



A Year of Engagement

*Annual Report of the National Allied
Health Professions Patients' Forum
2011-2012*

DH INFORMATION READER BOX

Policy	Clinical	Estates
HR / Workforce	Commissioner Development	IM & T
Management	Provider Development	Finance
Planning / Performance	Improvement and Efficiency	Social Care / Partnership Working

Document Purpose	For Information
Gateway Reference	17855
Title	A Year of Engagement
Author	National Allied Health Professional Patients' Forum
Publication Date	20 August 2012
Target Audience	Medical Directors, Directors of PH, Directors of Nursing, Directors of Adult SSs, PCT Cluster Chairs, NHS Trust Board Chairs, Directors of HR, Allied Health Professionals, GPs, Communications Leads, Emergency Care Leads, Directors of Children's SSs
Circulation List	PCT Cluster CEs, NHS Trust CEs, SHA Cluster CEs, Care Trust CEs, Foundation Trust CEs, Local Authority CEs, Special HA CEs, Directors of Finance, Allied Health Professionals, GPs, Voluntary Organisations/NDPBs, Council of Deans of Health, Health Professions Council, Allied Health Professions Federation, Centre for Workforce Intelligence, Skills for Health, Skills for Care
Description	The National Allied Health Professional Patients' Forum was established in 2010 to provide the patient perspective to both inform and influence decisions made by the National Allied Health Professional Advisory Board concerning workforce planning and development for the allied health professions. This report, written by patients, outlines their achievements in 2011/12.
Cross Ref	
Superseded Docs	
Action Required	
Timing	
Contact Details	Lisa Hughes Co-Chair, National Allied Health Professional Advisory Board Professional Leadership Team Department of Health Skipton House 80 London Road SE1 6LH
For Recipient's Use	

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Professions Patients' Forum*

2011 - 2012

Prepared by Steve McNeice

Vice-Chair, National Allied Health Professional Patients' Forum

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Executive summary

This Patients' Forum was established to support and guide the National Allied Health Professional Advisory Board in an attempt to put the patient voice at the heart of workforce planning for the allied health professions. Such an innovative group had not previously been established and so Roswyn Hakesley-Brown CBE Chair of the Patients' Association and a national patient champion was appointed as chair of the Forum.

There have been many highlights and outcomes throughout the year, which were built upon and around the broad range of patients, patient groups and networks represented. These include:

- The creation of the Forum itself has demonstrated how patients and the public can engage effectively and reveal systemic flaws in the way that some policy makers miss the opportunity to communicate with patients and the public.
- The Forum developed a focus group based case study, which demonstrated the poor understanding of the role and function of the allied health professional by patients and the public. This raised the awareness of the Professional Advisory Board for the need for increased visibility of the allied health profession contribution to rehabilitation and re-ablement.
- The Forum initiated and established a database of patient stories about their interactions with allied health professionals.
- The Forum engaged effectively with the 'listening exercise' and emphasised the need to invest in Public and Patient Engagement.
- The Forum is represented on the 'Health Education England Transition Advisory Group' and is stressing the willingness, capacity and capability of patients and the public for Public and Patient Engagement.
- The Forum acts as a driver and catalyst in keeping patients and public at the centre of all initiatives for instance championing the voice of the patient and the public where it is seemingly not being used as well as it could be.
- Members of the Forum have undertaken and supported speaking engagements at national and international conferences.
- The Forum raised papers about national workforce issues including Prosthetics and Orthotics, Pain and Cancer. There continue to be on-going work streams around specific client groups.
- A national award has been established in collaboration with the Patients Association for Allied Health Profession Support Workers.

The costs of running and maintaining this Forum during the financial year 2011/12 amounted to £12k.

Foreword

I congratulate all concerned on the production of this Annual Report for the National Allied Health Professions Patients' Forum.

I would first like to take this opportunity to thank the patients' and stakeholder groups who have given so much to support and contribute to this Patients' Forum, which has meant that the influence of the group has grown steadily and extended ever more broadly. I am particularly pleased that the Patients' Forum have been able to involve some of the more hard to reach groups, who sometimes have a greater need, but I would also like to emphasise that if it were not for this patient and stakeholder involvement, the many achievements and outcomes reflected within this annual report could not have been realised.



I would also like to thank the National Allied Health Professional Advisory Board, whose vision and drive has and continues to ensure that the patient voice is not only heard but is central to allied health professions workforce planning and education.

Despite the current economic situation, the opportunities to help improve patients' health and well-being, and outcomes are there, and all allied health professionals are ideally placed, given their implicit rehabilitation and re-ablement focus, to exploit the many commissioning opportunities that may not have been there before!

So I would further like to highlight the opportunity to join with me and the many other healthcare professionals in the challenge to seek out and work collaboratively with your most valuable, cost effective and underutilised resource that is the patient. The rewards of working co-operatively to this, our common goal, will go a long way to ensuring that we collectively succeed in improving the future of health and social care service provision to all.

I am particularly proud, that this Patients' Forum has taken the opportunity to present its own agenda based upon genuine patient concerns and need. This agenda being presented with a real spirit of collaboration and with a drive and commitment not just to improve but also to achieve. So as workforce planning, pre- and post-registration education and training, and continuous professional development move forward within Health Education England, lessons should be learnt from this unique patient engagement at the same time seizing the opportunity to build upon its shared values and priorities, whilst benefiting from the diverse and broad, but importantly independent views and opinion.

Finally, the National Allied Health Professions Patients' Forum would like to record its gratitude for the wealth of knowledge, skills, experience and care provided in rehabilitation, re-ablement and independent living, that all the many caring allied health professionals provide so willingly day after day, whether working individually or as part of a service provider, who have and continue to help so many patients stay independent and mobile, keeping them out of hospital wherever possible and providing support as needed.

A handwritten signature in black ink that reads "Roswyn A. Hakesley-Brown".

Roswyn Hakesley-Brown CBE
Chair of the National Allied Health Professions Patients' Forum
Chair of the Patients' Association

Patients' Forum Quotations

Bill Davidson, member of the Patients' Forum said: "While I have had only passing experience



of the valuable work of allied health professionals in a relatively healthy life, I have unfortunately had to experience, and appreciate the input of these skilled professionals during the lengthy treatment and care, and eventual death of my youngest son through Hodgkins Lymphoma. His many varied treatments through chemotherapy, stem cell transplant and radiotherapy had been radical, uncomfortable and at times very painful. But his courage and spirit were helped, especially in the later months, by the involvement of very caring nursing staff and the skill and personal attention and encouragement of the physiotherapist and dietician. With their knowledge, gentle coaxing and genuine friendly warmth and concern, they were able to enhance the quality of his remaining days and lift the spirit of both my son and those of us who loved him. I have the feeling that, through their generosity of time, kindness and skill they also received much in return and shared in the sadness of his passing. I will remember them."

Gillian Francis Health Inclusion Worker for Travellers and Gypsies, Homerton University NHS



Foundation Trust said: "it is so important to raise awareness of the culture and health needs of groups seen as 'hard to reach' such as Gypsy Travellers, which is why the London Gypsy and Traveller Unit and I are happy to help and work strategically through the Allied Health Professions Patients' Forum to identify and remove barriers to health care provision, going some way to ensuring that excluded groups are better understood and included as part of

any education and workforce planning. This being highlighted most eloquently by Christine an Irish Traveller who said: "It's interesting how people can change their point of view if they're given enough information"

Philip Satherley, representative from the end-of-life rights charity Compassion in Dying, said:



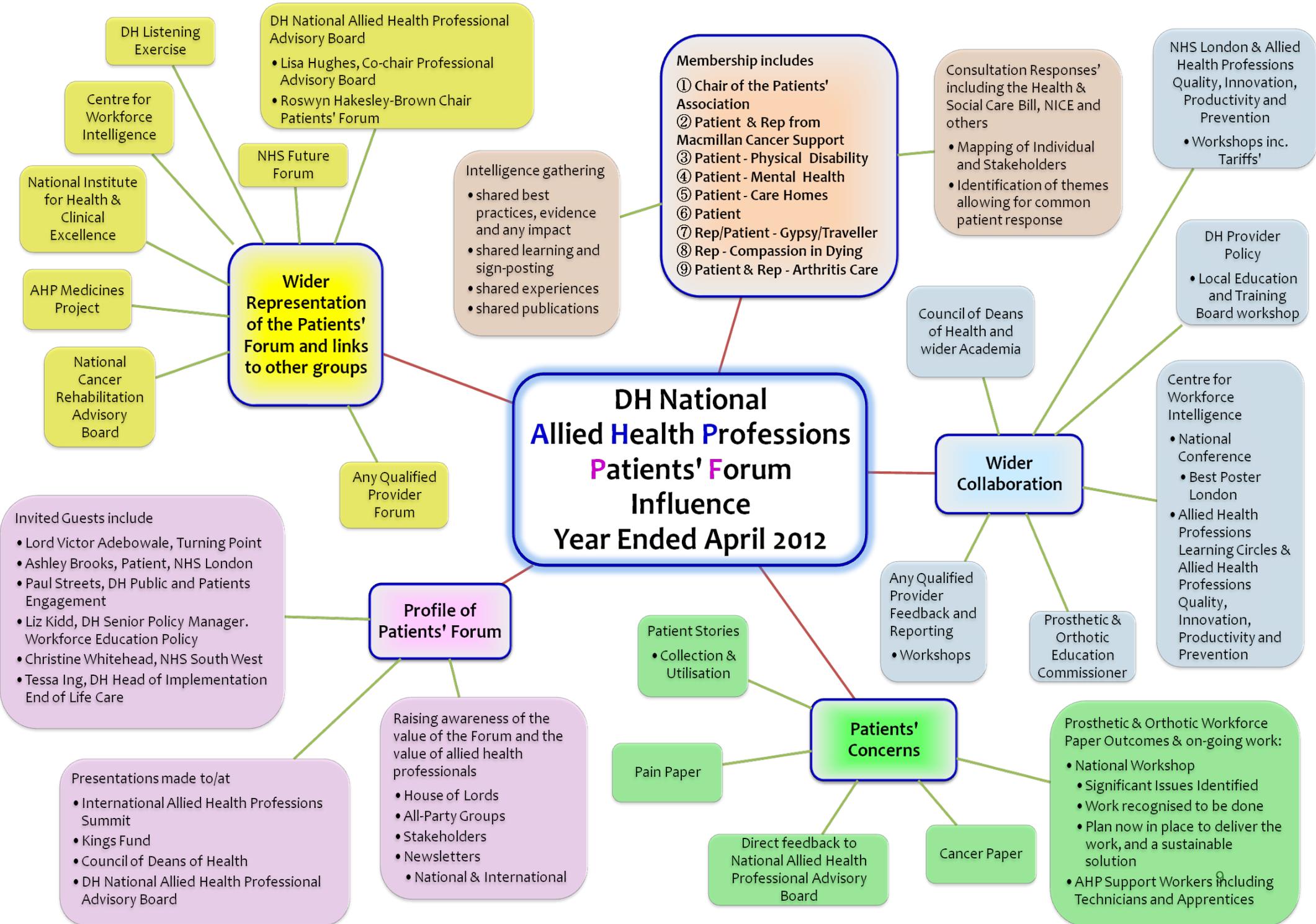
"Allied health professionals are important during all aspects of a patients care and their skills are particularly tested when working with those patients at the end of life. Through the Patients' Forum I am able to raise awareness of end-of-life care amongst allied health professionals and to influence how the workforce is planned, alongside education and training needs. Recently, there

has been an emphasis on allowing people to die in their preferred place of care - something that can only be achieved with the right mixture of health and social care professionals.”

Steve McNeice, Vice chair of the Patients’ Forum said: “As a patient with an array of long-term conditions including double above knee, arm muscles and finger amputations coupled with severe hearing loss; I have and continue to personally experience and benefit from an array of non-specialist and specialist allied health professions clinicians including prosthetists, orthotists, physiotherapists, and occupational therapists; and whilst these individual allied health professions are distinctly different in the skills, knowledge and expertise that they possess and also the services they provide, they are in my opinion inextricably linked in the common goal of all allied health professions, that being to keep the individual patient mobile, independent, dexterous and out of hospital. So as an individual who will need the many skills and expertise of allied health professions’ for the rest of my life, I feel privileged, that I am able to benefit from the mobility and independence afforded to me by my caring allied health professionals’.”



DH National Allied Health Professions Patients' Forum Influence Year Ended April 2012



Wider Representation of the Patients' Forum and links to other groups

DH National Allied Health Professional Advisory Board

- Lisa Hughes, Co-chair Professional Advisory Board
- Roswyn Hakesley-Brown Chair Patients' Forum

DH Listening Exercise

Centre for Workforce Intelligence

National Institute for Health & Clinical Excellence

AHP Medicines Project

National Cancer Rehabilitation Advisory Board

NHS Future Forum

Intelligence gathering

- shared best practices, evidence and any impact
- shared learning and sign-posting
- shared experiences
- shared publications

Membership includes

- ① Chair of the Patients' Association
- ② Patient & Rep from Macmillan Cancer Support
- ③ Patient - Physical Disability
- ④ Patient - Mental Health
- ⑤ Patient - Care Homes
- ⑥ Patient
- ⑦ Rep/Patient - Gypsy/Traveller
- ⑧ Rep - Compassion in Dying
- ⑨ Patient & Rep - Arthritis Care

Consultation Responses' including the Health & Social Care Bill, NICE and others

- Mapping of Individual and Stakeholders
- Identification of themes allowing for common patient response

NHS London & Allied Health Professions Quality, Innovation, Productivity and Prevention

- Workshops inc. Tariffs'

DH Provider Policy

- Local Education and Training Board workshop

Council of Deans of Health and wider Academia

Wider Collaboration

Centre for Workforce Intelligence

- National Conference
- Best Poster London
- Allied Health Professions Learning Circles & Allied Health Professions Quality, Innovation, Productivity and Prevention

Any Qualified Provider Feedback and Reporting

- Workshops

Prosthetic & Orthotic Education Commissioner

Profile of Patients' Forum

Invited Guests include

- Lord Victor Adebawale, Turning Point
- Ashley Brooks, Patient, NHS London
- Paul Streets, DH Public and Patients Engagement
- Liz Kidd, DH Senior Policy Manager. Workforce Education Policy
- Christine Whitehead, NHS South West
- Tessa Ing, DH Head of Implementation End of Life Care

Any Qualified Provider Forum

Raising awareness of the value of the Forum and the value of allied health professionals

- House of Lords
- All-Party Groups
- Stakeholders
- Newsletters
- National & International

Presentations made to/at

- International Allied Health Professions Summit
- Kings Fund
- Council of Deans of Health
- DH National Allied Health Professional Advisory Board

Patients' Concerns

Patient Stories

- Collection & Utilisation

Pain Paper

Direct feedback to National Allied Health Professional Advisory Board

Cancer Paper

Prosthetic & Orthotic Workforce Paper Outcomes & on-going work:

- National Workshop
- Significant Issues Identified
- Work recognised to be done
- Plan now in place to deliver the work, and a sustainable solution
- AHP Support Workers including Technicians and Apprentices

About the National Allied Health Professions Patients' Forum

Purpose

To provide the service users and their carers' perspective to both inform and influence decisions made by the National Allied Health Professional Advisory Board¹ concerning workforce planning and development for the allied health professions² collectively as well as individually at a national level.

Membership

Roswyn Hakesley-Brown, Chair of the Patients Association is the Chair of this Patients' Forum, and together with Steve McNeice, the Vice-chair, provide strong leadership in order that the independent patient voice is more prominent.

The membership deliberately reflects the diverse range of patients and service users that allied health professionals work with, and is a combination of service users, carers and organisations representing patient groups with each representative encouraged to have a named alternative. The outreach of the group has grown steadily and extended ever more broadly and the forum has benefited from patients representing Cancer, Physical Disability, Mental Health, Care Homes, Carers, Arthritis and the Gypsy and Traveller Community, as well as stakeholder representation from Macmillan Cancer Support and Compassion in Dying. The membership is iterative in nature, and is well supported by the Department of Health in terms of all secretariat and advisory services.

Functions

To ensure, that the patient's voice is heard and considered in all decisions made by the National Allied Health Professional Advisory Board.

To report and guide the National Allied Health Professional Advisory Board with recommendations concerning all aspects of allied health professions workforce planning, education, training and development, from the service user's perspective, with particular reference to contemporary issues.

To receive and review outcomes of recommendations made to the National Allied Health Professional Advisory Board with a view to making further recommendations if required.

¹ The National Allied Health Professional Advisory Board provides professional oversight and expertise to the Department of Health, informed by patients and external partners, to influence decisions about the planning and development for the allied health professions and secure the workforce necessary to improve the quality of care.

² Allied Health Professions within the scope of the Patient's Forum are Art therapists; Chiropodists & Podiatrists; Dietitians; Drama therapists; Music therapists; Occupational therapists; Orthoptists; Paramedics; Physiotherapists; Prosthetists & Orthotists; Radiographers – therapeutic and diagnostic; Speech & language therapists

Process

The Forum meets bi-monthly in advance of the National Allied Health Professional Advisory Board in order that any feedback can be taken account of in a timely manner. Joint meetings of both the National Allied Health Professional Advisory Board and the Patients' Forum have evolved and have found to be extremely useful in collaborative working.

A project management approach to the work of the Forum continues to be adopted utilising task and finish groups, which consist of forum members and expert stakeholders as appropriate.

Highlights

Membership

Given the broad range of patient groups and networks represented improved Intelligence gathering has been made available beyond workforce planning and education, as the membership have and continue to:

- ✓ share best practices, evidence and any impact on outcomes
- ✓ share learning and sign-posting
- ✓ share patient experiences including patient stories
- ✓ share publications

Important consultation responses including to the Government Health and Social Care Bill, and National Institute for Health and Clinical Excellence consultations on varying topics have and will continue to allow the Patients' Forum to map both the Individual and Stakeholders responses in order to identify common themes, which then provides a broader common patient response allowing for better and improved decision and policy making.

Direct Outcomes

The Patients' Forum provides direct feedback on any issues raised or any advice sought by and to the National Allied Health Professional Advisory Board including national strategies and priorities.

The Patients' Forum encourages patients to share their experiences both good and bad, acting as a focal point for the collection of those patient stories, which can then be used and shared more strategically to better inform on decision and policy making.

Individual papers highlighting particular areas of patient concern include pain and cancer, which are currently under review and also the opportunities to better use of the prosthetic and orthotic workforce. Originating out of this prosthetists and orthotists paper, members of the National Allied Health Professional Advisory Board worked in collaboration with the Patients' Forum, and the Centre for Workforce Intelligence to organise and hold a national workshop. This national workshop included patients, employers and service providers, universities and education commissioning. Outcomes from the national workshop included the identification of improvement opportunities, and a plan of work has now been instigated. This national workshop is reconvening in the summer of 2012 to support the on-going work towards the provision of a sustainable solution to national workforce planning of prosthetists and orthotists that are best able to deliver improved quality of life outcomes whilst recognising the increasing needs of patients.

Wider Representation and Links to Other Groups

Exploiting the uniqueness of the Patients' Forum has enabled wider representation of the 'patient voice' by facilitating members to better share the patient experiences and knowledge in order to maximise patient engagement across decision and policy making more widely. Wider representation was within the following structures including the Centre for Workforce

intelligence; Allied Health Professions Medicines Project; Government Listening Exercise; National Cancer Rehabilitation Advisory Board; NHS Future Forum and the National Institute for Health and Clinical Excellence.

The Patients' Forum has and continues to evolve working and building collaborative links to other groups including the Centre for Workforce Intelligence Learning Circles; the Council of Deans of Health and wider academia; policy engagement; NHS London and NHS North West.

Connie Trafford, a resident at Berry Hill Retirement Village, a member of the National Allied Health Professions Patients' Forum and a wheelchair user, said: *"the Patients' Forum gathers information from NHS patients about their experiences of visits to hospitals and appointments with allied health professionals like a physiotherapist or an occupational therapist. The Forum discusses the best and worse practices they come across, in order that the future needs of the patient can be improved"*. Connie added: *"It is something that I feel is worthwhile for all people who may have to use the NHS at some time, and I would encourage anyone who has the opportunity to provide some feedback."*



Key Priorities for 2012-2013

Building upon the achievements and successes of the past year, it is important to maintain the impetus of the Patients' Forum and exploit the many opportunities that it provides.

Existing and future health and social care and public health service providers will need to have the ability and skills to be able to innovate and change and improve both service and equipment delivery in order to meet the many increasing challenges of quality and individual outcomes; and so it is important that educators and educating institutions must also innovate and change and improve pre- and post-graduate education and training, and continuous professional development within an overall national workforce plan in order to provide for a modern and sustainable workforce.

A modern and sustainable workforce should be adaptable and flexible and better able to deliver high quality services based upon individual need. Therefore it is essential that the shape and skills of the future health and social care and public health workforce need to be iterative in nature and thereby have the capacity to evolve constantly in order to sustain and deliver high quality health and social care services and continue to improve public health despite the challenges of demographic and technological change.

As the needs of patients and public health should be served by a workforce that has the skills and knowledge to provide safe, effective and compassionate care at all times; it is also important that the patient voice is not just listened to but heard through real engagement and be reflected at the centre of workforce planning, pre- and post-graduate education and training, and the development of new healthcare professionals.

To achieve a sustainable modern iterative, adaptable workforce capable of meeting or surpassing the existing and future changing needs and expectations of patients, it should be recognised that it is no longer acceptable to constrain patient input, and it is only by real 'patient' representation by the widening patient participation through meaningful engagement can a better understanding be achieved, adopted and implemented in a timely and effective manner.

Patients have shared values and priorities, and are able to provide meaningful up-to-date advice and input, which would be useful in transparency of communication and also in horizon planning.

Therefore, if education outcomes and delivery models are to be improved and are to be able to meet the many challenges of service delivery, then it is hoped that the patient will continue to be kept as the central focus, thus forming an important component part of workforce planning, pre- and post-graduate education and training, and continuous professional development.

About the allied health professions

The allied health professions are: art therapists, drama-therapists, music therapists, chiropodists & podiatrists, dietitians, occupational therapists, orthoptists, prosthetists & orthotists, paramedics, physiotherapists, diagnostic radiographers, therapeutic radiographers, and speech and language therapists. Each profession is represented by its own professional body.

Allied health professionals are a diverse group of practitioners who deliver high quality care to patients across a wide range of care pathways and in a variety of different settings. Allied health professionals' normally begin their careers as graduates of their chosen profession rather than sharing a generic entry point and branching off into specialities as their career progresses although from day one, allied health professionals are skilled practitioners in their profession of choice.

Generally allied health professionals are first contact practitioners who perform essential diagnostic and therapeutic roles; work across a wide range of locations and sectors within acute, primary and community care; perform the functions of assessment, diagnosis, treatment and discharge throughout the care pathway – from primary prevention through to specialist disease management and rehabilitation; and their particular skills and expertise can be the most significant factor in helping people maintain their independence through both physical and mental rehabilitation.



All allied health professionals have to be registered with the Health Professions Council. There are 158,815 Allied Health Professionals registered with the Health Professions Council in the UK (April 2011).

The allied health professions are:

- **Art therapists** provide a psychotherapeutic intervention that enables clients to effect change and growth by the use of art materials to gain insight and promote the resolution of difficulties.
- **Chiropodists & Podiatrists** diagnose and treat abnormalities of the foot. They give professional advice on prevention of foot problems and on proper care of the foot.
- **Diagnostic radiographers** produce high-quality images on film and other recording media, using all kinds of radiation.
- **Dietitians** translate the science of nutrition into practical information about food. They work with people to promote nutritional wellbeing, prevent food-related problems and treat disease.

- **Dramatherapists** encourage clients to experience their physicality, to develop an ability to express the whole range of their emotions and to increase their insight and knowledge of themselves and others.
- **Music therapists** facilitate interaction and development of insight into clients' behaviour and emotional difficulties through music.
- **Occupational therapists** assess, rehabilitate and treat people using purposeful activity and occupation to prevent disability and promote health and independent function.
- **Orthoptists** diagnose and treat eye movement disorders and defects of binocular vision.
- **Orthotists** design and fit orthoses (calipers, braces etc.) which provide support to part of a patient's body, to compensate for paralysed muscles, provide relief from pain or prevent physical deformities from progressing.
- **Paramedics** are ambulance service health professionals who provide urgent and emergency care to patients. They assess and treat patients before transferring or referring them to other services, as appropriate.
- **Physiotherapists** assess and treat people with physical problems caused by accident, ageing, disease or disability, using physical approaches in the alleviation of all aspects of the person's condition.
- **Prosthetists** provide care and advice on rehabilitation for patients who have lost or who were born without a limb, fitting the best possible artificial replacement.
- **Therapeutic radiographers** treat mainly cancer patients, using ionising radiation and, sometimes, drugs. They provide care across the entire spectrum of cancer services.
- **Speech and language therapists** work with people who have communication and/or swallowing difficulties.



Acknowledgements

The Patients' Forum would like to thank the following members for their valuable contribution.

Andrew Cumella, Board Administrator
Bill Davidson, Patient
Connie Trafford, Patient
Frances Boyce, Arthritis Care
Frieda Schicker, Director, London Gypsy and Traveller Unit
Gillian Frances, London Gypsy Traveller Unit
Gordon Conochie, The Princess Royal Trust for Carers and Crossroads Care
Jacqui Graves, Macmillan Cancer Support
Jonathan Piper, Patient (Macmillan Cancer Support)
Julia Gale, Board Secretary
Kirstine McDowall, volunteer (Arthritis Care South England)
Lisa Hughes, Co Chair National Allied Health Professional Advisory Board
Philip Satherley, Compassion in Dying
Sarah Joiner, Trustee of the MS Trust
Steve McNeice, Patient
Roswyn Hakesley-Brown CBE, Chair Patients' Association

In Memoriam



The late Comfort Onyewumbu was a valued and much loved member of this Patients' Forum at the Department of Health. Comfort was able to bring her own rich experience, not only as both a qualified nurse and midwife, but also as someone who knew what it was like to be a patient in the latter years of her life. She was very appreciative of the work of allied health professionals and valued greatly their contribution to the re-ablement and rehabilitation of patients. Her counsel was wise and gently given and she was never afraid to ask difficult questions. We would have so liked to have had a photograph and comment from Comfort but regrettably that was not to be. We shall miss her greatly and remember her with love and respect.

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First published August 2012

Published to DH website, in electronic PDF format only.

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