Public involvement – benefit or burden?

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‘...I want us to move to are more mutual NHS where partners have real involvement, representation and a voice that is heard...’ Nicola Sturgeon M.S.P. (The Scottish Government 2007)

Until about 10 years ago, I thought little about how healthcare was managed. At the back of my mind I had a vague feeling of comfort that it was there. That changed when, during a routine surgical procedure, I became what is now known as an ‘adverse event’. The same day the surgeon came to my bedside to apologise and told me how to make a formal complaint. He explained that he had taken the course of action that he did owing to severe waiting list pressures prevalent at that time. At the postoperative ‘check-up’ the next day, it appeared the procedure had been successful. Returning home and with time to reflect, I felt nothing was to be gained by making a formal complaint. However, I decided, somewhat naively, that waiting lists should not be too difficult to sort out and I would become involved.

This was the beginning of a 10-year journey. It has taken me from being a member of the public with a new interest in healthcare to being the non-executive chair of an organisation with a budget of circa £180 million. In addition to my current roles as a non-executive member of a Health Board, I am also a member of a programme board for a national approach to adverse events, Chair of a healthcare-associated infection (HAI) programme board and I am also involved in several university-based research projects focused mainly around preventing and reducing HAI. I have developed knowledge and understanding of how healthcare systems work, how HAI can be managed and the value that the public can add to the management of this agenda. I have gained a certificate in public involvement and satisfaction from feeling I have made a valued contribution to making healthcare more effective.

Although Public Involvement was in its infancy when I first started and not many opportunities existed, I took advantage of those that did, initially applying to be a member of my local Health Council. While I was a Council member a request came from the Government for lay people to join the working groups attached to a HAI Taskforce, a Government policy advisory group. I applied for, and was accepted to join the working group that was tasked with producing the ‘National Cleaning Specification’ for

healthcare premises. I would recommend any member of the public wanting to be involved in healthcare not to wait for opportunities that directly relates to their area of interest but to apply for any that come along as once you become involved your interest develops.

My work on the Cleaning Specification allowed me to gain a better understanding of the effects of poor hygiene. I was invited to attend infection control events, many of which were related to what could be considered highly complex infections. Early on I realised that the last thing I wanted to become was some sort of pseudo expert. I was, and always will be, a lay person in this field. I therefore developed a technique which allowed me to absorb enough information to understand the subject without trying to be anything other than a lay person. I have always found staff respect that position and will take time to ensure that I understand ‘enough’ and I am not shy to ask if I don’t! I would define ‘enough’ as the amount of knowledge that allowed me to play a full part without being led to pre-determined conclusions. Being empowered to know ‘enough’ was important to me as I felt this demonstrated that my views as a member of the public were respected. It also helped me contribute to the discussion. The group dynamic plays an important part in ensuring that the public member is confident to speak. I must have made many silly comments during my involvement, but the fact that none jump readily to mind illustrates how well the groups dealt with it at the time! When seeking a volunteer to contribute to a project, it is important, at the selection stage, to assess their confidence in speaking their mind.

When the National Cleaning Specification work was completed I was asked to join another national group developing the monitoring framework for the cleaning specification. I suggested, and this was had accepted, that a certain percentage of all cleanliness monitoring should have public representation. I helped set up the public involvement for this in two regions. One of these regions went on to win an innovations award and the part I played was recognised in the submission. This acknowledgement gave me great

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satisfaction. I was credited with translating national policy, knowledge of which I had gained at the Taskforce, into front line public involvement practice. This made everything I had done up to this point all seem worthwhile and of value.

Subsequently, I was asked to represent the local Health Council on my local Primary Care Trust, this enabled in me to gain a wider knowledge of healthcare management and its governance structures. It is important that any member of the public working in an organisation as a volunteer understands the structure of the organisation as this enables them to understand and value their own contribution. It is wrong to assume that the member of public will come armed with this knowledge.

I went on to chair the regional healthcare Public Partnership Forum and undertook the training for and was awarded a certificate in 'Investing in Public Representation'. This is a nationally recognised certificate for those participating in public involvement in healthcare. The training comprised a range of elements such as communication, advocacy and confrontation. These, and other aspects of the training, certainly gave me more confidence in voicing my thoughts, and in managing my relationships with health professionals.

Towards the end of 2006 I was asked by a national quality improvement organisation to chair a health technology project investigating the 'Clinical and Cost Effectiveness of Screening for Meticillin Resistant *Staphylococcus aureus* (MRSA)'. A member of the public was also invited to join the group. He had suffered serious harm as a result of an MRSA infection contracted during a hospital stay. I was struck by how pleased this person was to be invited to be part of the group and how he felt he was being listened to for the first time. This appeared to be an issue of culture within certain healthcare organisations. The gentleman in question had a lot to offer the healthcare system but felt he never had the opportunity. Every organisation or group has some people who are better communicators than others. It is essential that the initial contact person for the public partner has good communication skills. This in turn leads to a feeling of empathy which maximises the benefit of engaging with the public. To me, that is the essence of good public involvement.

In my role as chair of the public partnership forum I was fortunate to have a very able deputy who, prior to retirement, had held senior posts in healthcare. Coming from a background in the private sector and still operating my own business I sometimes found the bureaucratic processes hard to deal with and my deputy helped form our thoughts in a way that was acceptable to all. It is important that all people feel they have something to contribute to a public involvement group. Not just those with the loudest voice. The group should reflect society as far as possible. The role of the Chairperson is extremely important. They must ensure a fair hearing for all. It is important that public groups have

a lay chairperson. Often the drivers for action in healthcare are complex. If you work in the service and the budget is increasingly a main driver. It is essential that the public realise that change is not just about cutting service. Different models of delivery can lead to service improvement but only if the public are involved and subscribe to the change.

My appetite for public engagement did not diminish. I was accepted as a lay inspector with a national regulatory organisation responsible for inspecting healthcare environments. I found this work to be fascinating as it involved assessing healthcare organisations against the National HAI Standards which I had previously participated in developing, and it gave me a much greater understanding of the pressures Health Boards work under. It is essential that public participants know and understand the parameters of any project they are involved in. These parameters may be about scope, benefit or finance. The public should be involved in the selection of options not just at appraisal stage. In the Healthcare Environment Inspectorate, myself and other lay inspectors had their training needs recognised and addressed. For me, a strong feature of this work was the feeling of being valued as a team member. A sense of value is given by understanding how your contribution has been considered and accepted or rejected. In other words, taking time to explain the process and give appropriate feedback. This is heavily influenced by the culture of the involving agency, which in this case was very pro public involvement.

I had also been asked to join the National Patient Safety Advisory Group. This group was established to oversee the introduction of a national patient safety campaign based on tested methodologies pioneered by the Institute for Healthcare Improvement. I presume I was asked to join because of the Government's commitment to public involvement and the fact that I had a basic knowledge of the issues involved. I think the latter is important. It is tokenistic to involve a member of the public in a complex issue unless they have some prior knowledge or you are prepared to give adequate training prior to commencement of the project. I say this from experience as the Health Technology Assessment I had previously been involved in had a paucity of hard evidence to work with and involved a large degree of computer modelling. Before becoming too involved I had a session with an academic to ensure that I had a basic understanding of the process. Actions like these are essential if tokenism in public engagement is to be avoided:

'Involving the public in research can have a wide range of benefits: for the researchers, the universities, the public involved and society at large. It must, however, be real engagement with researchers working collaboratively with service users, carers and members of the public to improve current research, widely disseminate findings and identify the most important areas for future research.' (Personal communication; Professor Jacqui Reilly, Glasgow Caledonian University)

I have also been involved in three research projects. These have included public attitudes to MRSA screening, public attitudes to acceptability of ward closures during norovirus outbreaks, the role of the World Health Organization fifth moment in hand hygiene practice and my most current and the most challenging to date, the whole genome sequencing of the *Clostridium difficile* pathogen. This experience has shown me that the role of the public partner within a group is different to the other members and this must be recognised and allowed for. Most research and health professionals have a very structured thought processes which are essential for their day-to-day work. The advantage of the lay involvement is that they may pose questions so obvious that the professionals may not have thought of them! However, the lay person will normally only see the other group members at meetings or speak on a teleconference while the group members will be working together. This must be compensated for by ensuring that the whole group is regularly updated as the project moves forward. A lay person should never be engaged in a project whose complexity may result in them becoming disengaged. A staged approach should be used; selecting someone who has a basic knowledge of the issue, then identifying what, if any training needs the person may have, but without including training that makes them think like the professionals!

When I first became involved in public involvement, there was little recognition in large areas of healthcare that the public had anything to offer. This was compounded by the fact that many of the healthcare staff appointed as public involvement coordinators had little training or experience and therefore might not be familiar with best practice or legislative requirements. This could cause problems when they were challenged. The culture is totally different today. Most healthcare organisations now have knowledgeable staff who could point you towards a public partner should you require someone to assist in a project.

It is essential to recognise that there is a balance to be struck between being a mentally uncluttered, novice public partner and someone like myself who has acquired a fairly

broad spectrum of healthcare knowledge. For some projects, my extensive experience would make me an inappropriate choice as a public partner. However, both experienced and inexperienced partners have a valued part to play. There may be little benefit in involving a novice in a project that is highly complex from the outset as this may lead to them becoming disengaged. It is equally important to recognise that some projects require a public partner who has no previous exposure to 'the system' or has knowledge specific to a particular condition. Many projects can benefit from the involvement of different types of partner.

In 2010 I spoke at a Participation and Health event in Glasgow. Speakers from various countries outlined public engagement in their own country. The presentation which sticks most in my mind was that from Italy. The approach there appeared to be adversarial and founded on EU law, happily not a direction we are likely to follow. My hope is that the role of public participation continues to be fully recognised as an asset to healthcare and not a burden. Public involvement in healthcare has a two-fold benefit: the service takes account of the public view when planning services and the public get an understanding of service constraints, financial and otherwise. There are many healthcare organisations doing excellent work in this field but in common with many other areas of service delivery, more could be done to share good practice.

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