

Patient and public partners briefing master sheet v0.2

Document history

Date	Creator	Distribution	Updates
18.02.10	E Code A	Code A Dickon Weir-Hughes, Code A A Code A	Created to provide briefing prior to 23.02.10 patient and public partners meeting
25.02.10	E Code A	N/a	Update AvMA details
15.04.10	E Code A		Update to include A Dignified Revolution

Action on Elder Abuse

Daniel Blake – Policy Manager Attended last meeting

Aims and overview

AeA work across the four countries of the UK and aim to challenge elder abuse within people's own homes (whether by family, friends or paid staff), within sheltered housing, and within care homes and hospitals. It was established in 1983 and are a small charity, based in South London, and is funded through grants (including various grants from DH), donations and membership fees. As well as its campaigning work, it run a helpline, produce newsletters, publications, conferences, and training on elder abuse issues. It also operate a specialist helpline for Southern Cross Healthcare, the biggest provider of residential care in the UK.

Code A

Key personnel and links

Membership is open to all including patients and family members, people working in the sector, professionals and academics. Its board of trustees is elected by its membership. Their CEO is Gary FitzGerald, Daniel Blake is their policy manager. A number of celebrities have publically supported its work, including Tony Robinson and Richard Briars. It has strong links with A Dignified Revolution, a Welsh campaigning organisation. It has long standing links with Age Concern and at one point shared offices.

Involvement with NMC and related issues

AeA have been vocally critical of the NMC's work in the past, in particular in relation to the Haywood case – they know Mrs Haywood well and she is speaking at their upcoming conference. However they have made clear their desire to work with the NMC in the capacity as a “critical friend” and have invited us to some of their events. They took part in a working group on our raising concerns work, and are hosting a workshop for us at their conference in March. They originally asked us to open the second day of the conference for them, but we have not been able to do this.

Likely issues:

- Whistleblowing
- No Secrets – they were involved with the DH England's adult protection review and have been highly critical of the consultation process and DH's apparent lack of action in this area. They are aware that the NMC may be doing some work in this area and are likely to ask about it.

Action for Sick Children

Margaret Jeal, Trustee Attended last meeting

Aims and overview

AfSC refer to itself as “the UK’s leading children’s healthcare charity”. It is a small charity run largely by volunteers and has been in operation for over 40 years. It campaigns in particular on hospital services for children and publishes a variety of information for children and their families related to healthcare, in addition to resources for healthcare professionals. It is England based but is affiliated with organisations in Wales and Scotland.

Key personnel

Margaret is a trustee and a former childrens nurse.

Involvement with the NMC and related issues

Margaret was involved with the pre-registration nursing education review and sat on the Child Field working group.

They are members of National Voices.

Action Against Medical Accidents (AvMA) Updated 25.02.10

Action Against Medical Accidents

<http://s-app-2cm-v01:5555/NMC/sfa/accts/edit.aspx?id={FACA72C8-8D44-DE11-913C-00505600000D}#>

Aims and overview

AVma is an independent charity which promotes better patient safety and justice for people who have been affected by a medical accident. A 'medical accident' is where unintended harm has been caused as a result of treatment or failure to treat appropriately. It operates across the UK and has recently celebrated its 25th anniversary (it was previously known as Action for Victims of Medical Accidents). As well as campaigning work, it provides a free advice line for people affected by medical accidents and a casework service where required. It maintains a database of clinical negligence solicitors and provides various services to this group, including training, conferences and accreditation programmes. It charges for these services but are keen to stress its independence from the legal profession.

They are often quoted in the press, for instance recently speaking out unfavourable over the GMC's handling of the Gosport case, and very recently (16 February) they gained widespread media coverage for their FOA requests to the National Patients Safety Agency (NPSA) highlighting Trusts failure to comply with patient safety alerts. In the past they seem to have particular links with The Independent.

They have submitted responses to the Ministry of Justice's *Review of Civil Litigation Costs* by Sir Rupert Jackson. They are broadly in support of the findings but want to ensure "equality of arms" for patients. They sit on the No-fault compensation review group in Scotland (with Christina McKenzie).

They support a full public enquiry into failings at Mid Stafford FT.

Key personnel and links

Peter Walsh is their CEO, who has a long track record in patient campaigning. Catherine Hopkins is their Legal Director, and herself a former midwife and lawyer. Malcolm Alexander, Chair of the National Association of Links Members, is on their Board of Trustees.

They run the Patients for Patient Safety programme in collaboration with the NPSA and have strong links with the NPSA.

They are running a pilot scheme on the support of vulnerable witnesses in FtP cases with Witness for the GMC.

AvMA has been working with local patients' group Cure the NHS, providing specialist casework support to individual families who have been subject to the 'independent case note reviews' at Mid Stafford FT.

They are members of National Voices.

Involvement with NMC and related issues/campaigns

AvMA have met with a number of NMC personnel over the past year and have been involved in our working group on raising and escalating concerns (Ian Todd and Peter have known each other for a long while). Of particular interest to them are campaigns for:

- A “Legal duty of candour” (Robbies Law) - a legal requirement to practise being open and honest with patients or their next of kin when harm is caused. We have directed them to relevant areas of the Code but they would like the NMC to openly campaign with them on the issue, which we have not done.
- Indemnity insurance – a particular interest area for Catherine, who published a paper last July on professional indemnity insurance and independent midwives in *Clinical risk*. It concludes that insurance should be made mandatory, but also that "The way in which information should be given is not stated [by the NMC] and the practice is not consistent". She was also invited onto Woman's Hour to discuss this issue.
- Regulation – following *Trust, assurance and safety (2007)* they campaigned for an independent information, advice & advocacy service for patients/members of the public who may need to report a dangerous health professional to the fitness to practise procedures of the regulators (run by AvMA!?).

Ian Todd is speaking at their annual clinical negligence conference in the summer and we are looking at a joint event in the autumn.

They have requested to work with the joint regulators PPI group to help raise awareness of the group amongst patients and to help make information for patients, particularly details of how to make complaints, available on all regulators' websites, including more details about AvMA themselves. This has been approved by the Chief Executives Group.

Catherine Murphy hopes to attend a hearing in the near future as an observer. She attended the 23.02.10 patient public partners group and later emailed to say she was pleased to see us taking a pro-active approach on indemnity insurance and HCSW. She has requested a meeting with Dickon in the near future.

Alzheimer's Society, England

Ben Cavanagh, Policy officer New attendee

Aims and overview

Alzheimer's Society is a membership organisation, which works to improve the quality of life of people affected by dementia in England, Wales and Northern Ireland (note Alzheimer's Scotland is a separate organisation). It has 25,000 members and a network of branches providing support to over 30,000 people a week, in addition to providing advice and guidance on the condition. They have a strong research programme and also campaign for "a fairer deal for people with dementia and their carers".

They have recently gained widespread publicity for their report (*Counting the cost*) on the high cost of dementia care in hospitals and calls for a reduction in the length of stay.

Key personnel and links

Louise Lakey (Senior policy officer) was on the reference group for the review of pre-registration nursing education (Ben is standing in for her as she is unavailable). In late January it was announced that the CEO, Neil Hunt, was to leave after nearly seven years. Ruth Sutherland, the COO, is acting up until a replacement is found. As well as a board of trustees headed by Alastair Balls, they have a number of vice-presidents and ambassadors, including Dame Judi Dench and David Blunkett. They have worked closely with DH England on the National Dementia Strategy.

They are members of National Voices and of the Health Hotel.

Involvement with NMC and related issues

Alzheimer's Society have been working closely with us on the review of pre-registration nursing education. In particular they have adapted the wider consultation for those with an interest in dementia care and are running workshops to aid their consultation response. Their recent Counting the cost report called for nurses to be better equipped to deal with dementia – we issued a public statement supporting this and noting how important this was in our pre-registration education review.

Board of Community Health Councils (CHCs) in Wales

TBC, member New attendee

Aims and overview

CHC in Wales provide advice and help with problems or complaints about NHS services, provide information about access to services and support local people in making their views about services heard. The work of the CHC is steered by its voluntary members, who number approximately 400 in total. There are currently nineteen CHCs across Wales who are supported by a Board of CHCs. However from 1 April 2010 seventeen CHCs will be dissolved and six new CHCs created in their place, with the same boundaries as the new Health Boards. There will also be changes to the Board of CHCs in Wales, which will be made smaller and have its chair and vice chair elected by the whole membership.

Key personnel and links

Mrs Carol Lamyman-Jones is the Director of the Board of CHCs. Each local CHC has a number of members appointed to it by the Minister for Health and Social Services. Members are drawn half from the National Assembly, one quarter from local authority nominations and one quarter from voluntary sector bodies. There are between twelve and twenty members in each CHC appointed by the Minister, but each CHC may co-opt additional members locally if it needs to do so. We are awaiting details of their representative on 23rd.

Involvement with NMC and related issues

The CHCs have largely been concerned with the restructuring of the NHS in Wales of late and, latterly, their own restructure. A number of CHC advice workers attended our workshop for helplines and advice services last year and we have been in touch since, and their consultation and liaison officer (Andrea Matthews) has been supportive in distributing information on our consultations.

Age Concern/Help the Aged

Tom Gentry, Policy Officer Colleague Charlotte Potter attended last meeting

Aims and overview

Age Concern and Help the Aged merged in 2009 and will be known as Age UK from Spring 2010. This “family” will include Age Scotland, Age Cymru and Age NI. The organisation will include the large network of local Age Concern groups, who work locally to support older people, in addition to campaigning, research, product development work and a national information line. The merger has taken a long time to go through and there have been subsequent restructures in the policy team.

Key personnel and links

Tom Wright was appointed CEO in early 2009. Charlotte Potter was their main health policy officer, she was recently promoted and Tom started late last year. We have already met with him to brief him on our work. They have a long standing campaign against malnourishment in hospitals and have produced a resource pack in collaboration with the RCN.

Help the Aged are members of the Health Hotel.

Involvement with NMC and related issues

Age Concern were involved with the development of the *Guidance for the care of older people* and a number of local Age Concern branches have distributed the guidance and accompanying leaflet. Age UK have been involved with our review of pre-registration nursing education, sitting on the Adult Field working group. They are also supporting us in developing targeted consultation documents for older people and their families.

A Dignified Revolution

Aims and overview

A Dignified Revolution (ADR) was established in January 2008 by four people, some of whom are nurses, who want to improve the care of older people in hospital, and largely sparked by incidents of poor care received by loved ones. They are particularly concerned with poor nursing care and believe that some nurses are not interested in “basic care” and instead leave this to healthcare assistants and aim to raise awareness of these issues with professionals and the general public. Key additional areas of concern are the attitudes of nurses and ageism, the hospital environment, nurse education, accountability and regulation and protection of vulnerable adults. All work is undertaken by volunteers and they exist on donations. They run courses for professionals and publish a monthly email newsletter. They concentrate their activities in Wales.

Key personnel and links

Monica Dennis is the Chair and does the majority of the day to day management of the organisation. She is a nurse herself and owns, with her husband, Healthcare Alliance, who conduct training courses and consultancy services for the NHS and voluntary sector. Lorraine Morgan is a prominent member, dealing with the public face of the organisation. She is Academic Manager (Health and Nursing) at the Open University in Wales and also lectures on Ageing, Care Management and Nursing Practice. She is an RCN council member as well as sitting on the Welsh Assembly Government Dignity in Care group

They are active members of the CHRE stakeholder network and have strong links with both Action on Elder Abuse and the Socialist Health Association.

Involvement with NMC and related issues

ADR have been extremely vocal in their criticism of the NMC in the past, including over the Haywood case but going back to before this time. They believe that the current regulatory structure is ineffective *“particularly where individuals have reported nurses and medical staff and received the response is that there is no case to answer, and that they have no right to appeal against the decision”* (ADR website 15.04.10) and hope to influence CHRE to change the performance regulatory framework accordingly. They are particularly against the “no-blame” culture, which they see as lack of accountability, in the NHS. They are concerned about the move away from “practical” nurse education and the increasing divides between registered and unregistered staff.

In the past they have openly spoken out against the NMC and are keen to find examples of poor NMC work. For example they spoke at a regulators conference in late 2008 regarding the perceived poor quality NMC consultation exercise that, in fact, was based on incorrect information. However they have also been constructive more recently in supporting the distribution of the *Guidance for the care of older people* and in publicising consultations and publications through their website and newsletter.

February 2010 Judith Allen dissatisfied with response she received after contact the Professional Advice Centre. Her query was in response to Dickon's statement: "One of the myths that's worth shattering is that there has to be a complaint to the NMC for something to be done, because there doesn't...". A long response was sent but it did not answer the question. [Code A] subsequently answered her query and apologised. Ms Allen suggested more thought needed to be given to the way we respond to members of the public. She also hoped that the advice line would be updated.

March 2010 expressed concerns that expenses not paid for attendance at pre-registration nursing education Q & A event in Cardiff, and use of expensive venue.

National Childbirth Trust

Roxanne Chamberlain, Policy officer Elizabeth Duff attended last meeting

Aims and overview

NCT is the largest UK parenting charity and help over a million mums and dads each year through pregnancy, birth and early days of parenthood. It offers antenatal and postnatal courses, local support and information to help all parents. The NCT started in 1956 and has over 100,000 members across the UK. It campaigns on issues such as choice in place of birth, a better birth environment and raising awareness of the benefits of breastfeeding.

Key personnel and links

Their CEO Belinda Phipps has a strong relationship with the midwifery team. They are members of National Voices.

Involvement with NMC and related issues

The NMC sits on a number of groups with the NCT, including Midwifery 20/20. Currently they sit on the user group for the review of midwives rules and standards. Roxanne in the past was involved with the review of pre-registration midwifery education. As an organisation their position is in favour of maintaining choice in maternity services through the continuation of independent midwifery, and they support setting up a national framework of training and competencies for maternity support workers, including identifying what can and cannot be delegated from a midwife.

National Voices

Jeremy Taylor, CEO Colleague Nick Hoile (Policy Officer) attended last meeting

Aims and overview

Formed in 2008, National Voices is a coalition of more than 200 national health and social care organisations, coming together with the aim of ensuring a stronger voice for all those who come into contact with the NHS and care services, and the voluntary organisations that help them. It is independent of government, although received funding from Department of Health England to establish themselves (they are an England only organisation). It has a complex governance structure involving a Board of Trustees, an Assembly and an Advisory Group. They are largely funded through membership fees and have a small staff of six based in London. It provides briefings to members and campaigns on particular issues. It also has a User Panel drawn from various voluntary organisations they represent. It is currently working on its General Election manifesto which will take the angle of how much 'control' over the direction of the NHS patients and the wider public should have in the future.

The organisation was created from the ashes of the Long Term Conditions Alliance, and there was a degree of discontent about its creation. Although starting out as a highly expansionist organisation, there is a degree of uncertainty around its future.

Key personnel and links

Jeremy Taylor is the CEO, who was appointed last year (he replaced David Pink, who had been the CEO since LTCA). We have strong links with their Director of policy and public affairs, Mark Platt. Their Chair is Jeremy Hughes, who is also Chair of Breakthrough Breast Cancer.

National Voices has particularly strong links with CHRE and hosted joint dinners with them during the party conferences. It is a consortium member of Healthcare Quality Improvements Partnership (HQIP), which includes the RCN. It is a member of the Health Hotel. It regularly works with the Department of Health England and, with the NMC, sits on its stakeholder communications forum. Although its membership is wide, there are some notable exceptions including the Patients Association.

Involvement with NMC and related issues

We have worked with National Voices on a number of occasions, including supporting a session they held with the Irish Travellers Movement in Britain and meeting with their Service User Panel (both late last year). They have been involved in our work on Raising and escalating concerns.

The organisation has a number of Associate Members who pay to publically support the work of the organisation. Jeremy is current trying to negotiate the NMC joining this – Code A and Code A are meeting with him in early March to discuss the way forward.

Parkinson's Disease Society

Daiga Heisters, National Education Advisor Attended last meeting

Aims and overview

The Parkinson's Disease Society was established in 1969 and is a charity providing research and support. It provides information and advice through publications and a helpline, has a network of over 300 local support groups, and campaigns on issues such as free prescriptions and more funding for research. They work across the UK.

Since 1989 they have championed the role of the Parkinson's Disease Nurse Specialist (PDNS), emphasising their importance in delivering against NICE guidelines. This has included jointly investing in the posts with NHS organisations – there are now 230 posts across the UK.

Key personnel and links

Their CEO is Steve Ford, who has been in post since 2005.

It is a member of National Voices and of the Health Hotel.

Involvement with NMC and related issues

Daiga has been a member of the Adult Field working group on the review of pre-registration nursing education.

Patients Association

Kieran Mullan: Director of policy and public affairs Sent apologies last meeting

Aims and overview

The PA is an independent charity that “highlights the concerns and needs of patients”. It is largely funded through individual membership fees (c.£200k 2007/8) and doing “research” amongst its members for external organisations. It has been running for 50 years with a small team, but a relatively high media profile. As well as campaigning work on issues such as better access to information for patients, it runs a helpline (which they are currently expanding), produces information booklets and publishes a variety of “research” reports. It will be launching its general election manifesto in April, and are currently running an online survey for members on what this should contain (update 31.03.10)

Key personnel and links

Katherine Murphy is its director and driving force, and a former nurse. Kieran has a medical background. Claire Raynor is the president, with a number of high profile “Vice Presidents” including Angela Rippon, Baroness Masham of Ilton, Dr Phil Hammond and Sir Richard Branson. They have links with Patient Choices and a variety of local organisations, and in the future hope to launch an awards scheme. Roswyn Hakesley-Brown CBE (former President of the RCN) is chair of PA and has been involved with FEPI on the draft patients’ rights bill. There have been some instances in the past where different members of the organisation have given us, and the media, different messages.

It is currently developing a “Patients Network” of organisations to launch joint campaigns. It is a past-member of the Health Hotel and, with the NMC, sits on DH England’s stakeholder communications forum.

Involvement with NMC and related issues

We have a long track record of involvement with the Patients Association and have met with them recently, including meeting with Code A in early January, and giving their new helpline staff an introduction of FtP on 22 February. Michael Summers (vice-chair of PA, also an FtP parallist) sits on the advisory group for pre-registration nursing education review (PRNE), although has not been able to devote as much time as he would have liked. Katherine and Kieran have been briefed by the PRNE team and will be submitting a response to the consultation.

In August 2009 it published *Patients not Numbers, People not statistics -16 first hand accounts of patient care in hospital* to draw attention to some incidents of poor nursing care. We were not asked to contribute or named directly, although it calls for “cruel” nurses to be struck off the register and for other nurses to “blow the whistle”.

The PA condemns the current “confusion” for patients in CQC’s annual health checks, states that systems regulators are not working effectively together, and has called for reform of the NHS complaints system. It has a long running campaign to highlight patient safety to Boards.

Likely issues:

- Nursing education: The PA are concerned that that nursing education had become too academic and that nurses do not have the practical skills of their counterparts in the past. They feel that people going into the nursing profession have low levels of qualifications, and that higher education institutions did not test to ensure that applicants had the right motivations and temperament to enter the profession. They have spoken out publically in the past against the move to degrees.
- Raising concerns: The PA have stated that health professionals have a responsibility to raise concerns about patient safety and feel that strong local leadership is important.
- Basildon and Thurrock: The PA have welcomed our “pro-active” approach on this issue and hope to see more along these lines in the future.

Welsh Council for Voluntary Action: health, social care and wellbeing network

Rosalyn Williams, of Age Concern Cymru New attendee

Aims and overview

WCVA are a new contact for us, and part of its role is to facilitate third sector representation in key policy developments, largely involving the Welsh Assembly. It promotes and gather consultation responses from the sector, promotes best practice in citizen engagement, shares information and disseminates best practice.

It has a health, social care and wellbeing network which is largely national organisations, and facilitates twice yearly meetings with ministers for health and social care in Wales. They also host regional policy events four times a year. Key areas of work at the moment relate to ensuring effective third sector involvement in social care and in the restructure of health services in Wales.

Key personnel and links

Constance Adams is their Senior Policy Officer for health and social care and is our main contact point. Their strongest links is with the Welsh Assembly and, at a local level, with CVSs (Council for Voluntary Services). Rosalyn Williams works for Age Concern but will be representing the group as a whole.

Involvement with NMC and related issues

Constance and her team have distributed consultation details for us recently, and have facilitated finding organisations to contribute to the review of midwives rules and standards. There may be a particular link to the HCSW agenda as they are used by a number of organisations that they represent. We hope to develop this relationship as a way to access the large number of health charities operating in Wales.

Un-confirmed attendees 18.02.10

Code A

Apologies

Code A

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