Welcome and introduction of the Guest of Honour

Professor the Baroness Hollins, Chair of BMA Board of Science

Presentation of Awards

Announced by Miss Jacky Berry, BMA Librarian

Presented by Professor Ilora Baroness Finlay of Llandaff FRCP, FRCS, FHEA, FLSW
Professor of Palliative Medicine at Cardiff University School of Medicine

Presentation of the BMA Patient Information Awards special prizes
• Special award – information that aids decision making
• Special award – innovation
• Special award – learning disabled
• Special award – long term conditions
• Special award – mental capacity
• Special award – screening
• Special award – self care
• Special award – user involvement

Presentation of the BMA Patient Information Awards Reviewer of the Year award

Presentation of the BMA Patient Information Resource of the Year Award 2014

Address by Professor Ilora Baroness Finlay of Llandaff

Closing address by Dr Andrew Dearden, BMA Treasurer

The ceremony will be followed by a drinks reception in the John Snow Room on the ground floor.
Professor the Baroness Hollins, FRCPsych, FRCPCH, FRCP

Professor the Baroness Hollins is Emeritus Professor of Psychiatry of Disability at St George’s University of London (her tenure as Professor was from 1990-2011). She was appointed an Independent member of the House of Lords in 2010. She was President of the Royal College of Psychiatrists for three years from 2005-2008.

She was educated at Notre Dame High School, Sheffield and St Thomas’s, University of London.

She is on the GMC Specialist Register as a Learning Disability Psychiatrist and a Child and Adolescent Psychiatrist. Until she retired from clinical practice in 2006, she had been a Consultant Psychiatrist in Learning Disability in South West London for 25 years.

She is a Fellow of the RCPCH and Honorary Fellow of the RCPsych, RCP (London), the Medical Women’s Federation and the Colleges of Medicine, South Africa. She is an Honorary Member of the British Society of Couple Psychotherapists and Counsellors.

She is a member of the Scientific Advisory Group, Centre for Child Protection at the Institute for Psychology of the Pontifical Gregorian University, Rome.

Her clinical and research expertise has primarily been concerned with the mental and physical health of people with developmental learning disabilities, with a focus on access to healthcare, deinstitutionalisation, palliative care, and the effects of bereavement, and sexual abuse on mental health.

She is Executive Chair and Editor of Beyond Words which has recently been launched as a not for profit spin out company from St George’s. The Books Beyond Words series of 40 picture story books cover health and social care topics for people with communication disabilities.

She is Patron of Living and Dying Well—a not-for-profit policy thinktank, and of RESPOND (a charity providing therapy for children and adults with intellectual disabilities who have experienced sexual abuse).
Professor Ilora Baroness Finlay of Llandaff FRCP, FRCGP, FHEA, FLSW

President of the British Medical Association 2014-15 and currently President of the Chartered Society of Physiotherapy, she is a Past President of the Royal Society of Medicine. Ilora Finlay is an internationally renowned expert in palliative medicine and the care of the dying.

She has led Palliative Care Strategy Implementation in Wales since 2008, and chaired the Welsh Medical and Dental Academic Advisory Board since 2012. She has also been leading a national conversation on unscheduled care provision in Wales.

She chaired the Commission on Medical Generalism for the Royal College of General Practitioners (2011) and the Inquiry into Carbon Monoxide poisoning for the All Party Parliamentary Gas Safety Group (2011), now its follow-up inquiry for the All Party Parliamentary Carbon Monoxide Group, which she co-chairs.

She holds an Honorary Doctorate of Science from the University of Glamorgan; is an Honorary Fellow of Cardiff University; and was the Johanna Bijtel Professor at Gröningen University, Netherlands 2000-02.

She was a general practitioner in inner city Glasgow before returning to Cardiff to work full-time in care of the terminally ill, now the specialty of Palliative Medicine. She works at the Velindre Cancer Centre, covering SE Wales when clinically on call. She started the Marie Curie Hospice in Wales and since 2008 has responsibility on behalf of Welsh Government for strategic oversight of all hospice and palliative care services in Wales. She initiated iWantGreatCare, a dynamic patient feedback evaluation of these services, to empower the patient voice in care provision across Wales.

She has authored many books, book chapters and papers on palliative care, from being co-author of Care of the Dying: A Clinical Handbook (Churchill Livingstone 1984), to co-edit the Oxford Textbook of Communication in Cancer (2011). She has written on palliative medicine, medical education, ethics and service provision. She established and co-chairs the independent think-tank Living and Dying Well.

She is an Independent Crossbench Peer in the House of Lords (since 2001) and has served on a number of its key committees including: Science and Technology for which she chaired the influential inquiry on Allergy in 2008. She served on the Committee on Assisted Dying for the Terminally Ill and more recently on the Select Committee inquiry into Public Services and Demographic Change. She introduced the Smoking in Public Places (Wales) Bill, took the Sunbeds Act through the Lords and is responsible for the post of the Chief Coroner being re-instigated.
2014 BMA Patient Information Awards

Highly commended resources – the Winner of the BMA Patient Information Resource of the Year 2014 will be announced from this shortlist

Aftercare: A Guide for Teenage and Young Adult Survivors of Childhood Cancer

Children’s Cancer and Leukaemia Group 2014

There are an increasing number of teenage and young adult survivors of childhood cancer, and this group is the intended audience for Aftercare. This group will often have many questions about what happens next and how their diagnosis and treatment will affect their future life: it is designed to provide answers to these questions. It emphasises the importance of long-term follow up, and provides key information about ‘moving on’ with life, including education and employment, equal opportunities, feelings and emotions, lifestyle and keeping healthy. This new redesigned version of Aftercare has been written and edited by the CCLG Late Effects Group, led by Dr Helen Jenkinson, consultant paediatric oncologist and late effects specialist, in conjunction with the CCLG Publications Committee, comprising multiprofessional experts in the field of children’s cancer. Review of the text and design at various stages of development has been undertaken by both groups. The CCLG Publications Committee includes parents and young adult survivors who are full members of the committee and therefore in a position to contribute at any stage of the development process. In addition, this booklet has been reviewed both as text and at the design stage by target users (i.e. young adult survivors of childhood cancer) who provided input to the text and useful feedback on the design to ensure that the end product meets the needs of the target audience and is presented in a welcoming, useful way. Finally, young adult survivors were also asked to submit small case studies, which have been used as quotes throughout the publication. The main reference source for this publication is expert advice from the clinicians, nurses and those of other relevant clinical disciplines whose daily working life concerns the treatment and care of children and young people with cancer, and in particular those with expertise or a special interest in the management of late effects and long-term follow-up. In recent years, there has been an increased focus on cancer survivorship and the need for tailored services specifically for survivors of childhood cancer to monitor and manage late effects. The development of Aftercare has been informed by these initiatives, most notably the National Cancer Survivorship Initiative which is an approach to improve the quality of aftercare for survivors of childhood cancer i.e. http://adc.bmj.com/content/98/Supp_1/A80.2.abstract The hard-copy booklet is provided free of charge through the national network of principal treatment centres for children and young people with cancer, as well as related paediatric oncology shared care units. CCLG has provided publication display racks to centres so that our information resources can be displayed in key areas and are always available to those who need them. CCLG has a designated resource contact in each centre that has responsibility for maintaining publication stocks. Individual booklets can also be ordered by patients/parents directly from CCLG and are provided free of charge. The booklet is also available as a PDF on our website. The Aftercare booklet is the first stage of an intended package to be developed, which will include an online resource and additional fact sheets covering specific areas in more detail. We will also promote the availability of this resource through our social media channels, which are likely to reach the target audience for this publication. Initial feedback to the new design has been very positive, including from the young people involved in the development of the resource. All of our booklets contain a request for comments to be fed back to us. Feedback forms have also been provided to our resource contacts in all centres to facilitate the provision of feedback, and a recent decision has been taken to include feedback forms when publications are given out. On the relevant page of our website, there is an email link alongside each publication to encourage comments. Any comments received are logged, and fed into the review cycle when the publication is next reviewed as part of the Information Standard requirements.

“This is a really strong example of patient information that pulls information together for service users, but more importantly empowers and inspires them to get the most out of life. The human interest throughout makes it really engaging for readers and provides multiple opportunities for role models and reassurance that ‘things can be OK’. The level of information feels appropriate – it tackles sometimes technical issues but using clear language, though in some places it could have gone even further in being more conversational and less formal. Overall there was a strong sense of the young people behind the publication – both those who helped develop it and those who it is aimed at, and that says a lot about the exceptionally strong user involvement and development process.”

Autologous Stem Cell Transplant

Lymphoma Association 2013

Stem cell transplants are a common treatment for lymphoma and many people have this treatment every year. Improvements in technology and in supportive care mean that autologous stem cell transplants (transplants using your own stem cells) are now more successful than ever. This booklet is for people affected by lymphoma who may be considering this particular treatment. It is also aimed to help those who may be close to someone facing a stem cell transplant. This booklet is the third edition of a booklet first published in 2009. It has been reviewed and rewritten in 2013 by a member of our medical writing team who is a qualified nurse previously specialising in haematology. It has been further reviewed by two expert lymphoma clinicians both of whom have extensive transplant experience; Dr Prem Mahendra (Consultant Haematologist, University Hospital Birmingham and Queen Elizabeth Hospital Birmingham NHS Trust) and Dr Paul Revell (Consultant Haematologist at Stafford Hospital). We also sought review from a Post BMT Clinical Nurse Specialist, Michelle Kenyon (King’s College Hospital, London). Our own professional medical writing team (two doctors and one oncology nurse) all provided feedback at various stages of the information production process. Extensive feedback on the previous edition of this booklet was sought from our ‘Pre-Authorship Group’ during 2013. This group comprises of people affected by lymphoma who volunteer to help us review our information. Many of these people have been through treatment in recent
months or have someone close to them who has been affected by lymphoma. We invited particular group members (those who have had an autologous transplant) to feedback their thoughts. We have found the feedback from this group enormously valuable as it helps give us a clear idea of what the user group would find helpful which is vital before we put ‘pen to paper’. Once we have an agreed first draft we show further lay reviewers – typically our ‘buddies’. These are people who have had experience of lymphoma who volunteer to be put in touch with others in similar situations. Again our buddies provide insightful feedback and their important contributions help us to continually grow and develop ensuring that we produce really high quality information for people affected by lymphoma. Sometimes our buddies raise new queries which we put to our expert reviewers. In addition we also involve our current helpline team who are in touch with both people affected by lymphoma and health professionals who order our information for their patients. Their feedback reflects the sorts of enquiries that they are receiving over the phone, in the chatroom or via email on a daily basis. The resource is disseminated in many ways. It is: sent to enquirers via our helpline team; sent to anyone who requests copies from the organisation free of charge such as cancer information centres and hospitals; available on the LA website to read and download; promoted through our facebook page and twitter account; promoted at medical and nurses haematology meetings on exhibitor stands; promoted in the quarterly Lymphoma matters newsletter; promoted in the Lymphoma Association monthly e-newsletter, promoted to the network of healthcare professionals known to the LA which includes a medical advisory panel of 30 leading lymphoma clinicians and a nurses forum of over 200 nurses and other allied health professionals; promoted through our contact with other charity representatives working in the field of haematology/oncology and particularly transplantation. We encourage people affected by lymphoma to provide feedback about our information via a survey link on our website as well as an invitation to get in touch with the publications department and patient services team directly. We collect all this feedback and use it to further improve future editions. Recently we have been refining a professional evaluation questionnaire which we have designed in consultation with a market research consultant. We intend to send this to people who have received copies of our new booklet. This will enable us to look in more detail at the impact of our information. We do know that callers to our helpline have many questions relating to their treatment particularly about the process of transplantation. These questions help us informally evaluate the booklet content and range of information we provide. We have very close relationships with leading lymphoma experts and continually liaise with nurses and doctors at medical meetings who reinforce the fact that people find our information very helpful and informative.

“This is a superb resource beautifully produced and written in a very patient friendly manner. My one and only critique might be that it is a little long, however, the patient audience will be motivated to read it and dip into it regularly. This is a very user friendly resource which covers everything you might want to know and it certainly matches all the judging criteria. I am very impressed.”

Bowel Health & Screening
Bowel Cancer UK 2012

This consists of a step-by-step guide to bowel health and screening for people with learning disabilities, an explanatory booklet for carers, an instructional DVD, and accompanying training for all carers of people with a learning disability in Scotland. Findings from a lottery funded project indicated that people with a learning disability (PWLD) and their care providers have a lack of awareness about bowels, good bowel health, bowel cancer and bowel screening. Therefore it is now more important than ever that PWLD have equal access to screening services and health information which could help to reduce their risk and enable early diagnosis, which is of particular importance in the treatment of bowel cancer. The resource aims to address the poor uptake of bowel screening in PWLD and bridge an identified gap in available accessible resources for them on the topic of bowel health and screening. The project was also designed to improve the knowledge of carers and increase their skills in talking with service users about an important yet sensitive subject. A working group of experts and professionals in this field was formed at the beginning of the project, with specific responsibilities allocated. These included: Claire Donaghy, Senior Health Improvement – Cancer, NHS Greater Glasgow & Clyde; Isla McGlade, Clinical Academic Lecturer Practitioner, School of Health & Life Sciences, Glasgow Caledonian University; Susan Biggar, Community Learning Disability Nurse, Bennyknoves Resource Centre; Catherine McKay, Scottish Consortium for Learning Disabilities. Once the final draft was completed, the resource was reviewed by the following groups/organisations before going to first print in September 2012: PWLD; The working group; Scottish Consortium For Learning Disabilities; Learning Disability Nurses; Health Improvement professionals; internal expert; NHS Health Scotland Equality Assessment Framework; Bowel Screening Coordinators. Our primary focus was to ensure that PWLD and their carers informed the shape of this project at every stage, so we held five separate focus groups in various locations within Greater Glasgow & Clyde. We also consulted staff/carer groups who could not attend in person via questionnaire. The information gained from this consultation was thoroughly reviewed by the working group and greatly influenced the final decisions made regarding the look, feel and content of the resource. As listed above, both the drafts and final version were reviewed by PWLD and their carers to ensure it was fit-for-purpose, which also gave our focus group members a sense of ownership over the resource. We also held a photo-shoot for the resource images with members of the focus groups (PWLD), and all members were invited to the resource launch event. We commissioned the Good Life Group, an advocacy group made up of PWLD who want to change people’s attitudes towards disability, to write and perform a short play which was performed at the launch event. This illustrated the difficulties PWLD have with accessing the bowel screening programme at present, and the difference our resource makes to their ability to be able to engage with the programme either independently or with the help of their carer. We conducted a thorough literature search at the beginning of the project to see whether any similar resources existed already. We held a launch in September 2012, and invited over 200 people from Learning Disability and Health Improvement services in Scotland. The first stage dissemination plan intended to cover NHS Greater Glasgow & Clyde region only as a pilot, and 1,000 copies of the resource were printed for this purpose. NHS Health Scotland issued an internal press release which went to all Learning Disability Nurses and Health Improvement practitioners in NHS GGC, and they were asked to contact Bowel Cancer UK directly or order copies. Furthermore, Bowel
Cancer UK is currently in discussion with MENCAP about amending the resource for roll-out in England (as some of the data is Scotland-specific). It was always intended that the information in our resource and training programme was consistent, well-managed and could be easily updated and amended for use in other regions. It evaluated extremely well, with all attendees indicating that they now felt confident discussing good bowel health with those they care for, and 100% said they would now confidently use the Bowel Health and Screening resource with their clients. The outcome from the resource will hopefully be an increase in uptake of the screening programme for PWLD. In addition, we will measure the impact in the following ways. A resource evaluation sheet has been included with every pack – this will allow us to see how the pack is being used in different settings and will allow feedback and any ideas or comments. Monitoring of attendance at training courses will allow the project to measure who is attending the training, so we can target future training dates to specific audiences if required; Evaluation of the training day, from attendees will measure the success of the training i.e. what skills and knowledge has been gained, any increase in confidence to discuss this subject, etc. Post training action will be used to follow up with the training attendees six months after the training to measure impact of the course. We will look at who else has benefitted from the knowledge they gained, how many people they have been able to help using the knowledge, has their increase in confidence remained, and the impact that this has had on the client group. The project will also undergo a full project evaluation. An external evaluator has been collecting evaluation data from the beginning of the project. This has included data from the working group and service user focus groups. The evaluator has also been looking at the joint working aspect of the project, making sure that the working group were happy with the developments and that PWLD and their care providers were consulted and listened to throughout the process. The final evaluation report will be published in December 2014.

“This is an excellent resource. The consultation and working parties included health improvement specialists as well as medical staff who work directly with people with learning disabilities, so a wide range of professional input was received. People with learning disabilities and their carers were involved at both draft and final stages to ensure the material was suitable and a resource that was accessible. The applicant consulted both official, clinical resources and existing resources aimed at people with learning disabilities. It is stated quite clearly on all the resources within the pack and on the pack itself (inside the front cover) that the resource is aimed at those with a learning disability.”

Breast Screening: the Facts
Breakthrough Breast Cancer 2013

Breakthrough’s online guide NHS Breast Screening: The Facts clearly sets out the facts surrounding NHS breast screening, based on the best possible evidence. It is aimed at all women aged 50 to 70 in the UK. Its aims are to: Provide clear, balanced information on the risks and benefits of breast screening; explain the process of breast screening; Support women aged 50 to 70 in making an informed choice about whether to attend their breast screening appointment. Following confusion in 2012 about the scale of the risks associated with breast screening, the guide demystifies this controversial topic and empowers women to make the right choice for them. It uses an innovative and engaging design and mix of animations, expert and case study videos, imagery and text to best support women in understanding the complex and controversial facts surrounding mammography. An engaging, novel and mobile-supported design was developed to capture people’s interest, help them to digest key information and to promote sharing of the guide with others. Breakthrough places a high value on the opinions and advice of experts in the development of our health information. We seek to involve representatives from all key specialities related to the topic. For this online guide, we involved experts in informed choice and risk presentation and interpretation, the breast screening programme, and healthcare professionals involved in breast screening delivery, breast cancer diagnosis and treatment. For this guide, it was crucial that we presented information on breast screening in an innovative and engaging way to best support women in understanding the facts and making an informed choice. Seeking input from users to ensure the guide meets these aims was – and continues to be – an integral part of the project. We are committed to sharing the experiences of patients and the public and including their perspective in our information. For this guide, we included case study videos to allow three women to share their own experiences of breast screening. We used insight from the following sources to inform our plans for the guide: Analysis of quantitative and qualitative data from our information line (telephone, email and web) to gain an understanding of the unmet needs of people seeking information about NHS breast screening from Breakthrough Breast Cancer; Attendance of a three-day Citizen’s Jury on information for women about breast screening run by Informed Choice About Cancer Screening. This provided a wealth of information about the questions women have about breast screening, the information they find more difficult to interpret and how this can be best presented, how to support informed choice optimally, preferred phraseology to use and format; The guide was user tested by four laypeople. We aimed to recruit women with varying levels of experience of the breast screening programme and with familiarity with digital technology. This review was structured to provide focussed feedback on: ease of use and understanding, balance, completeness, and the optimal guide title. Any additional feedback was also welcomed. The feedback of each user was recorded, considered and acted upon appropriately. We filmed three women talking about their personal experiences of screening services. The videos were filmed using prompt questions. Women were invited to give any additional information they felt was important to their story. The stories give valuable anecdotal insight on how other women have found the experience of going for screening and how they made a decision about whether to attend. We were unable to find a woman willing to explain a decision not to attend breast screening. We have included an invitation for further case studies at the end of the guide, so we may add this in the future if someone with this experience is willing to contribute (see http://breastscreeningfacts.org/#-the-end – Tell your story). We invite feedback on all our health information from users. All feedback is recorded and used to inform future editions of our materials. Where necessary, it is acted upon more urgently. For NHS Breast Screening: the Facts we are invite feedback via a structured online survey. Insights from this survey to date are included in a later section of this entry form. The interactive guide is aimed at all women across the UK aged 50 to 70 years old (the age range for routine NHS breast screening). At launch in May 2013, we promoted the guide to over 48,000 supporters through our own communication channels, including
our e-newsletter, Facebook and Twitter pages. We also promoted the guide to over 40,000 GPs via the Royal College of General Practitioners e-newsletter and to over 33,000 primary care nurses via Nursing in Practice, so that healthcare professionals may act as intermediaries to promote the guide. It was also showcased at the Patient Information Forum annual conference 2013 for promotion and to share best practice. The website is responsive, meaning that the navigation and display are optimised whether viewing on desktop, tablet or Smartphone. This means women can access the guide at home, in the office or library, or on the move. Supporting use on smart phones was important for us, as more people now access the internet this way than through desktop computers. A mobile-enabled design supports sharing of the guide with family and friends through social media. The guide includes prompts to share specific sections with others, to further promote social sharing. Ongoing digital promotion of the guide includes Google standard search advertising. We have piloted Facebook promoted posts and Google Pay Per Click advertising for promotion and are evaluating the cost effectiveness of these mechanisms. We are currently seeking promotion via NHS Scotland and hope to do the same with the English NHS screening service. We are also piloting promotion through local authorities. The guide has an in-built survey feature, allowing people to give instant feedback. The results show that women have found the guide very useful and informative. Over 90% of respondents found the guide either very easy or easy to use, and almost 90% would recommend the guide to a friend. Importantly, two thirds of surveyed women making a decision about screening said the guide helped them to make a choice. We also conducted a split test, to evaluate the supplementary actions on the last screen that people would prefer to see. This showed that the newsletter is of greater interest than a donation ask. In 2014 we hope to further our reach through additional sustained promotional activity. Our initial aims are to reach 54,000 women per year, which would represent one in 100 women making a decision about breast screening. In mid 2014, we will conduct a formal evaluation, seeking further quantitative and qualitative feedback from key stakeholders and the public. The guide’s evidence, content and functionality is due for review and update by May 2016.

“Breakthrough’s online guide NHS Breast Screening: The Facts clearly sets out the facts surrounding NHS breast screening, based on the best possible evidence. It is aimed at all women aged 50 to 70 in the UK. There are individual leaflets for each of the target audience, using appropriate language, typeface and images so that no recipient is overwhelmed with information or has to struggle to find what they are looking for. This is a multimedia pack so and also includes information for carers so all levels. This is a novel and fun way to present information is useful bite-sized chunks. I particularly liked the way alternative ways of navigating the site and alternative versions of the site were offered as the ‘journey’ along the trial may run slow on older computers. There was also an issue with the alternate, simple, version of the site loading below the content list at the top of the page and I couldn’t see any ‘back’ options from the different sections to the top which I would have expected to see.”

Easy Read Suite of Information Leaflets for Adults with Learning Disabilities
Guy’s and St Thomas’ NHS Foundation Trust 2013

Guy’s and St Thomas’ is committed to providing quality, transparent patient information across our entire readership. Although all of the publications we produce meet Plain English standards of accessibility we were, until recently, lacking a suite of information appropriate for the thousands of patients with learning disabilities who are cared for at our hospitals each year. There are an estimated 6,000 adults living with mild to profound learning disabilities in Lambeth, Southwark and Lewisham boroughs. For the majority of these adults, having a learning disability affects their ability to read and understand new information, as well as their ability to communicate. Easy Read is a format designed to help people with learning disabilities understand complex procedures and processes. It combines simple, straight to the point sentences with clear, colourful, and self-explanatory graphics to assist effective communication and informed consent. Although Easy Read was developed primarily for patients with learning disabilities, it is also an invaluable resource for those who struggle with reading, those with English as a foreign language, and patients with temporary communication difficulties, such as those with delirium, dementia or who have suffered a stroke. Our growing suite of patient information includes: How to make a Comment or Complaint – designed to ensure that patients with learning disabilities have a voice and are equipped with the means to express their views on our hospitals and their care; How to keep your hands clean – based on our existing infection control manual and developed to ensure that hand hygiene is promoted across all patient groups; Welcome to St Thomas’ Hospital/Welcome to Guy’s Hospital – two leaflets, identical in content but separated out by site to reduce confusion for patients with learning disabilities, developed to minimise anxiety by explaining simply what patients can expect from their stay; The Patient Passport – a working document (to be completed by healthcare professionals) detailing the specific needs and preferences of patients with learning disabilities to ensure consistency of care across healthcare settings, even where patients are unable to communicate their needs for themselves; Useful information about St Thomas’ Hospital/Guy’s Hospital – two simple signposting leaflets to direct patients with learning disabilities to useful hospital facilities; A range of leaflets on services for adults with learning disabilities in the community, developed to assist patients in finding appropriate healthcare facilities once they have left acute care settings; Information about Radiotherapy – How will I Feel after Radiotherapy? – two leaflets developed to prepare adults with learning disabilities for the complex and frightening experience of having radiotherapy treatment; The pictorial menu – designed to reduce reliance on descriptive text and improve nutrition (and choice) amongst patients who struggle with reading. To date, the Trust has produced over 25 Easy Read resources, and is currently working to develop further materials relating to specific conditions. A list of key clinicians involved in the development of each information resource is available upon request. Leaflets were edited and made audience-appropriate by the Equality and Diversity/Language Support Manager (Manal Sadik), the Senior SLT for Adults with Learning Disabilities (Wendy Walker) and the Publications Officer for Adults with Learning Disabilities (Amy Obradovic), all of whom have undergone training in writing for and communicating with patients with special or complex needs. Finally, publications were reviewed by members of our Patient Publications Group (PPG) who are responsible for checking that all internal processes have been followed, that heads of services have been involved and
that information is evidence-based (where appropriate). We engaged our patients, volunteer readers and an external learning disabilities group when developing the Easy Read suite of materials. These groups were consulted throughout the process, and in reviewing drafts, provided valuable observations and comments, which were incorporated where possible and/or appropriate. Leaflets explaining community-based services were developed alongside adults with learning disabilities at drop-in centres across Lambeth, Southwark and Lewisham. The Patient Passport was developed in consultation with patients and staff across King’s Health Partners (Guy’s and St Thomas’, King’s College Hospital, South London and Maudsley).

Our Easy Read leaflets are available through a number of channels to ensure that the right patients receive the right information at the right time. Having worked with local authorities, the Trust’s patient information management system is now able to identify and flag patients with learning disabilities, and protocols are now in place to ensure that pathways of care are reasonably adjusted to meet their needs. This includes the dissemination of appropriate (Easy Read) patient information. Hospital and community staff members can access and print leaflets from the Trust intranet to send to patients alongside appointment letters (Easy Read letter templates also available on Trust intranet), or to go through with patients presenting at healthcare settings. Leaflets are further available on our public website via an Easy Read hub (section of the site dedicated to patients with learning disabilities), so that patients who need or prefer information in this format are able to access materials for themselves at home. Our GP network across Lambeth and Southwark also has access to our Easy Read materials. In order to do this, we will continue to evaluate the effectiveness and audience-appropriateness of these materials. In order to do this, we will require continued input from patients, learning disability groups and patient-facing staff.

13 resources have been supplied. The entrants have involved a full range of staff at GST to advise on their special interests. A team of three named staff who deal with Equality and who have been trained in writing for learning impaired users reviewed the language and presentation of all the resources. A final check was made by the Patient Publications Group (PPG) who checked that the correct specialists had been involved and the appropriate procedures had been followed. I rate the scope and extent of this consultation to be Exceptional. The pictures are of a high quality. I don’t know if they were photographed specifically for this resource but they look as if they have. I liked the fact that named individuals have a picture so these must have been made for the resource. This is a very impressive range of resources which the patient group has coordinated over the whole range of GST services and specialties. The resources are well laid-out and easy to use.”

Guide for Patients having Radiotherapy to the Head, Neck, Mouth and Throat at Mount Vernon Cancer Centre

The purpose of this leaflet is to provide a step by step guide to patients about their radiotherapy, advise them about the radiotherapy side effects they may experience, and give them tips to help them manage any such side effects as they occur whilst on treatment. The LMC Information Team produces a range of literature that is specially written to be relevant and appropriate for patients under the care of an oncologist at Mount Vernon Cancer Centre. This publication has been written in conjunction with three clinical oncologists, two Head and Neck clinical specialist nurses, three expert therapeutic radiographers, one oncology dietician, one Speech and Language Therapist, research, ward and out-patient oncology nurses who are all clinical experts in this treatment modality, as well as patients and carers. The process follows an accredited process called the 12 Point Plan to ensure accuracy and readability. This process has been certified by the Information Standard. For more information about our process please go online to http://www.ljmcc.org/1_services/information.html. As part of the 12 point plan process, this publication has been reviewed by patients and users who are members of our Patient and User Volunteer Information Panel. They contributed to the evolution of this resource, including both its format and content during its recent revision to ensure it meets the users’ needs and continues to comply with the Information Standard. They were then invited to comment on each subsequent version during the production phase to ensure the content and its presentation was suitable and understandable for the target audience. Once comments had been received from all stakeholders the final draft version was compiled. It was then discussed and agreed by our Volunteer Patient and User Panel. We produce a range of information leaflets about our local services and treatment as well as any information to support
Patients in coping with their diagnosis and the effects of treatment. This publication is produced specifically for patients who are to undergo radiotherapy treatment as part of their cancer management at Mount Vernon Cancer Centre. It is given to all relevant patients during a pre-treatment information session to explain the treatment, treatment process and any possible side effects. Its use assists with the consenting of these patients prior to them attending for their treatment planning session. This consent process is undertaken by the clinical oncologist and a Head and Neck Clinical Nurse Specialist. This leaflet forms part of the information prescription given to the patient prior to, and during their radiotherapy. Comprehensive patient satisfaction surveys are undertaken by our research team in conjunction with the head and neck clinical nurse specialists to monitor and evaluate the effectiveness of the information and support provided to our head and neck patients during the pre-treatment, treatment and follow up phases of their cancer journey. Patients’ and users’ feedback about this information leaflet is acquired as part of this process and any feedback is considered and implemented to ensure this resource is useful, relevant, comprehensive and understandable.

Overall the results from these surveys have been positive. We repeat these evaluation exercises every year, to ensure this resource and others used continue to meet the needs of our patients, their family and carers.

“This is an excellent leaflet. If I were a patient facing radiotherapy treatment for head and neck cancer this is what I would want: it answers the sort of things I would want to know clearly. It is not glossy, smartly produced or cleverly designed which might put it at a disadvantage compared with other information leaflets which are better resourced financially. However it is very thorough and the involvement of health professionals and patient panels is comprehensive.”

Heads Up, Tim-Tron
The Children’s Trust 2014

Heads Up, Tim-Tron is a 32-page picture book for children aged between five and nine with acquired brain injury. Published literature and our own clinical experience have pointed to the difficulty children with brain injury have in understanding their condition. This can lead to further difficulties in goal-setting, attainment and the adoption of strategies as children don’t have the requisite awareness of their injury. Our aim in developing a colourful story has been to support children (and their siblings, family and friends) in their understanding of brain injury. The book is about a little robot that bumps his head, and must find new ways of doing things in school and in social situations. By presenting evidenced strategies for managing brain injury, we hope to have given children a digestible way to understand their condition. By reading the book with their parents, we hope children will develop their awareness about brain injury in a safe and enjoyable way. Ultimately, of course, we hope to improve outcomes for families in their communities. These families may feel misunderstood because of the often ‘invisible’ effects of brain injury, and our hope is that the book helps mitigate the feelings of isolation parents report. The story was written by our editorial manager (who had previously created a resource for parents of children with brain injury). The story was then reviewed by a number of our clinicians, including our director of rehabilitation, our head of research and our head of play. Their suggestions informed a number of rewrites before we arrived at the final draft of the text. Parents of children with brain injury were sent early drafts of the book to read with their families (nearly all of them said it was too long), and we responded to their feedback in subsequent drafts. After commissioning a professional illustrator, we consulted children directly about the look and feel of our lead character. Children were asked to pick their favourites from a range of robots, and this decided the look of Tim-Tron, star of the book. We are disseminating the book via an online bookshop. Families can order the book by paying a handling charge of £3.50 (there is no charge for the book itself) www.thechildrenstrust.org.uk/books.

Dr Carol Hawley’s work on advocacy and information suggests that children whose parents are from ‘non-managerial/professional groups’ are more likely to sustain a traumatic brain injury. What’s more, their parents find it more difficult to access information and to advocate on their child’s behalf. It was therefore important to us to make the book available at as low a cost as possible. Through charitable donations, we have been able to provide the book for an affordable handling charge. We have also made the story available as a free, downloadable audiobook, narrated by Top Gear presenter Richard Hammond, who himself sustained a brain injury while filming the programme http://www.braininjuryhub.co.uk/tron-world/brain-injury-books. Our hope is that this broadens the appeal of the book, while giving families with learning or access difficulties a way into the story and its themes. By identifying with a celebrity living with a brain injury, we also hope to mitigate families’ sense of isolation. The book itself invites users to feedback about their experiences of the book, but we are also in the process of developing a user feedback survey to distribute when the book is in wider circulation. We have also distributed the book to healthcare professionals without a charge, in the hope that it will prove useful to families in their care. In exchange for receiving the resource without cost, we have asked all of these healthcare professionals to feedback about the book and its impact with families.

“This is very well-produced with an interesting story of Tron who helps explain acquired brain injury to young readers. The language is very clear both for children in the book and adults in the grown-up guide.”

HIV, GPs and other Primary Care
NAM 2012

There are many good, medically beneficial reasons why it is recommended that people with HIV have a GP and that they disclose their status. The aim of this booklet is to set out the role that GPs can play and address some of the key issues that people with HIV raise as reasons for not wanting to make more use of primary care. NAM is aware that there is concern among HIV patients of both a real and perceived lack of knowledge about HIV and discriminatory behaviour from primary care providers. This booklet aims to: Encourage people to register with a GP and a dentist; Set out the practical and medical benefits of engaging with primary care services; Address some of the most frequent issues, anxieties and concerns expressed by people with HIV about primary care services; Inform people of their rights and explain confidentiality and non-discriminatory policy and procedures including how to seek redress should they experience poor service delivery; Help people to make the most of their GP, including a range of other primary services that might be of potential benefit to people with HIV; Inform people about their eligibility for free primary care treatment. We developed this booklet in partnership with the British HIV Association who identified a need to have a resource that could help support
the referral process and encourage their patients to access the range of support that primary care services offer. This resource is written for people living with HIV. We envisage it being particularly relevant to those individuals who are more likely be encouraged to register with a GP because of other medical conditions for example co-morbidities, pregnancy, cardiovascular related health problems or for those who have questions around contraception and managing a healthy sex life. It is also intended that healthcare staff in HIV clinics and other agencies will use this booklet in consultation with patients. NAM’s patient information materials are developed, reviewed, and updated in consultation with a medical panel. This resource was developed in collaboration with: The joint BHIVA/RCGP Primary Care Working Group including: Dr Ian Williams (chair); Sheena Castelino; Dr Hilary Curtis; Dr Martin Fisher; Dr Philippa James; Dr Ranjababu Kulasegara; Fr Ewen Stewart; Dr Fiona Thompson; Shaun Watson; and Dr Ed Wilkins. Other professionals who reviewed and shared comments and suggestions included: Leanne Bobb, Network Co-ordinator, South West London HIV & Sexual Health Clinical Services Network (SWAGNET); Allen Reid, Specialty Registrar in Public Health and dentist, NAM involves patients and information users in a range of ways and at various points in the development process. We involve users from initial concept to delivery; either directly by engaging users in surveys or running face-to-face interviews and by sending materials for review or indirectly by working closely with organisations who support people affected by HIV. NAM’s African Communities Engagement Officer (Big Lottery funded project from 2010-2012) worked closely with community groups gathering feedback in person, on a range of key issues. As well as fear about stigma and confidentiality, it was clear that misunderstanding around immigration status and access to primary care was a potential barrier to uptake of primary care services for these communities. The Terrence Higgins Trust Health Trainer service in London, representing the HIV patients they regularly work with, had input into the initial stages of this resource. Specifically they shared the most common concerns and questions that patients were expressing about GPs including disclosure, stigma, confidentiality of medical records. At the point of sharing this information, THF were also involved in a ‘shared care’ pilot, involving King’s College Hospital, St Thomas’ Hospital and four GP practices HIV-positive Community representatives from the BHIVA/RCGP Primary Care Working Group reviewed drafts of the resource, feeding back comments and suggestions. In February 2011, NAM achieved certification with the Information Standard, a nationally recognised quality mark. We distribute printed copies of the booklet through a range of channels to ensure it reaches people with HIV: HIV clinics: we have an existing dissemination network of HIV clinic and sexual health services across the UK. We targeted key primary care services operating in the catchment areas of the main HIV centres in London encouraging them to request copies for their clients and patients. We have made the booklet available online, in PDF, flipbook and html format on NAM’S website www.aidsmap.com/HIV-GPs-other-primary-care/page/2521996/ We have marketed and promoted the print and online version of the booklet using the following communication channels: A feature link on the homepage and a blog post to mark the launch of the new title (http://www.aidsmap.com/page/2532783/); Promotional messages about ordering print copies or reading the online version were included in our e-bulletins: HIV Update, aidsmap news, aidsmap insight; Social media including, Facebook and Twitter; The British HIV Association autumn and spring conference: copies taken to distribute to delegates and ‘launch’ the new booklet to a key audience. We have used a range of methods to assess the impact and usefulness of this resource. In line with our Information Standard certification, the content and usefulness of the resource will be reviewed and evaluated every two years and in light of feedback received from individuals and healthcare professionals as well as new research or policy changes. Changes will be made as appropriate. We monitor both the print distribution figures and the levels of visitor traffic to the online, PDF version of the booklet. To date, NAM has distributed 7644 print copies of the booklet and had over 3126 visits to the online version of the booklet. We included a feedback form in the back of the booklet as well. The form invites users to answer a series of questions designed to help us assess the impact of the booklet and how well it achieves its objectives. We record feedback on a central database and refer to this in the review and development cycle. NAM commissioned an independent consultant, Peter Keogh to run a consultation exercise including a survey and interviews with over 255 clinic staff across the UK to assess the awareness and uptake of a range of our resources. Over half of the survey respondents indicated that they were aware of the booklet and over 70% indicated that it would not be difficult to access a copy whilst in a consultation with a patient; Through regular engagement with our clinic and CBO networks, we gather informal feedback about the uptake of resources including this one. For the future we would like to conduct follow up research with GPs and primary care services as well as with HIV health professionals and community groups to see if this booklet been perceived to be helpful in encouraging individuals to engage with their primary care providers.

“I think this resource provides useful information and practical advice in a helpful and caring way. I think it has the potential to improve people’s lives. I think the way the NAM team developed and promoted and evaluated this resource demonstrates best practice and that shows in the resource itself. Possible ways to improve the resource might include: highlighting key messages so they stand out in a more obvious way, perhaps reinforcing those messages with quotes from people with HIV, and providing a list of actions that people can follow if they want to get the most out of primary care. This might help all users, but particularly those with low health literacy who might struggle to read the whole resource. The involvement of health professionals and users fulfils so many of the criteria for excellence that I think an exceptional rating seems appropriate. A multidisciplinary team of experienced and well-qualified health professionals with highly relevant expertise, who come from a number of different organisations, have been involved in what seems to be a systematic and thorough way throughout the lifecycle of the resource. The health professionals have contributed their own views as well as insight based on the patient groups they represent. Users were consulted right from the beginning. Users’ input on a range of issues, concerns and questions helped shape the content of the resource. Users have been actively involved in the writing and review process. Minority groups who are potentially hard to reach were consulted. Individual patients were consulted as well as organisations that liaise with, and support, large numbers of patients.”
BMA Public Information

The BMA Public Information team deals with around 3000 requests each year for help and information on a wide range of health and healthcare issues. Approximately half of our enquiries come from patients and the public and the other half from a mixture of professional bodies and healthcare organisations, educational organisations, charities, government and local authorities, NHS staff, students and doctors.

The enquiries we receive are diverse in nature. For example, we answer questions about BMA policy, reports and campaigns and on current hot topics in healthcare. We also give general information on medical ethics issues, such as patient confidentiality and health records. We explain to patients how the NHS works, and direct them to information on GP and hospital care. We hope that this ultimately makes a positive contribution to the doctor-patient relationship and helps patients to get the most from their consultations and health care. A key part of our work involves signposting to information such as how to find a suitable specialist, doctors’ fees and where to find reliable health and clinical information.

Our team acts as an interface between the public and the BMA. We help provide insight on public feeling to our policies and campaigns, and feed this information back to other BMA departments. We also aim to give patients and the public clear information about BMA policy and campaign work, through our information service and our public information web pages. This often involves turning complex health policy and information into patient-friendly material that is suited to our diverse audience, which can include young people, the elderly, people with mental health issues, asylum seekers and people from many countries around the World.

Our team recognises the importance of high quality patient information, and we are very pleased to present this year’s award for Information that aids decision making.

Our public information web pages can be found at:
bma.org.uk/patients
The BMA Ethics Department

The BMA’s ethics department provides a wide range of dedicated services and products designed to support doctors in their professional lives. These include the following:

**Ethics advice service**
We offer a dedicated individual ethical advice service for doctors, responding via First Point of Contact (the BMA helpline for doctors) or directly. We receive enquiries on a wide and varied range of topics, including confidentiality, consent, child protection and the provision of treatment to patients lacking the capacity to consent to specific interventions.

**Publishing advice and guidance**
The advice service is supported by written advice and guidance covering all areas of ethics in medicine. In addition to our main ethics handbook, *Medical Ethics Today*, we produce a number of short tool kits on specific issues such as the Mental Capacity Act and consent.

**Providing training**
We also seek to promote good practice by giving talks and training sessions to groups of doctors and medical students. The topic and format of these sessions depend on the needs of the audience and the wishes of the organisers but most are on core topics, such as confidentiality, mental capacity and consent and many involve facilitated case-based discussions.

**Monitoring and influencing medical law**
In order to provide accurate and up-to-date advice to doctors, we monitor developments in medical law, both statute and case (judge made) law across the UK. We also seek to influence the development of statutory law to ensure it reflects the highest standards of medical professionalism.

**Campaigning for changes in public policy**
We seek to influence public policy, through a combination of published reports, talks, lobbying, media work and liaison with other organisations.

Our team works extensively in the area of mental capacity and we are pleased to present this year’s award for mental capacity.

Our website pages can be found at: www.bma.org.uk/ethics
Living with Motor Neurone Disease
Motor Neurone Disease Association 2013

This resource aims to enable people living with and affected by MND to: find out about the disease and its impact; plan for the practical, emotional and financial challenges ahead; feel better informed through top tips that people with MND ‘wished they had known at the start’; gain directions to further information, support and services; achieve the best possible quality of life with MND. We work under strict criteria for The Information Standard, which requires expert review, evidence storage for feedback and version control at draft and for final deliverables. The range of expertise for this project was wide to ensure we obtained detailed review across the complex range of symptoms and care for MND. The 11 external experts are: Idris Baker, Consultant in Palliative Medicine, ABM University Health Board, South Wales; Pam Bostock, Consultant Occupational Therapist – Neurology Adult Ability Team, Staffordshire and Stoke on Trent Partnership NHS Trust; Amanda Campbell, Clinical Psychologist, Community Neuro-Rehabilitation, Walsall Healthcare NHS Trust; Alison Dick, MND Network Co-ordinator, Northern Ireland MND Care Network; Belfast Trust; Timothy Harrower, Consultant Neurologist and Senior Clinical Lecturer, Royal Devon and Exeter Foundation Trust Hospital; Emma Husbands, Palliative Medicine Consultant, Gloucestershire Hospitals NHS Trust; Lesley Johnston, Advice and Information Officer, Carers Northern Ireland; David Oliver, Consultant in Palliative Medicine, Wisdom Hospice, Rochester Honorary Reader, Centre for Professional Practice, University of Kent; Beth Simmons, Home Enteral Feeding Dietician, South Warwickshire Foundation Trust; Nina Squires, Specialist Speech and Language Therapist, County Health Partnerships, Queen’s Medical Centre, Nottingham; Linda Tuttle, MND Specialist Nurse and MND Care Centre Coordinator, Leeds General Infirmary. Prior to development, the following sources were used to determine user perceptions: Over 200 feedback forms for our previous core guide Your personal guide to motor neurone disease were evaluated. A further survey with 50 respondents tested inconclusive areas from the feedback forms. This included people living with MND and carers, volunteer Association visitors who have front line experience with families affected by MND (often ex-carers), key staff and care centre coordinators from MND Care Centres. Four branch AGMs/meetings were attended to address concerns raised about the physical presentation of the previous guide, through face-to-face feedback and handling of sample deliverables. These meetings were attended by a mix of people living with and affected by MND, branch members and Association visitors. This pre-work provided background evidence to support decisions on content, providing a framework for the project. During development, members of our dedicated review group were engaged in user testing the draft content. The review group consists of an average of 25-30 members at any one time and we look for ten responses (this was achieved). The guide is published in an A4 book and sent in a wallet folder to allow for additional items to be included, such as our publication list, the feedback form and our quick guide for carers. It is also available online as a standard PDF, an interactive PDF and in extracted section PDFs for ease of access to specific subjects. This helps us to give it wider awareness at events too, e.g. the extracted section on eating and drinking can be used at events about nutrition for people with MND and help target professionals. www.mndassociation.org/livingr. General dissemination is ensured by: Launching and repeating messages about the guide in our media, including our quarterly members magazine and our newsletter for volunteers; Staff and volunteer communications to raise internal awareness, with delivery through our send-out process and stock tracked; Engaging with our 25 regional staff (regional care development advisers) to further raise awareness to regional audiences; Engaging with our 350 voluntary Association visitors who help to introduce the guide into the homes of families affected by the disease; Project leads attending our annual Association visitor forum to encourage dissemination and provide guidance on how to introduce the guide; Communicating about the guide to care centre coordinators at MND Care Centres (which we part fund) so they can provide the guide to people living with or affected by MND, as appropriate following diagnosis. To put this into context, we have approximately 3,000 members living with MND at any one time. The initial mass send out for Living with motor neurone disease occurred in the first five months between the launch of the guide in April 2013 and September 2013, as follows: hardcopies: 1,629; total downloads from website: 256; total unique views on website: 797. Room for free comment on content that may be missing or needs improving; room for free comment to voice any other ideas. The form also allows us to break down the results into responses from: people living with MND; people close to someone with MND; people who are caring for someone with MND; health and social care professionals. The feedback form is supplied in the wallet folder with the guide, but can also be accessed directly online, through Survey Monkey. Those received in hard copy are entered manually and retained as evidence. In addition to the feedback online link provided in the guide, there is also a link on the website for those who access the guide onscreen. We also provide an info-feedback email address and full postal address in the guide, for anyone who prefers to write in longhand about a specific concern or idea.

“This is an excellent resource for people living with MND. It takes readers along a logical and comprehensive pathway, acting as a friendly, but independent guide to the issues and questions that they may face. The resource is well-structured with an excellent lay out and good use of colour. It is lives up to its aim to be a companion and guide to those affected by MND. A wide range of health professionals from different disciplines and different hospitals have been used. Every possible specialty seems to have been covered. Users have been involved at all stages of production and their views have been used to shape the resource. Various methods have been used including feedback forms, surveys and meetings. Particularly notable was the follow-up survey to text ‘inconclusive areas from the feedback forms’ and the ongoing use of the review group throughout the development process. Another very comprehensive feature of the resource is the addition of ‘further information’ sections at the end of each chapter. These not only give links to more in-depth factsheets on specific aspects, but also give external links to other sources of help. This is very effective as it they are given in the context of each chapter, rather than a long list at the end. This resource has an excellent layout and design. The use of colour on the page edges enables the user to distinguish easily between the five sections and once familiar with the document to navigate quickly to the section of choice. Within each section the use of headings, again in the section colour, helps to break up the text. The quotes and occasional illustrations are also well-spaced. The guide follows a well-structured pathway.”
Looking after Me: Our Guide for Women with Terminal Ovarian Cancer
Target Ovarian Cancer 2012

Target Ovarian Cancer’s Looking after Me guide aims to improve the quality of life for women with ovarian cancer that is terminal or life limiting. It focuses on the practical and psycho-social challenges of terminal cancer, with information to make the most of life, access palliative care services and take care of what is needed, so that women feel confident that their wishes and opinions are respected. We worked closely with a number of health care professionals and experts: The Hospice of St Francis, Berkhamsted – Dr Ros Taylor, Hospice Director, Sarah Russell, Director of Education and Research and Fay Richardson, Clinical Nurse Specialist were all consulted about the format and content of the guide and then all wrote specific sections of the guide. Mr Richard Hutson, Consultant Gynaecological Oncologist from Leeds Teaching Hospitals NHS Trust wrote about the complex issue of bowel obstruction and surgical options in late stage ovarian cancer; Dr Alison Farmer, an oncology nurse and visiting lecturer for the University of Southampton who has had ovarian cancer, contributed to the guide with a section about helpful thoughts – her professional and personal experience has given her valuable insight into this subject. We also worked closely with Camden and Islington Palliative Care Teams, in particular Chi-Chi Cheung, Consultant in Palliative Medicine and Robert Lutyns, Clinical Nurse Specialist who wrote about community palliative care and the relationship with one of their patients. All these sections were then reviewed by an expert and lay panel which included: Vivienne Jones, from the School of Health Science, University of Salford; Tracie Miles, Gynae-Oncology Clinical Nurse Specialist from Royal United Hospital Bath; Mr Desmond Barton, Consultant Gynaecologist Oncologist at the Royal Marsden Hospital. Their comments were incorporated into the guide drafts ahead of design. By adhering to the information standard, we ensure that all our resources are useful, relevant, well-researched, created in partnership with our beneficiaries and health professionals, and peer reviewed by expert panels. Target Ovarian Cancer involved users in the production of Looking after me from start to finish. Women Living With and beyond Ovarian Cancer, family and friends are featured in Target Ovarian Cancer’s resources to ensure an authentic, engaging and warm communication with the target audience, so the reader is hearing from ‘someone like me’. It was a particular challenge to find women who could be involved in the development of this guide, given the sensitive topic. Women at this stage of ovarian cancer are very unwell and have a lot of psycho-social and practical concerns to deal with, hence the need for the guide. We held a focus group at St Francis Hospice to establish the key areas the guide needed to cover, and then we drew on the expertise of women we were lucky enough to have a relationship with through their contact with us. This included Sarah Crockford, Pat Pumfrey and Margaret John who feature throughout the guide and wrote sections themselves. Elish and family, June, Chris and Paul are featured in photos and provided us with valuable insights into living with terminal ovarian cancer. Sarah Crockford and Julie Hanks also reviewed the guide and the sections written by experts to ensure it was understandable, easy to use and ‘accessible’. To ensure that users came from a variety of backgrounds, we advertised widely (e.g. on the website alongside working with Gynae Cancer CNS’s and Macmillan Cancer Voices etc). The charity offers travel bursaries or involvement through telephone conferences if travel is not an option.

When the guide was completed we held a launch event for all the contributors in London to thank them for their support. When the guide was launched, we promoted it to our database of Clinical Nurse Specialists (CNSs) and consultants through a mailing and a reminder mailing, and we also told CNSs about the guides when we spoke with them about other resources. We sent a special mailing to palliative care nurses and teams across the UK, and to hospices to inform them about the guides and offer them the opportunity to order copies. We send reminder mailings to health professionals about all our support publications and events on a regular basis, which includes Looking after Me. We developed a strategy for promoting it online as this had to be handled very sensitively. We also promoted the guide sensitively through our newsletters and Twitter and Facebook feeds. When new people get in touch with us (for example signing up to our e-newsletter), we send them an email which explains the range of services that Target Ovarian Cancer offers, including offering our guides. We have agreed key messaging for how we talk about this guide, so as to be able to inform people about its availability, yet not upset people by thinking of a negative outcome to their disease before they are ready. This wording has been circulated to all staff to use in all their communications. Since its launch, we’ve distributed over 2000 copies of the guide, plus over 300 have been downloaded from the website. We developed our first impact evaluation of all our supportive services shortly after this guide was produced. We wanted to ensure that women felt our support enabled them to live well. We asked them which of the guides they had received and how the guides contributed to their knowledge of ovarian cancer, to them feeling more confident to do things they hadn’t done since before their diagnosis, to reducing their isolation and to how supported they felt by Target Ovarian Cancer. This information will feed into an impact report at the end of our financial year. We also collect and track any ad hoc feedback we receive from women, their families and health care professionals. Looking after Me will be reviewed in September 2014 and we will use the ad hoc feedback and evaluation information to feed into the review, adapting the language and messaging as appropriate and updating information to reflect new research and clinical practice. We are very proud of the Looking after Me guide and continue to promote it as one of our flagship products.

“This is a very thoughtfully produced and well-researched publication, appropriately targeted with sensitivity and understanding, tackling a difficult topic well. I’m not sure of the logic behind the very anonymous looking front cover: is it to be discreet so that you can carry it around with you without broadcasting the fact that you have ovarian cancer? Maybe. They have worked closely with a number of health care professionals: the names of those involved and contributions they make are listed. An exceptional effort has been made to contact and involve women with this condition throughout the process. The sensitivity of the topic made this a particular challenge. Also it uses very thorough and conscientious system for evaluation with evidence that it is followed through and used to inform future publications.”
People with a cancer diagnosis often face a range of treatment options. This booklet is written to help them make decisions about their treatment. It describes how to find out about the different treatments, understand the aims of treatment and any potential side effects. It also explains statistics and has a section on weighing up risks and benefits. The booklet aims to support people in making important decisions at a difficult time. This booklet has been written, revised and edited by Macmillan Cancer Support’s Cancer Information Development team. It has been approved by our Chief Medical Editor, Dr Tim Iveson, Macmillan Consultant Medical Oncologist. Other contributors are: Dr Belinda Hacking, Consultant Clinical Psychologist; Dr Christopher Hewitt, Consultant Psychologist; Kathleen Mais, Nurse Clinician; Dr Alastair Smith, Consultant Haematologist. Macmillan Cancer Voices (volunteers who have had or have cared for someone with cancer) commented on draft and provided quote. Booklets have been distributed via Macmillan’s website Be.macmillan.org.uk The information is also available online at http://www.macmillan.org.uk This has only recently been available to order so has not been evaluated. Over 1000 copies were sent out in January 2014.

“This resource would be very helpful for a patient making a treatment decision. As well as covering useful topics like side effects of treatment it also covers areas that can be challenging to explain to a non-medical professional like statistics and risk. The booklet also provides helpful lists of questions that a patient may like to ask before making a treatment decision and other organisations that may be able to provide them with information.”

2014 BMA Patient Information Awards

Making Treatment Decisions
Macmillan Cancer Support 2013

People with a cancer diagnosis often face a range of treatment options. This booklet is written to help them make decisions about their treatment. It describes how to find out about the different treatments, understand the aims of treatment and any potential side effects. It also explains statistics and has a section on weighing up risks and benefits. The booklet aims to support people in making important decisions at a difficult time. This booklet has been written, revised and edited by Macmillan Cancer Support’s Cancer Information Development team. It has been approved by our Chief Medical Editor, Dr Tim Iveson, Macmillan Consultant Medical Oncologist. Other contributors are: Dr Belinda Hacking, Consultant Clinical Psychologist; Dr Christopher Hewitt, Consultant Psychologist; Kathleen Mais, Nurse Clinician; Dr Alastair Smith, Consultant Haematologist. Macmillan Cancer Voices (volunteers who have had or have cared for someone with cancer) commented on draft and provided quote. Booklets have been distributed via Macmillan’s website Be.macmillan.org.uk The information is also available online at http://www.macmillan.org.uk This has only recently been available to order so has not been evaluated. Over 1000 copies were sent out in January 2014.

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My Journal: Life after Childhood Meningitis and Septicaemia
Meningitis Now (Formally Meningitis Trust) and Meningitis Research Foundation 2013

Guidelines for managing children with bacterial meningitis and septicaemia, produced by the National Institute for Health and Care Excellence (NICE), England, Wales and Northern Ireland, and the Scottish Intercollegiate Guideline Network (SIGN) recommend that health professionals give parents or carers and/or children and young people information about recovery, potential long-term effects and how to get follow-up care before they are discharged from hospital. My Journal has been designed to fulfil these recommendations so that children/young people (age 18 and under) and their families can be given information upon discharge from hospital, which guides them through the follow-up care every child should receive, recovery, potential after-effects and ongoing help and support available following meningitis and septicaemia. Each child’s experience can be very different, My Journal allows the family to keep a personal record, providing the user with an opportunity to detail information, including: Personal details; Hospital contacts; Follow-up appointments, including notes about questions to ask; After-effects and ongoing care; Prescribed medication. All these details can be shared easily amongst the child’s/young person’s health carers, school, respite, rehabilitation or anyone involved in ongoing care and support. This information can include photographs and personal accounts from both the individual and their parents. During our focus group sessions with parents of children post meningitis, it became very clear that having all information in one place was so important, particularly if the child needed ongoing care and support from a multidisciplinary team. When children have meningitis or septicaemia at a very young age, it can be very difficult for them to understand what has happened to them, and for some, why they are left with permanent disabilities. My Journal can also help these children see exactly what happened at the time of their illness, and parents are encouraged to write down their account of events. A Your Guide – Recovering from Bacterial Meningitis and septicaemia booklet is always inserted into the front of My Journal. This booklet provides detailed information to back up each section of My Journal. Further detailed fact sheets are also available online covering a range of after-effects and complications, and topics relating to help and support. www.meningitisnow.org Relationships were established with three Royal Colleges in the very early stages of development leading to endorsement from all parties, details below: Dr Jo Lawton – Education Programme Manager, Royal College of Paediatrics and Child Health (RCPCH); Dr Alistair Thomson – Consultant paediatrician, Vice President (education) RCPCH – was our lead medical consultant throughout the project. All first drafts of text were sent to Dr Thomson in the first instance, his amendments were then included before comment was received from Janice Alister, Fiona Smith and Simon Kroll. Dr Janice Alister – Child Health Representative, Royal College of General Practitioners; Ms Fiona Smith – Advisor in Children and Young People’s Nursing, Royal College of Nursing. We followed protocol for all Royal Colleges in order to gain endorsement and use of their logos. Prof Simon Kroll – Paediatrics and Molecular Disease, Imperial College, London. Professor Kroll acts as Medical Director for Meningitis Now and gives final sign off for the content of our written materials before they are published. Client focus groups were used throughout the process. Our own data base was used to invite parents whose children had recovered after meningitis or septicaemia. The groups were made up of carers, with their children’s outcomes ranging from a very good recovery, to children with severe disabilities needing 24 hour care. Focus groups met twice during the development process, each time sharing ideas and making necessary changes to content and presentation. Individuals who could not attend meetings were also consulted on a one-to-one basis. The ideal route for My Journals to be given to families is at point of discharge from hospital. Contact has been made with all major children’s hospitals and hospitals with paediatric units. To date we have reached 164 organisations with over 300 Journals. We have started to see clients coming to us having been given My Journal when leaving hospital. As an organisation we have used our own website, and social media to reach out to families. We also visit families in their homes and offer My Journal at that time. To date 392 My Journals have gone directly to families. A programme of promotion will continue, including working with partnering charities, rehabilitation centres and Public Health England. In June/July 2014 (one year after production) surveys will be sent to families and health professionals who have received
My Recovery Pack for My Hip/Knee Surgery
Guy’s and St Thomas’ NHS Foundation Trust in partnership with Janssen Healthcare Innovation and DePuy Synthes 2013

Guy’s and St Thomas’ NHS Foundation Trust, a leading centre for elective orthopaedic care that treats 6,200 patients a year, undertook a project to radically change its clinical pathways for patients undergoing hip and knee replacement surgery. The aims of this project were to: Significantly reduce length of hospital stay following surgery from five to seven days (average); Involve patients in their own care before and after surgery; Move recovery from ward to home, and provide support to facilitate this; Enhance patients’ experience; Improve efficiency, reduce bed occupancy and help to reduce waiting lists. To achieve these objectives, the orthopaedic department partnered with Janssen Healthcare Innovation and DePuy Synthes to develop Care4TodayTM, an interactive enhanced recovery programme for patients undergoing primary hip and knee surgery at Guy’s Hospital. As a result of this partnership, we: Developed a range of bespoke patient information that is accessible and relevant to our varied audience, including older people; Made our innovative ‘hip and knee school’, an interactive class that helps patients understand what to expect before and after surgery and during their recovery, a compulsory part of the patient pathway; Based our new programme on a radically different approach to multidisciplinary working and home care; Decided to offer this innovative approach, based on patient participation and engagement, to all patients, regardless of age and complexity of their care. Our bespoke patient information was central to this ambitious initiative and was designed to help achieve its key objectives. It includes a printed recovery pack as well as an interactive website that puts the patient at the centre of their own care. Providing information in multiple formats means that each and every patient has an access to high quality information, regardless of their preferences. Both the pack and website have enabled our multidisciplinary team to interact with patients from the moment they are scheduled for surgery and throughout their hospital stay and recovery, providing valuable support and advice. They also allow our patients to leave hospital from day two after surgery, as long as it is safe to do so, and to continue their care from the comfort of their own home, supported by the hospital team of nurses and therapists. The pack comprises: Quick Guide to My Joint Replacement Pathway, which provides an overview of the entire pathway; Preparing for my Surgery, which helps patients prepare before they are admitted to hospital; My Hospital Stay for my Hip/Knee Surgery, which explains what to expect during surgery and a patient’s hospital stay; My recovery at Home after my Hip/ Knee Surgery, which provides information on the recovery period. We have strengthened the focus of discharge planning so patients know exactly what will happen on the day that they are ready to leave hospital and how they will be supported at home to include a furniture height measurement form used by occupational therapists to help patients prepare for, undergo and recover from their surgery. These tools are designed to complement each other and provide patients with a multimedia experience that combines education and engagement as they prepare for, undergo and recover from surgery. The pack and website support continuity of care and enable patients to interact with their healthcare team like never before. We have: Told patients what to expect at every stage of their care; Enabled them to set their own recovery goals; Increased awareness of vital admission and discharge activities; Provided advice and exercises to help patients at every stage of their care, irrespective of their level of health and well-being and ability to engage with the programme; Improved dialogue between patients and their healthcare team; Enabled patients, relatives and carers to track progress and participate in the recovery process; Empowered patients to raise questions and actively engage in their care. We conducted interviews with the whole healthcare team to understand what mattered most to our patients, and used this feedback to help us develop bespoke recovery packs and online resources. All of the materials and tools were reviewed and approved by the Trust’s patient publication
team to ensure they followed our patient information policy and represented evidence-based best practice. Feedback was collected via focus groups involving patients who had undergone hip/knee surgery as well as those who were about to have surgery (eight patients in total). It was important for us to understand what information patients wanted at each stage, so that we created a package to meet the needs of their care effectively, without overloading them with information. We consulted patients on the development of the website and printed packs from the early stages of the project, and asked for comments on the structure, design and content. Patients told us they wanted a wide mix of materials, from printed information on how to prepare for surgery and exercise booklets, to interactive online tools. They really liked the communication options on the website and they said it made them feel confident when returning home, knowing they could contact someone in the team directly. All patients booked for a hip or knee replacement receive the recovery pack when they come to their first outpatient appointment. Immediately after that, they meet a member of the Care4Today team who talks them through the printed pack and the website www.myjointrecovery.co.uk, and provides them with their unique login details. Patients are also booked to attend the hip and knee school, an interactive class that helps them understand what to expect during the pathway and recovery, and enables them to further discuss the information in the pack. The class is led by an occupational therapist who can answer any questions they might have. Evaluation has been continuous and a detailed evaluation is due to be completed in June 2014. We have held feedback sessions with our patients to discuss the information they were given before their surgery, and how the Care4Today information has played a part in their treatment and recovery. Four patient focus groups with five to eight patients have been held to evaluate the recovery pack and website. Two focus groups were conducted with patients who had been through the programme using the new resources as part of their care; the other two with patients who had not. The objective was to compare experiences of patients in both groups to better understand what drives patient satisfaction and participation. The healthcare teams also participated in the focus groups to assess the impact of the resources. Measures of success have been very positive and we have delivered our ambitious objectives. The programme has enabled staff to share skills and increase efficiency, and boosted team morale.

"I think this is an excellent resource: it’s been well-thought out, has a clear purpose and objective and is achieving that. The mix of formats is good, the summary is helpful and the exercises are particularly well-explained. It’s practical and tells patients what they need to know. It’s well-laid-out to high design standards and has clearly been planned and executed well. There is a lot of information here but it is well-divided between the resources and presented in bite-sized chunks with a quick guide summary and a summary at the start of each booklet. It uses colour coded sections, navigational aids and list of contents. It is very practical in nature with particularly useful information about coming into hospital and life at home. What lets it down is the language; there are health service terms and phrases like the word pathway or the phrase ‘you will experience...’ and the tone is very passive. Having said that, it’s an enormous step forward in health information to see it being taken so seriously.”

Physical Health and Wellbeing Handbook for Service Users and Carers
South London and Maudsley NHS Foundation Trust 2014

The need for attention to physical health of mental health service users has come more to the fore recently and it is now required by commissioners. The audience comprises service users, carers, clinicians and commissioners. The objectives are: To improve the uptake of physical health checks on inpatient units, particularly for those people prescribed anti-psychotic medication; To inform service users and carers about the physical health risks associated with experiencing a severe and enduring mental health problem and steps they can take to improve their health; To empower service users to be more involved in the physical health care; To promote health and wellbeing across the patient journey; To provide a resource to facilitate discussions between service users, carers and clinicians. This is a collaborative initiative between service users, staff in South London and Maudsley NHS Foundation Trust and Institute of Psychiatry, King’s College London. We combined service user experience, clinical knowledge and academic skills to co produce the service user handbook. Following focus groups with service users, a mental health nurse academic with research, teaching and clinical experience in the field of severe mental illness and physical health, lead on developing the content of the resource. A project team including senior clinicians and managers from clinical services across the Trust, a communications office, Patient Information Manager, administrator, and two service users regularly reviewed the content and provided feedback. Two service user focus groups were asked for their views about the content and style of the booklet. They were also asked about their views about why people using inpatient mental health services often refuse physical health checks. The focus groups were facilitated by service users and took place before work on the content began. The focus groups participants were very keen to have detailed information about each of the physical health checks offered when in hospital. They wanted to know what happens every step of the way, the rationale for each test, how long each takes, what do the results mean etc. They fed back that the main reason for refusing physical tests is because they believe staff do not explain sufficiently why test needs to be done, what it will involve etc. Focus group participants were also keen to include service user art of positive images that evoked a sense of wellbeing and wholeness. The Bethlem Art Gallery and Head of SLAM Arts were also consulted and collaborated on this part of the design. We involved several local service user artists who were paid for their artwork. We have printed 8,000 copies which will be disseminated to each inpatient and community service throughout the Trust. We have clinicians in each clinical area who take a lead role in coordinating the physical health care of services user in their service. They will take the lead in ensuring every service user and carer has access to it. The handbook will be publicised through existing Trust committees (including the Physical Health Committee) and events. Members of the project team are currently developing a brief (ten minute) online training session to educate clinical staff about the handbook and disseminate findings from the service user focus groups. Evaluation methods are still under consideration as the booklet has only recently been published. We expect this to include obtaining patient and carer feedback, audit and small scale pilot studies within clinical teams to see whether the booklet has influenced take up of physical health tests.
BMJ Evidence Centre

The BMJ Evidence Centre’s support tools bring trustworthy, evidence-based information to help patients and clinicians to make decisions about people’s health. Whether used to support diagnosis and treatment at the point of care, decision making, our tools give quick, accurate answers to patients’ and doctors’ clinical questions. They also provide access to the latest research, guidelines and information.

Within the Evidence Centre, the consumer health team is focused on supporting patients in their decision-making. They produce jargon-free, evidence-based online resources for patients, and patient decision aids – accredited materials to help guide patients through decisions about their care. These are reliable, easy-to-understand medical information for individuals.

Many of us use the internet to research our symptoms, medical conditions and treatments. But it’s hard to know which information to rely on – and frustrating to have to deal with misinformation. People need reliable, evidence-driven information to help them understand their condition, and clear explanations about what to expect from their treatment options.

The BMJ produces online resources that provide the general public with patient information leaflets on over 190 common medical conditions, from depression to breast cancer to high blood pressure. Using the most up-to-date research evidence, the leaflets outline the benefits and side effects of over 1,500 treatment options, to understand how medical research can help them make choices about health and wellbeing.

Written in plain English, the leaflets provide high-quality information about the causes and symptoms of common medical conditions, and helps people understand how their condition might affect their life.

By translating clinical research evidence and expert opinion into language that everyone can understand, BMJ gives people the knowledge they need to take part in critical decisions about their treatment and ongoing care.

Patients can make more informed decisions with their doctors, learn about managing their condition, and gain a realistic appreciation of the benefits and risks of the treatment or procedure they are considering.

BMJ patient information leaflets can be seen at http://bestpractice.bmj.com/best-practice/patient-leaflets.html.
“I feel that the combination of the process followed to produce this resource, together with the clarity of the information presented and the beautiful use of colour, (particularly from the users’ artwork) make this an exceptional resource and highly impressive. There are a couple of small omissions (e.g. lack of contact information or feedback mechanism) but I feel they don’t detract from the quality of the resource. The purpose of the resource is crystal clear as far as service users themselves are concerned. It provides lots of information clearly presented to help people understand the purpose of the various tests and activities and to motivate them. The format is well-signposted and easy to follow. It makes good use of headings and questions to guide readers and use of standard format in each section, so despite there being a lot of information it is not confusing. The subject matter is also one that is too often neglected and so I believe it will be a very valuable resource. This resource reflects the user perspective and this is a real strength of this document. Whilst user views are not quoted directly, it is clear that their views have contributed significantly to this resource. My only real criticism is that whilst it says it is a resource for carers, it doesn’t really talk to or about carers directly at all. I think a section on how carers can help their family member to manage their health, perhaps also addressing the need for carers to look after their own health too, would have been a useful addition. One thing I would like to have seen is a section for family/carers, which talks about how they can use the resource to help their family member improve their physical health.”

POPS Home Project: Vaginal Pessary Self-Management Video

Cambridge University Hospitals Foundation Trust 2014

The video is an outcome of the POPS Home project, part of The Health Foundation’s ‘Shine programme, being run by Cambridge University Hospitals NHS Foundation Trust (CUH) POPS Home aims to teach women to self-manage their pessaries for pelvic organ prolapse (POP). Vaginal pessaries offer an effective alternative to major surgery for many women with POP. In the UK it is standard practice for women using pessaries to have their pessary changed at least twice a year by a healthcare professional. Unfortunately many women find their pessary changes uncomfortable, and the frequent visits to clinic inconvenient, which leads a proportion of women to opt for major surgery to correct their prolapse. We were interested in whether it was possible to teach women to change their own pessaries at home, and were keen to see whether this would improve patient experience and thereby reduce the likelihood of women choosing a surgical solution. We also hoped that self-management would enable women to individualise their pessary use and empower them in their health care. The video has been designed to encourage women to choose pessary self-management as a treatment choice rather than remain on doctor-led care. Through discussion with patients and healthcare professionals we encountered some surprising presumptions about the type of woman that might be able to self manage or the difficulties that people might have. We also found that in general women know very little about their gynaecological anatomy and find it a difficult topic to talk about. For this reason we felt that a video that could be accessed online would be a perfect teaching tool, and we felt strongly that patients that had learned self management should feature on the video to give their stories and show that it is something that anyone can learn to do. The target audience are women who are pessary users but also we hoped it would be used by other healthcare professionals who may be interested in setting up this service. The video was devised by Miss Rohna Kearney (Consultant Urogynaecologist), Claire Brown (Specialist Women’s Health Physiotherapist) and Myfanwy Champness (Project Manager) with Addenbrooke’s Media Studio. Planning of the video was undertaken by the team through meetings to discuss the aims of the video. A synopsis and script were devised by the project team with the support of Media Studio. Anatomical drawings were discussed and developed within the team. The physiotherapist attended the filming with patients to ensure accuracy of information and to help put the patient at ease whilst filming. A patient satisfaction questionnaire has been designed to capture patient’s experiences on the pathway of six monthly pessary changes by a hospital doctor or GP. The results of the questionnaire show 67% of women would like to learn how to change their own pessary and 60% are happy to use an online tutorial to learn pessary self-management. Forty-six women were telephoned after they declined to join the pessary self-management service. The most common reason women gave for not wanting to try self-management was they thought it would be too difficult. Therefore previous patient experiences were an important feature in the video explaining how easy they found pessary self-management. The patient stories allow other women to relate to the patients in the video and will hopefully encourage others to join the service. Feedback from appointments revealed women commonly asked how the pessary works. Therefore an animated video of how the pessary holds up the pelvic organs was a vital part of the video. Scripts were emailed to pessary self-management patients to check the content. A first draft of the video was also viewed by patients after their appointment to check content and clarity of the video. Comments included spending longer time viewing diagrams and to make diagrams clearer of how the pessary held up pelvic organs. The video has been published on the Addenbrooke’s website and will be looking to see whether the launch of the video on the Addenbrooke’s website coincides with an increase in patients asking to self manage. A focus group will be held towards the end of the self-management programme (June 2014) and patients using the service will feedback on the learning tools provided by the service. We will start to ask women at their follow-up telephone consultations whether they have looked at the video and whether they found it useful.

“This is a very well-balanced video which conveyed its message enabling patients to confidently carry out a very personal procedure themselves. It makes good use of diagrams and filming of patients. It will work well with the clinical support given to patients. It is an excellent visual aid to communicating a very sensitive and personal procedure. There is a very useful summary at the end of the video. Information about quality of life issues is done by the patients themselves in a very effective way.”
Primary Breast Cancer Resource Pack
Breast Cancer Care 2013

The audience for this pack is anyone recently diagnosed with primary breast cancer. It features information particularly relevant to this group as well as space to customise the pack with other information, depending on their individual treatment. It features a personal record so that people can list down details that are useful and relevant – like the names and contact details of healthcare professionals. It also has room for notes and ideas for questions they may want to ask about their treatment. The pack has empty pocketed dividers to break up the content and allow people to add their own extra information, however, the pack is supplied with Breast Cancer Care’s booklet on Exercising breast cancer and a leaflet on Exercises after breast surgery (as the vast majority of breast cancer patients will have some form of surgery and post-operative exercises play an important part in recovery). We also include a leaflet on the services Breast Cancer Care provides to people who are newly diagnosed and having treatment. In the back of the pack we explain the medical terminology people may hear and give information on further support and other titles that may be of help. As with all our information, this pack was produced by a member of the publishing team in conjunction with an expert nurse from our clinical team. It was then reviewed by other healthcare professionals outside the organisation. We sent the pack for review to: two clinical nurse specialists in breast care; a clinical psychologist; a breast surgeon; a counsellor specialising in breast cancer. We involve patient reviewers in all our information and three lay readers reviewed the draft copy. The pack is available on our website and through our Helpline and national and regional centres. The majority of our information is ordered by healthcare professionals to pass on to their patients. We have previously evaluated this pack via paper questionnaires and telephone interviews and feedback that into its continued development. Plus we carried out online survey with patients and healthcare professionals in March last year to ask about the format of the pack. Following feedback from this survey and from our volunteers we made changes to the format to increase capacity to customise it and bring it in line with our other resource pack in terms of quality.

“This is a really good resource, thoughtfully put together with a real aim to personalise it for each individual. It allows the reader to find out the basics and then get more information about the areas they want to know. There is space for notes, contact details, test results etc and a great device to encourage questions. There’s also a glossary of terms. The person who submitted didn’t give much information in a couple of areas and this is where is scored a bit lower, because the information wasn’t there to judge it on. It’s a got a very reassuring and supportive feel to it, which is what it is aiming for, and it focuses on support rather than facts. The tone and language used is excellent: it’s informal without being patronising. It contains small amounts of information, with additional resources where appropriate and clear information about how to get hold of more. It does a good job at not overwhelming people: this is really well done.”

Smoking and Your Lungs: Why It’s Never too Late to Give Up
British Lung Foundation 2013

The objective of this resource is to provide stop smoking information that is aimed specifically at people with a lung condition who smoke. It is an alternative to the more generic smoking cessation information that is often presented to them by healthcare professionals. The purpose of the resource is to inform people who have already been diagnosed with lung disease of the dangers of smoking when you have a lung condition, as well as the significant benefits of giving up. The key message is that it is never too late for people with a lung condition to give up smoking. The booklet includes information on the effects of continuing to smoke when you have a lung condition, the benefits of giving up, the basics on how to stop smoking and details of organisations to go to for more information on quitting. It is motivational in tone and specific to those living with lung disease. The intended audience is anyone with a lung condition who smokes. This material is aimed at smokers who already have a lung condition, rather than anyone who smokes or might take up smoking. We wanted to avoid producing another generic piece of stop smoking information and actually target people living with a lung condition who come to the BLF for advice on smoking or lung disease generally. The resource is aimed at helping people living with chronic lung disease take responsibility for their health by deciding to quit smoking. It does this by clearly presenting the benefits of giving up smoking, providing tips on giving up and clearly signposting to support services for smoking cessation. A key objective is helping those with chronic lung disease manage their condition better and do more to look after their health. This resource was written by freelance writer Catherine Ross who is a senior cardiac nurse for the British Heart Foundation and has considerable nursing experience on cardiac and respiratory wards. The BLF also received feedback on the resource from Dr Chris Stenton, consultant physician in respiratory medicine at Newcastle upon Tyne Hospitals NHS Foundation Trust. Dr Stenton gave useful advice on some of the wording used in the resource and the definitions of some complex medical terms such as FEV1. Finally, we sought feedback from Ren Gilmartin, advanced nurse practitioner and specialist smoking cessation counsellor, who advised us to avoid dwelling on the fact that smoking is harmful, as most smokers are already aware of this, and focus on the benefits of giving up and how to do it. Before planning the content of this resource, we sought feedback from people with lung disease on an older publication we wanted to replace, called Stopping Smoking. We received seven feedback forms and fed the comments into the brief for the new resource. Suggestions included more information on the financial savings made by stopping smoking, less information on why people smoke and more information on the support available. Our responses to this initial feedback included placing more emphasis on how stopping smoking can prevent further deterioration of the lungs for people with COPD, and decrease the risk of getting other conditions, such as stroke. We also updated the list of available stop smoking aids and NRT treatments, and placed more emphasis on the incentives to stop smoking, including saving money. After the new resource had been written, edited and designed, we then brought it to a focus group of people with lung disease who belong to a BLF patient support group in Camden, London. We received a lot of very useful feedback from this group, including positive comments about the language used and the use of graphs and diagrams. They also suggested we make the information about saving money clearer, and include a picture of a woman to make the resource easier to relate to for both men and women. We took all these comments on board when revising the final draft. This resource is available to order through the BLF website, or by calling the BLF helpline. It is also listed on a printed order form which is sent out with all health
2014 BMA Patient Information Awards

information orders. We have promoted the resource via our email newsletters, social media and no smoking campaigns, and have also made it available at BLF lung testing events across the UK and at our recent smoking cessation training for health care professionals in the north east of England. We seek feedback from users of all of our publications, providing details in the booklet of how to get in touch with the BLF to give comments. We are also planning to get feedback from the health care professionals attending our smoking cessation training to ask if their patients would find it useful. This will be through feedback forms. We will also be seeking user feedback again when we come to review the resource under the requirements of the Information Standard scheme.

“This resource is easy to read and I think it illustrates the benefits of quitting smoking very well. The focus of the booklet is on the benefits of stopping smoking, such as how much money can be saved and the almost immediate improvements in quality of life. I think this is more encouraging and realistic than just telling someone how bad smoking is as the majority of smokers know this. The booklet is intended to be an alternative to the generic stop smoking information usually provided at GP practices and the main message is that it isn’t too late to quit. This fits with the intended audience who are slightly older and living with a lung condition. The front page of the booklet makes it clear that the resource is intended to help people quit smoking. It also states the booklets theme which is ‘it’s never too late to give up’. I found it really interesting, and thought facts such as how much someone would save per week/month/year was excellent at demonstrating that the benefits of quitting aren’t just health related. The booklet is also realistic and has a section on relapsing. This section is encouraging and outlines how common this is, and bullets ways to quit for good. The resource is made up of six concise and easy to understand chapters. The amount of information given is appropriate as the booklet aims to provide people with straightforward guidance on stopping smoking and the language used is to the point and easy to understand. I also really liked the way Lynne’s case study was used – I think it is good to have a fellow sufferer’s perspective and to show how she managed to quit after smoking for so long. The use of clear graphs and charts also help demonstrate how stopping smoking at any time will have a positive impact on quality of life, no matter how old someone is. I found the resource was realistic: it highlighted how common it is to relapse, but provided helpful tips to overcome cravings. I also really liked the two charts which illustrated the time it would take once someone had quit for their health to benefit. Overall, this is an interesting and informative resource.”

Supporting People to Make Decisions: Applying the Mental Capacity Act

Headway the brain injury association 2012

The booklet is for anyone concerned about another person’s capacity to make decisions. It explains the principles of the Mental Capacity Act and provides information on how to apply to the Court of Protection. Two experienced solicitors working at Inwin Mitchell’s Court of Protection (COP) department were consulted on drafts of the booklet. The booklet was based on a previous booklet by the same solicitors called A guide to the Mental Capacity Act. An expert capacity (Prof. Jenny Kitzinger, Professor of Communications Research, Director of the Health, Science, Risk, Media Research Group, Cardiff University) also commented on drafts. Several brain injury survivors and carers with experience of capacity issues and of applying to the CoP were recruited via Facebook and Twitter. They provided a number of suggestions which were incorporated into the final booklet. The booklet is sold online to the general public via our website shop. It is publicised to Headway support groups via email and our in-house magazine and is available at a discounted rate to the groups. The groups use the booklet with their service users and make them readily available in day centres. The booklet is sent out free of charge to helpline callers with communication problems. We send out feedback forms to helpline callers who we send the booklets to. We provide a feedback form on our website for comments on publications. Headway groups and branches are contacted for feedback and focus groups are run occasionally at the centres.

“This is a very good leaflet which handles a complex and sensitive issue which will be distressing for those involved. The booklet covers the legal aspects of this difficult situation, in sufficient detail to help and support people going through this situation. Although the amount of information is large, it is appropriate given the subject matter, and it is presented in an accessible way for the intended audience. It is dealt with sensitively with empathy, but at the same time gets the facts across. It is very clearly set out with clear contents, logical sequence, numbered pages, clear headings, key points at the end of each section and a summary at the end. It is very professionally produced, clear and easy to follow and to check back through. The icing on the cake would have been a glossary and abbreviations list but this is certainly a very useful booklet to have.”

Surgery Support Pack
Prostate Cancer UK 2013

Urinary incontinence and erectile dysfunction are the most common side effects experienced by men having radical prostatectomy (surgery to treat prostate cancer). The National Cancer Patient Experience Survey shows that the support and information men receive to help them understand what to expect during and following treatment for prostate cancer and how to cope with side effects, vary across hospitals. Products available on the NHS also vary throughout the country. Some hospitals provide a small supply of incontinence pads when a patient is discharged after the catheter is removed, or via a district nurse, whilst others don’t. It aims to support all men undergoing surgery to treat prostate cancer, wherever they are based in the UK, by ensuring they are provided with complete, quality information, at the right time, to help them recover as quickly and easily as possible. The Surgery Support Pack includes: Tool kit fact sheets and booklets – providing detailed information about what the operation involves, and how to manage side effects. These are reviewed by medical experts every two years to ensure they are accurate, up-to-date and reflect medical practice; Sample incontinence products – allowing men to try out different things and help them find what works for them; Information about the services we offer – we have a range of services to support men, their family and their friends, including Specialist Nurse helpline, one-to-one support, and online community forums; Information about other support organisations that could also help. The pack aims to complement the information and advice given by health professionals, highlighting Prostate Cancer UK as a support to health professionals, as well as encouraging them to promote our services to their patients. We asked urology clinical
nurse specialists and consultant urologists to help us identify how the packs would fit within current clinical practice. They also advised on suitable products for the pack to help men cope with the side effects of the surgery. For example, they advised on the absorbency level of incontinence pads that would be most beneficial immediately following catheter removal. These health professionals are the primary contacts for preparing men for surgery and are most aware of their experiences such as telling us which types of incontinence pads men found comfortable, advising on male specific pads. Our Specialist Nurses also fed into the scope of the pack by outlining what would be considered the ‘gold standard’ of support and information throughout the man’s journey from treatment decision to follow up care. We piloted the Surgery Support Packs at 12 hospitals in the UK. Clinical nurse specialists gave the packs to men having radical prostatectomy. The pilot ran for three months. The hospitals then provided us with information on their current practice, number of packs distributed and any patient feedback they received. The health professionals involved in the Surgery Support Pack pilot were: Pam Ferrar, Macmillan Uro-Oncology CNS, Northampton General Hospital; Tina Smith, Uro-Oncology CNS, Chelsea and Westminster Hospital, London; Miranda Benney, Specialist Nurse, Royal United Hospital, Bath; Allison Robertson, Urology Nurse Specialist, Ninewells Hospital, Dundee; Debbie Gray, Uro Oncology Nurse, Darlington Memorial Hospital; Patricia McClurey, Prostate Cancer Specialist Nurse, James Cook Hospital; Vanessa Baskett, Senior Uro-Oncology CNS, Queen Alexandra Hospital, Portsmouth; Jane Booker, Urology CNS, The Christie Hospital, Manchester; Hilary Baker, Uro-Oncology CNS, Wycombe Hospital; William Cross, Consultant Urologist, St James University Hospital, Leeds; Paul Clark, Urology Nurse, University of North Tees Hospital; Mandy Jeffrey, Prostate Cancer CNS, Royal Country Surrey. In August 2012, we conducted a survey with men who have previously had radical prostatectomy to understand the level of information and support they received and what specific information/ items were missing that they would have found useful had they been given a support resource prior to the operation. The survey also drew out information about what specific experiences men had following surgery such as how long the side effects lasted. We used the responses to model the pack based on men’s needs. For example, men said that they valued discretion when leaving the hospital with incontinence products. We therefore developed the packs with a plain, opaque bag without our name or logo. The factsheets and booklets included in the pack are reviewed by men with prostate cancer to make sure it’s easy to read and understand, and meets their needs – as part of our information production process. The pack is designed to be given to men at the most valuable time, which is prior to the operation. This allows them time to use the information to understand what the operation will involve, what side effects they are likely to experience and how to cope with them. It also gives them the opportunity to familiarise themselves with the products before needing, for example, learning how they can start pelvic floor muscle exercises ahead of the surgery to minimise the impact of erectile dysfunction. To enable this, our primary method of dissemination is via urology nurses in hospitals who prepare men for surgery once they have decided to have this treatment. The Surgery Support Pack can be ordered by health professionals through our website. It has been advertised through email promotion targeting urology nurses and consultants, in the British Association of Urological Nurses (BAUN) newsletter and Prostate Cancer UK health professional’s e-newsletter, conferences and events. Our regional community nurses also have links with local hospitals and promote the packs where relevant. Men who call our Specialist Nurse helpline are offered a pack if they are due to have radical prostatectomy and haven’t already been offered a pack by their nurse. To date, we have distributed over 700 Surgery Support Packs since their launch and we used feedback from patients and health professionals involved in the pilot study to evaluate its impact. Each pack included a patient feedback survey for the man to complete and return. Every man taking part in the study received a follow-up call. This allowed us to delve further into their responses. The packs have now been launched in full across the UK. We are still committed to receiving patient feedback so that we can continue to monitor how well they are received and make any necessary improvements.

“This resource has been very specifically thought through to include advice on what to expect after PC surgery. It is bulky as it includes examples of patient care products but it is useful to have them available with the text. It must be always tempting for patient organisations to put their logo on all resources but PCUK have avoided the temptation to put their logo on the discreet black bag. PCUK use a clean graphic style which looks authoritative and is easy to use. PCUK have gained the Information Standard and the booklets are well-designed. It uses full page colour pictures of men or men with their partners. They are captivated by quotes from the personal histories so the picture and the context are related. All of the booklets discuss quality of life aspects and the comments and advice are based on patient case studies. This particularly applies to the sex life booklets. The research approach is excellent based on named expert health care staff and patient consultation and feedback.”

Target Ovarian Cancer’s Clinical Trials Information Centre

Target Ovarian Cancer’s Clinical Trials Information Centre is a simple, effective, online tool to enable discussion between women with ovarian cancer and their clinicians. It supports both women and health professionals to find the right trials as part of a goal to increase the number of women taking part in trials. The site is searchable by postcode or keyword, mobile-friendly to enable sharing at appointments, and trial information can be easily emailed or printed. Both health professionals and women with ovarian cancer have contributed to the site, giving additional reassurance to users. Target Ovarian Cancer’s Pathfinder Survey 2012 confirmed anecdotal evidence that only 30% of women surveyed had had trials discussed with them, down from 39% in 2009. This despite 90% of women being willing to consider trials. In the same survey, clinicians told us that they didn’t have the resources to find trials. The goal was a tool that is easy to use, for busy clinicians and concerned women; and easy to maintain, for a small charity with limited resources. In establishing the initial need for the resource, Target Ovarian Cancer’s Pathfinder Study consulted 122 UK Gynaecological Oncology Clinicians. In establishing the clinical trial data that sits behind the site, the team has consulted with ovarian cancer clinical trial administrators/leads. In developing the actual site, the pages incorporate a short film by Dr Ben Goldacre, and our site/ campaign links closely with his activities to increase participation in clinical trials. We also worked with a number of clinicians both individually and at professional events to get feedback on the resource as it developed, and post-launch. In establishing
The initial need for the resource, Target Ovarian Cancer’s Pathfinder Study consulted 382 UK women diagnosed with ovarian cancer within the last five years (Fieldwork conducted April–May 2012). In developing the site, the pages incorporate a short film of Rona Passmore who has taken part in a clinical trial. The purpose of this film is for women with ovarian cancer to hear from ‘someone like them’ and gain reassurance. We also tested the site with a number of women at our face-to-face events, and with our group of Research Advocates – women with ovarian cancer, friends and relatives, who help shape our research activities. The site has been promoted via: website, which reaches women with ovarian cancer, friends and families, health professionals and more. As well as an initial launch news story, the Clinical Trials Information Centre microsite is integrated into our main site navigation, and repromoted regularly through our homepage features, Target Ovarian Cancer’s printed and electronic newsletters, reaching mainly women with ovarian cancer. The Clinical Trials Information Centre is re-advertised every two months in the e-newsletter; Social media, including Facebook and Twitter. The film of Rona Passmore is also available on our YouTube channel; Face-to-face events: Target Ovarian Cancer runs face-to-face events for women with ovarian cancer across the UK. The site is promoted at these events. We attend a number of events for health professionals, including clinicians – as well as having promotional stands, we’ve also been invited to present to participants about clinical trials for ovarian cancer, and introduced the Clinical Trials Information Centre; We also have a business card for the Clinical Trials Information Centre. One side is for clinicians, the other for women with ovarian cancer, both list the web address and include a QR code to make it even easier to find the site. We give these out at events and in meetings.

“This is a very good resource and I would strongly recommend it to the panel. The video content is good but the background music makes it difficult to hear the presenter and the sound recording is not great quality. It has a good navigation structure which is easy to follow. It is nice to see contact details on this microsite rather than relying on a link back to the main site as so many others do. A website seems to be a good option to collate the clinician trials information. I imagine this is a fantastic resource for people searching for trials. Overall the resource is very well designed however, small minor improvements could be made.”

**The Dementia Guide: Living Well after Diagnosis**

Alzheimer’s Society 2013

This guide aims to provide much-needed support and information to people after being given a diagnosis of dementia. Before The Dementia Guide was developed, there were very few resources available to people at the point that they were given a diagnosis of dementia. While the resources that did exist were useful, there was a strong need to bring all of the relevant information together in one authoritative, credible place. It’s objectives are: Provide people with dementia and their carers with a comprehensive information pack at the point of their diagnosis (closing the current gap); Provide an overview of the information that is useful now and the topics that can be raised to plan for the future; Signpost people to other services and sources of support; Develop a distribution strategy that will allow the product to reach the majority of the people who will be diagnosed each year. There was no well-established, free resource for people at the point of diagnosis and the launch of The dementia guide has rectified this situation in the dementia marketplace. It is also helpful to professionals who have also struggled to find useful information on dementia to give to their patients. Due to the various areas that need to be covered in The Dementia Guide (from about dementia, to treatments, how to live well, how to plan for the future, how to access services and support), we asked a range of experts to review the content for us. Many of these experts are leaders in their specialist field in dementia: Dr Daniel Harwood, Consultant Psychiatrist, IoW Memory Service; Dr Mani M. S Krishnan, Consultant in Old Age Psychiatry, Newcastle upon Tyne Memory Services; Dr Reinhard Guss, Consultant Clinical Psychologist, Dover and Dementia Lead, British Psychological Society, Faculty for Older People; Prof Louise Robinson, Professor of Primary Care and Ageing, Newcastle University & Joint Clinical Champion for Dementia, RCGPs; Dr Gwyn Grout, Independent Consultant Nurse; Dr Jill Rasmussen, Joint Clinical Champion for Dementia, RCGP; Sarah Pickup, ADASS; Alice Moody, Clinical Specialist Occupational Therapist, College of Occupational Therapists; Gary Vaux, Money Advice Service; Adam Smith, Programme Manager, DeNDRoN, NIHR; Annette Goodfellow, Dementia Adviser, Wigan, Alzheimer’s Society; Katie Goodall, Dementia Support Worker, Widnes, Alzheimer’s Society. It is endorsed by the RCPsych, RCGP, ADASS and supported by the Department of Health. Staff from all of these organisations were also involved in its development by reviewing and commenting on the content relevant to their area of expertise. We interviewed many people with dementia and their families to include quotes throughout the book. All of the people who appear in the photographs were photographed specifically for this publication and are affected by dementia. We involved eight carers of people with dementia in the review of the text as part of our regular publication review procedure (outlined in Information Standard accreditation). We involved three people with dementia who commented on the text. We attended a service user review panel at Alzheimer’s Society in Royal Tonbridge Wells (a group of people with dementia who meet regularly to give Alzheimer’s Society feedback on various initiatives).

Around eight people living with dementia commented on the design and layout of the publication. We have distributed The Dementia Guide in strategic partnership with the Department of Health. As The Dementia Guide is the definitive resource, endorsed and used by the NHS, for people in the UK who are diagnosed with dementia, the DH has given us access to their Health and Social Care Publications Orderline. The printed booklet is also available through Alzheimer’s Society’s usual channels, so a central warehouse for ordering and also our local offices across England, Wales and Northern Ireland (we don’t operate in Scotland). The content of the guide is also available to view on our website: www.alzheimers.org.uk/dementia-guide. We are working on translations of the guide which will be added to our website next month. We are also working on a film of The Dementia Guide which will be launched in the summer on our website and on DVD. It will include English subtitles and subtitles and voiceovers in the languages listed above, as well as BSL. We did two promotional mailings to the 300 memory clinics in England to ensure that they are aware that it is freely available for them to order and have had great take up. We have also mailed 8,000 GP surgeries in England to let them know about it so that they can give it to their patients to support them after a diagnosis. GP knowledge of how to support someone with dementia is frighteningly low, so this is a useful tool to them as well as their patients. Lloyds Bank is now sponsoring The Dementia Guide for the next three years, and they intend to make it available through their
facilities for clients who come to them to discuss dementia-related matters, such as lasting powers of attorney. We have a feedback form in the back of the printed booklet inviting feedback from people who have used it. We have heard back from professionals and people affected by dementia. We began the development of the project with a commissioned research study into the information needs of people with dementia at the point of diagnosis, which greatly informed the development of the publication. We intend to commission this research agency to do an evaluation of the success of the guide after it has been in circulation for 12 months. The need for dementia information was extremely high when this product was launched. As at the end of February 2014, we have distributed approximately 120,000 copies since we launched at the end of July 2013. It has been extremely well received by professionals, and people affected by dementia.

“This booklet is of a very high standard and manages to be very informative and practical whilst remaining interesting and relevant. The chapters cover a range of issues around dementia and are able to go into detail without becoming difficult to understand. I really rate this booklet and I like certain touches throughout including the pictures of real people with dementia, the techniques used to ease navigation (like the side page chapter titles) and the quotes from those with dementia which are pragmatic and uplifting. I read this booklet and thought it was excellent. I love some of the touches throughout which include the pictures of real people with dementia, the techniques used to ease navigation (like the side page chapter titles) and the quotes from those with dementia which are pragmatic and uplifting. The booklet covers a lot of key issues in an informative and practical way whilst remaining interesting and easy to understand. I think this booklet is excellent and would definitely recommend it. The information in the resource is straightforward and to the point. The booklet includes short patient/family quotes from a variety of people which are realistic but also encouraging. When discussing treatment options the booklet provides information on a wide variety of options, including non-drug therapies such as talking and memory therapies and drugs commonly used to treat dementia. It is also very clear at the start of the chapter on treatments that there is no cure for dementia but that a combination of treatments can benefit patients. There is no bias towards a particular treatment. At the start of every chapter there is a key point section which explains what the chapter is going to look at and provides some background information on dementia. It includes some advice and useful tips such as keeping a large diary so that sufferers know what is coming up in the day. At the end of some chapters there is also a summary which includes information such as questions patients can ask a doctor. There is a lot of quality of life information running throughout this booklet, and one of the aims is to provide information on life after a dementia diagnosis. This includes quotes from patients and carers which provide first hand experiences of what a diagnosis meant to them and what helped them e.g. talking to a counsellor. There is a chapter on ‘living well’ which provides information for people who have been diagnosed on living as well as possible. This includes suggestions on making life a bit easier such as keeping glasses/keys more visible in one set place. It has tips on making the home safer and also on how to remain social and active. There are regular quotes from patients and carers throughout the booklet which include comments on what helped them after a diagnosis and how they maintain a good quality of life. Some also say they were glad to get a diagnosis because they were unsure of what their symptoms were. There are pictures throughout the booklet of people who have dementia who are doing everyday things such as walking the dog. This also illustrates that those who have dementia are still able to continue on with many things they did before the diagnosis. This booklet is aimed at those who are newly diagnosed so it doesn’t really detail later stages of the illness. The booklet includes information on where to get further information throughout. This includes the charity website address and helpline number at the bottom of each page. Throughout the booklet when there is an ‘i’ sign (which is quite often) there is a reference where readers can find out more information on a topic in a different section of the booklet (e.g. in the ‘about dementia’ chapter there is an ‘i’ which says ‘for more information on rarer causes of dementia see factsheet 442’ which refer to factsheets on the Alzheimer’s Society website which provide more in-depth information. The booklet also lists other organisations that can help those who have a diagnosis and the list covers a wide variety of organisations catering for a variety of people. Every chapter has a clear title and the booklet also has sub-chapter headings and titles for paragraphs. This means it is easy to navigate through the booklet. The chapter numbers and titles of chapters are on the side of the pages which means when you flick through the booklet you can quickly find each chapter. In addition, each chapter page has a contents page for the chapter which means people can go straight to the section most relevant to them. Tips on how to deal with aspects of living with dementia are laid-out in a grey box which are easy to find and summarise parts of the booklet e.g. tips on personal budgets – this is within the living well section. The booklet is available in different formats, including Braille. The font is large and in a typeface that is easy to read. The main colours used against a white background are black and blue text. These are easy to read and also make it easy to distinguish between standard text (e.g. an explanation of treatments) and the chapter/sub-headings/quotes. The blue bold text is also used in paragraphs to highlight a point or useful number. The pictures show real people who have dementia carrying out everyday tasks. This is encouraging to those reading the booklet that has had a recent diagnosis as they are uplifting and show that carrying on with many tasks will still be possible.”

The Little Guide for Transplant Patients (leaflet and animation)
Anthony Nolan 2014
The Little Guide for Transplant Patients, leaflet and animation, are aimed at pre-transplant patients and their friends and families. The leaflet and animation give people the key facts about what is involved in allograft bone or stem cell transplantation. They break this complex process down into stages – covering how we at Anthony Nolan search for a donor, how the donor is chosen, and what happens when you prepare for and have a transplant. We recognise that there are many people in the UK with low literacy levels and that people’s literacy levels can drop even lower when faced with challenging health situations. Therefore these resources are innovative in that we made them brief, accessible and friendly – using images in leaflet and through the engaging short web animation which uses our branding ‘characters.’ We hope that these bite-size resources will help reassure patients and answer key questions at what can be a worrying time. It also lets them know that we’re here for them. Expert clinicians were involved in developing and reviewing the content of these resources – checking the clinical accuracy of wording and animation script. The experts involved include: Dr Bronwen Shaw, Chief Medical
The Road Ahead: Your Guide to Heart Tests and Treatments

British Heart Foundation 2013

This is a collection of twelve short broadcast-quality films about common cardiac tests and treatments, told through the words and experiences of the patients experiencing them and the health professionals conducting them. Covering medical procedures ranging in complexity from echocardiogram to coronary bypass surgery, these films aim to: offer information, support and reassurance to heart patients and their friends and family members about common heart tests and treatments; help them understand what is involved in a test or treatment and feel comfortable with the details, what will happen afterwards and how they will recover – leading to an improved patient experience; demystify and normalise the processes so that people realise that they are not alone in their worries or anxiety, letting them know that many people like them undergo these procedures every day; and help patients feel more involved in their care, more confident about their procedures and also empowered to ask questions as necessary. The intended primary audience for the films is adults in the UK who are scheduled to have one of these tests or treatments. There are two secondary audiences for these films: partners, friends and family of the person undergoing the test or treatment who may be seeking info or reassurance; and healthcare professionals and other intermediaries who can signpost patients to the films and/or use them in group or clinical settings. A priority audience for BHF is people who have a low level of health literacy and potentially find it hard to understand what their doctor tells them about their test or treatment and who do not feel confident asking questions. In line with our work with South Asian people, who are at increased risk of coronary heart disease, the DVD is subtitled in Bengali, Gujarati, Hindi, Punjabi and Urdu. To maximise reach and accessibility, it also includes subtitles in English and In-vision BSL interpretation. Working closely with professionals at St. George’s Hospital Tooting; John Radcliffe Hospital, Oxford and University Hospital South Manchester, over 50 healthcare professionals from many disciplines took part in filming. For example at St George’s Hospital alone we worked with consultant cardiologists, echocardiologists, anaesthetists, the Pacing and ICD manager, Theatre manager and the TAVI surgical team. During the project, medical professionals were involved at four key stages: During planning, when the BHF team of Senior Cardiac Nurses developed the brief and worked in conjunction with a project manager to define and research key messages and information. The medical lead on this project was Maureen Talbot, Cardiac Nurse Manager. During the planning phase, when key professionals at the hospitals worked with the BHF and production company TwoFour to advise on the approach and find professionals and patients to contribute to the films; During filming, when Maureen Talbot and the hospital medical staff ensured the messages being put across were medically correct, reflected current best practice and were discussed in the most understandable and clear way; During the edit phase, when Senior Cardiac Nurses at BHF were involved in medical review of the films before giving them final approval. The films were developed following research commissioned by the British Heart Foundation in March 2012. The research was carried out by agency Healthfocus and, through focus groups with hospital and community nurses, identified the following: Films can play an important role in preparing patients for procedures, providing insight into clinical environments and reducing anxiety; Very short films suit people from more disadvantaged communities, if an overtly educational tone is avoided; It is important to continue to produce DVDs because many nurses face difficulties in accessing the internet in some healthcare settings. By putting patients at the centre of each film, we’ve enabled their stories and experiences to lead the narrative. Featuring 12 adults undergoing heart tests and
treatment, and their families, the patient contributors were involved throughout the shoot, being sensitively led to reveal and discuss their ongoing condition, treatment and hopes for the future. The films have been disseminated through two major channels: online and on DVD. Online, our films are available on the YouTube video sharing platform, via the BHF website and through a partnership with NHS Choices. We also developed a promotional strategy, approaching health and lifestyle media targeting the 50-75 age range and additional high risk communities (i.e. South Asian and African Caribbean) as well as media aimed at healthcare professionals. As part of this strategy, we conducted an opinion poll of 2,000 adults about their anxieties when faced with common tests and treatments. Using the results of this poll, we created bespoke news stories for our two target audiences – prospective patients and healthcare professionals – each with a slightly different call to action. For prospective patients this was to access the new films and for healthcare professionals this was to signpost patients to the support the BHF offers on preparing for heart-related tests and treatments. This approach secured us mentions in The Guardian Healthcare blog, Health Matters, Talk Health Blog, Medical News Today, The Consultant and About My Area website. The Daily Mirror ran a story about the launch of our new films on 24 November 2013 that included a link to the BHF website where visitors were signposted on to the films. SAGA magazine also featured a story for its health section. We also promoted the online films and DVD with a feature in Heart matters magazine – a BHF-published magazine with a readership of over a million heart patients, other people interested in looking after their heart and healthcare professionals. This proved successful as each set of banners received an above benchmark clickthrough rate at an average of 0.36% (Google’s performance benchmark is 0.02%). In mid 2014, once the films have been available to the public for one year, we will be commencing an evaluation exercise with the aim of mapping: Awareness of the films among people who have been referred for hearts tests and treatments and the health professionals who refer people for them – and how they heard about the films; Satisfaction with and comprehension of the main themes of the films from users. There will also be an email or postal survey circulated to people who ordered the DVD to gather their views.

“I think this resource should definitely be shortlisted, as I would like the panel to discuss it. This is very well-balanced information that integrates the patient perspective with the clinical procedure. It has clear animated diagrams. I think it is an excellent resource but have a number of reservations. I do not understand why there were no sections to assess the use of diagrams or pictures which I felt were relevant here. I was not happy with the general summary about heart disease at the end of each section which included advertising for financial support for the charity. I would prefer to see each short DVD produced separately but I suppose cost is the issue. I thought some of the detailed filming of the procedure might be frightening for some patients, and there was very little mention of the risks involved or prevention of further problems.”

The Yorkshire Dialysis Decision Aid (YoDDA)
University of Leeds 2014
The aim of the resource is to help patients with chronic kidney disease make an informed decision about which type of dialysis treatment would fit best in their life. The Yorkshire Dialysis Decision Aid (YoDDA) provides evidence-based information about chronic kidney disease, dialysis treatments and guidance to support making a well-reasoned decision. YoDDA is designed to be read by patients on their own outside the professional-patient consultation. YoDDA was developed so that predialysis teams would be able to integrate it into their usual care practices so that they could support patient’s dialysis decision making more effectively. It is one of the only decision aids to be developed and evaluated that helps patients make a choice that will impact on their day-to-day management of their established kidney failure for the rest of their lives. YoDDA was developed and evaluated as part of a three year, multi-disciplinary, multi-centre project. The team developing YoDDA included decision scientists, renal consultants and nurses, primary care professional, patient representatives, and health service researchers. The Chief Investigator: Dr Hilary L Bekker had overall responsibility for writing the resource and leading its evaluation. Co-investigators were: Dr Andrew Mooney (Consultant Nephrologist, NHS Leeds); Dr Martin Wilkie (Consultant Nephrologist, NHS Sheffield); Prof Simon Davies (Consultant Nephrologist, University of Keele; Mrs Lorraine Edwards (Renal Nurse, NHS Sheffield); Prof Nigel Mathers (Primary Care, University of Sheffield); Mr Dennis Crane (North West UK patient representative); Mr Ken Tupling (South Yorkshire UK patient representative) had responsibility for contributing the content of the resource, advising on its integration in practice and evaluating its acceptability for staff and patients. YoDDA and the associated research has been disseminated at UK, European and International conferences over the last three years for peer review. YoDDA has been evaluated by the UK Renal Czar, head of the Renal Association, and head of the European Renal Best Practice Association. YoDDA has been presented to the National Kidney Federation and evaluated by its members, and the patient representatives of Kidney Research UK. YoDDA and its research has been used to inform dialysis decision aid development in the USA, Australia, Switzerland and the Netherlands. We applied for funding to carry out our project to develop and evaluate YoDDA. The funders were: Kidney Research UK in partnership with Baxter Healthcare Ltd, the British Renal Society & Renal Association; The Yorkshire Kidney Research Fund; The Informed Medical Decision Making Foundation. The multi-disciplinary team contributed to each stage of the research process from research questions to study design to execution of research to dissemination of resources in practice. The project to develop and evaluate the Yorkshire Dialysis Decision Aid (YoDDA) when delivered as part of usual predialysis care was carried out in three phases of research. We carried out reviews of evidence describing patients’ experiences of dialysis decision making, websites and resources about kidney disease and treatments, and patient decision aid literature to identify YoDDA’s content. We carried out interviews of YoDDA with staff and patients in Yorkshire. Phase 2 – assessing YoDDA-paper acceptability to patients (September 2011-February 2013); we carried out a before-and-after study of YoDDA across six renal units in Yorkshire. From March-August 2012, 105 participants completed questionnaires about their experience of predialysis education. From September 2012-March 2013 all patients received YoDDA, and 84 completed questionnaire about their experience of predialysis education. Phase 3 – assessing the acceptability of YoDDA-web to patients and staff (October 2012-December 2013): we carried out a randomised controlled trial of YoDDA-web. It was advertised to all UK renal units and NKF members; 16 units, and people affiliated with a further 35 centres, participated (n=123 patients and
87 staff; January 2014). Kidney Research UK will host YoDDA in web format and PDF format on its health information web page. Kidney Research UK will be advertising YoDDA’s availability to all renal units across the UK. Since 2012, there have been requests from renal centres for access to the booklet version of YoDDA. Now that the study is over, those units can have reprints of YoDDA to hand out with their usual pre-dialysis education. YoDDA2014 is currently with the Kidney Research UK team for adaptation to their organisation’s requirements. We are emailing a PDF of YoDDA2014 to all the centres that took part in our research (n=24 renal centres), and those where we have patients who took part in our research independently of their renal unit (n=51 centres), at the end of the month (February). The evaluation of YoDDA-booklet was completed in March 2013 but the YoDDA-web is recruiting until the end of February 2014. The European renal best practice website has offered to host a copy of YoDDA. Currently there are several Dutch centres exploring the adaptability of YoDDA for the Netherlands. Our study website will host the PDF and the website version of YoDDA. We found that YoDDA-web was not utilised in everyday pre-dialysis education practices. More patients and staff preferred having the YoDDA-booklet. However, people from more regions across the UK were able to access YoDDA-web as they were not reliant on receiving YoDDA through their renal centre. Renal centres may have had a lot of reasons to (not) take part in our study, so restricting access to YoDDA-booklet. A summary of the findings from our three phases of research are: all patients who got the YoDDA-booklet read it, with most reading it more than once. About three-quarters of patients shared it with family members. We are applying for funding to evaluate the impact of YoDDA on patients dialysis choices and health outcomes now that YoDDA is freely available to services worldwide.

“This is a great resource and meets the needs of the audience for the purpose very well. It’s great as a decision aid as it covers the choices to make very comprehensively and helps the reader to make judgements based on their lifestyle and needs. What lets it down a little is the language and tone: it would help if it addressed the reader directly (‘the spaces in the booklets are for you to jot down notes about what is important to you’) and was less paternalistic and formal (the resources uses the words ‘the patient’ a few times which says ‘the doctor wrote this’) and using contractions could also help with the tone (don’t instead of do not, you’re instead of you are). Other than that it’s excellent and has clearly been thoughtfully and robustly developed. The decision making process take into account daily life issues away from health matters, such as social life, holidays, caring responsibilities and studying. It deals very well with balancing the information and the pros and cons of different treatments. It also deals with what happens if you choose to do nothing or choose conservative care.”

**The Young Woman’s Guide to Pregnancy V2**

Tommy’s the Baby Charity 2014

Each year in England around 40,000 young women under the age of twenty will give birth. While teenage conception rates in the under 18's are at their lowest for 20 years, the rate of teenage births in the UK as a whole is reported to be the highest in Western Europe. Teenage mothers suffer social and economic deprivation and the impact of teenage pregnancy on the health of mothers and their babies is well-documented. Babies born to mothers under the age of 18 are at an increased risk of prematurity and are 25% more likely than average to have a low birth weight. There is a 60% higher than average infant mortality rate in babies born to mothers who are under 18 years of age. In turn, these outcomes are associated with a much greater risk of death and illness in infants and increased lifetime morbidity. In 2007 Tommy’s funded scientific research that examined the link between these outcomes and the diets of teenage mothers pre and post birth. A primary objective of the Teenage Pregnancy Health campaign, which was informed by the ATE study was to develop pregnancy health information specifically for teenagers. In order to identify the information needs of this group Tommy’s conducted research with young mothers, the front-line professionals who work with them and with the strategic professionals who develop regional services for pregnant teenagers. The research indicated that both users and health professionals felt that a printed book was the most suitable method of delivering the information. The objectives of the book are as follows. Objective one: to bring about behaviour change by highlighting and repeating key pieces of information that will contribute towards healthier pregnancies and babies. Objective two: to offer accessible pregnancy health information targeted specifically at teenagers. Health professionals were heavily involved in every aspect of the development of this resource. At the time of its inception quantitative and qualitative surveys of health professionals were carried out to gather feedback on the format of the resource. In total, 125 front-line professionals took part in these surveys. Of these 109 completed an online questionnaire, 13 took part in face-to-face interviews and three were interviewed over the telephone. The professionals had a wide range of roles although the largest percentage of interviewees was specialist teenage pregnancy midwives (35%). In addition 109 strategic professionals who work to develop services for pregnant teenagers gave their views in an online survey. As the content covered every aspect of pregnancy, we established an expert advisory group (EAG) with experts from all the different subject areas, e.g. diet, smoking, antenatal care. The EAG fed into the contents list as well as all subsequent copy and designed drafts. Once V1 was published and had been available for a year, we undertook post-launch surveys to seek feedback on the guide and to explore health professionals’ opinion on areas for improvement or development. The surveys sought the views of health professionals. The target audience for the quant research was midwives and other front-line professionals working with the target audience (i.e. pregnant teenagers). Group discussions were held in March/April 2009 with: Five midwives working in south east London; Four frontline professionals working directly with the target audience, based in North London. In addition a qualitative survey targeted midwives who were part of the Teenage Pregnancy Midwifery Network (TPMN) and other frontline professionals who work with pregnant young women. A total of 87 midwives and health professionals completed the survey between January and March 2009. In 2013 a follow-up survey was carried out targeting health professionals who had ordered the guide on the Tommy’s website. This survey was completed by 71 health professionals. The feedback was overwhelmingly positive. We had requests for inclusion of extra material (postnatal and fathers) and some feedback on readability. To address the issue of readability (which was also one of the points that came out of the user-survey) a new writer was contracted. Jenny McLeish is a freelance researcher/writer on poverty, maternity and family policy but also has extensive experience with the subject.
2014 BMA Patient Information Awards

Type 2 Diabetes and Me (e-learning programme)

Type 2 Diabetes and Me is free interactive e-learning programme for people with type 2 diabetes. It is designed to help people understand and manage their diabetes more confidently and to help them to enjoy a better quality of life with fewer complications. The programme is aimed at adults who have recently been diagnosed with type 2 diabetes (typically 45-65+) and haven’t attended any education courses in their local area. It is also relevant to partners and/or carers of people with diabetes having previously worked on the front-line with the Maternity Alliance and the Teenage Midwifery Network. A new EAG was established to feedback on content development. The members of this group fed back on drafts of the guide until it reached the printer. It included: Lou Atkinson, Senior Researcher, Applied Research Centre in Health and Lifestyle Interventions, Coventry University; Rebekah Barry, Information Officer, Gingerbread; Joelle Bradly, Writer, Researcher and Blogger; Annette Bixley, Consultant Midwife, King’s College London; Rachel Coomber, Nutrition Scientist, National Programme Delivery – Nutrition, Health Improvement Directorate, Department of Health; Dr Helen Crawley, First Steps Nutrition Trust; Lisa Fendall, RGN, RM, FreelanceTrainer, Smoking in Pregnancy; Alison Hadley, Director, Teenage Pregnancy Knowledge Exchange, University of Bedfordshire; Natasha Hezelgrave, NIHR Doctoral Research Fellow in Obstetrics, Women’s Health Academic Centre, King’s College London; Professor Louise Howard, Professor of Women’s Mental Health, King’s College London and Honorary Consultant Psychiatrist, South London and Maudsley NHS Foundation Trust; Cindy Hutchinson, Research Midwife, King’s College London; Sheila King, Verification Standards Co-ordinator, Nationwide Community Learning Partnership/Prospect Training Services; Dr Anne McPherson, Adolescent Task Group, Royal College of General Practitioners; Jan Mitcheson, Head of Practice Development, One Plus One; Wendy Nicholson, Professional Officer – Nursing, Department of Health; Sarah Perrins, Teenage Pregnancy Adviser, Home-Start, Derbyshire; Andrew Shennan, Professor of Obstetrics, King’s College London; Ilidko Tombok, PhD Student, Department of Epidemiology and Public Health, University College London; Diana Weeks, Parents with Prospects Course Facilitator, London Borough of Hounslow.

Users were involved in the development of this guide from conception. In total 54 teenagers took part in the first survey that Tommy’s carried out into the information needs of pregnant teenagers. Of these, 34 were pregnant and 20 had given birth within the previous 12 months. Forty four of the interviewees gave their input in group discussions working with the target audience (i.e. pregnant teenagers). Group discussions were held in March/April 2009 with; Five frontline professionals working with the target audience of young women, it was decided to undertake pre- and post-publication surveys. The baseline survey took place between 29 September and 20 October 2008 and achieved 174 responses. The post-publication survey took place between January and March 2009 and achieved 50 responses. The survey looked at behaviour change as well as seeking feedback on the format, tone and style of the guide. At the moment we are distributing around 30k copies a year. Once V1 was published and had been available for a year, we undertook post-launch surveys to seek feedback on the guide and to explore health professionals’ opinion on areas for improvement or development. The surveys sought the views of health professionals. The target audience for the quant research was midwives and other frontline professionals working with the target audience (i.e. pregnant teenagers). Group discussions were held in March/April 2009 with; Five midwives working in south east London; Four frontline professionals working directly with the target audience, based in North London. In addition a qualitative survey targeted midwives who were part of the Teenage Pregnancy Midwifery Network (TPMN) and other frontline professionals who work with pregnant young women. A total of 87 midwives and health professionals completed the survey between 19 January and 26 March In 2013 a follow-up survey was carried out targeting health professionals who had ordered the guide on the Tommy’s website. This survey was completed by 71 health professionals. The feedback was overwhelmingly positive. We had requests for inclusion of extra material (postnatal and fathers) and some feedback on readability. Post-publication survey (2009): In order to assess the impact of the book on the target audience of young women, it was decided to undertake pre- and post-publication surveys. The baseline survey took place between September and October 2008 and achieved 174 responses. We are committed to reviewing the guide completely again in 2017 and this will include gathering feedback from health professionals and teenagers once again.

“I would say this was an Excellent resource for the Teenage ‘mum-to-be’. The developers have listed a comprehensive list of the health care personnel involved. It is also aimed at young dads as well as mums and aims to help young mums have a healthy pregnancy and prepare for birth. It includes peer reviewed research as well as national guidelines. There are lots of personal real life experiences (even the editorial is written by a young woman who fell pregnant at 16), quotes and photo stories with young women and it is bright, engaging and easy to read. It is very much about enhancing quality of life through healthy pregnancy and giving healthy start to the baby. It is very much written in Plain English and uses only the most relevant medical terms where appropriate and explains them very well. I think the order of the information could be better arranged to follow the reader’s journey. Consider moving the contraception section to ‘After the birth’. Ideally page 58 should be titled ‘Sex during pregnancy’ and a new page at the end of ‘After the birth’ titled ‘Sex after birth’.”

Type 2 Diabetes and Me

Diabetes UK 2013

Type 2 Diabetes and Me is free interactive e-learning programme for people with type 2 diabetes. It is designed to help people understand and manage their diabetes more confidently and to help them to enjoy a better quality of life with fewer complications. The programme is aimed at adults who have recently been diagnosed with type 2 diabetes (typically 45-65+) and haven’t attended any education courses in their local area. It is also relevant to partners and/or carers of people with
Type 2 diabetes and those who have gaps in their knowledge or want a refresher on a specific aspect of their condition. The programme was co-created with users and there are five easy-to-digest modules covering a range of topics. The modules include information about what diabetes is, how it is treated, leading a healthy lifestyle as well as covering practical aspects of living with diabetes such as holidays, driving regulations and insurance. The course can be completed at the user’s own pace and in their own time. The course takes approximately two hours to complete from start to finish. All the modules are very interactive and individual modules won’t take longer than 20 minutes to complete. In order to get the most from the course, we recommend that users complete at least one module per week. The programme was developed by the Head of Clinical Care & Clinical advisors at Diabetes UK and approved by our medical advisor and Director of Diabetes Intelligence and Healthcare Professional Liaison. Feedback was sought from the Diabetes UK board of Council of Healthcare Professionals. The programme was developed in partnership with Bupa who were also involved in the review process. The programme was co-created with people with diabetes. People with diabetes were involved in development workshops, testing at the alpha stage as well as being filmed for certain sections and providing case studies. The programme, developed in partnership with Bupa, was launched in June 2013 and to date we have had 10 000 learners. It will be formally evaluated in the run up to its first birthday. Initial evaluation showed 74% of learners were satisfied or very satisfied and 86% said that they would recommend it others. We have advertised at the Diabetes UK Living with Diabetes Days, Bupa/Diabetes UK Healthy Lifestyle Roadshows, Diabetes Professional conference and Diabetes UK Big Event. There have been adverts and stories in Balance and Update magazines (Diabetes UK publications for HCPS and people living with diabetes) and alerts through our contact with other charity representatives working in the field of Type 2 diabetes and those who have gaps in their knowledge or want a refresher on a specific aspect of their condition. The programme was co-created with users and there are five easy-to-digest modules covering a range of topics. The modules include information about what diabetes is, how it is treated, leading a healthy lifestyle as well as covering practical aspects of living with diabetes such as holidays, driving regulations and insurance. The course can be completed at the user’s own pace and in their own time. The course takes approximately two hours to complete from start to finish. 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Your Body, Intimacy and Sex
Breast Cancer Care 2013

The audience for this booklet is anyone who has had breast cancer and is concerned about the effect the various treatments have had on their self-esteem, body image and sexual relationships. The first part of the booklet looks at changes to the body after breast cancer and how this can affect confidence; the second part looks at sex and intimacy and how they can be affected by this loss of body confidence. The booklet aims to show that many women experience changes to their body image after breast cancer and that this is understandable. It also seeks to address the idea that changes to body image and loss of self-esteem are not a small price to pay when compared to surviving an illness like breast cancer, which is why we also include a checklist for readers to be able to give to their healthcare professionals if they’re experiencing emotional or physical problems that are negatively affecting their quality of life and their ability to recover. As with all our information, this booklet was produced by a member of the Publishing team in conjunction with an expert nurse from our Clinical team. It was then reviewed by other healthcare professionals outside the organisation – some in the NHS, others working in other voluntary sector support organisations like Macmillan Cancer Support and Relate. We sent the booklet for review to: a consultant in psycho-sexual therapy at Relate; a clinical health psychologist at Royal Bolton Hospital; a clinical lead at Macmillan Cancer Support; a counsellor who deals mainly with breast cancer patients; a clinical nurse specialist in breast care at Imperial College; and a lymphoedema therapist. We involve patient reviewers in all our information, plus for publications of this type which focus on psychosocial aspects of breast cancer, we use case studies to illustrate the text. These are usually drawn from our panel of Breast Cancer Voices, but in the case of this publication we also sent the draft text to our body image advisory group which is made up of healthcare professionals and people with breast cancer. Three lay readers reviewed the copy and we featured quotes from 12 people who completed a questionnaire about their experiences. The booklet is available on our website and through our Helpline and national and regional centres. As it also formed part of a wider campaign by Breast Cancer Care on body image after breast cancer treatment. It was also promoted in some print and online media, for example, in Woman&Home magazine. Breast Cancer Care also has a Nursing Network of around 950 external healthcare professionals who spend at least 50% of their time with breast cancer patients. We’ve promoted the booklet to this group (and the checklist it includes) through the Nursing Network News magazine. At present we are running a paper evaluation of the booklet where our distribution house is putting a copy of the evaluation form in every copy of the booklet sent out. There’s also an option to complete an online evaluation form on our website. A copy of the form is also being sent to our Breast Cancer Voices for feedback. Anecdotal feedback has so far been very positive. The results of these evaluations will be analysed by our in-house Research team, allowing up to check it is fit for purpose or make changes when it’s reviewed in two years time.

“This leaflet is very much about quality of life issues: coming to terms with the change and re-establishing good relationship with partner. It has involved a good range of women living with breast cancer.”

Your Guide to Support, Practical Help and Complementary Therapies
The Royal Marsden NHS Foundation Trust 2014

This booklet aims to promote the support services available both within and outside the Trust, as well as supporting the patient with a cancer diagnosis in a holistic fashion. The emphasis of the booklet is to empower the patient to live with and beyond cancer in a positive light. Following the pilot study and subsequent additions, this booklet has proven to be one of the most valuable and requested publications that we have to offer. It has been written by a number of qualified staff, both clinical and non-clinical. It is then put through a rigorous review process to ensure that the content is correct, up-to-date and patient friendly as well as conforming to the Information Standard principles. This booklet was originally piloted in 2011. As part of the pilot we printed 1000 copies of the booklet and inserted a feedback form requesting that patients and carers let us know their thoughts on the booklet, whether it was useful and any suggestions as to how it could be improved. As well as this, the booklet was presented to our Patient and Carers Advisory Committee for their comments and suggestions. The
response to the booklet was encouraging, however further amendments were made, such as the title being changed from Directory Plus the format was changed to an A5 booklet to make it easier to read and in places some of the wording was changed so that it was more easily understandable. This booklet was recently updated and again we gained further feedback by way of user feedback forms, to ensure that patients and carers were still happy with the format and the content. Further amendments were made following this feedback before the booklet went to print. We have this publication on display through the Trust such as on wards, in our outpatient areas and in our Help Centre. It can also be accessed online through The Royal Marsden website. All patient information goes through a rigorous review process which includes content checking, reference checking, gaining used feedback and incorporating this feedback into the publication where appropriate.

“I think this is an excellent resource: it provides an invaluable reference resource for cancer patients, their carers and families, about the range of support services and therapies that are available to them alongside their cancer treatment. It is designed very well – it is easy to read, easy to navigate and well- laid out. I think the resource would be very well- received by patients, who would want to know about all the options that are open to them and how to access them. It also signposts to lots of other useful sources of information. The layout is very clear, with a good use of headings, bullet points, space to make notes and an easy to use contents page. Most of the resource is black typeface on a white background, making it very easy to read. The pink headings/subheadings add a nice splash of colour but are still easy to read. As well as mentioning physical symptoms of cancer and cancer treatments, the resource acknowledges the emotional strain placed on patients, carers and families, and it gives practical information on what resources are available to help with this side of things.”

Commended

10 minutes to Change your Life Series
British Heart Foundation 2014

The 10 Minutes to Change your Life booklets are designed to introduce adults with poor literacy to some of the risk factors for coronary heart disease (CHD) and to motivate them to start making healthy lifestyle changes to protect or improve their cardiovascular health. The five titles are: Time to Eat Well; Time to Get Moving; Time to Quit; Take Time Out; and High Blood Pressure. People from the lowest socio-economic groups of the UK population are disproportionately affected by CHD and there is a strong link to low literacy in these groups. We decided to expand our range to offer short and simple information on risk factors for adults aged 35 and above with a reading age of 14 or below that may not have the motivation or ability to read BHF’s longer booklets on the same topics. 56% of working age adults have literacy skills below GCSE level and another 17% have a literacy level below that expected of an 11 year old. The 10 Minutes Series is designed to be visually engaging, informative and encouraging, to inspire people to change. The booklets aim to: Help people understand the importance of living a healthy lifestyle; Help people identify if and how they need to change their lifestyle; Set a seven day challenge that starts people on a journey to a healthier lifestyle; Encourage people to form heart healthy habits in the long term. Further booklets on high blood cholesterol, diabetes and alcohol will be following in the spring. BHF’s in-house specialists were involved in advising on the key messages to go into the booklets and they signed off the final content for medical accuracy, relevance to the target audience and consistency with the wider health messages of the organisation. They were: Doireann Maddock, Senior Cardiac Nurse; Chris Allen, Senior Cardiac Nurse; Tracy Parker, Heart Health Dietitian; Lisa Purcell, Physical Activity Specialist, To make sure we got the booklets right for the target audience, we ran a series of focus groups in October 2013. We tested responses to design concepts for the healthy eating booklet supplied by our chosen design agency, Rose. We spoke to 23 participants over three focus groups. All were recruited from the target group: Aged 35-65; With GCSE level education (many with less); Women slightly over-represented; Readers of publications written for the reading level of the target group, e.g. The Sun, The Daily Star, All About Soap, Take a Break, or People’s Friend. Two participants identified themselves as having a heart condition and three identified someone in their family as having a heart condition. Key findings from the focus groups included: Positive reaction to the idea of an interactive chart or challenge – unprompted, some said they would complete it as a family and stick it on the wall at home, Strong preference for the bold ‘clocks’ design route that became the basis of our chosen design; Endorsement of the inclusion of a case study; Preference for literal, rather than conceptual illustration style; Preference for a traditional format booklet. In addition, we also conducted a reading exercise where participants highlighted words or ideas they didn’t understand, to allow us to check intellectual accessibility. Participants largely endorsed the level at which the text was pitched. When the content was being put together, we included a case study in each booklet. Research conducted for BHF by Frontline consultants in 2011 recommended that we engage people in our health information by featuring the experiences of case studies they can identify with. The booklets are currently available to download on the BHF website and printed copies will soon be available to order by members of the general public, healthcare professionals and other intermediaries supporting people to improve their health. The new booklets were trailed in a BHF e-newsletter at the end of January and in the next four weeks gathered over 10,000 pre-orders for the printed versions. The promotional strategy for the booklets will include: Signposting visitors to BHF’s website to highlight the new series; Promotion in the BHF’s Health matters Magazine – readership over a million; Promotion to BHF’s funded and supported healthcare professionals – over 800; Dissemination at heart health awareness training run by the BHF as part of its Healthy Hearts train the trainers programme for health promoters; Media work targeted to publications and websites favoured by the target audience; Online search marketing. Once the remaining three titles in the 10 minutes series are produced, we will monitor how well the booklets are reaching their target audience through regular analysis of: Numbers of booklets downloaded from BHF website; Number of printed booklets ordered; Demographic information about members of the general public ordering booklets; Information about the types of professionals ordering booklets and how they are using them; Gathering
Ali Gets Hearing Aids
The National Deaf Children’s Society 2014

This child-friendly comic tells the story of Ali getting hearing aids for the first time. This comic is aimed to support parents in explaining to their child what will happen at the audiologist and the different stages to getting a hearing aid made. The comic is aimed at children under the age of ten with the intention that older children can use it independently whereas younger children can read it with their parents. The objective of this resource is that children understand what will happen at the fitting, how to take care of the aids and the benefits of using them. It is really important that deaf children understand this stage and have a sense of ownership over what is happening so that they view their hearing aids positively. This resource follows on from the title Going to the Hearing Clinic. This resource was written by an audiologist, Vicki Kirwin, who also works at NDCS as the Development Manager (Audiology and Health). A focus group with parents took place to establish the usefulness of an earlier resource (Harvey Gets Grommets) for sharing with their children. As part of this focus group parents identified the need for a resource to explain to their child what happens when they go to the audiologist to have hearing aids fitted. Parents wanted a resource that was bright, colourful and fun and also suggested a space be included for children to share their feelings on having a hearing aid. Parents also noted that this would be a useful resource to share with siblings and possibly classmates as well. The NDCS youth team and Senior Graphic Designer ran a focus group with children to choose the style of illustration used in the comic. The paper chosen for the comic reflected the need for children to be able to draw or write on the resource. The resource is available from NDCS (to order online, via the helpline or at NDCS events). It is promoted within our resources catalogue, membership magazine and email updates to both families and professionals. We will also submit the resource for review with ENT news. All NDCS resources are available to order in bulk to be distributed for free by external organisations such as doctors and audiologists. Some of the feedback from parents has fed into Ali gets Hearing Aids such as the need for fewer characters and clearer definition between the illustrations. Parents confirmed the value of their child being able to draw on the comic so the paper used in the print allows children to write or draw on this comic. Further evaluation will take place with focus groups and an online survey. We will also revisit the suitability of the design with the target audience (children under ten) before further developing the range of comics. The resources will also be submitted for review with ENT news and for our membership magazine.

“The resource is attractive and will appeal to a difficult reach group (young children) and provides useful information to help them manage their feelings about an experience that they may be nervous about – and also to support them to talk to friends and family about it. The pictures are fun and colourful and were selected by children. The images make an important contribution to telling the story. The leaflet avoids using complicated terms and conveys the necessary information using simple language. The tone is fun and light-hearted. The process of identifying the need for this resource and seeking input from parents and children to the content and design is excellent.”

Bladder and Bowel Problems: Commonly Experienced Problems and How to Manage Them
Age UK 2013

The intended audience for this free information guide is older people aged 50 plus. The aim of the resource is to explain in simple terms how someone can recognise urinary or bowel incontinence and what the causes are of this condition, and to advise on self-managing the condition as well as seeking help. The guide is written in plain English and is intended for someone who is coming to the subject for the first time, with no medical knowledge. Bladder and Bowel Problems was written with advice from Sheelagh Donovan who is the Age UK Technical Advice Support Officer for Health and End of Life. In July 2013 we held a focus group with older people who gave us feedback on the guide, resulting in some significant changes (for example, the title of the guide was changed from Managing Incontinence to Bladder and Bowel Problems on advice from the group). We have also included a real-life case study to help promote engagement with the content of this resource. This information resource is delivered free to members of the public through our Age UK network (including information displays in the shops of over 160 local Age UK partners), through orders taken over our Age UK telephone advice line, through hospitals and GP surgeries. We publish the guide on our website at http://www.ageuk.org.uk/Documents/EN-GB/Information-guides/ AgeUKIG15_Managing_incontinence.info.pdf?dtrk=true. We receive feedback from local Age UKs on the impact of this guide and plan future focus groups of people who have ordered the guide to help evaluate this resource.

“This is very well-presented, detailed and readable. It covers a wide range of issues and has an excellent tone which is reassuring, unpatronising and prompts to seek professional help where appropriate. I particularly liked the ‘What will a professional need to know?’ section 2.”
The Patient Information Forum (PiF) is the UK association for people that work in consumer health information.

If you produce or provide health information for patients or the public, or simply have an interest in the field, then PiF is YOUR organisation.

We campaign to ensure that information is central to high quality, patient centred care and we help producers and providers to develop high quality information for their users.

PiF is one of the standard setters for consumer health information; bringing people and organisations together, sharing best practice and highlighting research and evidence. We are currently working on the UK’s first practical, producer-led guidance and best practice on creating great health information resources.

We all want to create the best information we can; information that makes a real difference to the people who use it. There is a growing need to understand ‘what good looks like’ and how to produce it consistently. One of the best ways to do that is to learn from what others are doing; see what works and what doesn’t and be able to see clearly what ‘good’ looks like.

PiF aims to help you do just that. We produce practical materials, tools and guidance that will help any individual or organisation to achieve consistently high standards.

Our members
PiF is a non-profit, independent organisation with members in all healthcare sectors and in every country in the UK. PiF is more than just a network, it is a whole community. We provide opportunities for our members to discuss the key issues, find solutions, share their expertise and support each other.

We provide a range of services for members and the wider consumer health information community. These include a web site, weekly email newsletter, events, guides, query service and online specialist groups and a regional coordinator network.

Whatever your level of expertise, and whatever sector you work in, PiF has something for you. So join us, and make a real difference!

To find out more about PiF, our work and our members, or to join go to www.pifonline.org.uk or contact membershipservices@pifonline.org.uk
Complementary Therapy and Parkinson’s UK 2013

Parkinson’s UK produces a suite of information resources for people affected by Parkinson’s and the health and social care professionals who support them. Complementary Therapy and Parkinson’s is designed to give people with Parkinson’s, carers, family and friends, who are interested in using complementary therapies alongside their Parkinson’s medication, unbiased and accurate information. The purpose of this resource is to answer some of the common questions about complementary therapies, look at the safety of various therapies and examine whether there is any evidence to support their use as a way of managing Parkinson’s symptoms. The resource is intended to provide positive, but measured and realistic information about complementary therapies. It seeks to clarify the lack of robust, scientific evidence surrounding complementary therapies, but it also encourages people to explore what may work for them and indicates clearly the personal opinions of people with Parkinson’s and their carers, and what they have found useful. It begins with a section looking at what evidence is, and what sort of evidence is needed before a conventional medication or therapy can be used to treat health conditions and how evidence around complementary therapies is often more limited. It also explains to the reader how to judge evidence surrounding complementary therapies for themselves. was a key aim for this resource, as we’ve heard from many people with Parkinson’s who believe that some complementary therapies may act as a ‘cure’ for the condition, based on something they may have read from an unreliable source. The resource provides information regarding everything a person may want to think about when considering whether to use complementary therapies, including safety, cost, and how to access them. The booklet lists the most popular therapies in alphabetical order, explaining clearly what each one involves, how it may help, safety issues and where to go to find out more. It states the facts and gives information in a straightforward way – making it easier for people to decide which complementary therapies, if any, are right for them. Information about every therapy is supported by icons to show what the people with Parkinson’s and their carers we consulted as part of our research for this resource used each therapy for, for ease of use. Our reviewers came from academic and NHS backgrounds, with specialties in the area of complementary therapies. They were asked to rigorously assess the evidence for each therapy we included and ensure our information reflected the weight of the evidence. On the back page of the booklet you can find details of the healthcare professionals who were involved in reviewing this booklet: Rachel Clark, Lead Palliative Care Walsall Healthcare NHS Trust; Helen Cooke, (MA Complementary Health Studies, BSc College of Medicine; and Professor George Lewith, Professor of Health Research, University of Southampton. We involve people affected by Parkinson’s in the production of all of our resources. The resource was a rewrite of an existing booklet. We asked five people affected by Parkinson’s – both people living with the condition and carers – to review the existing booklet and give their thoughts about what they liked, what they didn’t like and what they felt was missing from the information, if anything. We also sought the advice of a Parkinson’s nurse to verify that the final list of therapies we included reflected the most popularly used therapies. Once we gathered this feedback, we re-wrote the resource, in line with current evidence, to meet the user’s needs and to refresh the tone of voice. Once this draft was reviewed by experts, we asked users to review it. This book is free to order by anyone in the UK. This helps us to reach a wide range of people affected by Parkinson’s and health and social care professionals involved in their care. The resource can also be viewed or downloaded for free from our website. On average, 330 copies of Complementary therapies and Parkinson’s are ordered from our distribution house each month, and more than 278 are downloaded from our website each month. The resource is also disseminated by our helpline team to appropriate callers and by our information and support workers, who offer one-to-one support in the community. Another important distribution channel is our network of more than 360 local support groups. They all hold information for their members and have shown a real interest in this book. Parkinson’s nurses across the UK regularly order resources, including this one, to make them available to patients in their clinics. But this booklet has the potential to reach professionals in ways other than direct order. Parkinson’s UK publications are used by our team of staff and volunteers who deliver education sessions to health and social care professionals, and are taken to conferences for professionals to pick up. Local staff and volunteers also aim to get our information in healthcare settings wherever possible by distributing information locally to GP surgeries, hospitals and community centres. After publication, we published a news story about the booklet on our website and on social media channels (Twitter and Facebook). We also included information about the booklet in our membership magazine, The Parkinson. One key way of measuring the impact of this resource is to monitor how many are being ordered from our distribution house. This gives an indication of how many people we’re reaching. We can also compare the number of booklets ordered to the previous version to see if it’s more effective. We also signpost from the books to an online feedback form that collects quantitative and qualitative information. The form prompts readers to rate the book’s usefulness, and asks about how easy it is to read and understand. We also ask readers about any additional information they’d like to see included. We log all the feedback and will use it when we review the resource. We also collect feedback from our website and social media.

“This is an excellent resource which is beautifully presented: a lot of thought has gone into the production of this and how it will be used and monitoring its use. I think it is an excellent effort all round. I really like that it includes vignettes in each section and makes each chapter attractive. Vignettes are included in the therapy sections, they give a first name and often a year of diagnosis which I think is excellent considering this is a progressive disease. The booklet is mainly about improving the quality of life issues but also makes very clear that each therapy may or may not suit an individual – excellent. It is a very nicely laid-out booklet, the information is easy to read and to find, a lot of material is contained in it without appearing to be dense or overwhelming. I like the choice of pictures – they are bright and colourful and appropriate to each section. The sections on background material such as evidence and what complementary therapies are is also excellent. It was a pleasure to review this booklet.”
How to Cope with Hearing Voices
Mind 2013

The aim of the booklet is to provide information about voices which will normalise the experience as far as possible, and reassure people who hear voices, and to offer sources of help and support for those for whom voices are a problem. It suggests ways that people can help themselves, as well as giving information on the sorts of treatment that may be offered. Its primary audience is people who hear voices, and it is also for friends and family, professionals and other providers of support. The booklet was written by Katherine Darton, a physiologist who has been working in the field of mental health for 20 years, and has read widely on the topic. The first draft was reviewed by three people who themselves hear voices. The web page also includes links to three personal blogs, from different individuals, on psychotic experiences, on hearing voices, and on writing as a form of self help in coping with unshared perceptions. The information exists as a printed booklet and also on Mind’s website as pages that can be read online, or printed as a downloadable PDF. We have distributed 4,279 hard copies so far. Of that, 3,280 sent to local Minds (free of charge), 750 taken by the Mind training team to hand out during their courses, 249 sold through the mail order service. The web page has received 24,149 unique views at 31 January 2014. People are invited to provide feedback on the resource, mainly via the website, and also on a form which is sent from mail order.

“The booklet was written by Katherine Darton who has experience in this field. The first draft was reviewed by three people who themselves hear voices. The web page also includes links to three personal blogs, from different individuals, on psychotic experiences, on hearing voices, and on writing as a form of self help in coping with unshared perceptions. It is a very well-laid-out leaflet which supports the appropriate audience and purpose. It can also be accessed online and downloaded as a PDF. The layout is very clear with good contents page and clear headings and subheadings.”

Idiopathic Pulmonary Fibrosis and other types of Interstitial Lung Disease
British Lung Foundation 2013

The aim of this resource is to provide information about interstitial lung disease (ILD), including the most common type of ILD, idiopathic pulmonary fibrosis (IPF). The cause of IPF is still unknown, but it is the second most common lung condition that people call our helpline about. ILD is the third most common. There are more than 200 types of ILD, and people are often told that they have pulmonary fibrosis, or scarring of the lungs, rather than a specific condition. So there is a real need for good quality information out there for people with IPF or another type of ILD. This booklet is for people with IPF or another type of ILD, their friends, families and carers. There is a lot of confusion around ILD and IPF, and clear definitions and explanations are needed. The resource aims to provide the basic facts about IPF and interstitial lung disease, including how they are diagnosed, what the causes might be, how they are treated and what the outlook might be. It includes clear diagrams, and goes into more detail about treatments for three of the most common types of ILD: collagen vascular diseases and ILD (CVD-ILD), extrinsic allergic alveolitis and ILD caused by drug side effects. It also gives information about how to manage a condition like IPF, for which there is currently no cure. There are around 15,000 people with IPF in the UK. Around 5,000 are diagnosed each year and the number of cases is increasing. This is a very specialist area, and there are only a handful of specialist IPF nurses across the UK, so people with this condition often need more information and support. As well as providing basic information about IPF and other types of ILD, the booklet signposts readers to useful sources of information. This information was written by Colleen Shannon, a freelance medical writer who specialises in medicine. She was advised by Dr Toby Maher, a consultant physician who specialises in IPF and interstitial lung disease. The content was then reviewed by Dr Maher and also by Dr Sherwood Burge, who specialises in work-related lung conditions. IPF expert Professor Richard Hubbard also contributed to checking the facts around the incidence of IPF. Before planning this resource, we sought feedback from people with lung disease on an older publication we wanted to replace. This was a booklet about idiopathic pulmonary fibrosis. We received seven feedback forms and fed the comments into the brief for the new resource. Suggestions included more information on the importance of keeping fit and pulmonary rehabilitation, and explaining about the change in the shape of fingernails and toenails. Once the new draft had been completed, we sought feedback from a patient with IPF who said the booklet was very easy to read and user-friendly. He made a few suggestions, which were then incorporated into the text. For example, he suggested that patients should be given information about referral to the lung transplant unit, and that we should mention recent NICE guidelines on the treatment of IPF. The booklet, IPF and other types of ILD, is available to order through the BLF website, via the BLF Helpline or through paper order forms that are sent out with all orders of health information. The booklet is also distributed at the BLF's 'Meet the Experts' events for IPF patients and carers across the UK. The booklet was launched during IPF Week last year, and was promoted as part of the BLF’s PR work around IPF Week through our newsletters, website and social media. We have plans for more IPF 'Meet the Expert' events and will continue to publicise the information at those events and online. We have sent out feedback forms to an IPF patient group to get some feedback on the booklet. We are also planning to ask for feedback from both patients and health care professionals about the booklet at future IPF 'Meet the Expert' events.

“Relevant people were involved at various stages of the production process and users commented on the earlier version of the leaflet and their comments were used in
the new version. Specific thought has been given as to how this resource will reach the group it is intended for. The information given is very good and users’ feedback was used to design the content. The layout on the website and the downloaded PDF document is very good with clear images with clear labelling.”
Managing your Bowels: A Guide for People with MS
MS Trust 2013

The aim of the resource is to provide information and strategies to support people living with MS and experiencing bowel problems. To understand why bowel problems can be part of MS, gain the skills necessary to successfully self-manage where appropriate, become aware of support and treatment options available and become partners with healthcare professionals in decisions about treatment and management. The target audience for this publication is anyone living with MS who experiences bowel problems, or symptoms which may find embarrassing to raise with health professionals. Although more common as MS progresses, this can include people at any stage along the MS pathway.

Health professionals who reviewed the publication were: Nikki Embrey – MS Specialist Nurse; Maureen Coggrave – Clinical Nurse Specialist Neurogenic Bowel Dysfunction; Debbie Quinn – MS Specialist Nurse; and Anna Cavey – MS Specialist Nurse. Additionally the in-depth views of 24 MS specialist professionals were elicited at the MS Trust Conference November 2012 in terms of resource content and design. A group of six people (three men and three women) living with MS and bowel problems came together for a two hour open discussion around continence issues. A phenomenological approach was taken and the session facilitated by Nikki Embrey MS Specialist Nurse. Questionnaire surveys were also sent out to people who had requested a previous resource on bowel problems to determine what additional information they would like to see. Comment was additionally elicited on social media and input requested via the MS Trust blog. Members of the focus group and an additional four members of the MS Trust Readers’ panel reviewed drafts of the resource.

The publication was featured in the MS Trust newsletters (Open Door reaches over 23,000 people living with MS and Way Ahead 4,000 health professionals working with people living with MS). The resource will be the focus of MS Awareness Week in April 2014 with supporting “Continence question time” video content which features health professionals and people with MS considering questions previously submitted on social media about continence issues. Managing your Bowels was launched at the MS Trust conference for health and social care professionals in November 2013 and promoted at the joint RCN Continence/Neuroscience conference (November 2013). Health professionals are a vital conduit for disseminating MS Trust information to people living with MS. Managing your bowels: A guide for people with MS is available to download from the website as a PDF or to read online. The resource is promoted via MS Trust social media. User feedback surveys have been included in the publications distributed throughout February 2014 and a feedback form is also available online. Mechanisms are in place to capture all user feedback spontaneously received.

“This is a very detailed, informative and readable booklet. Specialist nursing and neurological staff were involved in the consultation around the production of this booklet and opinion/feedback was sought from a wider audience at a conference. MS patients with direct experience of bowel problems were involved in the production of this booklet and views were garnered from a wider audience via social media and patients who had previously requested information on bowel problems.”

My Diabetes My Way
University of Dundee/NHS Scotland 2014

My Diabetes My Way is the NHS Scotland interactive website for people with diabetes and their carers. It contains a variety of validated multimedia resources aimed at improving self-management. These include traditional information leaflets, interactive educational tools, videos describing diabetes-related complications and testimonials from people with diabetes talking about their experiences with health services. It also offers users access to their clinical data via a novel electronic personal health record. The service is overseen by a multidisciplinary project board that provides guidance and strategic direction. This group involves healthcare professionals from both primary and secondary care (Dr Debbie Wake, Consultant Diabetologist; Dr James Walker, Consultant Diabetologist; Dr Alistair Emile-Smith, General Practitioner; Dr Ian Dickson, General Practitioner; Lyn Wilson, Diabetes Specialist Nurse) and IT professionals (Dr Scott Cunningham, Technical Consultant; Massimo Brailante, Software Engineer; Brian Allardice, Software Engineer). Lyn Wilson is responsible for content identification, development and review, overseen by Dr Debbie Wake. The multidisciplinary project board also involves patients who contribute towards the strategic direction of the project. All new content is reviewed by patients for comment and feedback via the Scottish Diabetes Group’s “Diabetes Care Focus Group” which exclusively consists of patient representatives. The project lead has taken considerable time to engage beyond organisational structures to deliver overview and awareness presentations at local Diabetes UK patient groups (Lothian, Fife, Greater Glasgow & Clyde, Lanarkshire) and patient events in Tayside, Fife, Lothian, Greater Glasgow & Clyde, Grampian and Ayrshire & Arran). These awareness presentations showed example Microsoft PowerPoint screens depicting a system demonstration and allowed participants to feed back their opinions, and in some cases their experiences, so that enhancements could be documented. Each method of user engagement has also assisted in the assessment of usability and accessibility using feedback received. Based on the discussion following these presentations and anecdotal feedback received from the participants, comments were noted for further discussion and in some cases, development. In order to engage with the wider clinical community, project status is reported to all health boards and diabetes Managed Clinical Networks (MCNs). Information and awareness materials are sent directly to diabetes MCN managers and lead clinicians to disseminate more widely within each health board. Presentations have been delivered by the project lead directly to the Scottish Diabetes Group and national eHealth leads. Usage of the general information component of My Diabeets My Way was recently presented at the Diabetes in Scotland Conference in February 2014 (http://www.mydiabetesmyway.scot.nhs.uk/PDF/DiabetesMDMWN_DiabetesMyWay_2014.pdf). This highlighted the most popular resources and showed that usage has continued to increase since launch. Much more thorough analysis has been performed on the novel electronic personal health record component of My Diabetes My Way. Prior to accessing this service, 144 (82%) of 176 My Diabetes My Way registrants completed an evaluation survey to gauge opinions of records access. Users indicated that they wished to check their diabetes control, medications and transfer home recordings. They wanted to check the accuracy of their data, report errors and ask questions. Additional motivational factors were to improve knowledge and assist in meeting goals. 98% believed the intervention would significantly improve diabetes care across Scotland. Following the first year of live use, we followed up users via a second
survey to find out how user experiences compared to their expectations. There were 55 respondents, of which 53 (96.4%) of active users at this time) had successfully logged in to access their diabetes information at least once. 89% believed the system contained all the features they expected. Analysis has begun on the impact on clinical outcomes following the first two years of use. Provisional data has shown that those who have accessed the system show improvements in process outcomes including blood pressure, weight, cholesterol, creatinine and HbA1c one year after first login. Work will continue to expand on these data for peer-reviewed publication.

“This is a well-thought-out and developed resource which aims to personalise information on diabetes (people choose what they want to know and there is also a log in tracking and monitoring section for each person). It’s easy to navigate around and find what you want. It’s an excellent resource, well-produced with good input from health professionals and patients. I like the ability to personalise and select the information you want and the standard approach to each section which makes navigation easy. The choice of formats is great, as is the opportunity to get people’s perspectives on living with diabetes as well as the facts. It includes resources from a range of different producers, and covers many areas of life with diabetes. The language and tone lets it down a little in places – it’s a bit paternalistic in places (the patient) and sometimes switches between addressing the reader directly and then indirectly. Other than that it’s achieving its purpose and objectives very well.”

Post Traumatic Stress: A self Help Guide
Northumberland, Tyne and Wear NHS Foundation Trust 2013

This resource is a self help tool aimed at mental health service users and the public. The series of booklets (23 titles) are used by many primary care and IAPT services. Dr Lesley Maunder and Dr Lorna Cameron, Consultant Clinical Psychologists (NHS) were involved with contributions from service users (using Trust services) and health care staff. All materials have been subject to review and editing by service users. This process considered design, content and structure. Some of the materials have been produced in partnership with service users through focus groups, and service users have been involved in drafting some materials. A number of booklets have been subject to studies in the clinical setting of their efficacy. The main academic literature on each topic and current Cognitive Behaviour Therapy literature have been consulted in the development of the booklets. The authors also considered what other self help materials were available on the listed topics. The research base on the efficacy of self help for each area was also considered. The booklets are free to download at www.ntw.nhs.uk/pic/selfhelp. The guides are also available as a free App from Google Play and iTunes stores. The guides are available in the following formats: A4, Large print (booklet printing option available to print AS), GP version – as the request to local GPs a smaller print version of the booklet was developed in order that the guides could be printed out quickly and easily during patient consultations; Audio format; MP3 download file; Video introduction to the guide. The booklets are also available to purchase in hard copy. The booklets are also referenced at www.patient.co.uk and are crawled by NHS Evidence. A number of booklets have been subject to studies in the clinical setting of their efficacy. Online users of the guides are able to feedback on the content and rate the guides: reviews are available on the website at www.ntw.nhs.uk/pic/selfhelp.

“I found this easy to read, relevant, generally concise and pleasantly neutral in tone; it gave no sense of being patronising, but was human and helpful. I found it approachable, informative, clear and easy to use. The layout is exemplary and the tone is direct, helpful and unpatronising. The language is clear and follows basic plain English principles. Sentences could often be briefer. The whole booklet aims to help PTS sufferers to live more easily and effectively. There are many practical suggestions to help sufferers gain insight, balance and perspective. It makes constructive suggestions, aiming always to encourage the sufferer to try approaches. It is never didactic.”

Top 10 Exercises for Back Pain Relief
Healthy Back Company (now known as Spring Active) in collaboration with BackCare

This series of booklets have taken the 2009 NICE guidelines for back pain and provided bite sized information based on these guidelines. They provide back pain suffersers with cognitive behavioural therapy for back pain, prevention and treatment advice and exercise programmes for back pain relief. The principle author of the booklet series is Nick Sinfield, Clinical Director at the Healthy Back Company and a registered Chartered Physiotherapist. During the development of the booklets Nick worked closely with Trish Wisbey-Roth, an Australian physiotherapist, who is currently the Director of Bounce Back Active Rehabilitation Systems and also continues to work clinically in Sydney. They have also worked collaboratively on the Bounce Back Edition of The Back Pain Personal Health Plan. Contributions were made by Dr Adam Al-Kashi, Head of Research at BackCare the National charity for back pain and feedback was given from Dr Paul Butler, a physiotherapist; Dr Talib Alabucker, a Luton GP; and James Langdon an Orthopaedic Spinal Surgeon. During the development of the booklets numerous physiotherapists, osteopaths, GPs and other healthcare professionals have been consulted. Nick Sinfield was asked to supply online back pain exercise programmes to the National Health Service (NHS); following this programme, his low back pain and sciatica exercise programmes achieved an average score of 4 out of 5 from 339 people. Many of these exercises are included in the booklets. The information included in the booklets was used in the Four Week Clinical Trial at the HPO Clinic in Hertfordshire in 2012. This trial was titled the Benefits of a Back Pain Personal Health Plan in the self-management of long term back pain. The trial was run over a four week period with eight participants attending a one hour class every week. The classes consisted of educational and practical components in the self-management of back pain. The feedback from the trial participants helped provide the booklet information. Information from the booklets was included in a series of articles in the quarterly magazine TalkBack produced by the charity BackCare. The articles ran over three editions of the magazine consisting of cognitive behavioural therapy back pain information, prevention and treatment advice and exercise programmes.
“If you eat your crusts your hair will go curly.”

Truth or Myth?

Not all health and care information can be trusted, but Information Standard members help the public untangle the truth.

The Information Standard is a certification programme which helps people quickly identify reliable sources of high quality, evidence-based information through the use of an easily recognised quality mark. This means that they can make better, more informed health and care decisions for their families.

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Understanding Pancreatic Cancer. What is Pancreatic Cancer and How is it Diagnosed?

Pancreatic Cancer Action 2013

This booklet is one of a series of patient information booklets which provide information at each stage of the journey through pancreatic cancer from diagnosis to managing symptoms. Each booklet addresses a specific aspect of the pancreatic cancer journey so that those affected can be more informed about the illness, and be better equipped to ask the most relevant and useful questions of the medical advisors. The booklets are presented in a clear, user-friendly format and are intended to provide useful information at the relevant point in time, for example at the point of diagnosis as in the present submission. Pancreatic cancer has suffered from low research investment and low awareness. Consequently the aim of the charity is to raise awareness about the disease and to support those who are diagnosed with or affected by the disease by providing good quality clear information when and where it is most needed. The patient information booklet series purposely do not include statistics that may scare or overwhelm the user, but instead intends to present clear and balanced information to the user. The information booklets have been produced with the assistance of Insight Medical Writing LTD with additional input and review of the product from Mr Ross Carter Consultant HPB Surgeon at Glasgow Royal Infirmary, and from Mr Neville Menzes Consultant HPB Surgeon at Guildford Royal Surrey County Hospital. Both are specialists in the field of pancreatic cancer. Mr Ross Carter has authored and co-authored over 65 peer-reviewed articles and 15 book chapters, has sat on the NICE advisory board and NCRI pancreatic subgroup, and on the editorial board of HpB reviewing research and clinical papers for various international journals. Mr Neville Menezes sits on the Board of Trustees for this charity. The initial impetus for producing this series of booklets came from the PCA Founder Ali Stunt who, when diagnosed with pancreatic cancer, found that there was limited information available to her as a newly diagnosed patient. Given the poor awareness surrounding pancreatic cancer – both among the public and medical professionals – there was paucity information available to those newly diagnosed, their friends, family and carers. Such a lack of information causes confusion and distress to the patient, friends, family and carers, and the present series addresses this issue. During the course of producing this information we consulted our panel of lay reviewers in order to hone the product before production. Currently our information has been disseminated through our website ordering facility. We plan to send the information out to CNSs and other medical professionals who are present at each relevant stage of the pancreatic cancer journey in order to ensure that the information is made available at the most critical and relevant point in time to the patient, their family, friends and carers. We have an ongoing review process in which we ask our panel of reviewers to review the information resource in order to gain ongoing feedback by which to evaluate the continued usefulness, accuracy and impact of the resource. We are in the process of creating an evaluation form to send out with our patient information booklets, in order to gain feedback about the information product.

“This is an excellent and much needed resource. My main concern is that there is so much technical and medical language within the resources that some people may feel overwhelmed even though it is extremely informative and covers such a lot of detail. The technical terms and medical terms are explained, but there is so much that it might well still be intimidating for some people. However, it is a very valuable resource, and I can imagine that patients would keep this leaflet and keep referring to it at different stages because there is a lot to take in. The impetus came from patient need, and patient and support groups have been involved in the production of the resource.”

Vision and MS

MS Society 2013

The purpose of the booklet is to explain how MS can affect vision, as well as outline how problems can be treated. It also aims to acknowledge the emotional and practical impact that vision problems can have, and signpost to further sources of support and information. In order to better meet the aims of this booklet, we made some changes to this new edition: increased the font size, to make it easier for people with visual problems to read; included more on the impact of MS-related sight problems; removed the general information about living with sight problems, and instead signposted to reliable organisations who could give more in-depth information and support. The audience for this resource is anyone with MS-related visual problems, and their friends and family. Because problems with vision are a common early symptom of MS, a key part of the audience is people who have been newly diagnosed, or are going through the process of being diagnosed with MS. Dr Simon Hickman, a neurologist specialising in neuro-ophthalmology, reviewed the text of the booklet, as well as checked the evidence we used. Two MS nurses also gave us their feedback on the booklet. People with MS were involved in all aspects of developing the booklet. We consulted with a number of people with MS prior to making the changes to the content, and asked for their views on what we could do to make the booklet easier to read for people with visual problems. A number of people reviewed a draft of the booklet, giving their feedback on the
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tone and style, as well as the detail of information given and the structure and content of the booklet. All of the personal experience quotes in the booklet were provided by people with MS, either in response to an email request for quotes or via the message boards on the MS Society website. Dissemination is through: network of over 300 local branches around the UK – volunteer groups offering information and support in their local area; network of 152 info points – located in hospital outpatient, neurological or MS departments, community hospitals and rehabilitation centres; Online promotion through www.mssociety.org.uk; A freely accessible online ordering system; Promotion to health and social care professionals through the MS Professional Network; Promotion to professionals and patients at MS Society events, including local Living with MS days and our national biennial lifestyle event, MS Life, and Cross-referring in other information resources as appropriate. We also offer an audio CD version for people who have difficulty reading print, and a large print (22pt) Word version. Evaluation of the impact of this resource is carried out on an ongoing basis, through a variety of channels: By request – when we ask people who are affected by MS or those who work with them to review a specific title; Informally through our everyday contact with professionals and end users; Through our online survey: https://www.surveymonkey.com/s/RMHH9PGJ; and Through telephone interviews carried out with people who have ordered information resources from us.

“This is not a flashy or innovative resource in its visual appearance but it does what it does very well and in my opinion is of an excellent standard. The format, layout and depth of content are pitched just right. It explains everything clearly and in a very human way and it provides information in a way that makes explicit the link with MS whilst also acknowledging that there may be no link whatsoever. It is at once reassuring and realistic in tone. I liked how the information was organised and presented in a reasonably concise way but making explicit the links between each condition and MS and what this means in terms of diagnosis and treatment. They resisted the temptation to be too wordy but balanced this well by proving sufficient detail and depth. It uses quotes from people with MS in a really helpful and engaging way; they illustrate the point and give a personal touch to the explanations of each condition. If I were a person with MS experience visual problems, I would find this a very helpful introduction to the subject.”

Vita online
Breast Cancer Care July 2013

This online resource is an extension of our already very successful patient information quarterly publication Vita, the breast cancer magazine. The magazine itself is unique and innovative as it is the only lifestyle magazine available to women affected by breast cancer. It is now joined by Vita online at www.vita.org.uk to make it feel even more like the sort of lifestyle magazine readers see in everyday life. It includes interactive elements such as a topical poll and a Vita twitter feed. Vita on Twitter has more than 600 followers. Vita online has broadly the same aims as the magazine. Namely: to try to give information that enables people to become better informed breast cancer patients, with all the well-evidenced benefits that this entails; to reach out to and engage an audience that we don’t normally get to with our more formal patient information materials. The target audience is people with breast cancer in the UK, although the online resource is available for anyone who wants to read it. It also targets people who read the magazine as it contains complementary and additional resources to the printed version, and there is mutual signposting back and forth between the online and hard copy Vita. The clinical information that appears on this site is taken from resources that have gone through our Information Standard certified editorial processes. These include being written by and/or checked by our own clinical experts and reviewed by members of our reader panel of external clinical experts, all of whom specialise in areas related to breast cancer. Our internal breast care nurses check all content and are involved in monthly content planning meetings. Everything on the site is timed so that nothing will remain on it without being checked again for longer than two years as a maximum. Our starting point was our 2010 Vita magazine reader survey, which was sent out with the magazine and answered by more than 1,000 readers. Ninety-three percent of these were people diagnosed with breast cancer, and about 5% healthcare professionals. We felt the results indicated an innovative expansion of the service supplied by Vita would be welcomed. For example 91% of respondents agreed that reading Vita helps people with breast cancer ask their doctors more questions about their treatment. The survey asked detailed questions about the style and type of content readers found useful and engaging, which we were able to transfer and expand on for Vita online. We also sent Vita online ideas and designs to Vita magazine subscribers for feedback. After making changes based on this feedback, we showed the new designs to Vita Voices, a group recruited from our 500+ user panel, called Breast Cancer Voices, as having a particular interest in the magazine and Vita online. We then made further changes based on their views before building the site. On a regular basis, we use both our online community of people affected by breast cancer (see http://forum breatncancercare.org.uk) our Facebook page and our wider Breast Cancer Voices panel to ask for people’s stories and insights to be shared at Vita online. Many are willing to share very personal experiences, principally in the Real Lives section. We disseminate information about the existence of Vita online through the quarterly Vita magazine and via our online community of people affected by breast cancer. Vita magazine itself is distributed quarterly to a subscription list of approximately 20,000, with many copies going to NHS breast care units, cancer information centres and a variety of breast cancer support groups. Evidence from our 2010 reader survey suggests that more than 50% of people pass on their copy of Vita after reading it so that we estimate each copy is read by approximately 2.5 people. The specialist team working on our telephone Helpline refer callers to the Vita online website where relevant, and there is mutual linking from Breast Cancer Care’s more formal web-based patient information to and from Vita online articles as appropriate. We promote specific articles, videos and other information on Vita online via our Twitter account and through Breast Cancer Care’s Twitter (100,000-plus followers) and Facebook (“liked” by nearly 50,000) accounts. Initially our evaluation is by web usage statistics and through informal feedback by letter and email. For example, within a week of launch in July 2013 Vita online had received 2,583 unique page views. These figures have increased month on month to 7,056 unique page visits in January 2014, the highest ever. This was over 2.5k more visits than in December. During the summer of 2014 we will be running another of our regular (previously done in 2007 and 2010) reader surveys in Vita magazine and through Vita online. This will include evaluation questions about Vita online content and presentation, and the impact of the site on people diagnosed with breast cancer.
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“What is MS? MS Society 2013

What is MS? is the MS Society’s most popular information resource about MS. The purpose of it is to provide a brief overview of the main facts about MS – such as how it’s diagnosed and treated, and the most common symptoms. The audience for the booklet is quite broad, and is essentially anyone with an interest in MS – including people with MS and their friends, families and colleagues, as well as health and social care professionals. As this booklet may be someone’s first ever contact with MS, it’s important that it gives the right impression. Feedback on the previous edition suggested it wasn’t doing this: it was A4-sized, more like a text book than an information resource, and contained so much information that it was simply too overwhelming for some people. With this new edition, we completely revamped and updated it to make it shorter, friendlier and more attractive. To do this we: reduced the amount of text on the pages; reduced the length; added illustrations; to help explain the information as well as make it more visually appealing; simplified the language and cut out jargon; included quotes from people with MS, to make it friendlier and balance the out the more clinical, factual information; reduced the size from A4 to A5, to make it easier to handle and carry about. The result is very much a new direction in the look and feel of the MS Society’s information resources. As part of the scoping for the project we identified which experts and professionals would be the relevant people to help us develop the resource. The people we identified were: MS Society Research who fed back on content, relevancy of content and the evidence we used to back it up; MS nurses reviewed the full text of the document, and provided detailed feedback on the design of the booklet as well as usability; MS Helpline fed back on appropriateness of content and layout and usability. Because this is such an important information resource for the MS Society, it was essential for us to get the views of our audience to make sure we were getting it right. People with or affected by MS were involved in shaping the booklet at every stage – in fact, What is MS? had more user involvement than any previous information resource we’ve produced. A number of people with MS commented on the initial proposal and content outline, and also provided suggestions for illustrations that could help to explain the information. A further eight people with MS reviewed a draft of the text, giving their feedback on the content as well as the tone and style. In addition, we carried out an online survey to get people’s feedback on the cover and layout of the booklet. In total we had 317 responses, of which 151 were from people with MS and a further 71 from people who had a friend or family member with MS. We also carried out interviews number of people with MS about their experiences of living with MS, from which we sourced the personal experience quotes in the booklet. Dissemination is through: Our network of over 300 local branches around the UK – volunteer groups offering information and support in their local area. Our network of 152 info points – located in hospital outpatient, neurological or MS departments, community hospitals and rehabilitation centres; Online promotion through www.mssociety.org.uk; A freely accessible online ordering system; Promotion to health and social care professionals through the MS Professional Network; Promotion to professionals and patients at MS Society events, including local Living with MS days and our national biennial lifestyle event, MS Life; Cross-referring in other information resources as appropriate; Social media – including blogs, Facebook and Twitter; The American Academy of Neurology has included it as an educational resource to be distributed at the 2014 AAN conference for neurologists and researchers. We also offer an audio CD version, a downloadable MP3 version (which is also available in seven different languages) for people who have difficulty reading print, and a large print version. Evaluation of the impact of this resource is carried out on an ongoing basis, through a variety of channels: By request – when we ask people who are affected by MS or those who work with them to review a specific title; Informally through our everyday contact with professionals and end users; Through our online survey: https://www.surveymonkey.com/s/RMHP9PJ; and Through telephone interviews carried out with people who have ordered information resources from us.

“...in my opinion, trustworthy. The booklet is that the info is transparent, open and in my opinion, trustworthy. The booklet is about the right size for a printed resource. There is clear navigation throughout so it is very easy to read and to follow the text. The text is clear and there is plenty of white space surrounding it. While there are splashes of colour, there isn’t so much as to make the resource look busy, the result is a clean and professional overall look. There is an ‘I’ symbol in several places in the booklet which indicate that there’s a resource from the MS society that covers the topic in more depth. I really like this because it avoids putting too much information into one resource and so avoids overwhelming the user.”

Younger People with Dementia: Living Well with your Diagnosis

NHS Health Scotland & Alzheimer Scotland 2013

The purpose of the resource is to provide clear, accurate and comprehensive information to those receiving a diagnosis of young onset dementia and their families in Scotland. The publication will also function as a resource for health professionals who may be involved in the diagnosis of individuals or who may encounter families and individuals during the course of their work. This resource aims to provide guidance to social and health services, legal matters and promotes a living well with dementia message for those with young onset dementia in Scotland. Consultation with health and social care professionals working in the field of dementia was extensive. In particular, the opinions of those involved or interested in young onset dementia were sought. Two workshops were undertaken to consult with service users, families and health and social care
professionals. Invitations were extended to a wide range of Health professionals including, neurologists, psychiatrists, Community Psychiatric Nurses (CPN) and Occupational Therapists and other Allied Health Professionals (AHPs). Over 70 people attended the workshops. A wide email consultation took place following the workshops. Professionals who commented and informed the development of the resource were: consultant psychiatrists and clinical psychologists; community psychiatric nurses; AHPs; clinical team leader with learning disability service; representatives from LGBT communities; driving assessment unit; RNIB; Deaf Connections; Carers organisations; Downs Syndrome Scotland Association; public health advisors on alcohol, tobacco, food and health and physical activity; academics; dementia nurse advisors; Central Scotland Regional Equality Network; health and social care specialist working with gypsy travelling community; solicitors; benefits advisors; and social workers. The accompanying DVD includes sections presented by consultant psychiatrist (Gary Stephenson), Health OT (Sandra Shafi) and Memory Clinic Coordinator (Maggie Simpson). Younger people with dementia and their families were sought at the events. Carers and people with dementia were also approached by Alzheimer Scotland, Glasgow Younger Persons Support Service (GYPPSS) to take part in filming and also comment on drafts of the publication. After initial filming consultation again took place to identify gaps and ensure the resource was on course to meet its identified objectives. User and carer groups such as the Scottish Dementia Working Group (SDWG) and members of the National Dementia Carers Action Network (NDCAN) were consulted at the drafting stage and also at the design stage of the publication. Carers’ organisation representatives were also asked to comment on drafts of the publication. The DVD was formally launched in November 2013 at a national conference for Younger Adults with Dementia. Another event will take place in Glasgow in March 2014 with over 100 delegates planned. Further dissemination included: booklet and DVD have been sent to all those who were involved in the DVD development process, as well as to individuals who have personally requested the resource; bulk copies have been sent to NHS Health Board Patient Education Resource Libraries, Alzheimer Scotland’s Dementia Helpline, services and branches including dementia link workers and Dementia Services Development Centre University of Stirling; single copies have been sent to carers’ organisations such as Age Scotland Helpline; email will be sent with links to resource highlighting resource and DVD. The resource is available on NHS Health Scotland and Alzheimer Scotland websites. Social media has been successful with comments from across the world including Australia through twitter. The resource has been pre-tested with target audience of people with diagnosis and family carers and health and social care professionals. Evaluation is planned for follow-up email to dissemination audience and to event delegates. The Glasgow event will also incorporate evaluation materials.

“I liked the way it presented the information to different target audiences and was comprehensive, but not overwhelming and allows users to dip in and out and also to follow up if they need more information. I liked the fact that patients and carers voices were very much represented throughout the resource and particularly the fact the information is available in different formats text, summary, quotes and DVD to suit different needs and tastes. The resources are accessible to people with visual and hearing impairments. A lot of care has been taken with this resource and it shows. The booklet contains user and carer perspectives both in the text and in quote bubbles. The DVD provides a wealth of information about the patient and carer experience using the voices of the people themselves. There are lots of suggestions for further information which can be accessed in a variety of ways, from the organisations who produced this resource and a wide range of other relevant sources.”
Special award – information that aids decision making
This award is for resources which facilitates the patient decision making process. This should be the main intention of the resource and the resource should show clearly how this is to be achieved. We have made this special award in order to recognise the importance of improving patients’ ability to take responsibility for their health.

Special award – innovation
This new award is for a resource which presents or disseminates information in a new or original way which increases its impact. The winner of this award will score highly in terms of its content but will also demonstrate an innovative approach to its production or dissemination. This might include innovative use of technology (such as web animation or interactive web devices) to maximise engagement with the intended user or innovative use of technology (such as PDFs, intranets or podcasts) to maximise the dissemination of the resource. It could also be a conventional printed resource. We have made this special award in order to recognise the importance of the measurement of impact. You will need to demonstrate clearly what you consider to be innovative about your resource and show how you have evaluated its impact.

Special award – learning disabled
This award is for a resource which uses accessible information or uses adaptive information for materials aimed at those with learning disabilities.

Special award – long term conditions
This award is for resources which meet the information needs of patients with long term conditions. A long term condition is one that cannot be cured but can be managed through medication and or therapy such as asthma, diabetes, coronary heart disease, some mental health conditions or chronic obstructive pulmonary disease (amongst others). We have made this a special award because of the high incidence of chronic conditions and in order to recognise the importance of patient information in its effective management.

Special award – mental capacity
This is for a resource which is concerned with mental capacity issues. It is designed to raise awareness of the Mental Capacity Act and to encourage the development of resources which aid decision-making in the care and treatment for people who lack, or who may lack, the mental capacity to make decisions on their own behalf.

Special award – screening
This is for a resource which discusses preventative strategies or an innovative screening.

Special award – self care
This award is for resources which promote healthy living or looking after yourself in a healthy way (such as brushing your teeth or self treating minor ailments). We have made this a special award in order to recognise the importance of the patients’ role in managing their health.

Special award – user involvement
This award is for resources in which users played an integral role in the creation of the resource. It considers factors such as the input of users in areas such as scope, design and content or in guiding the resource’s continuing development and engagement with its users. It examines the established channels through which user input is solicited/encouraged, appraised and integrated into the resource and the steps taken to ensure that users of different ages, backgrounds and perspectives provide input.

BMA Patient Information Awards Reviewer of the Year Award
This new award is chosen by the judging panel to acknowledge the work of our many volunteer reviewers who complete a detailed structured appraisal form. This award is made from the reviewers of the shortlisted books and is based on the thoroughness and insightfulness of the review.
The BMA Patient Liaison Group (PLG)

The Patient Liaison Group (PLG) was established in 2004 to ensure patients are represented within the BMA. The PLG acts as an internal reference group and provides the BMA with an informed patient view on matters of interest to the medical profession and to patients. It works to inform BMA policy by ensuring that patient views are represented. It also highlights areas of patient concern to the BMA.

The PLG consists of people from diverse backgrounds and draws on the expertise of lay members, including some with direct patient-based links. The group has seats for 11 lay members and five doctor members who work on a voluntary basis.

The PLG celebrated its ten year anniversary earlier this year. Dr Chaand Nagpaul, current Chair of the BMA General Practitioners Committee, commented: “Patients are at the heart of our lives; they are our allies and partners in the continuity of care we provide. It is important that the BMA has embodied the patient voice in our work and functioning, so that our policies are strengthened by the perspectives of patients we look after. It is with pride that we are celebrating the PLG’s 10th anniversary.”

The PLG has made progress in 2013-2014 on issues ranging from hospital discharge to out-of-hours care. The PLG fed into the BMA’s Your GP Cares campaign. The campaign is calling for long-term, sustainable investment in general practice. The group engaged with NHS England, the BMA General Practitioners Committee and numerous other bodies to ensure patients’ voices were heard on the healthcare issues that matter to them.

Catherine Macadam, PLG Chair, participates in the final judging panel for the BMA Patient Information Awards and will present the BMA Patient Information Resource of the Year.

The full mission statement and links to PLG resources can be found at: www.bma.org.uk/plg

BMA Patient Liaison Group