reference Group are very clear that older people are in the driving seat as regards managing and determining the nature of the support provided. Furthermore, what is perhaps unusual about the support provided by MACC is that it is not only administrative but also constitutes as an *'expert resource':*

'[The MACC Officer] is a fund of information, reliable and she is well informed'

'The briefing papers are great. They keep us up to date with many new policy developments and provide helpful information prior to meetings and conferences'

'I put the date [of the conference] in my diary and yesterday I learned that it was a ticket only job. I rang the [MACC Officer] and she said leave it with me - I will go and to the Department of Health web site and see what I can do. I got a ticket today - that I don't think that would be within my scope to achieve... She turns losers into winners... and allows us to work at new level that our own authority doesn't seem to.'

Views of Reference Group Members

While many voluntary agencies provide practical low level support to older people's groups and forums undertaking activities such as booking venues, speakers and arranging lunches, only recently has the potential for more *'professionalised'* support been highlighted. For example, Postle *et al.* (2005) describe a potential role for health and social care practitioners in supporting older people in their campaigning activity:

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'Much current social care practice in community care is individualistic thus limiting practitioners' ability to see the wider picture of people within their communities and to work with them in enabling and empowering ways to bring about change... [By working with older people in Forums] social care workers are supporting people to participate in active citizenship, contributing to rebuilding social capital, challenging age discrimination and preventing social exclusion'.

Postle *et al*. (2005)

However, if potentially empowering ways of working with older people are misconstrued as a form of radicalisation or politicisation, then the *'professionalisation'* of support services to older people's groups and forums can be contentious. Already the issue has arisen in Greater Manchester as to whether voluntary organisations, working to support older people's forums with funding from the statutory sector, should promote a *'critical perspective'* or share only very neutral kinds of information. A workable compromise seems to have been reached:

"[Discussing tensions which arose between the Reference Group and its sponsor, the Manchester Association of Primary Care Trusts during one the consultation] *The meeting reaffirmed the value we attach to briefing papers provided by MACC, but recognising that comments must be clearly owned by the Reference Group or MACC.*'

> Chair of the Greater Manchester Reference Group Activity Report June 2004 – March 2007

'I don't think professionals are always that keen on our coming to this kind of thing [the Reference Group]'

Reference Group Member

In delivering more professionalised support services to older people's groups and forums there is a resource implication. Reference Group members were aware that the value of the support provided by MACC far exceeded the £600 per year they were currently paid.

In the interviews with paid officers there was very little awareness of the Reference Group beyond its role in *'Training older people for LITs'*. It may be that there is much scope for more integrated and joined-up working around the development of future engagement and involvement practices.

What are the outcomes of older people's involvement on LITs/boards?

Reference Group members felt strongly that they were able to shape policy and make a difference to services through their work on the LITs. However, they did find it difficult to identify specific outcomes. Having become 'genuine partners' there is a sense in which it is almost impossible to discern older people's distinctive contribution as 'lay representatives' from that of the wider 'professional' LIT membership. Indeed, some of the newly recruited officers openly acknowledge that by virtue of their continuity of involvement (often five years plus), Reference Group members are usually more 'expert' on the NSFOP than they are. There is also the view that influence leading to change can be too subtle as to be undetectable. Put on the spot, key achievements said to have been instigated directly by the actions of Reference Group members include:

• The introduction of red trays to be used on hospital wards to alert staff that a particular patient may need assistance at meal times;

- Changes to hospital discharge policy where older people receive a telephone call two days after discharge to check that they have everything they need and are coping well;
- Older people acting as lay inspectors having the right to make unannounced checks on local care homes.

Finally, the area where the Reference Group feels itself to have had least impact is at the level above the LITs. The Reference Group found it difficult to identify key contacts at Strategic Health Authority level and only recently have key planning groups and networks opened their doors to older people's direct participation:

'I think they have given us very little of what I would call two way traffic, it has not seemed to me to be a very effective dialogue'. Reference Group Member

With the abolition of the Greater Manchester Strategic Health Authority the biggest risk to the future of the Reference Group is that the new northwest wide structure (NHS Northwest) launched in 2006, will sweep away these already fragile links leaving the Reference Group adrift and without funding once more.

5: Conclusion

Based on focus group discussions with members of the Greater Manchester Older People's Reference Group and telephone interviews with paid officers, this review gathered evidence on older people's participation on NSFOP Local Implementation Teams. Overall, the feedback from Reference Group members is very positive as compared to earlier reports of engagement practices across the northwest and nationally. Members view themselves as 'genuine partners' rather than 'token representatives' and believe their voices to be used to good effect. Despite changes in the policy and planning landscape, there is evidence of continuity of involvement with lots of new involvement opportunities linked to the NSFOP and the newer civic renewal and active citizenship agendas. Although difficult, members could identify specific outcomes or service improvements which they attribute to a direct result of their participation. However, members make the point that having become 'genuine partners' it is increasingly difficult to discern their distinctive contribution as 'lay representatives' from that of the wider 'professional' LIT membership.

In accounting for what is perceived as a significant '*culture shift*' in involvement and engagement practices, Reference Group members describe a number of important factors. First, the wide range of practical support delivered through the LIT is highly valued especially where there is a dedicated involvement officer. Longer-term relationships with key officers were thought to be most effective in achieving positive outcomes. Reimbursement and the payment of expenses, however, remain causes for concern.

Second, the work of the Reference Group itself is thought to be critically important in changing culture and practice especially at the level of

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empowering older people to work more effectively within their own LITs. Significantly, the support provided by the Reference Group is perceived to be qualitatively different to that provided through the LITs. By providing opportunities for networking and *'peer mentoring'*, the Reference Group enables members to develop a *'critical perspective'* (for example, through hearing about good practice developments in other areas) and to build confidence to *'speak out'* and advocate for older people within their own LITs. Underpinning the work of the Reference Group is the activity of the 'support agency' (MACC). What is distinctive and highly valued about this is that alongside basic administrative support essential to the day to day running the group, MACC also acts as an *'expert resource'* which is independent of the LITs. This is perceived by members to enable them to work at a *'new level'* which they do not feel they could achieve alone.

Third, the attitudes and values of LIT officers and other professionals are thought to be critical in shifting participation beyond tokenism. While most officers were said to actively support and encourage older people in their role as *'critical friends'*, adopting a negative or defensive attitude was felt to be particularly damaging and led to older people acting more cautiously and possibly dropping out.

Overall, this review supports earlier findings on involvement practice as regard how older people may be conceptualised as either 'service users', 'active citizens' or 'activists'. These distinctions have the potential to cause tension between professionals and agencies especially where empowering practice in support of older people's campaigning activity is misconstrued as either radicalisation or politicisation. Especially when the statutory sector is providing funding to the voluntary sector to support capacity building, there need to be clear terms of reference about the nature of the support that is to be provided. Very importantly, older people

need to be in the driving seat when determining and managing their own support needs.

Finally, as is the case for many non-statutory bodies, sustainability remains a continuing cause for concern (Cornes et al., 2006). The Reference Group's most recent funding came through a working group linked to the Strategic Health Authority which has since been abolished. While the involvement and engagement of older people now seem more systematic and routine at LIT level, evidence from this review suggests that this is not the case at the next level above. This suggests that, as a priority, the Reference Group may wish to take the lead in establishing links with NHS Northwest to improve practice standards and secure its own future.

Discussion Points for Future Reference Group Meetings

- 1. Should the Reference Group 'move on' or campaign for the reinvigoration of the NSFOP?
- 2. Does the civic renewal and active citizenship agenda maintain a strong enough focus on health and social care?
- 3. What is the distinctive contribution of the 'lay representative?
- 4. What can the Reference Group do to raise its profile with LIT officers?
- 5. What is the Reference Group's position on reimbursement and the payment of expenses? How can better practices be promoted across the LITs?
- 6. How can 'full cost recovery' be secured for voluntary and community groups working to support older people's participation?
- 7. How can the Reference Group forge links with NHS Northwest?
- 8. How will the Greater Manchester Reference Group work with parallel groups in the new regional structure?

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Glossary

Local Implementation Team (LIT): A group of professionals and officers from a range of agencies (usually including older people) which oversee plans for putting the NSFOP into action.

Local Strategic Partnership (LSP): A single non-statutory, multi-agency body, which matches local authority boundaries, and aims to bring together at a local level the different parts of the public, private, community and voluntary sectors. LSPs are key to tackling deep-seated, multi-faceted problems, requiring a range of responses from different bodies.

National Service Framework for Older People (NSFOP): A programme of action to improve services and service delivery covering the range of care and support older people and their carers might need.

Opportunity Age: A cross-government strategy on issues facing Britain as people live longer healthier lives, including strategies to enable people to extend their working life, support for active ageing and more choice and independence in service use.

Valuing Older People (VOP): A multi-agency programme to improve services and opportunities for Manchester's older population. It seeks to challenge Manchester's public agencies, businesses and communities to place older people at the centre of the extensive plans for the regeneration and reshaping of the city.

Appendix 1: Greater Manchester Older People's Activity Report for 2004 – 2007

SECTION 1: The following reports and briefing papers were requested by the core group and other members and circulated:

- Commissioning a Patient-led NHS
- Our Health, Our Care, Our Say
- Independence, Well-being and Choice
- Reconfiguration of the PCTs
- Active Case Management
- The Expert Patient Programme
- A Sure Start In Later Life
- Partnerships for Older People
- Choose and Book
- Paying for Long Term Care (Joseph Rowntree Foundation Report)
- Future Funding for Social Care in England (Wanless Report)
- Real Voices, Real Choices (CSCI)
- Free Travel Policy briefings
- Everybody's Business, a Summary
- Living Well in Later Life/ New Ambition for Old Age (Ian Philp)
- A Recipe for Care (Ian Philp)
- Older Minds Matter- reports from the general meetings on Dementia and Depression.
- Audit of Involvement (Mental Health Trusts GM)
- The Mental Capacity Act and Independent Mental Capacity Advocates,
- Connecting for Health,
- The Dignity in Care Campaign.

SECTION 2: Reference Group General Meetings covered the following topics:

- Our Health, Our Care, Our Say
- Effective Involvement
- Reconfiguration of the PCTs/SHAs
- Active Case Management/ Expert Patient Programme
- Choose and Book
- Review of the NSF for Older People
- Continuing Care
- Older People and Depression/Dementia
- Connecting for Health
- Sure Start in Later Life

SECTION 3: The following events and conferences were attended by members and supported by the Reference Group:

- The Northern Lights Event on Mental Health 26.09.05
- Connecting for Health 31.03.06
- Ageing in the Workplace
- General Medical Council; meeting on the NHS and Ethics.
- Elder Abuse a hidden problem 02.04.06
- A New Direction for Community Services 08.05.06
- General Hospital Care
- The Pensioners' Parliament
- The Telecare/Telehealth event
- The Celebration of the Continuing Care Leadership Development programme
- Dignity in Care Launch
- Intermediate Care-Next Step Developments
- Mental Health and Well-being Conference (postponed to May 21)
- Dignity in Care; Regional Launch.
- Alzheimer's Society Conference
- Intermediate Care Events
- Older People's Advocacy Alliance

(For a copy of the full report please contact Mary Duncan Tel: 0161 834 9823 email: mary@macc.org.uk)

LIT	LIT Status and Membership	Support Provided	Outcomes	Future Plans/Challenges
1	The LIT continues to meet on a		Older people are listened to and	As part of Local Area
	regular basis and just completed a			Agreement, the PCT is
	review of progress. There are 20 -	works across LIT and other		currently leading on the
	25 members which includes 7-8	areas). Pre-meetings/ Travel	to.	development of a tool to
	people. 2 older people are from the			measure public involvement
	black and minority ethnic	vouchers are available. There		
	community.	are plans for an away day for		
0		LIT members.	Olden needle ene listened te	
2	The LIT has been superseded by		Older people are listened to.	Difficulty in accessing
			Recent consultation with older	
		delivered by PCT and Age		don't receive services.
	'Partnership Board'. There is a network of around 50 older people	· · ·	Document.	
	who can be involved as required.	what training they need (50%)		
	Older people from black and			
	minority ethnic communities are	committee membership,		
	represented within the network.	chairing meetings, giving a		
		presentation. There are Pre-		
		meetings for older people before		
		board meetings. Re-evaluation		
		of involvement practices takes		
		place every twelve months. An		
		annual conference on older		
		people's issues is held every		
		year - which includes older		

	loop'. Older LIT members' role is to champion the 'ethos' of involvement and to keep involvement on the agenda.			older people feel that there is a lot of duplication.
6	The LIT and 8 sub groups are continuing to meet quarterly. There are 15 members (1 older member) The LIT has a separate service user and carer reference group – and a single representative of this group comes forward to sit on main LIT. Strong representation from carers on the various sub-groups. All original NSF milestones are perceived to have been met – with the exception of the Single Assessment Process (SAP) which has only been partially implemented. The LIT is currently at an 'interim point' as a new strategy is currently being developed around 'New Ambition for Old Age'	No formal support package or training package is provided for LIT service user and carers groups – It is recognised that the older people currently involved in the LIT are very 'experienced' and vocal. New consultation officer post has just been funded by adult social services and a review is planned of all aspects of current involvement practice and policy. A large conference (attended by 70 older people) was recently held.	'Individual issues' fed-in to the LIT via LIT service user/carer group. Older people were very involved in developing ideas for a bid for project monies. This was not successful but the ideas generated are being taking forward anyway.	Adult social services looking at developing a consultation panel – 'a bank of older people to generate different representatives every time'. Thinking of undertaking an annual service user satisfaction survey. Need to look at formalising feedback loop between LIT and its service user and carer group. Need to look at training for staff on how to take forward involvement and engagement.
7	The LIT has been superseded by a Partnership Board. Former LIT members (2) have moved across to participate on the board (both are representatives of the local older	No specific training is made available to older people on the partnership board largely because they are long standing members (established	The view was that older people's involvement is making a real difference – specific examples were at the level of project working (for example, older people have	undertaking involvement and engagement activities as part of their day to day

	people's forum which is very well established). The Partnership Board has a much broader remit than health and social care and although no single individual has sole responsibility for implementing the eight NSF standards – issues linked to the NSF are still actively taken forward. Current examples include targeted work around dignity and ensuring older people have access to good information. It was recognised that the policy landscape has moved on and that while losing the LIT may been seen as a form of rationalisation integration of LIT issues into the work of the Partnership Board was considered to be the most effective use of people's time vis-à-vis	colleagues) who do not require any 'induction'. Instead, older board members are funded to attend conferences, workshops and events in the same way as other board members. Emphasis is placed on informal and supportive ways of working between colleagues. There is no formal reimbursement policy. There is no dedicated involvement support officer post as such however a key contact is clearly identified. The Partnership Board adheres to the view that all officers need to see involvement and engagement as part of their day to day job (in effect working towards the mainstreaming of	been very active in working on all aspects of a campaign to encourage people to stay warm).	very important. The Board has put together some guidance for officers on how to conduct meetings in a participatory way.
		to day job (in effect working towards the mainstreaming of involvement activity).		
8	In 2004, the 'All Our Tomorrows Partnership Board' was established – taking forward some aspects of the LIT work but generally having a much broader focus on older people's health and wellbeing	Expenses are offered. No reimbursement is offered for attending meetings. No specific training is offered – in addition to any courses generally available. The	The shadow board is perceived to be very effective in ensuring that its voice is heard. Most significant achievements are perceived to lie in the area of tackling age discrimination – where, for	promoting and supporting older people's involvement is in securing funding. If

	issues. The 'All Our Tomorrow's Board' encompasses the 'Independence and Prevention Modernisation Group' and the 'Health and Well-being Modernisation Group'. The 'Independence and Prevention Group' is taking forward Standard 1 (preventing age discrimination) of the NSF. There is a <i>shadow board</i> comprising fifteen older people who underpin the work of the 'All Our Tomorrow's Board' (receiving the same paperwork etc,). Two representatives (older people) from the shadow board sit on the All Our Tomorrow's Board'. The Shadow Board are also able to place items / issue on the agenda in addition to following the work of the main Board.	Shadow board is facilitated by Age Concern who provide practical support (briefings, background papers etc, on specific issues) mentorship and any other support as required.	example, some services have now removed age limits as a result of pressure from the shadow board.	development of a <i>'hub and</i> spoke model' which will look at ways of how the shadow board can link to the wider community of older people (i.e. become more representative of a wider range of different views). A further key issue identified relates to ensuring that older people participating on boards do not become overwhelmed by the work load.
9	The LIT has recently been reconfigured and is now called the 'Older People 's Partnership' with a broad remit to provide strategic co- ordination to all older people's	The Service User and Carer Action Forum has received funding through the Local Strategic Partnership. This funding covers the cost of	been commitment to an 'open ear' policy which empowers front line staff to engage with services users	People Project POPPs is developing new forms of devolved decision making to newly formed organisations in each of the for borough

	workstreams including council wide preventive services as well as health/social care services. The various sub-groups attached to the NSF standards (and which have older people represented in the membership) now report to the Joint Management Team which co- ordinates the LIT health and social care work streams. There is one older person on the Older People's Partnership who represents the views of the well established 'Service User and Carer Action Forum'. This is an independent Forum which meets monthly.	meetings, hire of rooms, administration and travel expenses. A named involvement officer from the councils adult care services provides advisory support to the Forum to ensure older people's involvement is both effective and meaningful. A strategy and good practice guide for involvement and consultation in community care services was produced in 2004 by the Borough Council.	process, so that it becomes everybody's business. Senior managers attend forum meetings so that they can feedback and take forward the views	townships which will be able to commission low level preventive services and activities, and will have a voice at township level to influence local neighbourhod plans. The process is supported through POPPs funding with a view to them becoming independent orgainisations after 2 years. They will link with the user/carer action forum which continues to have a borough wide brief re involvement and representation of older people's views.
10	A 'Joint Implementation Team' was established to implement the NSF. This included one or two older people. Sub-groups were established for each standard and all included older people (usually representatives from local forums or other voluntary and community groups). The JIT has now disbanded and been replaced by many new groups. For example, the	Involvement Team and a Development Worker who lead on all aspects of supporting involvement and engagement. There is a standing group of service users and carers who can be consulted on a wide range of issues and who can ask their own questions.	Older people's voices were felt to be used to good effect – involvement and engagement was characterised as <i>"honest dialogue"</i> . One specific outcome of involvement is the introduction of red trays on hospital wards to help staff identify those patients who may need assistance at meal times.	A key challenge is how to ensure good practice becomes system wide. It was felt that this is more about delivering person centred care, choice and

	Standard 1 Group on 'Rooting Out Age Discrimination' has been replaced by a 'Dignity in Care Group'. In the new structures, there is perhaps less emphasis on older people participating on high level groups, with more emphasis on staff going out into the community to work with older people in their own groups.	met principally through occasional workshops.		
11	The LIT was disbanded over 2 years ago and was replaced by an Older People's Steering Group. This structure is currently under review with moves to develop a 'Partnership Board'. There is currently one older person on the Steering Group.	There are many different consultation and involvement activities taking place at any one time with training and support provided accordingly. There is an Over 50s Forum and Age Concern has trained a team of older people in research methods. A large open consultation event is held every year. This also acts as network through which older people can be contacted in the intervening period to be asked for their views on specific topics.	Older people's voices are felt to be used to good effect. The opening of a One Stop Shop was cited as one outcome of involvement.	Key challenges are around the issue of how to be more representative and how to engage with a broad range of older people with different needs. Clarifying expectations was also thought to be important as to whether an activity was purely 'consultation' or would enable older people to have the opportunity to participate in 'decision making'.
12	The LIT is still continuing but no representative was forthcoming			

For further copies of this report or information about the Greater Manchester Older Peoples Reference Group

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