A Review of Avon and Wiltshire Mental Health Partnership NHS Trust’s Approach to Involvement

Report by

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April 2012
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Who NSUN are

The National Survivor User Network (NSUN) is an independent network of individuals and groups who have direct experience of mental health distress and/or using mental health services. NSUN was created to give survivors and users of mental health services a stronger voice in shaping mental health policy and services. It brings together individuals and groups across England to learn from each other, share good practice and together influence policy makers and service providers.

Users and survivors working for the Sainsbury Centre for Mental Health (SCMH)\(^1\) carried out a survey of other service users in 2001-02, which led to the production of the report *On Our Own Terms*\(^2\) in 2003. This set out the findings of the research into the service user/survivor movement, and made a number of recommendations for strengthening the movement. The overarching recommendation was to develop a national collaborative strategy with the aims of:

- Building the capacity of the movement to support and represent service users/survivors
- Strengthening and developing user involvement nationally and locally so that it can have a real impact on service provision
- Developing a new integrated prevention, self-management, recovery and inclusion focus for all mental health services and related social and employment services

In support of these aims, one of the specific recommendations was that the movement should be financially resourced and practically supported to build stronger local, regional and national networks.

The vision was taken over by a group of users/survivors with a national profile and in 2005, and a conference was held in 2006 to consult on taking proposals for a network forward. Following the conference, a group of participants formed a Network Planning Group to apply for funding to create and run a network.

A successful bid to Comic Relief and the Tudor Trust, secured funding of £¾ million over a five year period to develop the National Survivor User Network (NSUN) across England.

**NUNS’s Mission is:**

“To create a network which will engage and support the wide diversity of mental health service users and survivors across England in order to strengthen the user voice.”

**NSUN’s Aims are to:**

- “Facilitate active links between service user groups and individuals
- Build capacity for service user groups

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\(^1\) Now known as the Centre for Mental Health

• Broker and facilitate access to service users for purposes of influencing and informing policy-makers and planners.”³

**NSUN’s vision is:**
To bring mental health service users and survivors together to communicate, feel supported and have the power and the platform from which to have direct influence at a national level.

**NSUN’s Values are:**

“Solidarity – Equity – Integrity – Diversity
• Openness and transparency
• To support user/survivor organisations – not replace or supersede them
• To ensure that currently under-represented groups have a voice
• Equality and respect
• Valuing diversity
• To be of value to the user/survivor movement”⁴

For more information see:


Other contact details are on the cover of this report.

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Executive Summary

- This report is a review of Avon and Wiltshire Mental Health Partnership NHS Trust’s approach to Involvement and Engagement.

- It covers user involvement extensively and refers to involvement of carers and the wider community in part.

- It was commissioned by Howard Lawes, Deputy Director of Quality and Healthcare Governance, Avon and Wiltshire Mental Health Partnership NHS Trust, May 2011

- There are seven terms of reference for this work:
  1. An assessment of the Community Engagement and Involvement Strategy
  2. A review of the full range of involvement activity in the Trust over a six-month period beginning 1 July 2010
  3. A review of the processes whereby patient feedback and service user involvement contributes to service improvement and the improvement of the patient experience
  4. An assessment of the Trust’s approach in relation to current best practice and statutory requirements
  5. A review of communications and partnership arrangements with service user groups
  6. The provision of advice and recommendations to strengthen the Trust’s approach and practice to involvement and improving the patient experience
  7. A meeting with service user groups and the Trust to discuss the advice and recommendations.

- Involvement has a long history, and certain health bodies are required under section 242 of the NHS Act 2006 to involve services users in certain service planning, development and decisions.

- Involvement or participation is a multi-faceted concept, involving different techniques and skills, and is about people, power and citizenship. Done well, it should be of value to users, carers and services and many other stakeholders.

- Avon and Wiltshire Mental Health Partnership NHS Trust (AWP) is a significant provider of specialist mental health services to adults and older people across Avon and Wiltshire, and specialist services to a wider population.

- Involvement within the Trust is facilitated at a strategic level by the Engagement and Responsiveness Team and at an operational level in Strategic Business Units (SBUs) by having Service User Involvement Workers, and key operational staff with responsibility for it.

- This review was undertaken by interviewing AWP Trust staff, service users, carers, user groups, voluntary sector staff, and commissioners, and by utilising various methods to
analyse those comments made, and the written paperwork provided.

- The Community Engagement and Involvement Strategy, which is due for review in March 2012, is generally good and has served its purpose. It could be updated and renewed, or completely re-written to fit in with new ways of thinking and operating.

- The review of the full range of involvement activity in the Trust over a six-month period was undertaken using two methods, but yielded limited results.

- The review of patient feedback processes demonstrates the Trust does this in many ways. These processes vary in their success around involvement. This is from both a process and outcomes viewpoint.

- The Trust’s approach in relation to current best practice and statutory requirements is seen by many stakeholders in many lights. There is some good practice and areas were there can be improvements.

- The Trust’s communication with service user groups has a long history and is difficult in places. Partnership working needs to be developed much further.

- The Trust should strengthen its work with individual service users more. They should do this by working with service users and carers to co-produce an embedded care and treatment philosophy.

- There are four options the Trust can take with respect to involvement at an operational and strategic levels:
  1. Do nothing and carry on as you are
  2. Make minor changes as in the recommendations in the findings section
  3. Make moderate changes by having systems to carry on collating and improving on patient experience, but outsource other involvement activity to an external agency
  4. Make major changes by rethinking involvement and participation and adopt wholly a co-production culture and of ways of operating

- There are frameworks and new thinking that can help this process.
The purpose of this report

This report is the result of a Formative Review of Avon and Wiltshire Mental Health Partnership NHS Trust’s Approach to Involvement and Engagement. Its purpose therefore is to give an assessment of various aspects of the Trust’s involvement activities, compare these to what we understand happens elsewhere, and give some recommendations on how the Trust can improve its performance in this matter. Involvement or participation is not an end activity in itself, rather a means to an end. That end being improvement of service response and quality to better meet, in this case, the mental health needs of those people who utilise its services.

In deciding what specifically NSUN should focus on, the review includes seven areas to consider and this forms the terms of reference for this work.

Terms of Reference

Meetings took place between Sarah Yiannoullou, the Manager of NSUN, and Howard Lawes, Deputy Director of Quality and Healthcare Governance, and Alison Griffin, Head of Engagement and Responsiveness, Avon and Wiltshire Mental Health Partnership NHS Trust to agree the terms of reference for this work. This happened between March 2011 and May 2011. They are as follows:

3. A review of the processes whereby patient feedback and service user involvement contributes to service improvement and the improvement of the patient experience.
5. A review of communications and partnership arrangements with service user groups.
6. The provision of advice and recommendations to strengthen the Trust's approach and practice to involvement and improving the patient experience.
7. A meeting with service user groups and the Trust to discuss the advice and recommendations.

To make things clearer for the reader, the author has decided to use the first five terms of reference as headings for part of the report under the Findings section. The items which fall under the sixth term of reference can be found in the body of the report, highlighted for ease of reading and in the conclusions section. Item seven falls outside of the scope of this report, and will happen as a result of the report in an effort of take matters positively forward.

Current terminology and how it originated

It is useful to point out here that within this report various forms of terminology are used. The terms used are those readily utilised by the organisations contacted. Language is contextual, and so it was felt that a uniform use of certain terms to describe the different people featured within this report, whilst some might consider tidy, would actually be sanitising and therefore incorrect. What follows is a brief explanation of some of the terms used.
The NHS tends to refer to people who use their services as ‘patients’. This happens to a lesser extent nowadays, certainly in the field of mental health. Most people with infrequent contact with services would not object to being framed as such. For those people with a long term condition, some feel the term ‘patient’ is patronising, particularly as they are not a ‘passive recipient’ of care as the dictionary definition suggests⁵. For some, they see their health situation as something to be fought or managed regularly, it is indeed part of them, and therefore they are very assertive in their attitude towards it and the relationship with services they use.

The term ‘user’ or ‘survivor’ is common parlance in mental health circles. ‘User’ is sometimes confused with that of ‘drug user’, and therefore some people feel this is inappropriate as drug users are sometimes seen as bringing their own misfortune upon themselves. Others would not wish to demonise people who use substances as they see that people are human beings with complex and sometimes difficult lives, and drug use is as a consequence of this. Discriminating against drug users therefore doesn’t help those people any more than the discrimination meted out in society to people considered disabled or mad. Generally speaking, people who use services are seen as being more in control of the service they use, on a par with it, the same as using the services of a business.

‘Survivors’ are people who identify as such because their experiences are seen to have been so traumatic that they have survived them. Therefore we find cancer survivor is common, and within such circles, survivors of sexual abuse. Survivors in this context would be survivors of the psychiatric system, or indeed of their psychiatric condition, most usually the former. Survivors of the psychiatric system self define as such due to the damaging experiences they feel they have experienced at the hands of services. Psychiatric survivors can also be survivors of other abuse or trauma in their lives. Sometimes peoples’ experiences of psychiatric services are felt to have compounded previous traumas. This stance can be a little hard for staff in a caring profession to hear.

‘Involvement’ is also a term with its issues. Involvement can mean different things to different people as it includes a range of activities. For some, Involvement is purely about being actively involved in one’s own care. Sadly, involvement is most often not seen in this context, surely the most important involvement activity of all. Involvement can also be seen to be about involvement in group activities, whether managed therapy, self help, or purely social. Involvement is often thought about in terms of services and service improvement. This can range from committee activities, service inspection or evaluation, research of many types, training of staff and peers and consultancy in a range of areas. The examples are exhaustive.

Involvement is another word for taking part, though involvement is not always seen as quite so active as ‘participation’ which is the general word for getting actively involved, joining in and taking part. So some, organisations use the word participation instead. The Social Care institute for Excellence use participation for example and has done so since 2002.

Beyond this, another term is currently gaining currency in health and social care, that of ‘co-production’. The term co-production dates from the 1970s and has recently become a new way of describing working in partnership with people using services, carers, families and citizens. As a

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⁵ The Oxford Dictionary, Oxford University Press, 1988
relatively new term co-production is defined in a range of different ways. The Department of Health uses the following definition:

“Co-production is when you as an individual influence the support and services you receive, or when groups of people get together to influence the way that services are designed, commissioned and delivered.”

The difference between some participation and co-production is a shift from service users/carers being consulted to being equal partners and the co-creators of products and programmes.

Various national organisations are shifting their thinking and working practices along these lines. The Think Local Act Personal Partnership which the Social Care Institute for Excellence (SCIE) hosts uses Co-production to describe their engagement activity. Other organisations such as the New Economics Foundation (NEF) and National Endowment for Science, Technology and the Arts (NESTA) have substantial programmes of work branded as co-production. SCIE itself is now looking to work with users and carers in a more co-productive way in its work.

In the mental health user/survivor and wider disability movement there is a lot of debate about terminology to reference how much actual ‘power’ users feel they have in organisations. This debate and power struggle has given rise to organisations being ‘user led’ or ‘user controlled’. There are no universally accepted definitions, although many attempt such, for example by stating the majority percentage of users on the decision making bodies within those organisations. Organisations of disabled people feel they should hold some of the power and if not, the influence to control their own lives. It is a political statement. It says that people, who identify as such, should be the ones who have the final if not, total say in what happens to them in their lives. This is opposed to being institutionalised for life with little or no say in how things happen around them. Anything less than user controlled, can be seen as a dilution of their voice, rights, understandings and risk people with disability, including mental health conditions, being seen and treated in a welfarist manner rather than the civil libertarian approach that most would seek.

Acknowledgements
The Project Manager, Tina Coldham would like to acknowledge all those that took part in this review. People gave their time and expertise freely, in amongst busy days and lives. Service users and those carers that took part sometimes went out of their way to be helpful and make sure their points of view were registered and understood.

The Engagement and Responsiveness Team were extremely helpful in providing information and clarification when asked. This assured the smooth running of the project.

Particular thanks go to Teresa Bridges, Acting PA to Alison Griffin - Head of Engagement & Responsiveness, and Foundation Trust Membership Administrator. With cheerful resolve she managed to organise people and places with great efficiency and reception, and was always on hand to clear up adminstrivia.

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6 Practical Approaches to Co-production DH 2010
Involvement and why it has become so important

Service user, carer and wider community involvement has long been heralded as good practice to ensure that services for those user recipients are appropriate. This has not come out of thin air. There are many reasons for it happening.

The mental health user/survivor movement has arguably come about as a result of dissatisfaction by those users/survivors with services offered, or indeed forced upon them. The various civil rights movements have helped to influence and galvanise energy within the mental health user/survivor movement. People who identify as such feel they are sometimes treated lesser than other people and not given the respect, dignity and life chances as others in society. Users/survivors want understanding and appropriate treatment so they can get on with their lives as they feel appropriate. The rise of the movement has led to much activity around self management, alternative understandings from the dominant medical model, rights and citizen based projects and activities including campaigning, and has meant that a diverse amount of work has been done and showcased and is helping to forward understandings around the issues, and helping people lead the lives they wish. There is no room for complacency though and there is still much to be done.

User and carer involvement has also come about by people feeling grateful for the care that they or their loved ones have received, and they therefore want to give something back. They want to be a part of something that has made such a big difference to them and can do for others.

Sadly, there have been various national scandals within the NHS that have highlighted serious failings in care and service provision and communication with patients and their families/carers. This has heightened the desire to have a National Health Service that is more responsive to its customers and eradicate any future major service failings.

One such was the Bristol Royal Infirmary Inquiry covering the period 1984 to 1995, with the report published in July 2001. In the report there are many recommendations. Ten of the recommendations are found under the heading ‘Public Involvement through Empowerment.’ The first being “The involvement of the public in the NHS must be embedded in its structures: the perspectives of patients and of the public must be heard and taken into account wherever decisions affecting the provision of healthcare are made.”

Apart from a grass roots appeal for involvement and national response to tragedies, there have been seminal documents which clearly state that involvement is an ideal or indeed a right.

In the World Health Organisations document ‘Health for all by the year 2000’ published in 1978, they state that people:

“have a right and duty to participate individually and collectively in the planning and implementation of their health care.”

Closer to home in the NHS and Community Care Act 1990, it states that:

7 http://www.bristol-inquiry.org.uk/index.htm
9 http://www.searo.who.int/LinkFiles/Primary_and_Community_Health_Care_HFA_S3.pdf
10 http://www.legislation.gov.uk/ukpga/1990/19/contents
“the individual service user and normally, with his or her agreement, any carers, should be involved throughout the assessment and care management process. They should feel that the process is aimed at meeting their wishes”.

The term “Nothing about us without us” has long been used by the international disability movement as a watch word to sum up how people in the movement feel they should be treated when decisions are made about their lives. This phrase has been used enough in recent years close enough to government, for an arguably lesser version being stated as a principle by the coalition government in the UK. “No decisions about me, without me” first began being used in July 2010 when the Secretary of State for Health announced the white paper Equity and Excellence: Liberating the NHS.11 The fact that this principle has been adopted by central government is testimony to the influence and achievement in recent years of disability activists and campaigners, including those in mental health.

In February 2011 the government published a new “cross governmental mental health outcomes strategy for people of all ages”, called “No Health without Mental Health”.12 The approach is based on the principles that the Government has laid down for its health reforms:

“Putting people who use services at the heart of everything we do – ‘No decision about me without me’ is the governing principle. Care should be personalised to reflect people’s needs, not those of the professional or the system. People should have access to the information and support they need to exercise choice of provider and treatment;”

Involvement Legislation
In terms of legislation, there have been acts of parliament that have enshrined involvement and consultation of patients and the public in health and social care service provision.

The National Health Service Act 200613 consolidated then much of the legislation concerning the health service. Section 11 of the Health and Social Care Act 2001, the duty to involve and consult, became section 242 of the NHS Act 2006. Section 242 was amended by the Local Government and Public Involvement in Health Act 2007. The duty on English bodies to involve users can be found in section 242(1B) of the NHS Act 2006. Section 242(1B) of the NHS Act 2006 came into force on 3 November 2008.

Specifically Section 242(1B) of the Act states:

“Each relevant English body must make arrangements, as respects health services for which it is responsible, which secure that users of those services, whether directly or through representatives, are involved (whether by being consulted or provided with information, or in other ways) in:

a) The planning of the provision of those services,

11 http://www.dh.gov.uk/en/MediaCentre/Pressreleases/DH_117360
b) The development and consideration of proposals for changes in the way those services are provided, and
c) Decisions to be made by that body affecting the operation of those services.”

The term ‘relevant English body’ refers to strategic health authorities (SHAs); primary care trusts (PCTs); NHS trusts (which are not relevant Welsh bodies); and NHS foundation trusts.

Section 242(1F) provides that a person is a ‘user’ of any health services if they are someone who is using the services or someone who may use them. Users can be involved “directly or through representatives”. A person is a representative when they are representing the views and opinions of another person or a group of people.

Going back to Section 242(1B) of the Act, it requires that users “are involved (whether by being consulted or provided with information or in other ways)”. The guidance laid out in ‘Real Involvement – Working with people to improve health services”14 states that:

“A number of activities can constitute involvement. Think about proportionality and appropriateness, understand and use a spectrum of involvement, and know when to use the different activities which range from giving information through to active participation in planning the provision of services. It is important to understand what the most appropriate approaches could be at the various stages of the commissioning cycle.”

In defining when users should be involved in:

“a) the planning of the provision of those services,
b) the development and consideration of proposals for changes in the way services are provided, and
c) decisions to be made by that body affecting the operation of those services”

the guidance clearly states that:

“Under a), users must always be involved when the provision of health services is being planned. For example, this may follow a needs assessment or a strategic or service review. Planning the provision of services can take place at:

- strategic level, for example the reconfiguration of mental health services across an SHA or PCT area;
- service level, when plans are being developed for the configuration of a service or services, for example maternity services; or
- NHS trust or NHS foundation trust level, for example when planning to provide a service from a different site.

Under b) and c), users must only be involved if the implementation of the proposal or the decision, if made, ‘would have an impact on – a) the manner in which the services are delivered to users of those services, or b) the range of health services available to those users’.”

The guidance goes on further to explain that:

“Users must be involved not only in the consideration of proposals to change services, but also in the development of any proposal that will change the manner in which a health service is provided or the range of services offered. For example, users must be involved in the development of a range of options for the way community services could be provided within a PCT area, not just asked for their opinion on a model that has been developed behind closed doors by health professionals and managers.”

As mentioned above in quoting the guidance, there is a spectrum of involvement. There are any number of activities that can make involvement happen at the different levels. The skill is the “proportionality and appropriateness” employed in utilising the different methods at different times in involvement.

The levels of user or carer involvement in services can be expressed as on the diagram on the following page. This was built upon a ladder of citizen participation as published by Sherry R Arnstein in 1969\(^\text{15}\), and it refers to power structures in society and how they interact. Although old, argued over and updated, it is still a popular model to understand levels of participation.

**Eight rungs on the ladder of citizen participation**

![Ladder of Citizen Participation](http://lithgow-schmidt.dk/sherry-arnstein/ladder-of-citizen-participation.html)

The bottom rungs of the ladder describe levels of "non-participation" that have been contrived by some to substitute for genuine participation. Further up the ladder are levels of citizen power with increasing degrees of decision-making. At the topmost rungs, citizens obtain the majority of decision-making seats, or full managerial power. The following diagram fleshes out the levels.

\(^{15}\) [http://lithgow-schmidt.dk/sherry-arnstein/ladder-of-citizen-participation.html](http://lithgow-schmidt.dk/sherry-arnstein/ladder-of-citizen-participation.html)
Levels of User & Carer Involvement in Services\textsuperscript{16}

<table>
<thead>
<tr>
<th>Type of Involvement</th>
<th>Nature of involvement</th>
<th>Level of Involvement</th>
</tr>
</thead>
<tbody>
<tr>
<td>NO INVOLVEMENT</td>
<td>So called take-it-or-leave-it planning (from the perspective of users and carers).</td>
<td>Least</td>
</tr>
<tr>
<td>INFORMATION AND PUBLIC RELATIONS</td>
<td>Consumer education and marketing of services. Staff develop solutions.</td>
<td></td>
</tr>
<tr>
<td>CONSULTATION</td>
<td>Communication is essentially one way.</td>
<td></td>
</tr>
<tr>
<td>CONSULTATION AND AGENDA SETTING</td>
<td>Market research and limited two-way communication with users and carers. Staff develop options and consult users and carers, but they also make their own recommendations to professionals and service commissioners.</td>
<td></td>
</tr>
<tr>
<td>JOINT PLANNING PARTNERSHIP</td>
<td>Listening and responsive systems in which there is open and wide ranging consultation and users and carers are involved in the analysis of problems and in proposing and assessing options for their solution.</td>
<td></td>
</tr>
<tr>
<td>USER AND CARER CONTROL</td>
<td>Collaborative definition of problems including pooled information, combined decisions and conjoint working.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Total user and carer control, including budgeting, service planning and development, and day-to-day decisions</td>
<td></td>
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</tbody>
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\textsuperscript{16} Adapted from ‘Managing to Listen’ & ‘Voices in Partnership’ © Tina Coldham 2002
Involvement activities and participation can therefore be seen as a struggle for power, whether at individual level or strategic level within an organisation.

It is also about citizenship and ownership.

Putting aside any ideology or idealism, involvement or participation is also about an obligation on public services to involve their patients, potential users and users of services, and families and carers, for the good of the service and whole community.

There will be times when higher levels of involvement are necessary or more desirable than others. Considered thought at the beginning of any work with users and carers would help guide the process.

If there is a people-centered, responsive agenda it will make sure that the NHS is more locally accountable and shaped by the people who use it.

As stated in ‘Real Involvement – Working with people to improve health services’:

“Where involvement is undertaken as an integral part of the normal, everyday business of an NHS organisation, staff should be able to do their jobs better, and the organisation should:

- have a better understanding of the needs and priorities of the local community;
- make better decisions;
- design services that reflect the needs of users;
- provide services that are efficient, effective and more accessible; and
- experience less conflict and adverse media attention as there is an increase in user satisfaction.”

The guidance also goes on to say what is in it for users too:

“It will give users a better understanding of the issues faced by the NHS and of why their health services may need to change. They should have more:

- information about the health of their community and local health services;
- commitment to, and ownership of, the local NHS;
- trust and confidence in local health services;
- ownership of solutions;
- awareness of the complexities and constraints of healthcare planning;
- influence over how and where health services are provided; and
- health services that meet their needs and preferences. “

Therefore there are many good reasons for doing good involvement. It is not a fad; it is something which the UK government has stated as necessary for the reasons given above and many more. Therefore we should embrace this as an opportunity to work together to find solutions to issues, concerns and problems, for the betterment of all.
Background to AWP NHS Trust

Avon and Wiltshire Mental Health Partnership NHS Trust (AWP) is a significant provider of specialist mental health services to adults and older people in: Bath and North East Somerset (BANES), Bristol, North Somerset, South Gloucestershire, Wiltshire and Swindon. They also provide specialist drug and alcohol services and specialised and secure mental health services including prison mental health services, to people living across a wider area.

The Trust’s strategic objectives during the next five years are:

- To be the organisation of choice for service users, staff and commissioners alike, providing a comprehensive range of specialist Mental Health services in primary, secondary and tertiary care settings, across our existing geographical area
- Person-centred services that intervene early, are highly accessible, focused on recovery, are high quality and leading edge
- A financially sustainable Trust through robust financial management, use of innovative technologies, efficiency and increased productivity.

Corporate Structures

The Trust’s Executive Directorate is set out as the following:
Under the Operations Executive Directorate sits 5 Strategic Business Units:

![Diagram of strategic business units]

Each Strategic Business Unit obviously also relate to the other Trust Executive Directorates for support and guidance, and to supply relevant performance information to.
There is a Nursing, Compliance, Assurance and Standards Executive Directorate which ensures that frameworks and guidance are in place for the trust. Under the NCAS Executive Directorate sit many functions, including the Engagement and Responsiveness Team:

Alison Griffin is the Head of the Engagement and Responsiveness Team, and has been so called since 2008. Under her are Sally Wood, the PPI Manager, with responsibility for national and real time surveys, LINks liaison, readers panel and coordinating Voluntary services; Jo Davis PALS and Complaints Manager, and those respective teams under her; Carer Engagement Manager, Lu Duhig; FT Membership Manager Nicolette Vos; and the Clinical Lead for Carers Gina Smith.

The Involvement Team who were in the Engagement and Responsiveness Team moved to the Strategic Business Units as of 1st July 2011. Therefore Jessica Reeves is now Service User Involvement Worker for Specialised and Secure Services, and Paul Smith was Service User Involvement Worker for Liaison and Later Life People until he changed posts recently. However, they between them were attempting to cover the wider AWP Trust patch.

As well as the above, certain key staff in the field have the responsibility for involvement within their brief. These staff formed the bulk of those interviewed on behalf of the Trust. Please see the following section on methodology for a comprehensive list.
How we did this review and who was involved

This was a team effort. The Project Manager undertook the major part of the work assisted by NSUN staff with expertise in certain issues.

The following members of NSUN took part in the review

<table>
<thead>
<tr>
<th>Staff Name</th>
<th>Job Title</th>
<th>Input to review</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tina Coldham</td>
<td>AWP Review Project Manager</td>
<td>Project Management, interviews, focus groups, analysis and report writing</td>
</tr>
<tr>
<td>Sarah Yiannoullou</td>
<td>NSUN Manager</td>
<td>Project Startup, interviews, analysis and report editing</td>
</tr>
<tr>
<td>Fran Singer</td>
<td>Co-Coordinator NSUN: National Involvement Partnership</td>
<td>Analysis and report editing</td>
</tr>
<tr>
<td>Mulimba Namwenda</td>
<td>NSUN Administration and Finance Officer</td>
<td>Transcripts and office support</td>
</tr>
</tbody>
</table>

Advice was also taken from Dr Yvonne Anderson at Cernis Ltd regarding the grounded theory approach to the methodology employed for the review of involvement activity part of this work.

AWP Trust nominated certain members of staff who had responsibility for involvement in their job descriptions. They were interviewed. Also initially identified were key user, carer and community groups, trust forums, individual involved service users and carers and other external stakeholders. They were also interviewed as individuals or as groups, and certain forums attended to observe only.

NSUN drew up a comprehensive interview question schedule, but took a semi-structured approach to its use, preferring to go with the flow of the conversation, listening to what all stakeholders felt was important for them to say, and prompting around certain key issues where necessary. This way, main factors were covered and the semi-structured approach allowed for tailoring to the person interviewed, and for them to have their say in the time allotted.

The following list of AWP Trust staff were identified by the trust and interviewed by NSUN mostly as individuals or on two occasions in very small groups during the months of June to August 2011.

<table>
<thead>
<tr>
<th>Staff Name</th>
<th>Job Title</th>
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<tbody>
<tr>
<td>Adrian Bolster</td>
<td>Head of Facilities, and Acting Head of Estates and Facilities Management</td>
</tr>
<tr>
<td>Alison Griffin</td>
<td>Head of Engagement and Responsiveness</td>
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<tr>
<td>Andy Johnston</td>
<td>Clinical Director for Adult Acute Inpatients</td>
</tr>
<tr>
<td>Carol Bowes</td>
<td>Operational Services Manager - Specialised and Secure Services</td>
</tr>
<tr>
<td>Debbie Spaull</td>
<td>Head of Psychology - Liaison and Later Life</td>
</tr>
<tr>
<td>Denise Claydon</td>
<td>Service Director - Liaison and Later Life</td>
</tr>
<tr>
<td>Duncan Garner</td>
<td>Patient Advice and Liaison Service Officer</td>
</tr>
<tr>
<td>Fiona Davies</td>
<td>Service Director for Adult Community Services</td>
</tr>
</tbody>
</table>
Gerard Campbell | Modern Matron - Specialised and Secure Strategic Business Unit  
Gina Smith | Consultant Nurse for Family work for Psychosis/ Clinical Lead for Carers  
Hazel Watson | Executive Director of Nursing, Compliance, Assurance and Standards  
Howard Lawes | Deputy Director of Quality and Healthcare Governance  
Ian Dickinson | Clinical Director for Specialist Drug and Alcohol Services  
Jayne Hayes | Clinical Director for Specialised and Secure Services  
Jessica Reeves | Service User Involvement Worker - Specialised and Secure Services  
Kelly Higson | Equality and Diversity Advisor  
Laura McMurtrie | Chief Executive Officer  
Lindsey Scott | Executive Director of Operations (at time of interview)  
Liz Meakin-Ward | Patient Advice and Liaison Service Officer  
Lu Duhig | Carer Engagement Manager  
Malcolm Sinclair | Director of Service Re-design  
Paul Smith | Service User Involvement Worker - Liaison and Later Life (at time of interview)  
Now Voluntary Services Coordinator  
Paul Townsend | Service Manager - Specialist Drug and Alcohol Services  
Rosie Brandon | Patient Advice and Liaison Service Officer  

Other staff were contacted as they were put forward by colleagues, as well as being contacts for some user groups. These afforded limited results.

Peter Greensmith, a Non Executive Director of AWP Trust, with a special interest in user, carer and public involvement also agreed to supply his thoughts. He took part in two trust forums that NSUN observed at, and had information on his attempts to reach out to certain user groups around certain issues. This was fed in by email.

The Engagement and Responsiveness Team helpfully supplied NSUN with contact details they had for user groups from their central database. This was also updated by Paul Smith, Service User Involvement Worker - Liaison and Later Life. The database list included some 50 service user groups, whether they were campaigning or activist groups, self help or support groups, local branches of the big mental health provider charities, and community groups who whilst not mental health specific, welcomed and worked with people with mental health problems.

All these groups were contacted whether by email or by letter where no email address was present. A reminder email/letter was sent less than a month later, and phone calls were made where NSUN felt the group or individual might have missed the previous communications or it was felt they were a pivotal group to this review.
During the course of this process, NSUN discovered that some contact details were out of date as groups had closed and addresses were sparse or emails bounced back. The usefulness of the central database and involvement database are discussed further in the section on communications and partnerships.

Various members of staff nominated users or carers that they thought would have a useful contribution to make. These were followed up. Also, staff from external organisations identified people they knew who might be able to contribute. These were also followed up. Paul Smith, Service User Involvement Worker - Liaison and Later Life was helpful in identifying people to talk to throughout this process.

The following service user groups were visited face to face by NSUN and focus groups were held:

- Battle Against Tranquilisers
- Bristol Survivors Network
- Service User Network Swindon (SUNS)
- Weston Support Meeting (formally Recovery Action Group)
- Wiltshire & Swindon Users Network (WSUN)
- Patients Council – Bristol

A total of over 30 people were present during these meetings.

A meeting was set with the Service User Reference Group (SURG) in early November but NSUN was notified this was cancelled the same day and therefore it did not take place.

The following service user groups emailed comments:

- Bristol Hearing Voices Group
- Bristol Survivors Network
- Second Step User Forum

Other service users were interviewed on an individual basis, either face to face or over the phone or by email contact. The number of individual interviews with service users totalled 11.

Service User Network Swindon (SUNS) asked in advance the sort of questions we were going to ask. They turned this into a questionnaire and Lauren Moyes, their Support & Development Worker took this along and held focus groups with SUNS members. The total members involved were 35 out of 6 focus groups held. NSUN is very grateful for this effort.

The Project Manager attended the AWP Trust Carer Forum held on 20th July 2011 where individual carers and carer groups were represented across the Trust.

8 carer groups and carers who are engaged with AWP Trust were contacted by email or letter.

1 interview with a carer took place and another carer emailed detailed comments.

2 interviews took place with voluntary sector representatives, and a voluntary sector worker emailed further comments.
The numbers of users and carers that were able to take part in this review is small compared to those the Trust is in touch with. However, we were concentrating efforts towards those individuals that have a current involvement brief, and groups that are active and in touch with the Trust around involvement issues.

External staff members from other agencies were contacted who were highlighted as possibly having useful insight to feed into this process. This yielded limited results. Interviews were held with the following:

<table>
<thead>
<tr>
<th>Staff Name</th>
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<tbody>
<tr>
<td>Cathy Boulton</td>
<td>Assistant Director of Commissioning - NHS South Gloucestershire</td>
</tr>
<tr>
<td>Glenn Townsend</td>
<td>User Monitoring and Development Coordinator - Mental Health Commissioning</td>
</tr>
<tr>
<td></td>
<td>NHS Bristol</td>
</tr>
</tbody>
</table>

The Project Manager also attended and observed the AWP Trust Links Meeting held on 20th June 2011, and the Patient Experience, Environment and Partnership Management Group held on 12th July 2011. Observations at the three meetings attended afforded NSUN the chance to see the Trust in action with stakeholders and enable contact to be made with certain groups or individuals.

All interview and focus group notes were typed up and other information printed and stored. These were read and analysed for recurring themes, useful quotations and ideas and suggestions.

Other processes involved in the review were the critical examination of the Community Engagement and Involvement Strategy by the Project Manager and NSUN staff.

The review of the full range of involvement activity in the Trust over a six-month period was undertaken using two approaches. One approach was systematically analyzing the various paperwork and thus data for involvement and highlighting anything of note that fits with the emphasis brought forward in other parts of the report. The other employed was a process called a grounded theory (GT) approach. This entailed working through the documents systematically, with a mind that was open but not empty (a prerequisite of GT), extracting the concepts within the data and clustering them to build categories iteratively. This approach gave the author the ability to isolate the core meaning from information that had originated from what was reported in varied formats. Thus it was possible to drill down to the mechanics of how processes work, and highlight the key issues.17

The Trust supplied NSUN with 5 Large A4 ring binders of evidence covering the period of 1st July 2010 to 31st December 2010 and also information either side of those dates. This was for the review of the full range of involvement activity in the Trust over a six-month period. Minutes of meetings

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Qualitative analysis for social scientists, Cambridge University Press, A Strauss, 1987
Basics of grounded theory analysis by B Glaser, Sociology Press, 1992
and reports were useful in showing levels of activity, but did not necessarily provide evidence of the quality or impact of the involvement.

This also helped to feed into the review of the processes whereby patient feedback and service user involvement contributes to service improvement and the improvement of the patient experience. Most of this information came through from the transcripts of interviews and from meeting observations.

In making an assessment of the Trust’s approach in relation to current best practice and statutory requirements all the evidence presented either in written form by the trust or from interviews or opinions offered was used to make the judgment on which this section is based.

The review of communications and partnership arrangements was based on the interview data, observations of forums attended, the information the trust provided as policies etc as against national practice and NSUN’s experience and knowledge of involvement.
Findings of this review - issues and concerns

What follows are chapters using the terms of reference for headings as a guide with themes brought out and discussed.

The information sought and provided was mainly from a user perspective although carers and voluntary sector views were also sought and welcomed. The main emphasis of this review is on user involvement as most disquiet about involvement has come from this quarter. However, it is useful to have carer and voluntary sector input to compare, contrast or indeed back up user views made.

The following symbols have been used during the Findings section of this report to highlight issues as the following:

- **Good practice**
- **Bad practice**
- **Good idea**
- **Recommendation on an issue**

Assessment of the Community Engagement and Involvement Strategy

Background

The Community Engagement and Involvement Strategy runs from 2009 to 2012. The version seen by NSUN was number 5.0 which was ratified by the AWP Trust Board on 25th March 2009. The authors of the strategy being Alison Griffin – then Assistant Director of Engagement and Responsiveness, and Jane Britton – then Deputy Director Integrated Governance with special responsibilities for patient and public involvement. The strategy came through the PEEP Integrated Governance Forum – 27th February 2009 and the Integrated Governance Committee – 3rd March 2009. It is due for review in March 2012, but is obviously being reviewed here as part of this process.

A strategy refers to a plan of action intended to achieve a particular goal or goals.\(^\text{18}\) Whilst its origins are military, it is common parlance in business and a useful tool to aid any organisation, large or small in defining what it wants to achieve.\(^\text{19}\)

The fact that AWP Trust has a strategy for engagement and involvement underpins the importance of such activity within a health service that has the vision to “enable and empower people to reach their potential and live fulfilling lives”.

Findings

The following comments address parts of the strategy from the beginning using the numbering system for ease of reference to the document itself.


It is understood that the title for the strategy was wanted by stakeholders who took part in the work to develop it. The strap line to the strategy is “Reaching out to involve people in our business”. When shown to some users, one of them balked at the idea that health service provision is ‘business’, and felt that this was indicative of a less than caring attitude being displayed by a health organisation. NSUN staff also felt that that use of the phrase ‘core business’ at part 3.1 is a hard statement, and that other things can be improved from the patient perspective like relations, experience, the patient journey.

In ‘3.2 Process of developing the strategy’, it acknowledges the partnership with stakeholders (including users and carers) had taken place previous to completing it, and lists the involvement activities. It is unfortunate however, that there is no acknowledgement of participant groups and also no comments from those who participated in drawing up the strategy. This would have afforded the opportunity to set the document as a shared one with those it is meant to relate to. It is understood that users, carers and also PPI Forums and latterly LiNks members contributed.

The Trust undertook a “You Said, We Did” exercise on the draft version of the strategy from January to March 2009. Feedback was sought on the draft and collated to show themes identified in the feedback received, the Trust response, and showing what changes were made to the strategy as a result and why.

At the last bullet point at 3.2, the team found this a slightly odd way of referring to equality and diversity – using it as an adjective for a group rather than for a policy or an agenda. There was a feeling that there is a ‘them and us’ way of phrasing throughout the document. Use of brackets to name groups emphasizes this. One could use the phrase “marginalized groups/communities”.

In ‘3.3 Aim of the strategy’ it clearly articulates a willingness to involve external parties in the development and delivery of AWP services, and that they would have a greater say of them. In qualifying this one of the statements is that AWP will “deliver service and quality improvement as a result of service user and carer feedback”. This of course is one method, but is low on the involvement scale. A stronger approach would be to work in partnership or co-production with users, carers and voluntary sector groups.

3.4 stated the development of a social inclusion strategy. From the strategy action plan though, this action point was not met as this action was “devolved into mainstream activity in 2009”.

In ‘3.5 Our Vision, Values and Standards’, the Trust values include “listening”. Whilst this is commendable in itself, listening is just one part of the equation. Really hearing and acting upon what is said would be seen as a more powerful value commitment. See 3.6 below.

Following on from this there is the statement that “We hold NHS values that guide behaviours that are expected from all service users, public and staff”. Whilst this may be true, it can feel a bit punitive to have this statement in qualifying the vision and values when it comes to service users. Of course we all want to see people behave in an acceptable manner, but mental health services are there to take care of people when sometimes they are not behaving as they normally would in the wider world. Also, with involvement you want to encourage this, and be understanding around people’s needs. This statement just feels a bit controlling, excluding, and off putting placed here.
In part ‘3.6 Our values underpinning Community Engagement and Involvement’, the values expressed are far more participative and supporting. These are good watch words by which AWP Trust could judge itself in its successes in involvement as it goes along; a friendly look over the shoulder.

**How the Trust is defining involvement**

Part ‘3.7 Our Standards in Community Engagement and Involvement’; there is a programme of work listed. This forms some of ‘how’ the strategy will be implemented. Three specifically refer to Foundation Trust status. One is around targeted work with people from Black and Minority Ethnic communities and children and young people. NSUN was made aware of work that was in and around the latter, but not the former. For help, NSUN in collaboration with Catch-a-Fiya a BME network have recently updated a report on the current under-representation of BME communities in user involvement, and what could be done to rectify this.\(^\text{20}\)

Also, there is reference to involving users and carers in research and development programmes. This is good as user involvement in mental health research is very well developed nationally. NSUN was not made aware of any activity that AWP Trust was carrying out in this area though.

In part ‘3.8 Our principles underpinning Community Engagement and Involvement’ there is a useful statement that the trust “will be clear that the final decisions rest with the Trust and its Board and where it is not possible to make the decisions that people have asked for, we will aim to explain our reasons and rationale.” This is important so that people can understand the limits of their influence and decision making powers. Although the tenor of the statement suggests that there is no local autonomy over any decision, which can’t be true, and does read a little off putting to involvement in the way it is phrased and being placed here.

Further down the principles acknowledge that Foundation Trust members who get involved in Trust activity are an addition to existing involvement activities within the Trust, and indeed that this will complement it. It is important that FT status and the involvement opportunities that brings doesn’t preclude all other activities.

In ‘4.1 Our definition of community engagement and involvement’, the bar is not set very high. It refers to people being able to ‘inform and influence’ action and decisions in their own care and wider. Informing or influencing remain low on the involvement scale and overlooks other methods and power sharing ways of participation e.g. partnership working, shared agenda setting, joint planning and devolved decision making.

Again the definition is further qualified by the remark that “This is not the same as making decisions which remains the responsibility of the Trust and is responsible and accountable for its actions.” Of course the Trust is ultimately responsible and accountable for its actions, but to say so here undermines the positivity around involvement which in itself could be made much stronger. In effect you are saying that we invite people to have some input into things, but hands off as we have the ultimate trump card. This could be better expressed away from the definition in a much more subtle but clear form. Alternatively it could be kept there and qualified by stating that “This is not the same as making *strategic, operational or financial* decisions which remains…”

In attempting to define “service user involvement” on page 14, again the qualification of involvement is set at a low standard around people informing or influencing (see levels of involvement). It also omits to acknowledge that service user involvement can happen at the individual level in a person being involved in their own care and treatment, which is fundamental. Service user involvement can also take the form of advice and recommendations, acknowledging their expertise.

On page 15 in “A community or voluntary organisation is” section, you could further qualify that there are many ways to set up community or not-for-profit organisations: types include non-charitable companies limited by guarantee, community interest companies (CIC)s, credit unions, housing associations, social enterprises, co-operatives, development trusts, charities and their trading arms, and Industrial and Provident Societies. This would show an appreciation of the complex landscape in the non-statutory sector.

**How to better engage unconstituted groups**

Further down, the text acknowledges that unconstituted user groups exist. For example, self help or support groups that exist as part of a voluntary group’s service provision. They might have a code of conduct for themselves, but are run informally for the immediate benefit of members themselves. Other groups might be social activity groups, user led groups taking a therapeutic approach forward, and various art groups. The list is not exhaustive. However, it is not for the Trust to insist that they have “appropriate accountability structures”, or that they have “mandated representatives and advocates”. In ‘Real Involvement – Working with people to improve health services’, it acknowledges that “users may be involved directly or by representatives”. The Trust should be prepared to listen to the collective perspective of small groups where they have opinions to voice on issues that affect Trust activity. It is important to respect the individuality and autonomy of different user groups.

**How representation at meetings work**

This subject is also repeated on page 18. Pure representation at meetings is a thorny issue and might be an inappropriate way of accessing views from user groups. When professionals attend trust meetings, do they always have a mandate to speak on behalf of their peers? It has been noted that when a service user taking part in consultation exercises with agencies is challenged as not representative this is experienced as undermining and used to block what a person is saying. ‘People have said to us “When we agree with them, we are representatives. When we don’t they say we aren’t” ‘(Croft and Beresford 1993, P28)21. Further, “Self advocacy and democratic representation are connected but they are not identical. Playing them off against each other should be recognised for what it is: a strategy for inaction”. 22 It might be more useful for the Trust to understand the type of group involved and whether the person present is bringing their own views only, a variety of members’ views, or whether there is an overwhelming agreement on a subject from that group.

Further down that page, the Trust “endorses and supports the role of campaigning groups and individuals...”

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21 Taken from Service User involvement – Synthesis of findings and experience in the field of community care, by Vivien Lindow and Jenny Morris, JRF 1995
22 Power to the people – The key to responsive services in health & social care, edited by Liz Winn, Kings Fund 1990
Sharing of power
In part ‘4.3 Benefits from Community Engagement and Involvement’ there is an acknowledgement that there can be a sharing of power and responsibility with AWP, by working with people. This is the first real powerful statement that involvement can happen at a higher level, which is good.

In ‘4.5 Methods of Community Engagement and Involvement’ there is an attempt to qualify involvement and state that it is not easy and there are different processes. Still however, the concentration in the text is overwhelmingly around receiving or providing information, consultation and informing trust decision making. On page 22-23 there is a hierarchy of involvement within the Trust which stops short in terms of what is seen as maximum power as expressed in Arnstein’s ladder of citizen participation or the levels of involvement presented above. Also, some of the examples given, depending on how they operate could be placed in different areas on the involvement scale. The issue is how much choice and control users have over the process/project.

On page 24 onwards there are explanations of involvement again. This time in ‘5.2 Involving individuals’, there is an acknowledgement that service user focused care planning, under the framework of the Care Programme Approach is “fundamental good practice”.

Under item C) in the same section there is a paragraph that the Trust will develop a Trust wide service user forum, covering the six local authority areas. NSUN is unaware of whether this has come to fruition.

In 5.1, paragraph 4 there is mention of “many notable examples of success” with regard to involvement activities. A small case study box would have been nice here.

Throughout the strategy there are references to Local Involvement Networks (LINks) and the Health Overview and Scrutiny Committees (HOSC) and their respective roles in monitoring services, or significant or substantial service change.

On page 31, at part 6.2 the ‘Involvement Database’ is discussed. The intention is that involvement opportunities “are met equitably for individuals”, and that the Trust can engage with a “wider range of individuals and monitor individuals training needs and support”. It is also intended to be a monitoring tool for the Trust. On the face of it, this seems a useful tool. The running of the database will be discussed further down in the report as this was an issue that service users brought up regularly.

In ‘6.3, Involvement Portfolios’ are mentioned. They are an example of good practice seen nationally in health and voluntary sector user settings, particularly for service users who have limited education and/or work experience. A portfolio can help create evidence of skills and experiences that are useful in building a user’s confidence and proving to others that they have necessary qualities to enable them to move on in life, e.g. mainstream employment. NSUN saw little evidence that the Involvement Portfolios were being used though.

Under part 6.5 regarding user and carer involvement in staff recruitment; mention is made of recruitment guidance. Again there is a warning that if those involved fail to follow Trust procedures, they will ‘forfeit their opportunity to be on that and future recruitment panels’. Obviously the Trust has to follow good employment practice, many issues that are enshrined in legislation around
openness or confidentiality, fairness and equal opportunities. It is indeed a minefield for employers. Service users and carers should be encouraged to understand these by receiving appropriate training around key issues and Trust processes to safeguard the Trust and ensure proper process for candidates for jobs. However, would we threaten a member of staff in such a manner before they are involved, or have this hanging over them as an occasional recruitment panel member? Usually a human resources expert is on hand to ensure proper process is observed by all.

In section 7, ‘Roles and responsibilities’, there is a part on the Trust Board responsibilities around the strategy. It might be more helpful to also include a section on how the governance of the strategy takes place, i.e. the process through which committees and how users and carers are to be involved in this.

In ‘7.2 Executive Management Team’; there is mention of the action plan for the delivery of the strategy being reviewed annually. Again, it might be helpful to explain more fully how this happens and if a 360°C reflection by users or carers is a method that could be employed to gauge success.

In part 7.4 under ‘Strategic Business Units’, the last bullet point mentioned that each SBU would identify a ‘champion’ for this area of work. This is the first time the role of Champion is mentioned in the strategy. It seems an important role that should be explained more fully in what this entails, and how this helps fulfill the strategy and is not just a tokenistic title tacked onto someone’s job description. However, during the course of interviews with AWP staff it became apparent that staff in SBU’s had taken on the responsibility for involvement in their remit. It would be better to explain here the role more fully, to give it credence with staff and external stakeholders, and also those ‘champions’, especially as they are expected to deliver and also review the strategy – see previous comments on reviewing of the strategy above.

Under ‘7.5 Engagement and Responsiveness Team’, it lists various responsibilities, one being to “develop and sustain an ongoing communications strategy about the Community Engagement and Involvement Strategy and its related action plan. This is also mentioned more specifically at ‘8.2 Communicating our approach’. NSUN was not aware of an ongoing communications strategy and comments from users and carers were variable about the existence of the Community Engagement and Involvement Strategy, see in sections below. There is a separate Community Engagement and Involvement Strategy Action Plan which does show progress on various issues.

Under ‘8 Monitoring and Review’, there is a statement that the strategy will be reviewed and what it includes. Again it is not specific how this might happen, although there is the existence of the Action Plan as stated above. You sometimes need to join the dots for readers outside of the Trust.

In ‘8.2 communicating our approach’, it lists how there will be a dedicated communication strategy. Apart from Trust newsletters, and non specific ‘networking, outreach and workshop events’ it doesn’t mention how the Trust intends to keep in touch with users and carers, user and carers groups, and wider community groups. This is a serious oversight. Effort should be made to keep in touch with the main stakeholders other than staff, and that there is a systemic approach to this. See below in the section ‘A review of communications and partnership arrangements with service user groups’ for further comments.
The References and Links section is most useful, as indeed is the list of abbreviations explained, as well as the jargon used in the report.

**General commentary**

Overall, the strategy is generally good and serves its purpose within the context of what takes place within the Trust now. The structure of the strategy was a bit repetitive in places and therefore possibly too long. It could be re-written and simplified, or for now just tweaked in places. However, see below.

The NSUN team felt that a map of the involvement process might help understanding in the strategy. However, during the course of this work a report to the Trust Board from the Head of Engagement and Responsiveness was made, showing ‘the process in place for acting and responding to patient experience data including individual and collective feedback.’ The accompanying flowcharts demonstrate the complexity of the processes with regards to the Trust organisational structure.

Indeed the team felt that whilst the strategy was about the ‘what’ there needed to be more about the ‘how’ running throughout, especially around governance, terms & conditions, process of recruitment. There are mentions of wanting to “employ a diverse range of methods to support involvement and engagement”. But these were not clarified in the report. There could have been a much more positive focus in some of the working, i.e. ‘who we involve’, in preference to “who do we want to involve” as at 4.2.

There could have been an explicit statement about what the Engagement and Responsiveness Team’s role is in helping to deliver the strategy, and where this stops and other staff responsibilities lay.

There are typos present in the strategy which should not be present. For example on page 14 bullet point 1 has a repeated sentence, “It is recognised that people may wish …” On page 18, the second paragraph has the word ‘create’ twice in the sentence. On page 19, there is a phrase which is more or less repeated from the opening phrase above (paragraph 3 and bullet point 7). In other places there are double full stops or tiny typos, which are unfortunate in a final strategy document signed off at board level. There is a grammatical issue when referring to BME groups at 3.1 and 4.2m, which can be read as separating them out and belonging to a different dimension than ‘local people’ - It just needed one more final proof read.

Whilst the author is sure that this is not intended, there comes through in places in the strategy a threat to users and carers if they do not behave in the way that the Trust expects. This could be off-putting and seen as demeaning by creating a childlike aspect to the relationship between the Trust and any user/carers involved. That language doesn’t have a place in the strategy, and should be rephrased and kept in operational guidance, or at least if the Trust feel it needs to be there, it is kept to a minimal mention in a general section. It should be phrased in such a way that there is enabling practice around involvement, however, transgressions from acceptable practice will be examined and action taken.

As mentioned in several places in this part of the report, the bar for involvement seems to be indicated at a low level around consultation, informing and influencing. Service users and carers
have said nationally that they want more choice and control over the services they use, and this too came out in discussion with AWP users interviewed. Consideration should be given to a fundamental shift in the understanding of what involvement actually means, and how this can take place. There should be more of a power shift to users/carers working in partnership, setting agendas, controlling aspects of projects or actual projects. NSUN is aware that AWP Trust does commission user led groups to provide services or consultancy already. No mention of this aspect is made in the strategy, which is an oversight to not list user controlled projects that are enabled by the Trust.

Indeed, leadership by users or carers is not mentioned at all. There are references to people taking personal responsibility in Trust documents, but developing leadership in some so they can inspire leadership in others, which is what can be found in user led groups, is a powerful force for change, in the individual and in the culture of an organisation.

Opportunities
There are opportunities for the future. Firstly, Foundation Trust status and the engagement with community members as governors and the membership, affords a new model by which AWP Trust can involve people in its governance structures in different ways. This is featured in the strategy and members and governors may be able to expand on what the strategy could look like in the future of a Foundation Trust.

Secondly, the Trust needs to keep an eye on the new health and social care structures being set up, for example Health and Wellbeing Boards and Clinical Commissioning Groups. At the time of writing the Health and Social Care Bill is still going through parliament. However, if it succeeds, there will be new mechanisms for assessing local needs and plans to address these through commissioning. The landscape will change considerably, and any provider will need to be on their toes. Also, opportunities for involvement of users and carers on these, or to these new groups will mean that providers will need to ensure that they engage appropriately with representatives who are being invited to take part in other forums which they might see as more influential from their perspective.

If the Trust does mean to “enable and empower people to reach their potential and live fulfilling lives”, as is said in its corporate vision, and work towards one of its objectives of “Person-centred services that intervene early, are highly accessible, focused on recovery, are high quality and leading edge”, there is now an opportunity to refocus its efforts with regards to involvement and participation, particularly as it endeavors to become a Foundation Trust, and this strategy is coming to its review date.

The Trust could sit down with users and carers and explore again what is meant by involvement, participation. What would this look like within a person’s own care and treatment as values and principles that can be adopted across the Trust? What does this look like on a ward, centre, venue, service basis; also across operations? What would involvement/participation look like in terms of strategic governance?

In interviewing staff from AWP, there is a strong commitment to involvement. Not all staff have the understanding of all the issues and are somewhat new to the concept. However, there are staff who are extremely knowledgeable, fiercely keen to deliver on this agenda, and could act as catalyst for
taking this work forward with users and carers, to explore the possibilities with the common aim to make services more person-centred, recovery focused (as defined by users), and create a trust which is empowering for its staff as well as its users. This might seem somewhat idealistic or even delusional! However, to quote the American poet Carl Sandburg, “nothing happens unless first we dream”.

There is a clear steer from the Department of Health that the notion of ‘co-production’ is a way ahead. Indeed in her interview, the AWP Trust CEO Laura McMurtie said that she wanted involvement as “cutting edge – the best”, also to “paint the future”, and talked of co-production as a way forward.

The Department of Health definition of co-production is around ‘influencing’ which as stated above in several places as rather weak if it’s just about informing people and consultations only. In fact co-production has also been refined as co-creation and parallel production.23 Really effective influence can happen as a result of more power sharing, power delegating and enabling, and better leadership from users and carers. Part of this would be them understanding that there are parts of the Trust’s responsibilities and accountabilities that are not immediately up for grabs. However, there is a majority that can be worked on in a co-productive manner around individual care and treatment, operational matters and strategic thinking and governance.

The Trust has two options:

A. To update the current Community Engagement and Involvement Strategy with what is said above, to be reviewed at the end of 2012.

Or

B. To completely rethink what the Trust wants to achieve from involvement from an individual, operational and strategic level, and co-write a new strategy with users and carers to include current thinking around co-production as a way of operating.

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23 Co-production: an emerging evidence base for adult social care transformation. SCIE research briefing March 2009
A review of the full range of involvement activity in the Trust over a six-month period

The review of the full range of involvement activity in the Trust over a six-month period was undertaken using two approaches. One approach was just systematically analyzing the various paperwork and thus data for involvement and highlighting anything of note that fits with the emphasis brought forward in other parts of the report. The other employed was a process called a grounded theory (GT) approach. This entailed working through the documents systematically, with a mind that was open but not empty (a prerequisite of GT), extracting the concepts within the data and clustering them to build categories iteratively. This approach gave the author the ability to isolate the core meaning from information that had originated from what was reported in varied formats. Thus it was possible to drill down to the mechanics of how processes work, and highlight the key issues.

The Trust supplied NSUN with 5 large ring binders of various meetings and groups that took place during 2010 to early 2011 in some places.

The terms of reference were to consider the activities of meetings/groups for a 6 month period starting 1st July 2010 and therefore ending 31st December 2010. Anything outside of this time frame was therefore discarded for the purpose of this exercise. Non-specific emails recounting user or carer involvement without detail or dates was of little use and therefore ignored.

The following areas were extrapolated from the paperwork with accompanying commentary:

**Liaison and Later Life SBU**
Various meetings, for example Patients meetings, PEAT minutes and action planning, adverts for carers events including those attended by the Trust as presenters, and in-patient benchmark meetings.

**Specialised and Secure SBU**
Community meetings, service user steering group minutes, CQUIN Action Plans and ideas, PEAT minutes and action planning, Pathfinder Service User Questionnaires. There are some precise follow up from previous meetings with updates on issues which is good.

**Adults of Working Age SBU**
Papers relating to SURG issues (these are detailed elsewhere in the report).

**Acute Care Forum**
Having a member of staff and also a service user co-chair the Trust wide acute care forum is good practice. NSUN is aware though that this did break down and was the subject of a separate report.

One thing of note is that the list of apologies is larger than the list of attendees for the first meeting.

Not all the papers were present to be able to form a judgment.
**Hillview Acute Care Forum**
This has good representation from the voluntary sector but lots of apologies. Is the meeting viable then? Also some people are named as Service User Involvement Workers when they are not. There is evidence of user ideas for service improvements being developed.

**PEAT Plan minutes for Hillview lodge.**
There were more apologies than attendees at times.

**Callington Road Hospital Acute Care Forum.**
Lots of user or carer focused items in the minutes including an advert for a carer’s art therapy group. This meeting was being co-chaired by a service user.

**Swindon Acute Care Forum.**
A user is the Chair for this meeting, and Service User Network Swindon (SUNS) have a regular place on the agenda.

There is variable quality in minute taking which meant that some people were not identifiable as staff or users or carers etc.

There is lots of anecdotal evidence of user involvement but nothing to evidence this or the quality of it.

**Patient Experience, Environment and Partnership Management Group**
This consisted of agendas and minutes with accompanying papers; Survey Project Group; Complaints, Praise and PALS Annual Report 09/10; Strategic framework for improving the Patient Experience 2011-2013; Complaints, Compliments, Concerns and Comments Policy and Procedures; PALS engagement dates

**Integrated Patient Experience Report - Complaints, PALS, and Praise**
Reports were very thorough with breakdowns per SBU and themes.

General observation - for the 2nd quarter report – July to September 2010, there were 57 formal complaints and some carry over from the previous quarter. In looking at the formal complaint outcomes for quarter 2 that totaled 86, 31 were unsubstantiated and 23 were unresolved. 15 complaints were re-opened in quarter 2.

For the 3rd quarter report – October to December 2010, there were 67 formal complaints and again some carry over from the previous quarter. For the outcomes there were 67 outcomes 35 unsubstantiated and 9 unresolved. 16 complaints were re-opened in quarter 3.

**Complaints, Praise and PALS Annual Report 09/10**
Out of a total of 252 formal and informal complaints, all dealt with in the given timescale, 68 were on the issue of 'communication', and 60 listed as 'behaviour/attitude – nursing staff', noticeably higher than any other type of complaint. 53 complaints were received by the Ombudsman. A fifth of complainants felt strongly enough to take their case further. This is interesting as one of the principle values in the Strategic framework for improving the Patient Experience 2011-2013 is 'listening'.
Strategic framework for improving the Patient Experience 2011-2013

This sets out to describe the Trust’s approach to improving patient experience, informing business planning, and indicating how the effectiveness of this approach will be assessed.

At the end in 5.4 'How we will know it’s made a difference', there are statements containing the words 'may' and 'might mean' with no indication of actual measurement. Item 5.4.2 says “The individual – involvement of service users and carers in discussions and decisions concerning their own individual care and treatment. It is closely linked to the overall care experience for individual services users and carers.” What does this actually mean in the Trust knowing it’s made a difference? Implementation of CPA and auditing of CPA might be an indicator here.

The author felt it was worth a more detailed approach to the analysis of the paperwork in relation to the Foundation Trust, and Service Redesign work. This was due to the fact that these are specific areas of activity, and they were early on in their development. Also, the quality of the recording and evidence was good.

In applying the Grounded Theory (GT) approach the following themes emerged.

1. **Statements of intent** by the Trust E.G. Policies on Involvement. Or to put it simply, 'What does AWP Trust say it will do?'

2. **Implementing the intent** or, 'What does AWP Trust actually do?'

   This through working with the theory through the paperwork was split into four further areas:
   - Proactive and inclusive practice
   - Less inclusive practice
   - Seeking feedback and testing
   - Evidence of real action

3. How/to what extent do 1&2 above have contributed to: Or, 'What difference does it make?'
   - Service Improvement – good or bad
   - Patient Experience

**Foundation Trust**

For the **statements of intent**, there were four examples of evidence appertaining to user involvement – Membership plan; Agreement over number of user and carer governors on the FT Board; Members’ update mentioning service redesign; and a repeat of the intention to have a certain number of user and carer governors on the FT Board.

Under the heading of **practice and inclusive practice**, there were also four solid examples – 131 separate FT recruitment events/days listed; Swindon Pride questionnaire results; Challenge to engage with people in rural areas in FT recruitment paperwork; Celebrating carers event leaflet.
There was one example under the heading of *seeking feedback/testing* – Quality Accounts Questionnaire.

There was one occasion of *evidence of real action* – Hearing stories from users and carers and staff about recovery for the Governors Induction Programme.

There was also an isolated item which doesn’t fit neatly under the headings above and that was the leaflet promoting mental health awareness goods that are available to FT members as a thank you for signing up other members. This is an example of proactive anti-stigma campaigning which would enhance relationships with users and carers.

**Service Redesign**

There were two examples of *less inclusive practice* – In a care packages steering group meeting, a service user at the end of the meeting asking for clarity and information on the subjects being discussed, i.e. the production of a glossary of terms. It can be read into this, that the service user felt excluded from the full discussion in the meeting due to not understanding the technical language being used. The following meeting had apologies from two service users and no issues being brought from this group due to this. One wonders whether this group had already ‘lost’ service user involvement due to the negative experience of the previous meeting.

There were nine examples of *evidence of real action* – A log of 15 meetings for service user and carer involvement regarding Easy Access Point; A service user co-chairing a community mental health forum; users attending Easy Access Point meetings; User involvement on a selection process work stream; A log of 3 meetings for service user and carer involvement regarding Payments by Results; Examples of changes to processes recorded as a result of ‘what you said and what we did’ document; Letter inviting users or carers to take part in further redesign work; Service user feedback from an engagement event; A service user reference group being set up with terms of reference; And a service user update document on the service redesign work.

There were four examples of **Positive Service Improvement** made – that the users attending this meeting were attending it as a first meeting of its kind on the subject of Easy Access Points within the Trust, Service User feedback on service improvements that they have ownership of, a service user group being asked to coordinate a survey around PEAT, and call centre facilities being available to a wider population.

There were two mentions of *negative accounts of service improvement* – In an Easy Access Point meeting minutes it is stated that only 'chosen members of the Board' could shortlist on a procurement panel. There was no rationale stated as to why service users or carers could not be involved in this; a comment that the Trust would discuss with service users their inclusions in certain work streams, but that it would be outside of the main meeting. This is not transparent or inclusive.
Commentary

Overall, from the Foundation Trust work it can be seen that there were strong statements of intent and many good and varied examples of proactive and inclusive practice. There were less examples of where the process had effectively started to close the loop on the process at this stage with just one actual action taking place and one example of seeking feedback and testing. This reflects the stage at which the Trust was at the time in the early days of FT status work.

When it comes to Service Redesign, there were nine examples of themes around involvement which in fact showed many more actual different occasions of real action. It stands to reason then that there were four examples of positive service improvement that were very service user focused or indeed user driven. There were four examples of negative practice or improvement, so there is no room for complacency. However, these can be seen as barriers being created or simple mistakes which are excluding.

There did not feel any need to do any more analysis on the information presented as it was patchy really when piecing together what was happening. Minutes of meetings are dry and do not give you the real feel of how business is conducted and how people feel about it. More detailed comments are made on certain meetings and forums in the next chapter.
A review of the processes whereby patient feedback and service user involvement contributes to service improvement and the improvement of the patient experience

How the existing feedback mechanisms work
What follows are examples of the mechanisms whereby patient feedback, in its widest sense, is used by the Trust to improve its service provision and thus the patient experience. It is a collection of items which came up in the course of the review, and some might not sit so well with the others, but are worth mentioning here as particular things of note.

**PALS**
The Patient Advice & Liaison Service (PALS) is a free, confidential and impartial service available to everyone who uses Trust services, their families, carers or anyone who needs advice, information, support or guidance with a particular issue. They are part of the Engagement and Responsiveness Team, and record cases on their database. This way themes from issues brought to PALS are picked up in their weekly meetings, which can be passed up through line management.

Whilst the database records themes and issues, PALS have stated that they want to be more sensitive to some issues so they pick out items of concern from those recorded. They have then conducted workshops with staff on these issues. They also stated that they have regular worthwhile meetings with Gina Smith who is the Clinical Lead for Carers to flag up any carer issues they are coming across.

PALS also told NSUN that they try to get to external organisations like LiNks, and those in the voluntary sector as well as attending local and Trust-wide Acute Care Forums.

It can be seen from the above that there are methods to highlight any recurring themes as well as address particularly troubling issues that PALS pick up with regard to improvement of patient experience and service improvement. The team is linked into the governance processes in the Trust, and reaches out externally to advertise their work and hear more views. A staff member commented that PALS are good as they want to sort problems out. PALS staff have to tread a very careful line being employed by the Trust and provide a professional service to their customers who are invariably criticising that Trust. Evidence suggests that they do indeed perform a valuable service to both PALS users and the Trust. Two service users described PALS as “good” and “excellent”.

What the contractual arrangements are

The Commissioners NSUN spoke to were helpful in pointing out what contractual arrangements are in place around gathering patient feedback to help show that the Trust was delivering a good service. These can be represented as thus:

<table>
<thead>
<tr>
<th>Performance indicator</th>
<th>Threshold</th>
<th>Method of measurement</th>
</tr>
</thead>
<tbody>
<tr>
<td>Quarterly PALS Complaints / Compliments report at individual PCT level</td>
<td>100%</td>
<td>Report to be submitted to Quality review meeting and to contain details of AWP response to all formal complaints / complements and all associated action plans.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Quality Requirement</th>
<th>Threshold</th>
<th>Method of measurement</th>
</tr>
</thead>
<tbody>
<tr>
<td>Complaint response times</td>
<td>Full compliance with national response standards for complaints including full response within 25 days</td>
<td>Quarterly report to Quality Review Group meeting</td>
</tr>
<tr>
<td>Patient Experience report</td>
<td>Quarterly Complaints reporting by PCT /SBU</td>
<td>Quarterly report to individual PCTs and Quality Review Group meeting</td>
</tr>
</tbody>
</table>

These of course only give you raw data regarding those people who feel strongly enough to complain or contact PALS for an issue. It does not give you more sophisticated information on everyday patient experience and service delivery levels. User and carer involvement and compliance with section 242 of the NHS Act 2006 does not appear to be monitored.

LINks meetings

AWP Trust meets with the LINks groups across their area quarterly. This group was established by the Trust and is chaired and minuted by them. There is a joint working agreement between the Trust and the LINks drawn up in May 2010 which is built very much around the sharing of information under the statutory ‘duty to involve’ people (see Section 242 of the National Health Service Act 2006). At the meeting NSUN attended, there were no user representatives present, not for the want of trying by the Trust, and there was 1 carer present, who is an individual and feeds in his experience to the proceedings. A point of note here would be that any terms of reference for meetings can include what to do with absenteeism from its members.

Things of note in the meeting were:

- LINks representatives fed back from their activities, and one “commended” a talk that an AWP Trust staff member gave to them on quality accounts at a recent meeting
Sally Wood, the Trust PPI Manager, has been out on an informal visit with some LINks representatives to an AWP Trust service

Recent Care Quality Commission (CQC) visits were discussed openly, and how AWP Trust is dealing with issues arising from these

The Trust presented results from the recently published CQC Community Mental Health Survey for the Trust set against national results

The Trust stated that they are continuing to carry out an annual In-patient Mental Health Survey, even though doing this is not a requirement by CQC now.

Peter Greensmith, a Trust Non Executive Director, was also present at the meeting and spoke to a Patient Experience Report. Both he and the senior involvement staff welcomed any comments from LINks members present on this, and indeed any other issues that LINks may bring

One observation from NSUN is that there was no challenge from those LINks personnel present. Indeed their focus was more around their own existence and the advent of HealthWatch. This is unfortunate as these meetings are only quarterly and an opportunity to challenge the Trust on their performance by these networks of individuals and community groups whose remit is to work together to improve and influence the way health and social care services are run. It is the job of each LINk to find out what people like and dislike about local services and feed this information back to health and social care providers, helping them to plan and deliver better and more relevant services. Two service users who were interviewed subsequently by NSUN were not complimentary of LINks. This meeting felt more like an information exchange and certainly the Trust supplying much information to LINks representatives on certain patient focused matters. In fact the meeting did demonstrate anxiousness by the Trust to show how they are acting on patient feedback.

It is recommended that the Trust revisit the purpose of this forum with a view to the future establishment of HealthWatch and their developing remit.

It did feel that overall this forum was about the Trust presenting evidence to LINks, a more information and public relations function. That said, any information on patient surveys, PALS activity etc that is presented is shown as collated reports with themes being identified. These themes are brought to the attention of the SBU’s and action plans are drawn up to improve the service quality. Therefore, this meeting demonstrates to LINks that there is a learning cycle and process around patient surveys which leads to possible service improvements being made.

NSUN didn’t get a sense that the LINks had regular communications with some of the more active user groups who would also be interested in this information and could add to the debate. Lack of resources was put forward as one reason as LINks do not appear to have the money to pay people to meet with them.

Something that came up at this meeting was that the Service User Research Forum was not running. A new director with this brief had just been appointed and there will be discussions about involvement activities within AWP Trust in research. Mental health user involvement, and to a
lesser extent carer involvement, in research is arguably at the forefront of research involvement activity across any disability groups.  

It would be good practice for AWP Trust to invest in user and carer involvement in research. Therefore, a start would be the Service User Research Forum group being resurrected.

PEEP Meetings
Patient Experience Expert Panel (PEEP) meetings have been in existence for some years. The managers of the SBU’s attend to present evidence of patient experience, various service issues, and how they are attempting to improve both. The PEEP meets every 2 months. It was noticeable that many apologies were sent to PEEP meetings from staff, without secondees being sent in place. This is unfortunate as no-one from some SBU’s were on hand to present their results from the Real Time Surveys for example. If this happens, NSUN didn’t get a sense that data for the PEEP was dealt with after for members or taken forward and perhaps issues might be lost. Is there a question of some staff losing interest in the PEEP and what it tries to achieve at a cross Trust level?

At the meeting that NSUN attended and observed there was only one carer in attendance. One service user was absent due to long term illness and the other had been absent from these meetings for a while and subsequently left its membership.

Any issues go to the Director of NCAS and the executive lead for the PEEP. Any items of concern or requiring decision might also be taken forward to the Executive Management Team (EMT).

An example of something that comes to the PEEP is the Patient Environment Action Team (PEAT) activity. There are monthly PEAT meetings on in-patient settings. These meetings will take on issues brought up at community meetings that need further guidance. The PEAT meetings are chaired by the modern matrons and can include service users or representatives from user groups. Part of what is discussed is around a set agenda, for example on infection control, environment, safety, also nutrition. Anything that is not solved locally can come to the PEEP for consideration.

Other PEAT involvement activity includes PEAT reviews. NSUN was informed that there are mostly carer representatives on Liaison and Later Life PEAT reviews, and sometimes LINks representatives. It was expressed that the NHS department responsible for requesting that these reviews take place often do so at very short notice which can make it difficult to get users or carers involved. On the day training is done for those involved. It was expressed that any user or carer involvement in PEAT reviews was important as users or carers see things that staff take for granted.

Before the main meeting of the PEEP there is a pre-meeting that users and carers can attend with the Chair and Trust staff so they can clarify any items on the agenda, bring in issues from other people, and therefore decide what might be included or better discussed outside of the meeting. As it seems such a packed technical meeting, it is good practice for ‘outsiders’ to have the opportunity to be clear about the meeting content from the start.

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24 See http://www.invo.org.uk/About_Us.asp
As an overall impression of attending this one meeting, there was a lot of information to take on board and therefore little time to really engage with it and discuss and perhaps challenge from a user/carers perspective. The papers do need a lot of reading through beforehand. The carer attendee commented after that whilst the meeting dates are set well in advance, and papers are also sent well in advance by email, the attachments are huge and therefore printing them off at home can be a task. The Trust needs to be sensitive to whether people have the necessary equipment at home to print off large files. It might be necessary to print these at the Trust and then send on by post. However, the carer spoken to felt he was “looked after very well” by the Trust generally.

The minutes of the PEEP meeting only appear to serve the PEEP. The exception to this would be reports that would go to the EMT. There was discussion at this meeting around how the Trust Board can be fully informed of patient experience across services, but without this being too cumbersome. This is work in progress. It was confirmed by a member of staff who wasn’t at this PEEP meeting that they felt there was too much on the agenda and the subject matter is too broad for attendees. They also felt that in terms of its function, not much came out of it.

♫ It is recommended that the PEEP meeting is reviewed as to its purpose and who it serves.

Community Meetings

These are the responsibility of the local ward staff to ensure that they happen for service user feedback on service provision at that time.

There are role descriptions for community meetings and the minutes from these meetings go to the ward managers and modern matron. NSUN was informed that changes do occur as a result of community meetings on wards, although some changes can take a while.

NSUN has seen some examples of community meeting minutes, the quality being variable. NSUN was informed that a lot of the in-patient community meetings are run by the service user groups/networks SURG and SUNS. Some are facilitated by staff working alongside users or helped to be set up and run by the Service User Involvement Workers. Whilst there is a standard form for community meetings, not all places are using this. Also, some staff have complained that meeting notes taken by some users were of a poor standard, particularly if staff have to type them up. Obviously people are unwell, and some might have lower levels of literacy than others. It is for staff to help users with this and be supportive around this issue.

NSUN was told about set agendas and guidelines for meetings being developed in one SBU. Certainly if any formats, guidelines, terms of reference are felt to work, then these should be shared across the Trust.

Community meetings also take place on most wards in Liaison and Later Life services. These often involve carers. NSUN was assured that community meetings also took place in specialised and secure settings and was described as “bread and butter” user involvement. Again these were facilitated either by staff or users themselves. In the Learning Disability provision minutes were produced in easy read format for service users.
The secure settings have a user representative for each ward. Community meetings are either weekly or 2 weekly, and these are chaired by the user representative. The staff and ward manager are also in attendance. The agenda is put up in advance on a notice board so that users can add items for discussion and any minutes go to the site wide service user group meeting. The modern matron for the secure wards chairs this meeting, and the ward user representatives attend. The user representatives can also attend the monthly service improvement groups where operational issues and standard setting schemes like Star Wards are discussed. Examples were given where users concerns were acted upon and service improvements made. NSUN was also told that user representatives are able to attend meetings off site depending on their leave situation of course.

**Real Time Surveys**

All wards have monthly Real Time surveys. These are on a three month rolling basis around the subjects of care planning, involvement in decisions about care and treatment, and dignity and respect. They have been running in the Specialist Drug and Alcohol SBU (SDAS) since December 2010.

There was a comment that SDAS service users and also some long-term service users felt that they are surveyed too much, and that it is getting boring. So now this directorate are looking at different ways of gathering this information.

The surveys have been running in the Specialised and Secure SBU since April 2010 and across the Adults SBU since Jan 2011. These surveys were adapted for use on the Liaison and Later Life wards to aid completion and have been running since March 2011 after being piloted in February 2011. There are 2 formats, one each for people with functional or organic problems. The Service User Involvement Worker covering Liaison and Later Life has helped with survey completion by sitting down with users and helping them through it.

At the time of interviewing staff it was still felt early days for finding patterns and themes in some SBUs from the surveys, but all staff considered that the surveys were really helpful with on the ground service feedback.

**Carer Survey**

At the beginning of June 2011, the Trust conducted a carer survey at the request of the lead commissioner. A letter and four page survey was sent to 2500 contacts and the Trust had 344 returns. Importantly, 91% of respondents were caring for someone who had used AWP services within the previous three months.

From the survey results, the areas identified for improvement were, identifying who are carers; ability to contact services; carer involvement in care planning; support and information; and service provision for both service users and carers. NSUN would see these as quite general areas and nothing of a surprise.

A Carers Survey Improvement Plan was drawn up as a result of this. The next survey is happening at the time of writing this report. Older people in memory clinics are intended to be included in this next carers’ survey. It will be interesting to see what improvements are being made and how this work can be taken forward.
**Carers Forum**
The Carers Forum is held quarterly at Trust HQ. NSUN attended as an observer at the July 2011 meeting. Each of the SBU Champions should attend the forum and report on progress of the Strategic Framework for Carers Implementation Plan. Also present are members of the Engagement and Responsiveness Team and the Trust clinical lead for carers. The meeting is well attended by individual carers who are involved with the Trust and also representatives from the voluntary sector who serve carers by being advocates for them and providing services themselves.

There were at this meeting, draft terms of reference for the forum. These need confirming. Other carer related items are discussed such as special events and projects. The role of the group is to mainly ensure compliance with Section 242 of the Act 2006, and to develop partnership working with carers in many and varied ways. In terms of governance, issues from this group can be taken forward up through the Executive Management Team and possibly to the Trust Board as appropriate. Although, some doubt was expressed regarding whether strategic issues are progressed within the Trust by a commentator from this meeting. NSUN considers that the Carers Forum is an important Trust wide meeting where there is opportunity for Carers’ issues to be aired and worked on together.

**Service Redesign**
The Trust is undergoing a service redesign around adult services. There needs to be a reduction in bed stays as these are too long, and also there will be fewer beds. There is also a question over access into services in the first place. Therefore, the community teams need to change to respond differently to crises for example. It was stated by many that there was not any community involvement until later on in the work around service re-provision, and that involvement wasn’t done in a meaningful way. There has been better involvement the last 2 years as there have been attempts to build relationships with service user groups to engage in this debate. SURG+ meetings are an example of this. They are monthly meetings with the SURG network specifically around redesign. The Chair of SURG and latterly the mental health lead commissioning manager co-chair this meeting. The Director of Service Redesign from AWP Trust attends this meeting and SURG+ has input through them, although the AWP Trust Service Redesign project board itself has no service users on it. NSUN understands that SUNS and WSUN were also invited to be a part of the SURG+ group, but do not take part in it, they have separate meetings on redesign.

Originally an “Easy Access Point” concept was being explored as part of the redesign. It was envisioned that there would be one point of access within the Trust, but this idea has since been challenged by the commissioners.

There were plenty of comments made by service users and also carers involved with the easy access point work. There was frustration that considerable time and energy went into this project for it to be abandoned part way through, although they knew the reason was that commissioners wouldn’t back it, but this was learnt by word of mouth and not by any written communication from anybody.

**National Surveys**
During the PEEP meeting on 12/7/11 the Trust fed back the results from the National Community Mental Health Survey. This is undertaken for the Care Quality Commission (CQC) who publish the results by trust and cover people who receive care and treatment for a mental health condition,
including services provided under the Care Programme Approach (CPA). The areas covered by the survey include the quality of response they received from the staff they see, medication issues, talking therapies, care plans/reviews, care coordination, crisis care and day to day living.

Without repeating the results here, this is a useful tool for the Trust as they are benchmarked against the other mental health trusts across the country. The results can be seen on the CQC website.\textsuperscript{25} It can also be seen on the website that the Trust fares in some areas much better than others, but also has areas which fall below the national average. These results point to very basic service improvements that should be made.

The CQC do not conduct a National In-patient Mental Health Survey anymore. However, the Trust continues to conduct this survey for their information to enable service feedback and therefore make improvements, which in itself are good practice.

\textsuperscript{25} http://www.nhssurveys.org/Filestore/documents/MH11_RVN.pdf
An assessment of the Trust’s approach in relation to current best practice and statutory requirements

What different people feel about the involvement

Whilst this section of the report is in reference to statutory requirements and good practice around involvement it is worth mentioning here the varied responses given by staff members and users and carers when asked generally what they felt about the Trust’s approach to involvement. In no particular order we heard that:

“AWP (Trust) do a lot more than acute trusts” – service user

“Reasonable network of engagement with users” – staff member

“Better at carer involvement at individual and strategic level!” – service user group

“I feel many of the people I have met and been working with are very supportive and interested in getting the input of service users and carers, but there is no doubt the system at the moment, in particular with carers, appears to be ad hoc and particularly un-joined up” – carer

“Doesn’t understand the implications of user involvement” – service user about a Sector Manager for their area. They went on further to state that when the previous manager had left, the staff had lost the vision for user involvement.

“Some staff are good about user involvement but others are poor” – service user

“Swamped by pure pressure of workload” and some people “really do get it” – service user group describing ethos around user involvement within the Trust.

“I feel that I have been able to contribute successfully to this process [Redesign project] and represent not just my own experiences but those of a broader spectrum of carers”. However they went on to say that “Over the last 18 months I have extended my resources and contacts and grown in confidence but I could not in all honesty say I have been supported in this by AWP” - a carer

“Informal and relaxed”, “very well”, “very discreetly”, “very good” – a service user about their involvement and being paid on the Readers Panel

“I think there were around 12 service users there from all parts of Wiltshire. [Staff member] updated the group as to where AWP is with the redesign and answered their queries. The group found the session informative and were pleased that they had an opportunity to talk directly to [staff member]” – voluntary sector development worker

“Service User representatives [including voluntary sector development worker] subsequently attended an Operational Manager’s meeting and received further information which will be fed back at the next meeting in Jan” – voluntary sector development worker
“I have to admit that I’m very frustrated by AWP’s involvement efforts; or rather lack of them and it seems endemic within the organisation. We do have some extremely good members of staff in Bristol, but I feel as though they are not supported by the Trust in their efforts and are often bogged down by ‘tick box’ exercise that preclude proper involvement at numerous levels” – service user

“Always trying to think outside the box” – staff member in relation to the involvement of users from forensic setting and learning disabilities

“Fragmented system around user involvement” – staff member

“User involvement isn’t working a lot of the time” – staff member

“Involvement is based on history and relationships. The Trust doesn’t engage with all sections of the community. Engagement needs to happen at a local level more systemically” – staff member

“Opportunistic process” – staff member describing user involvement

One senior staff member stated that AWP Trust put more resources into involvement than she’s experienced in other places, but clarifies this by saying that involvement doesn’t work as well across the Trust as it could do.

Staff confirmed that more has been done over the last year around user and carer involvement in Liaison and Later Life services. They had previous pockets of good practice and are now looking to mainstream this. There had been attempts to involve older people on existing groups, but it was said that impairment issues (being hard of hearing for example) and the length and pace of meetings were off putting. The SBU is looking at alternative ways of involving representative people in their strategic meetings.

It is recommended that the Trust consider some of the barriers to involvement that this client group have, and work to make meetings more accessible for all. This may involve slowing the meeting pace down and ensuring hearing loop systems are available for example.

One service user described their involvement in some recovery workshops in North Bristol. Each one was themed and there was a presentation by a user as well as staff followed by a debate. She found these to be “quite successful”. In relation to user involvement they added that some staff don’t want to get it as they want a “them and us” scenario.

Another service user described asking to be involved in re-design meetings. This process took 8 months and after attending it took 3 meetings for them to be sent the papers for the meetings. They described this as “ineptitude” and that user involvement was “not a priority in their [the Trust’s] thinking”. It was an “endemic culture”.

Another example of this was expressed by a service user. “In getting involved in the rehab review, I had to make a number of requests for user involvement and eventually was asked to join the steering
group. I frequently don’t get minutes of meetings, or dates of the next, or am told they’ve been cancelled less than an hour before they were due to take place”.

The Chief Executive of AWP Trust gave an honest account by stating that “Involvement hasn’t modernised as much as possible”. She went on to state that she would like involvement within the Trust as “cutting edge” and “the best”.

In terms of how the Trust operates around care for users she restated that the philosophy is one of recovery and the desire to work in co-production with service users.

In terms of involvement opportunities the CEO felt that there was a lack of recognition from service users that the Trust has certain “responsibilities and accountabilities”. She felt that approximately 75% of Trust ‘business’ was ‘up for discussion’, and 25% not so. Whatever the ratio, it is important for external stakeholders to learn about what is and is not possible. It saves everyone a lot of time and trouble. It does fall to the Trust though to help people understand what is possible and where the Trust has to draw the line due to these responsibilities and accountabilities. This was illustrated by a member of staff commenting on the service redesign and that users would be observers only in this process with the Executive Team having the final say. They felt that this situation was poorly articulated to users. An observation by NSUN would be that that users and carers can be more involved in the redesign process than this, with of course the final decisions being made by the Trust Board. Partnership working does not negate a board’s ultimate responsibility.

A carer commented that:

“I would say that the philosophy of inclusion of carers and services users needs to be embraced from the top and spread across the whole organisation as at the moment some areas are better than others”.

Another carer commented that there should be more carer involvement in the Trust as “carers are a critical point in the service”.

Users and carers involved with the Trust are aware of efforts made by other organisations around involvement and participation. One carer said:

“There are many areas of good practice out there and especially at a time of stress in society and the service it would be good to roll these out across AWP so people were getting a more equitable service”.

The point was made generally by a voluntary sector worker that there is a challenge of being members of meetings or forums from a user or carer perspective. This is if they are an individual without links to wider organisations or indeed an appreciation of strategic issues, then their involvement can be somewhat tokenistic. If their function is not to gather views systematically from peers to feed in, then you are only going to hear one view on some matters. It is therefore important that voluntary sector organisations that are better equipped to represent wider views and understand the landscape more are also invited to take part in Trust forums. They of course need proper resourcing to do so. The Trust therefore needs to understand how groups operate and what
it is they require of users and carers attending certain meetings to avoid tokenistic involvement and miss out on better quality input.

The reader can see that there were very variable responses around the user and carer involvement in the trust from specific examples of poor practice, to generalised comments that things happen well in places. Previous reviews in this area in other NHS trusts have yielded similar results.

What follows are themes and particular issues that came out of the interviews and discussions that took place, and have self contained commentary and if appropriate recommendations etc.

**Paying people for involvement**
The Trust has developed different rates of pay for different levels of involvement and no-one articulated any problems with this. Previously it was understood that there was no consistency around the rate of pay. Therefore, payment rates seem to be a success.

NSUN was told that SUIW’s will work with any user on benefits around this issue, supplying them with a letter to be taken to Jobcentre Plus. The Trust can pay expenses and fees as cash or by BACS as stipulated by users. It is important that out of pocket expenses are at least reimbursed quickly so that users on benefits are not financially disadvantaged. It is also important for the Trust to have an audit trail for its payments and have exercised sensitivity but a certain amount of openness around being clear that any benefits claimants should notify Jobcentre Plus of any monies they receive as a result of their involvement. The onus is on the claimant to declare payments and the Jobcentre Plus Decision Maker to decide whether the payment affects any benefit entitlement.²⁶ However, those undertaking involvement activities “are entitled to expect adequate support and information from the service provider” as per page 7 of ‘Reward and Recognition’ DH 2006.²⁷

NSUN recommends that AWP Trust revisit their payment policy and mechanisms to ensure they are up to date with current national guidance, and also consider the provisioning of specialist welfare advice for service users who undertake involvement for the trust as benefits recipients (see page 6 of ‘Reward and Recognition’ DH 2006).²⁸

At the time of writing, the UK government are undertaking a major reform of welfare benefits. Service users brought this up as an issue that was very unsettling for them. The threat of monetary loss makes most people anxious, let alone those people with a mental health problem. It has been reported widely in the national media from the large mental health charities that the reforms are adversely affecting service users’ mental health, even leading to suicide. Whilst this is not in the control of AWP Trust, it should be borne in mind when involving service users as a sensitive issue.

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²⁶ The Social Security Benefit (Computation of Earnings) (Amendment) Regulations 2009
Another thing of note is that the minimum wage was increased from 1st October 2011. £6.08 per hour is the main rate for workers aged 21 and over. Any involvement fees that the Trust make should reflect this increase as per the guidance ‘Reward and Recognition’ DH 2006.  

Some helpful guidance has just been issued by the Social Care Institute for Excellence (SCIE) with regard to payment of out of pocket expenses and payments for involvement. This can be downloaded from http://www.scie.org.uk/publications/atalgnce/atalgnce50.asp.

Another way of paying people is through third sector organisations. The guidance previously mentioned is helpful on this point. Some service users pointed out that the rates of pay for involvement that some voluntary sector organisations pay them is different, indeed less, than they would get if they ‘worked’ direct for the Trust. For some this is inequitable, however, they should factor in any support they get as a result of doing involvement through another agency. SUNS for example give users their travel expenses up front to enable people to travel to meetings; otherwise they might not be able to attend.

For the period 1st April 2010 to 31st October 2011 approximately £174,000 was paid as fees and out of pocket expenses for involvement across AWP Trust.

Engagement and Responsiveness Team
It is good practice to put resource into making involvement happen with users, carers and external agencies like the voluntary sector. It won’t necessarily happen otherwise, and if it does, it won’t happen so well. Other NHS Trusts have dedicated personnel to enable involvement to happen, for example see the Involvement Team at http://www.nottinghamshirehealthcare.nhs.uk/get-involved/involvement-team/, other Trusts are less obvious with their support, see for example http://www.southernhealth.nhs.uk/wellbeing/get-involved/what-can-i-do/involvement-in-adult-mental-health/. AWP Trust has gone some way in their investment to ensure involvement can happen by having a dedicated corporate team.

Having an Engagement and Responsiveness Team therefore demonstrates a positive corporate response to fulfilling the duties under S242 of the NHS Act 2006 and more. This Team enables the collation and analysis of data around performance of national and real time surveys; PALS and complaints work and data; LINks liaison; coordinating voluntary services within the Trust; Carer Engagement; FT Membership; and the readers’ panel. They give advice to staff on the ground about involvement, set up good practice, and advise the Board on matters of involvement and undertake specific projects around this area. NSUN could see that they work hard as a team and care about the work that they do, and the outcomes that come from this.

Having a dedicated Carer Engagement Manager means that there is an emphasis of ensuring that staff are “carer aware” from a strategic perspective, and therefore emphasizing the important role that carers can play in supporting service users during their crises and in their recovery. Linking in with the voluntary sector is also important as lobbying for carer rights is very strong here, and the voluntary sector have traditionally met carer needs in a support role. It is important that the Trust can work on strategic and individual levels with carers. This post therefore also helps to highlight

that staff must be aware that they should identify carers in the first place as someone who have their own needs that should be assessed, recorded, and if possible, met in their own right. It is usually from this that carers can be identified and supported to be involved in wider trust involvement activities.

A helpful tool developed for staff is the good practice checklist for carers. There is one for the community and another for inpatient settings. It outlines the possible care pathway for carers and as a checklist one can easily see what progress has been made around identifying carers, their needs, and setting up a care plan for them and what happens when the service user is working towards recovery. The good practice checklist is in itself ‘good practice’.

It was commented upon that there was a small pool of carers who were doing involvement for the Trust. This is not unusual as carers can be very busy caring, and others have other responsibilities outside of their caring role they must attend to. The author would venture that users have a different emotional investment in involvement than carers, and nationally users are more active than carers in involvement. Therefore the Trust needs to always maximise their efforts with carers and possible involvement.

All Strategic Business Units within the Trust have responsibility for involvement which was latterly devolved from the Engagement and Responsiveness Team. NSUN view this as a positive move to ensure corporate ownership of involvement and it not being seen as a centralised function only, or ‘something someone else does’. Certain key operational staff across the Trust have responsibility for involvement of users and carers. They were interviewed – see above. The point of this being that expertise and policy sits with NCAS and the delivery and growing expertise sits with SBU’s.

In terms of carers, there are carer leads within each community and in-patient team across the Trust, and a champion within each SBU to help implement the Strategic Framework for Carers. Each PCT and LA has their own carer strategy so AWP Trust mapped these and therefore have their own framework for carers with an implementation plan to monitor progress. NSUN have seen a copy of the latest Implementation Plan and can see that substantial progress has been made.

As the Trust CEO indicated in her interview, there used to be quite a fragmentation of services and variance in governance across the Trust before she took up post. PALS and Complaints services were centralised, and the Engagement and Responsiveness Team was created centrally too. During the course of this review, the Service User Involvement Workers that were part of the E&R Team were placed with individual SBU’s. The centrality of involvement was one of the issues that SURG and others had voiced as an issue hampering involvement at a local level. Having dedicated SUIW’s for each SBU at least would be considered good practice. The Involvement Leads for the various parts of the Trust can call upon their specialist services when required to work in a community development and enabling way with individual users and carers to maximize the success of involvement.

We have to be mindful that there are no national guidelines for service user or carer involvement. This is something that has exercised service users over many years, and is something that NSUN has
in mind to address. Other national organisations like Involv$^{30}$, who champion involvement in research, are also looking at national standards for involvement. Until such standards or guidelines are developed, there will be no set or accepted way of evaluating involvement.

There does seem though to be a disconnect between the E&R Team and some user groups which is very unfortunate and non-productive. This was stated by service users and also pointed out by some staff. This is further complicated by some staff seeing certain users as having closer relationships with certain executive members of the Trust, thus shutting out the E&R Team at times. It is ironic but not unprecedented that in trying to standardise user involvement across the Trust, some users and user groups have felt alienated from the E&R Team. There were various comments made by staff or service users alike that some people in the team don’t have a mental health background and therefore perhaps don’t understand the history of the user movement and that groups can come from a civil rights perspective.

It is recommended that the user involvement staff within the Engagement and Responsiveness Team reach out to certain user groups to dispel any myths around knowledge and understandings, with a view also to learning from those groups about their values.

Service User Involvement Workers
At the time of interviewing for this project, there were two SUIWs attempting to cover the whole Trust. The lack of sufficient SUIWs was a very prominent concern for service users on the ground.

One user in touch with Battle Against Tranquillisers group said that for her, in North Bristol, user involvement is patchy due to the loss of the Service User Involvement Worker for that area. They were in touch with the existing SUIW but this was not enough as they cover a greater area now.

Another user stated that their involvement happened because they were recruited by their CPN to do involvement, and the old SUIWs worked with them on a 1-2-1 basis. This was described as “hands on experience” with the SUIWs and that they got to know their own strengths and weaknesses which “operated very very well” as there was a “feeling of having a personal link” with the SUIW when in dialogue with the Trust on a professional basis.

Other service users mentioned previous SUIWs and how valuable they felt they were. They also commented on the amount of work that they were expected to do. Where there had been SUIWs and those people had left the post for it to remain unfilled or apparently lost, many service users commented on how there was less involvement. Those workers were instrumental in identifying opportunities for involvement, motivating staff around this, and supporting users to get involved.

There was also a worrying point made that where service users were involved in some places, it would be because staff “cherry pick” them and that some are “carving out a career for themselves”, which meant that other users didn’t get any work. They went on to say that they felt that this was “unhealthy” as this is tantamount to grooming users whose self esteem is so low that they respond proactively to this.

$^{30}$ http://www.invo.org.uk/index.asp
A comment was made by an external worker who supports users to get involved that “less well users so need workers to enable them.” Although they also pointed out that they “don’t have time to chase them”. This demonstrates the crux of the matter in that some people will need support to begin with and then become more confident and independent, others will always need some sort of support and this is part of the role of a SUIW, but can be very time consuming. This must be realised when planning resource around involvement.

A service user talked about “the posts that were funded for dedicated user involvement all seem to be vaporizing”. It was confirmed by the Trust and the commissioners that the posts for the SUIW’s were not ring fenced within the overall budget allocation. The Trust stated that it was up to each SBU to decide whether they indeed had a SUIW post.

Until the end of June 2011 the SUIWs were line managed by the Head of Engagement and Responsiveness Team. From July 2011 their posts went out to the SBUs. This was to ‘decentralise’ involvement as it is seen as everyone’s business and not that of one team alone. It was also to reflect the fact that service user groups didn’t see the centrality of the Engagement and Responsiveness Team as being close to them. One point of note is that the SUIWs do not have any dedicated administrative support which would also hamper their ability to be as effective as possible when engaging with supporting service users and carers. The SUIWs present try to spread themselves across their patch including working with users on organic wards, which by its very nature takes longer. They attend and support community meetings in the wards where they can be of best help, and not if one already runs well. They also liaise with the wider voluntary sector to try to work in partnership. They attend various meetings with service managers across their patch, supporting both user representatives present and getting involved with business on the ground and how they can aide involvement in such.

NSUN was told that vacant posts were not recruited to as there is a question mark over whether it is best use of Trust money. We understand that at the time of writing a SUIW has just been appointed for the Specialist Drug and Alcohol Services SBU and discussions are taking place regarding the funding of vacant posts. The provision of adequate resource in the form of workers to enable involvement to happen in a sensitive and empowering manner has been written about in many documents and would be seen not just as good practice but as essential. Even though various Trust staff have responsibility for involvement written into their job description, this does not necessarily equate to someone being able to do the job in terms of capacity building and enabling practice.

NSUN recommends that the Trust invest in at least one SUIW per SBU to enable the effective and user friendly provision of development so that user and carer involvement can be raised in

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‘Consumer Consultant’: Expanding the role of consumers in modern mental health services, International Journal of Mental Health Nursing, 2006
A guide to involving users, ex-users and carers in mental health service planning, delivery or research: A health technology approach, University of Leeds, 2002
Managing to Listen – A guide to user involvement for mental health service managers, Kings Fund, 1994, ISBN1 815717 075 X
profile amongst staff and users/carers, be adequately resourced, and properly supported to happen effectively.

The SUIW in the Specialised and Secure SBU is still getting more service users involved in secure setting meetings, although involvement is seen as more embedded here. Events also take place with users and carers, and have done so for some while in forensic settings. Also service users who have left secure services for community services have come back to talk about their experiences of recovery at staff conferences. Although there were comments that carer involvement was not as strong as user involvement here, work is in progress around this.

NSUN recommends that the SBU management team should include the SUIW’s in their annual planning of the SBU to ensure that those workers can be more strategic within the SBU to ensure effective user and carer involvement and their part in this. This would help to cement their role within the SBU, and make clear to staff their role and importance to successful involvement.

Apart from enabling people to take part in meetings and surveys, the SUIWs have worked on specific projects. The two SUIW’s in the Trust interviewed developed with two service users some induction and recruitment training for users and carers. This was based on the existing training for trust staff and adapted as felt necessary. Other valuable work has been to simplify the expenses and fees claim form for involvement. They also point people on benefits towards Citizens Advice Bureau for advice about involvement activity and benefits (see above section on paying people for involvement for further commentary), and have devised a letter for users on benefits to take to Jobcentre Plus offices regarding the involvement they are doing with the Trust. SUIWs can have many functions to smooth the process of involvement, importantly from a user perspective.

**Equality and Diversity**

The Trust has an equality and diversity advisor to ensure compliance with the Equalities Act 2010 and to improve good practice around equality and diversity issues. NSUN was told of many areas of work around particular issues including more user involvement in engagement events being run across the trust to air issues and share good practice, working with SURG+ around the Bristol redesign, and the development of a Swindon diversity pack for staff. It was explained that the AWP basic awareness diversity training was classed as essential training with other training opportunities to supplement this as required. Associate trainers help deliver the diversity training.

Equality and diversity is an important area, not just to fulfil legislative obligations, but understanding the vast range of issues and sensitivities across diverse populations will enable a better and more appropriate service response.

NSUN heard how the Trust was reaching out to diverse groups through its Foundation Trust membership recruitment. NSUN would hope that the Trust would always attempt to be in touch with diverse communities and marginalised groups to aide better understanding on both sides.

**Learning and Development Department**

Whilst no staff from the Learning and Development Department were identified for interview, NSUN did hear good things about their ability to involve users and carers in their work, which in turn helps
skill up frontline staff. The Carer Engagement Manager stated that they were good at working with her on involving people in their work. Other individual comments regarding training were:

“AWP (Trust) is strong on user involvement in staff training” – staff member

“User and carer involvement in recruitment training is good” – service user group

“Feel respected”, “right attitude”, “treated more equally” – service user/associate trainer

with regard to the Learning and Development Team

User and carer involvement in training is an area where a lot of work has been done over the years in mental health NHS and university settings. Training can be daunting for users and carers at first, but ultimately very rewarding. The opportunity to have a critical but friendly dialogue with staff on hypothetical issues as a user or carer leading a session can be very empowering. It is also well recorded that staff value this interaction greatly as it adds to their thinking. NSUN was pleased to hear positive views from various people about this aspect of the Trusts work.

The Learning and Development department have instigated a ‘Learning and Development Training Agreement – our shared expectations’ document. This clearly lists the expectations made of associate trainers and those of the L&D Team to one another. This is in the spirit of openness and transparency and could be considered good involvement practice and evidence of a co-productive way of working.

Foundation Trust Status

There was concern voiced by many service users that when the Trust gains Foundation Trust status, that it would be only ‘members’ that it would be engaged with, and that service user governors will be the only ones working at a strategic level. It is hoped that this would not be the case and that the Trust engages with its many stakeholders at many levels and continues to grow user and carer involvement in its many activities and thinking.

One senior Trust staff member stated that the user groups/networks SUNS and SURG are “strong, powerful and vocal”, but that the Trust wanted “a bigger voice” i.e. the inclusion of many more voices other than from those organisations. Certainly it can be seen from some Trust activity that they have attempted to reach out to diverse communities, and this has highlighted diversity issues as a result of this activity. It may be that the Trust keep trying to recruit members amongst its constituents, but it also must be proactive in engaging with many people, importantly users and carers, to help shape future service development.

One carer commented that the Trust could publicise themselves better around ‘selling’ mental health in the community. Perhaps Foundation Trust status would afford this opportunity.

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The following are isolated incidences reported to NSUN that don’t perhaps fit neatly into overall themes, but are worth mentioning in their own right.
The problems of ineffective practice and ideas for improvement

One user spoke of staff recruitment interview days, and having interview schedules which have allotted breaks included. However, it seemed that staff would work through these breaks so they are not taken. This is not good for anyone’s stress management, but breaks can be vital for service users to be able to maintain concentration and good mental health on that day, especially as this process can be very draining.

One carer stated that “to begin with I was not even aware I could get expenses paid... I have had no induction and no real inclusion in any volunteer structure (if there is one)”.

Another user stated that things could be cancelled at the last minute, so no notice is given which could be considered just ‘rude’ but can inconvenience people when they have to travel distances in good faith. Not everyone outside of ‘trust land’ carries a smart phone to receive last minute emails!

“The latest ignominy was on attending a public service user consultation at Speedwell on this review, a flyer said refreshments would be available. I arrived at the venue about five minutes early and was told to sit in a waiting area, no welcome, along with one other person. We were offered a hot drink, but no expenses for travel or time were given, and when I attended a second event for the same thing the residential unit where it was held had to pay out of their petty cash for my travel instead of it being taken out of an appropriate budget” – service user

The Trust has an intranet facility called ‘Ourspace’. There is helpful guidance from the Engagement and Responsiveness Team on how to involve people and various processes are clearly and comprehensively laid out. It seems that some staff are not adhering to this policy advice.

One service user spoke about a recent occasion of being phoned about being on a recruitment panel which was taking place the next day.

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On a more positive note, it is worth noting here some ideas that occurred to NSUN or came up during conversations, which the Trust might like to consider.

Ideas for better practice

A service user suggested that there is quarterly meeting that takes place across the Trust so that people can come together and discuss involvement issues and compare practice with a view to sharing good practice, ideas and do solution focused work.

Another suggestion was that there is needed a general feeling of transparency from the Trust CEO down across staff groups/grades regarding involvement. There could be an opportunity to
celebrate and advertise user and carer involvement activities. One method of doing this could be the regular but not onerous publication of an e-newsletter from the Engagement and Responsiveness Team sent to all those staff in the Trust with an involvement brief, and to all users and carers who are involved themselves and those external agencies that also support users and carers in involvement activities.

A service user made the comment that the Trust are not ‘looking after users who are involved’, i.e. people might need support after involvement in a Trust that looks after you as a patient. This is an insightful comment as relationships with staff are different when doing involvement work as a user or carer. The role as an involved user/carer is different and they have to be mindful that boundaries can become blurred on their side or the staffs’ side. It would be considered very good practice therefore that this is looked into between the Engagement and Responsiveness Team and some users and carers to bottom out the issues and co-create some safeguarding mechanisms that can be shared across the Trust. Useful reading can be found on this subject. One of the SUWIs also suggested that user representatives should have access to ‘clinical supervision’ after particularly difficult meetings. The Head of Engagement and Responsiveness also stated that she would like a debate with users around the issues of looking after involved users who are also unwell at that time – what would be best for all concerned.

One suggestion from a service user was that the Trust creates an on-line accessible webpage around guidance for involvement. Perhaps in the spirit of co-production, this idea is followed up. It could be that the information and practice guidance around involvement in ‘Ourspace’ is made more accessible to users and carers so they can use this for themselves, and remind staff of their obligations around involvement.

The Modern Matron for the Specialised and Secure SBU talked of setting up a mentoring scheme whereby pre-discharge service users can be trained to mentor those service users who are in the more acute phase of the care pathway. This seems a win-win for both service user mentors and mentees around taking responsibility and having positive role models. Peer support is gaining popularity in many mental health trusts, and this mentoring scheme, whilst not new seems a good investment for the trust to make.

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Conclusions
To remind the reader, the National Health Service Act 2006 states that:

“Each relevant English body must make arrangements, as respects health services for which it is responsible, which secure that users of those services, whether directly or through

32 The experiences of mental health service users as mental health professionals
representatives, are involved (whether by being consulted or provided with information, or in other ways) in:

   a) The planning of the provision of those services,
   b) The development and consideration of proposals for changes in the way those services are provided, and
   c) Decisions to be made by that body affecting the operation of those services.”

And that guidance for NHS organisations on the Act, i.e. the duty to involve and good involvement practice was published by the Department of Health in October 2008 in the document ‘Real involvement - working with people to improve services’.

However, whilst the law has been strengthened around involvement, and certain duties exist on some bodies around consultation, there are no nationally agreed standards on involvement, no inspection regime for this, and no map of what is required in what place to what effect. NHS organisations must ‘have regard to’ statutory guidance. ‘Have regard to’ does not mean that they are bound to follow the guidance in every case, but if they are not following the guidance they must have good reasons for departing from it. It remains to be seen who holds who to account.

As discussed above in the Involvement chapter, the notion of involvement has developed from various quarters, is not a new idea but in some publications a lofty aspiration, and for some people on the ground, a basic human right. The saying and actual doing can be very different.

The techniques for and levels of involvement are still best understood in reference to the ladder of participation. It is this that the Trust activities can be roughly compared against as well as taking into consideration the various views that stakeholders supplied during the course of this review.

Without plotting each activity against the continuum, it can be summed up that the Trust invests a lot of time and resource on patient experience in information gathering, analysis of, and supplying to Trust staff and others of this. The Trust seems keen to be actively improving upon the service standards by the comments made where possible.

Users and carers are involved in meetings, in which services are planned, on proposed changes, and decisions being made. The obvious regular ones, and perhaps very importantly for those there at the time, are the community meetings on wards, which can yield small but significant quick results.

There are meetings around service redesign which includes users and carers, although many expressed frustration at the process and progress of this. Other meetings include local and Trust wide Acute Care Forums which were mentioned only slightly in conversation with NSUN. The PEEP meetings are a well established route to compare SBU performance and discuss this with a very small number of users and carers. It is not clear whether users and carers are consistently and effectively included in all meetings which fall under the Trusts obligations to the law though.

The Trust does meet regularly and seems to have an open door approach to working with LlNks. The development of HealthWatch will prove an interesting development for the Trust to engage with.
Other areas where user or carer involvement takes place are not legislated for but are considered to be good practice in mental health and indeed other health or social care sectors and the Trust has made good progress in this respect, for example associate trainers working with the Learning and Development Department.

It is disappointing that user or carer involvement is not in place around research that the Trust does. Mental health user involvement in research features largely across user involvement in research generally and the Trust could make a mark here.

There is a two pronged approach to carer involvement. One is the recognising and responding to carers as people with their own needs. The other is carer involvement in Trust business. Whilst there seem to be few carers actually taking part in involvement activities, those that do feel they are making a difference, but that this can be improved upon. NSUN would hope that more carers can be recruited and supported to being involved, and that carer support groups or representatives from the larger carer charities are encouraged and valued within work that the Trust undertakes.

NSUN recommends that the Trust regularly audits meetings which it sees as falling under Section 242 of the Act to ensure that user and carer involvement takes place as is required.
A review of communications and partnership arrangements with service user groups

Communications
Communication is a two-way process. This is an obvious statement to make. But, it is key to the effective running of any organisation, especially large and complex ones like NHS Trusts; and key to individual relationships like the therapeutic ones we see in the mental health arena. It is a lack of communication that is often cited when ‘things go wrong’, and is a common failure when serious untoward incidences occur and are subsequently investigated. Indeed when talking to some of the PALS team, NSUN was told that most issues that they deal with are around communications.

There are many barriers to effective communication. Examples might include institutionalisation of services users and/or also staff; professionalism and the language and culture that goes with it, which can subtly or deliberately conspire to exclude; the environment that people are in; cultural difference; as well as the effects of mental health problems themselves. Service users and carers often talk about ‘not being heard’, although they would argue that they communicated clearly.

Here, we are concerned with communications between a large organisation which covers many geographical miles, distinct areas of population that might not associate itself naturally with its boundary neighbours, and service user groups who are often small in numbers, and local to the distinct area, or type of self help or support group they decide to be. David and Goliath can spring to mind when considering this difference. Those two biblical characters can also represent the perceived power difference held between the two, and the struggle that can take place when the smaller one tries to makes its point.

It is worth mentioning here that Avon and Wiltshire Mental Health Partnership NHS Trust can be seen corporately to be making substantial efforts to communicate with its wider public and user constituency through its efforts to obtain Foundation Trust status, and by having an Engagement and Responsiveness Team as part of its governance structure.

However, complaints of poor communication is in part one of the reasons for this review and report being commissioned in the first place. What follows are those issues that kept coming up during the course of the review and were key themes for discontent amongst stakeholders, particularly service users.

SURG concerns – the origins of this review
A key issue that came up as being the catalyst for this review were the concerns put forward by members of the Service User Reference Group (SURG) and their attempts at discussion around this with AWP Trust. This issue features here as it is an example of communication and partnership working difficulties.

The service users involved and some Trust staff are well aware of the history which goes back some years regarding the multi-faceted issues in and around the Bristol, North Somerset and South Gloucestershire regarding user involvement. Various accounts were heard from people about this, either from being directly involved or as second hand. No one person was able to give a full account of the happenings, although certain accounts were followed up with documentation that helped to
complete the picture somewhat. What follows is what NSUN could piece together and as such, as a brief history it is worth mentioning.

In February 2009, SURG wrote to the CEO of AWP Trust. They were “extremely disillusioned with user involvement within the Trust”. Issues included:

- A perception that user involvement was “superficial and tokenistic at best”
- Involvement did not happen “in the early stages, i.e. the very beginning of service development”
- The Trust not allowing for “sufficient time for meaningful engagement”
- There was “Insufficient time to effectively respond or to maximize potential meaningful involvement”
- Being “refused involvement altogether”
- A lack of commitment to user involvement, evidenced by a lack of Service User Involvement Workers (SUIWs)
- The role of Head of Service User Involvement (HSUI) being biased to the organisational needs of the Trust, not prioritising working with service users, and a lack of accountability to users.
- A marked decrease in direct contact with users from the HSUI
- Users and groups feeling isolated due to lack of SUIWs on the ground.

The Trust replied to SURG on 25th March 2009 to the concerns made. They acknowledged the issues and gave reasons for some practice and explaining the rationale behind some decisions. They also made commitments to improve on some performance aspects.

It is not clear what happened in the period after this letter was sent and the next sequence of events as some months had passed.

A Service User Group meeting was held on 1st April 2010, by Hazel Watson Executive Director of Nursing, Compliance, Assurance and Standards. It is not clear from the action notes, who else was present at this meeting and from what user group. Again a large list of issues was raised with regards to the Trust’s performance over service user involvement. This also included amongst others, a lack of involvement in the redesign project, difficulties with the database, and a lack of communication with the E&R team at an event. Proposals were put forward, and a commitment to meet further on these issues was made.

On 27th April 2010, the Service User Group meeting was held again. Hazel Watson chaired the meeting by agreement, and users from SURG attended. Service redesign was discussed at length as was the role of the Service User Involvement Workers and a Board seminar for the Trust was to be held to, amongst other objectives, raise awareness of the importance and improvement of service user involvement in the Trust.

On 15th June 2010 the next Service User Group meeting was held. Hazel Watson was joined by Lindsey Scott, Executive Director of Operations from the Trust. Other attendees included representatives from SURG, SUNS, and WSUN. Service redesign was discussed again and also the Engagement and Responsiveness Team – their purpose and working practices. From this point
Onwards, agreement to issues were being made, as well as other issues being raised for consideration.

On 29th June a following Service User Group meeting was held. This was again attended by Hazel Watson and Lindsey Scott from the Trust with representatives from SURG and SUNS. An action plan was proposed regarding issues including payment/reimbursements, the database, and the budget for SUIWs and their working in future more closely with the Operations Directorate. More concerns were raised by the users present and further action included holding another Service User Group meeting, other discussions re the database, and wider considerations around ways of working with users, user groups and a get together prior to the Board seminar.

A Service User Group meeting was held on the 13th September 2010. This time attended by Lindsey Scott, Howard Lawes, then Interim Deputy Director of Healthcare Governance, and Peter Brabner, Interim Deputy Director of Operations. Peter Brabner had in the previous meeting been identified as the “lead within the Operations Directorate for Service User work”.

The meeting updated everyone on the Redesign project and involvement intentions; that the Board seminar had been cancelled at that time; and a review of the database was taking place amongst other issues. This appears to be the last Service User Group meeting held.

It can be seen from the above that regular meetings between the Trust and service user group representatives had been taking place in 2010 with progress being made around intentions and on certain issues. An example of a solid outcome of these meetings was that the two forms used by the Trust for users to claim fees and also travel costs were redesigned and amalgamated. Other issues raised were for example about staff attitudes in the Trust, and other items that require longer term work to make positive changes.

As this meeting in September was the last to have been held, it is not clear what talks and progress on certain issues between the Trust and the service user groups involved. It was commented upon by one service user from a group that they felt the Trust “worked hard” to sort issues out. They went on to qualify this by stating this was so “hand on heart” and that “I won’t defend them” (AWP Trust). Other people commented that promises from the Trust side were not kept. It is after this period of activity that SURG started writing directly to the Strategic Health Authority (SHA) voicing their concerns regarding AWP Trust and service user involvement. NSUN is aware of ongoing correspondence between SURG and the SHA on this matter.

An AWP Trust Non Executive Director (NED) with a particular interest in involvement met with members of the SURG and also AWP staff responsible for redesign work in May 2011. The result of this was that the NED drew up a list of wide ranging suggested action points for both AWP Trust and SURG to work on. The action points were emailed to SURG for them to prioritise. The NED followed this up with 2 email reminders but apparently SURG did not reply and therefore no more progress has been made.

It is important to note that there is a lot of history before these protestations and meetings took place. The Patients Council, originally of Barrow Hospital, Bristol was first established in the 1970’s, arguably one of the earliest examples of such in this country. Following from this there was the
closure of Barrow Hospital, which was built in the 1930’s\(^{33}\), replaced by the more modern provision at Callington Road Hospital; changes in local governance structures by the Trust centrally as these were seen to be inadequate if not a “shambles”; tensions in contracting issues between AWP Trust and the PCT commissioners in and around Bristol; and especially for Bristol area service users, the provisioning of dedicated service user involvement workers and associated resource.

The latter issue is a particular bone of contention. It was explained to NSUN that there were originally two dedicated service user involvement workers for Bristol and surrounding areas. There was also originally resource covering forensic services and Bath. After the Engagement and Responsiveness Team was formed in 2008 at AWP Trust a review took place and user involvement became more centralised. The local user groups previously had input into the workers job descriptions and also a certain amount of management of those workers in the field as well as identifying work issues. This was lost when accountability was centralised. These posts were not ring fenced however and the money for this is now seen as part of the main contract for the area by AWP Trust. The commissioners confirmed that as part of block funding it is not specific about what user involvement it buys. It was described as a “black hole”. Over time there were staffing and operational issues which resulted in the loss of those dedicated workers, who were not subsequently replaced. The sense of loss of control and resource is acutely felt by service users in the area. The Patients Council talked of the importance of having Service User Involvement Workers to help enable users to get involved. This is especially important for those services users who are very damaged by their mental health and/or treatment. They sometimes need reminding about commitments and help accessing venues, and help with understanding the content of meetings etc. Although the latter would be a common need for outsiders involved in Trust business due to the culture, acronyms and jargon etc. It also appears that the involvement opportunities in the area dried up after the loss of the SUIW’s as they used to engage with and motivate staff to get users involved in projects. So, it is felt as an injustice and the service users in the area want the resource and previous arrangements restored. Several staff members also felt some sympathy for SURG’s situation.

The PCT commissioners feel that certain aspects of user involvement should not be undertaken by a provider trust and that this could be provided for by an external agency. This is a model that does exist in other areas. There are long term examples of this in parts of Hampshire where the local Council for Voluntary Services are contracted by the Local Authority to support user involvement in local mental health services. Certainly one of the user groups within the Trust area that are funded locally to supply and support service users felt that a central team take away their job for them.

The constant ill feeling around this issue between the Trust and service users involved continues to act as a block to effective relations. NSUN understands that SURG hope for a new meeting between themselves and the Strategic Health Authority, now part of the NHS South of England SHA cluster in an attempt to resolve this issue. They feel that AWP Trust are not hearing their concerns and are taking them to external agencies with some influence.

\(^{33}\) http://www.forlornbritain.co.uk/barrow.php
Other service users spoken to from the Bristol area remarked on how service provision had changed with a lot of people being discharged from services, sent back to primary care, and that there has been a de-investment in community groups and provision by the Trust.

AWP Trust centrally should assertively reach out to SURG again in an attempt to forge working relationships, resolve differences, and come to some understanding over certain issues.

The SUNS issue
Another delicate issue is the arrangement between the Trust and Service User Network Swindon (SUNS). SUNS is contracted directly to supply service users for various Trust activities across the Swindon area. This of course is fine in itself as this is a remit of SUNS and they take it upon themselves to adequately support users to fulfill this function if the Chair of SUNS cannot attend herself. In practice, the Trust has focused solely on SUNS as a source for finding service users for involvement in the Swindon area. This is unfortunate as it means that individuals are missing out on the opportunity for involvement, and the Trust is missing out on utilizing the skills and experiences of those individuals. Also, in overriding individual service users for SUNS users, the Trust runs the risk of alienating those individuals from future involvement. This was not reported as happening in other parts of the Trust areas covered. The other side of the coin is that SUNS stated they don’t get involvement coming from the Engagement and Responsiveness Team.

This practice of direct contact goes against the purpose of the Trusts database and also would be seen by many as not offering an equal opportunity for involvement by others, an issue which was raised generally across the Trust. Further, it was reported to NSUN that where individuals had been identified and who had agreed to be involved, this decision had been reversed, sometimes at very late notice, in favor of offering the involvement opportunity through SUNS only. The reasons for doing so appear to be about SUNS being offered the involvement only. It was not clear to NSUN why this was happening or indeed who was instigating this.

This practice could be improved for all involved as stated above, and should be investigated as a matter of urgency with a view to rectifying the practice or at least making it plain to all, when exactly individual service users in the Swindon area can be approached to be involved outside of those connected to SUNS.

NSUN did not hear of any instances of the quality of user involvement suffering because of this practice, and this is to the credit of SUNS. Indeed, SUNS users stated that they like the SUNS model of involvement as users can attend meetings, but if they are not well they know that the Support & Development Worker will go on their behalf. It would be hoped that the latter only happens in extremis so that suitably equipped service users can attend for SUNS, whether supported by the Support & Development Worker or not.

General comments regarding communications
What follows are some of the comments made by people interviewed to illustrate how they felt about communications between them and the Trust.
There was a comment made by a service user who is very well disposed to the Trust and is involved in various projects but said that the Trust is “Not an organisation that communicates across the board”.

A carer said that “I feel frustrated at times that there feels to be no real way of getting views heard and that my enthusiasm has certainly not really been harnessed”.

One service user group said that involvement was “still very much giving information, not discussing with”.

It was expressed by a commissioner that AWP Trust decides the models of service and then involves service users in shaping that. The Easy Access Point design work might be an example of this. Certainly this concern was echoed by SURG in their communications with the Trust.

Another service user said that they had not seen the Community Engagement and Involvement Strategy. Although they had commented on it they had heard nothing after.

A lot of comments made to NSUN during the course of this review were regarding specific issues that pointed to a lack of communication. There were staffing issues that whilst to a certain extent are confidential, the issue of the actual post and who fills it and/or whether it still exists is another thing and should be communicated. There was a lot said about the Trust database for involvement. This will be dealt with separately therefore.

With regard to user involvement, the point was made by one user group that they felt that some staff at directorate level ‘got it’, whereas there is not a cultural understanding of user involvement across the board. There were also other comments made about there being a culture clash between ‘trust world’ and that of some users and user groups ethos.

It was reported by one user group that there was confusion amongst some staff around emailing service users. Some staff were, some staff weren’t which made involvement difficult. Sometimes staff emailed via a third party to get over this. It would appear staff are being confused about emailing users regarding involvement work, and whether they should be emailing services users regarding their own care and whether there were confidential attachments about peoples own care and emailing this sort of thing through unsecured internet routes.

One staff member stated that small numbers of users won’t give you everything but they are well versed in local issues and politics.

It was reported by some staff that because of relationships between certain service users/group and certain executive staff, some staff whose main function is around involvement can feel left out of the loop and undermined. Senior staff need to be very wary of being boundaried around such issues and use the ‘chain of command’ effectively so as not to affect staff morale.

One service user group told the story of how they were willing and actively planning and recruiting staff to support a hearing voices group in one service. There was a promise of funding which didn’t materialise. This left the group feeling let down and therefore more reluctant to be involved with the Trust in other matters.
As is stated in the methodology, NSUN was provided with names and contact details for 50 service user groups of varying nature. On attempting to contact these groups we found that some groups had ceased to exist for some time, others had sprung up in their place, and addresses and emails were out of date. It was fed back to NSUN that some groups had attempted to update their details on the central database held by the Engagement and Responsiveness Team but to no avail. NSUN would acknowledge it is a job in itself to constantly update ‘directories’ as things go out of date almost as soon as they are published.

It is therefore recommended that the E&R Team review the service user and carer groups’ central database and update the details held. This way contact can be established and maintained with groups with the intention of having an on-going dialogue.

Database issues
The database of individual users and carers who could do involvement activities is held centrally by the Engagement and Responsiveness Team. It is useful for them as evidence of involvement they can prove to bodies like the SHA, PCT’s and Monitor. It is also seen as a tool to understand people’s interests in involvement, ensure equity of involvement across the Trust; ensuring people receive the appropriate training for involvement as required including induction training, and as a way for the SUIW’s to pick up issues around involvement across the Trust. It is meant as a way of filling gaps in involvement matched to users skills and the activities requirements, rather than for instance a user group arbitrarily sending a deputy in someone else’s place who may not be suited to the role. There is an obvious tension here of the Trusts’ requirements and perhaps being seen to be controlling against the autonomy of the service user group and their methods of representation.

What follows are some of the comments made regarding the database.

“Database is terrible, hardly anyone gets called” – service user

“One of my biggest annoyances was at their database, I did their induction training, completed information for the database and then received nothing whatsoever except a request to inform them of when I had done their induction training, approximately a year after I’d completed it”. They then went on further to say that “All the requests I’ve had to get involved in interviews have come from people who actually knew me or someone in AWP who’d recommended me” – service user

Another user group expressed the concern that there is no regular contact from being on the database, just when they are needed. Also, that some people haven’t had any involvement which therefore results in local staff choosing users they already know. This has created petty jealousies.

One service user said that although they had completed the recruitment training which was about 18 months ago, they hadn’t done any recruitment in the last year. They went on to say that they were asked to a workshop (unspecified) that wasn’t actually matched to their skills. They also said that other people have said that the database doesn’t work well.
Another service user said that they thought that the database to begin with was a good idea, but they have been contacted only 4 times over 3 years through this method.

There were concerns over inaccuracies on the database. Another service user stated that they felt the information they had to provide to be on the database was “unwieldy”. One of the SUIW’s said that some people did not want to be on the database due to fears about personal information being held, also with regard to information being held and their benefit status. This latter point was also acknowledged by staff members. NSUN was told that some people on the database were deleted by mistake and data protection was breached as one person’s details were sent to another individual.

The centrally held database was seen to break down local relationships by both service users and staff. Although it was also stated that some staff ignore the database sometimes and contact users and user groups directly. It was reported that staff will contact user leaders who then attempt to supply users they are in touch with. This can be onerous if the user leader is running their group in an unpaid capacity for their own aims, as this creates extra unpaid work for them, and might be outside of their remit. It also demonstrates the absence of Service User Involvement Workers who would perform this task.

As mentioned before in more detail, SUNS is not ‘signed up’ to the database. Any involvement required from SUNS members has to be funnelled directly through SUNS. This in itself is fine as SUNS can manage this process and support users as necessary. However, this practice does make the database unworkable in that area. The reasons for SUNS not supporting the database is that some users are frightened to be on the database and being identified as being able to do involvement, even if it wasn’t paid. This is due to users being on benefits and fears over the welfare reforms. Presumably those same users are happy with the system that SUNS use if and when paying people. Some people are just uncomfortable about having their names on a database to begin with. SUNS sense that the Engagement and Responsiveness Team ‘own’ the users on the database which goes against SUNS being an autonomous group.

A service user from the Swindon area that was interviewed stated that they are involved through different methods. Sometimes it is word of mouth with them following up on opportunities, sometimes it is through staff. This could be a SUIW or locality staff.

Part of going onto the database was induction training. This included those who had long standing involvement with the Trust, and this was felt as patronising. It was felt that there was no user involvement in the planning for the induction training.

Part of the point of the database is to show accountability and evidence involvement. Data would be sent to staff with the users consent.

The one carer, who said that the database was working well, was someone who does rather a lot of involvement one way or the other for the Trust. This bears out what others have said about possible inequalities of opportunity.

It is recommended that the Trust audit involvement as some users and carers could be doing rather a lot with the Trust and others nothing. There is a danger that involvement can fall on the
shoulders of those most capable and self sustaining but that the Trust then runs the risk of burning out certain individuals, doesn’t involve people from a range of backgrounds and experiences and misses out on the richness of this, and are left without someone to backfill this involvement if that person is not well or absent for whatever reason.

A service user group commented that invitations for certain events were sent out to individuals on the database but not also via user groups. It was felt that the Trust were missing an opportunity to network and have a wider reach.

**Partnership working**

A partnership is an arrangement where parties agree to cooperate to advance their mutual interests. Firstly there have to be those mutual interests. It is not always easy to work with users on issues as sometimes users and carers see things completely differently to the way statutory mental health services do, give things different weightings in importance, or have alternative perspectives/solutions to issues altogether.

It can be that one person’s partnership is another person’s arena for confrontation. Partnership is in the eye of the beholder, and if one ‘partner’ does not feel as such, then it is wrong to describe the relationship as a partnership. Being in a relationship confers on it a level of mutual understanding, common goals, and an equality of power.

None of the service users or user groups spoke about partnership working, so it is hard to comment on this for the review.

NSUN did pick up from staff a willingness to work in a partnership way. Some staff came across as understanding the dynamics about this possibility better than others when it came to the context of working with service users. There were enthusiastic individuals in the user/carer community within AWP who are willing to work in partnership. In discussions it appeared there was a great deal of scepticism from some user groups and individual users or carers to whether partnership working was indeed possible or ideal.

An example is that Bristol Patients Council reported disappointment that staff from the Trust sometimes didn’t always attend meetings that they were due to be at, and they stated that there was a history of this. Certainly NSUN witnessed absences from staff at the PEEP meeting we attended. This meant that certain agenda items could not be progressed. This issue was also reported to the Trust NED in his dialogue with SURG. This is an example where partnership working could easily break down.

A sense of partnership working can be easily lost if members of forums in the Trust do not attend meetings. Obviously it is courteous to give apologies and one senses that that happens, but that the absence is not always covered by other staff attending in place. Of course, emergencies arise and everyone accepts this, but it can be very frustrating for services users and carers to make the effort to attend and be active members of meetings, see that agenda items are not covered and agreed actions may not be followed up, by the absence of staff from those meetings.
Another service user who runs a user group and sits on various forums commented that there wasn’t always an understanding of partnership working from the statutory sector. It can be difficult to conceive of being in a partnership when you are an individual or small group without funding when comparing yourself with a large multi-million pound organisation, with many assets and resources at hand.

There was also feeling when in discussion with user groups that staff in the Engagement and Responsiveness Team were less visible to them in the field. People said that they haven’t seen them at meetings, or that they have little contact with them in other ways. It maybe that people are used to seeing those in their immediate health and social care community around them, and used to Service User Involvement Workers, from whatever time, working closely with them. It would also appear that they didn’t have an appreciation of what the E&R Team do.

It is recommended that the Engagement and Response Team make the effort to reach out to communities more. It is understood that they can’t be everywhere all of the time, but it might help if they prioritise attending meetings occasionally to be seen and active.

It is also recommended that the Engagement and Response Team devise a way of regularly reaching out to user groups, in line with any strategy, so that they can keep in touch, float ideas, form relationships and so further partnership working. An occasional newsletter by email on updates, opportunities, and even sharing ideas and issues from groups could be considered.

The recommendations are all part of a strategy to be in touch with the various communities more and be seen as less central and distant from some. It is understood that the Trust requires certain tasks to be performed from the team which require them to be at HQ, but some strategically worked outreach would go a long way to dispel any myths and start opening doors for better working relationships with service user groups. The groups themselves of course have to be willing to open the doors their end.
Conclusions

General commentary
To remind the reader, user and carer involvement can happen at an individual, operational and strategic level within an NHS Trust. This is a complex landscape, as can be seen from the findings above, as to where information is put forward on patient and carer experience, gathered and analysed, and subsequently used at what level for service improvement, and to better patient experience. What can also be gleaned from above is that you cannot compare organisations or benchmark them easily. No organisation or part of one is truly the same as another, and as previously stated, standards on user/carer involvement do not exist. Indeed, a lot of user/carer involvement is still ‘works in progress’.

User and carer involvement activities are therefore many and varied, at least aimed at meeting the requirements of Section 242 of the NHS Act 2006, and at most from a consumer perspective, tipping the balance of power to where the ordinary person has more of a say in the running of things. User and carer involvement has to be a concerted effort; otherwise gains can easily be lost. The culture of involvement has to become embedded within the organisation.

A staff member said that there was the full range of attitudes amongst staff towards service users. This ranged from paternalistic and power holding, through to empowering and having the ability for wider working. NSUN agrees that this can be seen in all NHS mental health trusts across the land. Some ventured that there should be a more of a recovery focus to working with service users, one which also helps staff to let go of some of the power in the relationship, and treats people with “intrinsic humanity”. Attitudes towards people count. Attitudes are arguably the hardest thing to change in people, so if they don’t value people with mental health problems, then they won’t really believe in user/carer involvement as a useful process, a way of empowering individuals, or a right for people to have a say in their lives. If enough people within the organisation believe this is the way forward, and make it happen, they just get on and do it and can act as a catalyst to change the culture of the organisation.

It should be stressed at this juncture however, that throughout this process, whilst many concerns and issues were raised, there was also unequivocal praise given by services users and carers for ‘good staff’. Those staff who performed their role as professional carer in whatever way to great effect, or indeed those staff who saw the value of user and carer involvement and paid attention to making this happen. One service user who had a very good experience of staff care said that there was “thinking outside of the box” that enabled their recovery from being an in-patient to successfully being introduced back into the community.

From a corporate perspective, one senior Trust staff member said that the Trust needs to be less “risk averse” in how it operates. NSUN would venture to say that in this day and age, the Trust must be positive thinking. Staff try, or should try, to imbue this in their individual working with people in mental health distress and crisis. It stands to reason therefore that if an organisation is serious about true involvement and participation, then it must take a positive stance towards it.

Of course there are tragedies that the media love to highlight, somewhat out of all proportion sometimes to the wider mental health landscape. There are always challenges that seem to come
out of nowhere to disrupt the normal course of activity. The eventual passing of the new Health and Social Care Bill will potentially have enormous effects on the way services are commissioned and operate. This last point doesn’t even take into consideration other ongoing government initiatives like Personalisation which also challenges traditional service models and service user relationships with professionals. There is never a good time to make changes if one is bogged down by these things. Therefore, the time is right now to really move the agenda on and arguably be better prepared and able to deliver on government proposed initiatives.

Within the Trust there is undoubtedly a lot of information being processed from surveys and community meetings and themes drawn from complaints, and PALS work etc. Some of this finds its way up to the Executive Board. The Head of Engagement and Responsiveness has drawn up what are very complex flow diagrams of how sources of information on patient experience are gathered, reviewed, and the process for it going to the Trust board.

However, much of this is Trust generated information and in talking to users and carers there was a sense of frustration that their issues were not being heard at the top levels. The controlled funnelling of information is useful to AWP Trust to know how it is performing and what the patient experience is. However, NSUN didn’t get a sense that users or carers with concerns were able to access a mechanism whereby these were presented to senior management, be seen to be heard, and responded upon accordingly (depending on any confidentiality issues of course). It is a difficult task to keep a Trust Executive and Board properly updated to effectively carry out their duties without bogging them down in too much detail. However, as the saying goes, ‘the devil is in the detail’. There is no conclusive road map to any of this, and this therefore is the joy, or frustration, of operating at whatever level within or without a large organisation like an NHS trust.

It may well be that if AWP Trust seek to empower the individual more in their own care, then this would solve some of the issues early on in proceedings. If there is good involvement activity with people on a personal basis, helping people to gain some emotional intelligence and life handling skills that will sustain them in being who they want to be in the bigger wide world, then ‘recovery’ as stated in the Trusts corporate aims has happened.

Options for the Trust

Involvement at a Service User Level
The Trust CEO made the comment that it is important to the core work of the Trust that they concentrate on the individual and do this around care planning, helping build resilience, consider long term interventions and encourage self management. NSUN would agree that this is the most important place to start – individual involvement. This is where the most difference can be made to the most people. Not everyone is interested or indeed motivated, by whatever reason, to become involved in operational or strategic involvement.

Whilst this individual involvement could be argued to fall outside of the remit of this work, NSUN took the view that it is intrinsic to the success of ‘involvement’ that people are empowered to be involved in their own care/treatment/recovery – whatever paradigm the consensus subscribe to.

NSUN does not itself subscribe to any one model or philosophy present in the mental health arena. Having said this, it does believe that service users must have more choice and control in their lives
and in the mental health services or support that they receive which lead to individual service user defined outcomes. There are many models, ways of working, and philosophies that enable this. NSUN certainly believes and advocate for user led ways forward.

It is for the Trust to work with service users to decide what they feel is the appropriate way ahead, whether this is based on a particular recovery model, variety of treatments or holding to certain values.

Therefore, NSUN recommends that the trust looks at how it engages with service users at an individual level, research ‘recovery models’ and look at user led initiatives, and co-produce with users and carers a philosophy that is recognised and operated from the ‘board to the ward’. This is no mean feat but one which is being explored in other mental health NHS Trusts.

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Involvement at an Operational and Strategic Level - Options
This would be to address the Trust’s requirements to meet Section 242 of the NHS Act 2006, and to be better at user and carer involvement in a systemic and cultural way.

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<td><strong>Do nothing and carry on as you are!</strong> This is always an option. It would however be a missed opportunity to take stock and work collectively and creatively to improve upon practice. <em>This doesn’t feel in tune with the enthusiasm that came across from AWP Trust staff to do better. Therefore this is not really an option to take.</em></td>
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<td><strong>Make minor changes</strong> as in the recommendations in the findings section above, refresh the strategy, tighten up practice, focus outwards more than inwards with involvement to build better relationships with users/carers and user groups. <em>This could be the safest option but NSUN believes runs the risk of not getting to the core of the issues and inertia soon setting in on all sides.</em></td>
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<td><strong>Make moderate changes</strong> by carrying on collating patient experience evidence and having systems in place to improve services from this, but contract all service user and carer involvement out to an external agency. <em>This is not unprecedented on a smaller scale, and could solve some of the ethical issues around involvement and win back more enthusiasm from disengaged service users and carers.</em></td>
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<th>Option 4</th>
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<td><strong>Make major changes</strong> by rethinking involvement and participation and adopt wholly a co-production culture and of ways of operating. <em>This would be a whole systems approach which would be more adventurous, take strong leadership, but which could yield the biggest and more sustainable results</em></td>
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Early on in this report, Arnstein’s ladder of citizen participation is referred to. There have been a number of diagrammatical versions of Arnstein’s ladder (two shown) used to conceptualise the idea of levels of participation and conflicting power agendas. This is a helpful model that has stood the test of time. However, more recent debates have argued the limitations of such a model. Tritter and McCallum point out, ‘A linear, hierarchical model of involvement (Arnstein’s ladder) fails to capture the dynamic and evolutionary nature of user involvement.’ Therefore it might also be helpful to look elsewhere for guidance around involvement.

Frameworks

**MARD framework**
A proposed framework for involvement could be built along the lines that were recommended in the Making a Real Difference report for the National Institute for Mental Health England (NIMHE)\(^{35}\). NIMHE was a part of the Department of Health that and had service development programmes and regional development centres, and set out to put people who use mental health services at the centre of everything it did. This was the first time a user and carer team worked to devise a whole systems approach to a national mental health organisation. Report recommendations led to subsequent products that were also produced by groups of users and carers.\(^ {36}\) Care must be taken as updates have not been made to these reports in the demise of NIMHE, but these are useful.

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| 1. **Stating a clear purpose for the involvement of service users and carers in AWP Trust.**  
  This would be to make it clear to all what users and carers can get involved with and why.  
  This could be outlined in a strategy which should also seek to increase the influence at least and ideally the power balance in favour of users and carers in AWP Trust. |
| 2. **A positive organisational culture.**  
  This is so involvement can flourish. Measure might include service user and carer focused leadership, more involvement in governance structures, staff development, further employment of service users and carers, setting out to ensure diversity, resources to make it happen, regularly monitoring and reviewing the impact of what has been out in place. |
| 3. **Provision of support to be involved.**  
  Ensuring diversity and flexibility around involvement, meeting practical and emotional support needs to facilitate involvement, which includes clear accessible information, prompt payment of expenses and fees, administrative support to those individuals without support elsewhere, and capacity building and training. |
| 4. **Structures for empowerment and representation**  
  Regular mapping of local groups and connecting these to AWP Trust so that they can be informed of and influence the work of AWP Trust, work in partnership and co-produce products and projects with AWP Trust, and enable user led alternatives to mainstream provision. |

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\(^{35}\) Making a Real Difference – Strengthening Service User and Carer Involvement in NIMHE – HASCAS, 2005  
\(^{36}\) Downloadable from http://www.nsun.org.uk/get-involved/survivor_involvement/
**PPPI Framework**

When NIMHE was closed the National Mental Health Development Unit (NMHDU) was formed. NSUN led a coalition of mental health organisations to assess and promote involvement of mental health service users and carers in all aspects of the NMHDU’s work programmes from June 2009 until March 2011.

Alison Faulkner conducted a report for NSUN and proposed baseline standards for good practice and recommended next steps for the future of involvement in NMHDU. She stated ‘in setting baseline standards for involvement, consideration needs to be given both to issues of good practice and to the potential for monitoring and evaluating progress.’

She calls this the **Purpose, Presence, Process, Impact (PPPI)** approach:

- **Purpose**: having a clear purpose for involvement enables everyone to understand their role and avoids the risk of tokenism and involvement for its own sake.
- **Presence**: the number of service users and carers involved; their characteristics in relation to the project/programme (e.g. age, gender, ethnicity, specific (service/diagnosis/treatment) experience, and so on);
- **Process**: at what level in the project/programme are service users and carers involved: what role(s) are they occupying? How is the process of involvement experienced by all? What support do they have access to: is the programme or work stream engaging good practice guidelines to involve people?
- **Impact**: what impact – if any – are service users or carers having on the programme or work stream? What impact is the involvement having on them?

A fuller explanation of the baseline standards are:

**Purpose**

The purpose of involvement needs to be clearly stated so that service users and carers know what they are getting involved in and why. The overarching purpose might be to increase the influence of service users and carers in projects/programmes, and beyond: in improving and developing services and to build capacity to support involvement. However, each individual work programme, project and role will need to have its own clearly articulated purpose for involving service users and carers. Explicit clarification of the purpose of involvement can help to identify roles and potential activities for service users and carers as well as an appropriate and transparent recruitment process. If, for example, it is required that a service user or carer sit on a board to represent the views of others, then they will need to be recruited from a wider group or network, and time will need to be given for them to consult with their wider constituency in between meetings.

**Presence**

Service user and carer involvement has taken and continues to take a number of different forms, both individually and collectively. A number of different roles have emerged for the involved service user or carer. People have been ‘ambassadors’ for some programmes, been employed as Expert

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Advisors, attended as members of reference groups or on programme boards and engaged in a number of different activities depending on the nature of the work. Several of these roles and positions have worked well; having a clear purpose for involvement can make the role(s) easier to identify. This is demonstrated by both the development of the role and the preparation for it (e.g. a process for recruitment, role descriptions). The role with a purpose might be one of the following (although overlap is clearly possible):

- Ambassador (i.e. committed to the ethos of the work stream or programme, promoting it, spreading the word, engaging others)
- ‘Critical friend’ (i.e. both programme and involved users/carers able and prepared to engage in meaningful debate to reach a satisfactory negotiation of work programme/policy/delivery)
- Delivery agent (i.e. working directly with programme members to deliver the work of the programme)
- Co-worker (employed as a member of the team to deliver the work)

**Process**

The key issues that fall under this heading are as follows:

- Clear communications
- Support for involvement:
  - Administrative
  - Supervisory
  - Emotional
- Training to enable equitable involvement
- Payment of fees and expenses
- Feedback to all who have been involved about the results of that involvement
- Provide a range of different activities or ways of being involved in order to attract a wider range of service users and carers
- Flexibility – to enable people to take advantage of different opportunities and to move in and out of involvement when they wish to or need to.
- One way of describing the process is to look at the levels of involvement as has been conceived of elsewhere (based loosely on Arnstein’s ladder of participation):

  - **Level 4:** Encouraging/ providing a platform for independent initiatives
  - **Level 3:** Acting together, in partnership or co-production
  - **Level 2:** Deciding together: seeking joint decisions
  - **Level 1:** Consulting on decisions, listening to opinions

**Impact**

This is the hardest element of involvement to establish, but also the most important. The questions to address here are: how do we know that service users or carers have been involved in a programme or piece of work? What difference have they made? Is the difference positive or negative? Has involvement strengthened the programme, improved its relevance to or influence on local services?
Impact might usefully be explored in the following areas:

- **Ethos**: has the involvement of service users and/or carers influenced the ethos and values of the project or programme: made it more acceptable and accessible to services and people locally? Made it more inclusive of diverse and marginalised groups?
- **Policy and Planning**: has the involvement of service users and/or carers influenced the development of policy or the planning of the project (at governance level)? Is it possible to pinpoint specific decisions or directions taken by the programme that was influenced by service users and/or carers? Have specific developments been designed or led exclusively by service users or carers?
- **Delivery**: has the delivery of the project been influenced by service users or carers?
- **Outcomes and outputs**: have the outcomes of the programme been influenced by service users or carers? Have any of the materials produced been designed or contributed to by service users or carers?

Whilst NMHDU has also closed, the above are being widely adopted at a strategic level and with partner organisations to NSUN. AWP Trust is already delivering on some of the elements above. A way ahead could be to work towards adopting the PPPI approach in its entirety.

**Co-production**
The AWP Trust CEO talked about adopting a culture of co-production within the organisation. To do this, it is important to know a little more about where this term came from. The following explanation comes from ‘A Manifesto for growing the core economy’.

“The term ‘co-production’ was coined originally at the University of Indiana in the 1970s when Professor Elinor Ostrom was asked to explain to the Chicago police why the crime rate went up when the police came off the beat and into patrol cars. She used the term as a way of explaining why the police need the community as much as the community need the police.”

“It was used again in the UK by Anna Coote and others at the Institute for Public Policy Research (IPPR) and the King’s Fund to explain why doctors need patients as much as patients need doctors and that, when that relationship is forgotten, both sides fail. It was then developed and deepened by Professor Edgar Cahn, the Washington civil rights lawyer.”

“The word ‘co-production’ is increasingly used in policy-making circles on both sides of the Atlantic. It is dropped into speeches by politicians of all persuasions. It is cited in support of a range of different innovations: some deserve it and some do not. When a good idea becomes a buzzword as this one has, there is always a risk that it’s meaning and purpose will be distorted. In the case of ‘co-production’, there is a danger that the radical critique of public services that it presents will be lost in the noise.”
“This is not about consultation or participation – except in the broadest sense. The point is not to consult more, or involve people more in decisions; it is to encourage them to use the human skills and experience they have to help deliver public or voluntary services.”

The elements of co-production

“Public organisations and charities that set out to co-produce with clients, and their families and neighbours, will have a range of different characteristics. They will not necessarily all look the same, but similar processes will be in place, which incorporate the following:

- Provide opportunities for personal growth and development to people, so that they are treated as assets, not burdens on an overstretched system.
- Invest in strategies that develop the emotional intelligence and capacity of local communities.
- Use peer support networks instead of just professionals as the best means of transferring knowledge and capabilities.
- Reduce or blur the distinction between producers and consumers of services, by reconfiguring the ways in which services are developed and delivered: services can be most effective when people get to act in both roles – as providers as well as recipients.
- Allow public service agencies to become catalysts and facilitators rather than simply providers.
- Devolve real responsibility, leadership and authority to ‘users’, and encourage self-organisation rather than direction from above.
- Offer participants a range of incentives which help to embed the key elements of reciprocity and mutuality.”

To signify SCIE’s new approach to engagement and participation it was recommended that they start to describe their work with users and carers as co-production from 2012 onwards. This would ensure that SCIE is using the most up to date terminology and allow them the opportunity to play a more visible role in defining co-production. This may be the opportunity for AWP Trust to define co-production within a mental health NHS setting.

Final word

None of the above is mutually exclusive, and indeed there is overlap between them. The important thing is that involvement is believed and enacted throughout the organisation as an ethos, and is fully resourced.

NSUN recommends that AWP Trust work with users and carers to consider a way ahead utilising some or all of the concepts explained above.

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Appendix A - List of recommendations

1. It is recommended that the Trust revisit the purpose of this forum with a view to the future establishment of HealthWatch and their developing remit. Page 41

2. It would be good practice for AWP Trust to invest in user and carer involvement in research. Therefore, a start would be the Service User Research Forum group being resurrected. Page 42

3. It is recommended that the PEEP meeting is reviewed as to its purpose and who it serves. Page 43

4. It is recommended that the Trust consider some of the barriers to involvement that this client group have, and work to make meetings more accessible for all. This may involve slowing the meeting pace down and ensuring hearing loop systems are available for example. Page 48

5. NSUN recommends that AWP Trust revisit their payment policy and mechanisms to ensure they are up to date with current national guidance, and also consider the provisioning of specialist welfare advice for service users who undertake involvement for the trust as benefits recipients. Page 50

6. Another thing of note is that that the minimum wage was increased from 1st October 2011. £6.08 per hour is the main rate for workers aged 21 and over. Any involvement fees that the Trust make should reflect this increase as per the guidance ‘Reward and Recognition’ DH 2006. Page 51

7. It is recommended that the user involvement staff within the Engagement and Responsiveness Team reach out to certain user groups to dispel any myths around knowledge and understandings, with a view also to learning from those groups about their values. Page 53

8. NSUN recommends that the Trust invest in at least one SUIW per SBU to enable the effective and user friendly provision of development so that user and carer involvement can be raised in profile amongst staff and users/carers, be adequately resourced, and properly supported to happen effectively. Page 54

9. NSUN recommends that the SBU management team should include the SUIW’s in their annual planning of the SBU to ensure that those workers can be more strategic within the SBU to ensure effective user and carer involvement and their part in this. This would help to cement their role within the SBU, and make clear to staff their role and importance to successful involvement. Page 55
10. NSUN recommends that the Trust regularly audits meetings which it sees as falling under Section 242 of the Act to ensure that user and carer involvement takes place as is required. Page 60

11. AWP Trust centrally should assertively reach out to SURG again in an attempt to forge working relationships, resolve differences, and come to some understanding over certain issues. Page 65

12. This practice could be improved for all involved as stated above, and should be investigated as a matter of urgency with a view to rectifying the practice or at least making it plain to all, when exactly individual service users in the Swindon area can be approached to be involved outside of those connected to SUNS. Page 65

13. It is therefore recommended that the E&R Team review the central database and update the details held. This way contact can be established with groups with the intention of having an on-going dialogue. Page 67

14. It is recommended that the Trust audit involvement as some users and carers could be doing rather a lot with the Trust and others nothing. There is a danger that involvement can fall on the shoulders of those most capable and self sustaining but that the Trust then runs the risk of burning out certain individuals, doesn’t involve people from a range of backgrounds and experiences and misses out on the richness of this, and are left without someone to backfill this involvement if that person is not well or absent for whatever reason. Page 68

15. It is recommended that the Engagement and Response Team make the effort to reach out to communities more. It is understood that they can’t be everywhere all of the time, but it might help if they prioritise attending meetings occasionally to be seen and active. Page 70

16. It is also recommended that the Engagement and Response Team devise a way of regularly reaching out to user groups, in line with any strategy, so that they can keep in touch, float ideas, form relationships and so further partnership working. An occasional newsletter by email on updates, opportunities, and even sharing ideas and issues from groups could be considered. Page 70

17. Therefore, NSUN recommends that the trust looks at how it engages with service users at an individual level, research ‘recovery models’ and look at user led initiatives, and co-produce with users and carers a philosophy that is recognised and operated from the ‘board to the ward’. This is no mean feat but one which is being explored in other mental health NHS Trusts. Page 73

18. NSUN recommends that AWP Trust work with users and carers to consider a way ahead utilising some or all of the concepts explained in the last chapter. Page 78
Appendix B - List of Options

Community Engagement and Involvement Strategy

A. To update the current Community Engagement and Involvement Strategy with what is said above, to be reviewed at the end of 2012.

Or

B. To completely rethink what the Trust wants to achieve from involvement from an individual, operational and strategic level, and co-write a new strategy with users and carers to include current thinking around co-production as a way of operating.

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Involvement at an Operational and Strategic Level

**Option 1**

**Do nothing and carry on as you are!** This is always an option. It would however be a missed opportunity to take stock and work collectively and creatively to improve upon practice. *This doesn’t feel in tune with the enthusiasm that came across from AWP Trust staff to do better. Therefore this is not really an option to take.*

**Option 2**

**Make minor changes** as in the recommendations in the findings section above, refresh the strategy, tighten up practice, focus outwards more than inwards with involvement to build better relationships with users/carers and user groups. *This could be the safest option but NSUN believes runs the risk of not getting to the core of the issues and inertia soon setting in on all sides.*

**Option 3**

**Make moderate changes** by carrying on collating patient experience evidence and having systems in place to improve services from this, but contract all service user and carer involvement out to an external agency. *This is not unprecedented on a smaller scale, and could solve some of the ethical issues around involvement and win back more enthusiasm from disengaged service users and carers.*

**Option 4**

**Make major changes** by rethinking involvement and participation and adopt wholly a co-production culture and of ways of operating. *This would be a whole systems approach which would be more adventurous, take strong leadership, but which could yield the biggest and more sustainable results*