BMA Patient Information

Awards 2017

Programme and awards winners

Monday 18 September 2017
BMA House, London
Programme and Award Winners

The BMA Patient Information Awards aim to support and encourage patient-centred care in meeting the needs of patients through the production and dissemination of accessible, well-designed and clinically balanced information which will promote greater awareness and understanding of health matters, and patient choice.

Professor Sir John Temple

Professor Sir John Temple is the BMA president for the year 2017-2018. He was born in Salford, Lancashire, England. He was educated at William Hulme's Grammar School in Manchester and studied at the University of Liverpool School of Medicine, graduating in 1965. Subsequently, he trained as a surgeon in Liverpool, before becoming a consultant surgeon first in Manchester (1974-79) and then in Birmingham (1979-2003). Professor Temple was the president of the Royal College of Surgeons of Edinburgh (2000-2003). He was chairman of the Specialist Training Authority of the Medical Royal Colleges (STA) from 2000 until 2008. From 2000 until April 2017 he chaired the Research and Development Council, and is also a trustee, of the Board of the Scarfree Foundation. From 1991 until 2000, he was regional postgraduate dean in the West Midlands and was chairman of the Conference of Postgraduate Deans (COPMeD) from 1995-2000. His clinical appointments include professor of general surgery based at the University of Birmingham, a post he has held from 1994-2003, and consultant surgeon to the Queen Elizabeth Hospital, Birmingham, from 1979-2003.

As special adviser to the chief medical officer in England, Professor Temple introduced Higher Specialist Training Reforms (Calman) for all disciplines in postgraduate medical education from 1995-2000. He chaired the Technical Group Working Party to look at a radical re-organisation of the SHO grade, as part of Modernising Medical Careers. He was chairman of the Medical Workforce Review for Scotland, which led to the publication of Future Practice in 2002 and Securing Future Practice in 2004. He was also the chairman of the Scottish Audit of Surgical Mortality from 2000-2003.

More recently he has carried out independent strategic reviews for a number of trusts, and in October 2009 he was independent chair of a Government commissioned enquiry into the European Working Time Directive and its impact upon the education and training of doctors, dentists, pharmacists and healthcare scientists. His report Time for Training was published in May 2010. In 2011 he advised the Norwegian Special Commission on the reorganisation of clinical services and in 2013 he chaired a review of Intensive Care Medicine in the UK leading to the publication of the report Collaborating for Quality in Intensive Care Medicine.

Professor Temple obtained the fellowship of the Royal College of Surgeons of Edinburgh in 1969 and the Royal College of Surgeons of England in 1970.

More recently he was awarded fellowships of the Royal College of Physicians in London and Edinburgh in 1999. In 2001, he was given an honorary fellowship of the Hong Kong College of Surgeons, and College of Surgeons in Ireland, fellowship of the Academy of Medicine of Singapore and honorary fellowship of the Royal Australasian College of Surgeons, in 2003 the Fellowship qua Surgeon ad eundem of the Royal College of Physicians and Surgeons of Glasgow, honorary fellowship of the Royal College of General Practitioners, the Faculty of Accident and Emergency Medicine, and the Royal College of Surgeons of England in 2004 and in 2005 fellowship of the Royal College of Anaesthetists.

Further awards include a DSc (Hon) from Bristol University and a FRCA (Hon) by the Faculty of Intensive Care Medicine in 2014. Finally in 2017 he was appointed to the International Academic Council of the Sechenov University Moscow which is the oldest medical school in Russia. He was a member of the Council of the University of Warwick between 2003-2009 and honorary colonel of 202 Field Hospital (TA).

Professor Sir John Temple was made a Knight Bachelor in the Queen’s Birthday Honours in 2003 for Services to Medicine and Medical Education.
**Buffet supper**

- Lamb and date tagine with ras el hanout
- Sustainable fish pie with crème fraîche and a potato rosti topping
- Roasted summer vegetables and polenta tart with gremolata dressing (vegan)
- Quinoa, freekeh wheat and broad bean pilaf (vegan)
- Steamed seasonal greens (vegan)
- Eton mess cheesecake

**Wine**

- The War Horse Chenin Blanc, Stellenbosch, South Africa, 2015
- The War Horse Shiraz, Stellenbosch, South Africa, 2015
- Juices and water

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**Welcome and introduction of the Guest of Honour**
BMA treasurer, Dr Andrew Dearden

**Announcement of Awards**
BMA council chair, Dr Chaand Nagpaul

**Presentation of the BMA Patient Information Awards**
BMA president, Professor Sir John Temple

**Special prizes**
- Special award – children
- Special award – decision-making
- Special award – easy read
- Special award – ethics
- Special award – innovation
- Special award – long-term conditions
- Special award – self-care
- Special award – trusts
- Special award – user engagement
- Special award – young adults

**BMA Patient Information Reviewer of the Year Award**

**BMA Patient Information Resource of the Year Award**

**Address by Guest of Honour**
BMA president, Professor Sir John Temple

**Closing address**
BMA treasurer, Dr Andrew Dearden

The ceremony will be followed by a buffet reception in the Lutyens suite on the ground floor.
The BMA General Practitioners Committee

The BMA UK General Practitioners Committee (GPC) represents all GPs across the UK, whether or not they are members of the BMA, from partners, to sessional GPs and trainees. The work of the committee is supported by specific representative subcommittees (for GP trainees, sessional GPs and four national committees) and specific policy groups, as well as a national infrastructure of local medical committees. GPC is recognised as the sole negotiating body for GPs under the GMS contract by the Department of Health and devolved administrations.

In addition to negotiating the GP contract each year, GPC has influence at national level on many key issues for GPs and general practice, championing on behalf of the profession. Working with partners, GPC has lead the development of IT infrastructure of local medical committees. GPC is recognised as the sole negotiating body for GPs under the GMS contract by the Department of Health and devolved administrations.

In addition to negotiating the GP contract each year, GPC has influence at national level on many key issues for GPs and general practice, championing on behalf of the profession. Working with partners, GPC has played a key role in supporting the development of multidisciplinary working within general practice, most recently with a focus on the wider use of pharmacists working directly with practices, and is championing sustainable working practices through collaborative arrangements.

General practice has been at the heart of the delivery of primary healthcare for decades, and is often described as the cornerstone of the NHS. Over recent years, general practice has faced increasing pressures on the service, including unsustainable workload, a workforce crisis and inadequate resources. GPC has undertaken significant research into the issues faced, including a large survey of general practice held in 2016 which showed that more than eight out of ten GPs believe they cannot provide appropriate and safe care to patients because of their level of workload.

GPC representatives sit on many national and local boards and committees and regularly liaise with key stakeholders to ensure we get the best for all GPs, whether at a local or national level. GPC has played a key role in negotiating with government on the support needed for the profession, and has been successful in securing a number of commitments to sustain and develop the service over the coming years, and will continue to work to ensure a viable and successful future for general practice.

The special awards will be made from this shortlist of highly commended resources

A diary of heart valve surgery
British Heart Foundation, Heart Matters magazine – July 2016

We decided to push boundaries and try something that the British Heart Foundation has never done before, by creating an interactive patient diary. There was no UK content that told the story in a diary format, using the patient’s own voice, other than blogs that had not been medically checked. Our diary offers patients an inside view of heart valve surgery, using the first-hand account of one of our Heart Matters magazine readers, Catherine Mackay. As you scroll through her diary, which is embedded on our website, Catherine’s annotated illustrations pop up, explaining the entire patient journey through heart valve surgery in an accessible, humorous way. This is important as, according to the latest UK data, 239 million people in the UK have heart valve surgery every year. For most people, the operation will greatly improve symptoms and quality of life, and the risks are low, but like all operations, it can be intimidating. In Catherine’s own words, when she was told she needed this surgery, ‘I had no idea of all the procedures that this would entail. I had no idea what to expect. So I hope my diary is of some use to people who need the surgery and will put their minds at ease.’ The diary was a fantastic vehicle for getting across key medical information, eg about angiograms, warfarin etc. in a way that was enjoyable to read. We also wanted the information to come directly from the patient’s mouth, so it would be engaging and relatable, in a way that an article by medical experts couldn’t be.

‘This is a lovely insight written by a patient. I found it had the potential to feel a little patronising with the cartoon style drawings but I accept that’s about me rather than the resource itself. While it may not suit everyone, I do think it will suit many in its style.’

Advance care planning: A record of your wishes and preferences ‘Just A Thought’

Walsall Healthcare NHS Trust – January 2017

The resource is aimed at all: patients, carers, families, users, members of the public, health professionals and social care professionals. The objective is to encourage people to communicate and record their preferences and wishes for the end of life and also to express what’s important to them should they lose capacity. Advance care planning is a process of discussing and/or formally documenting a person’s wishes for their future care. We focused primarily on the person’s wishes and preferences. This gives health and social care professionals the opportunity to understand how individuals wish to be cared for in the future should they become too ill to make decisions or speak for themselves. These materials, while simple and brief, are well-produced.
The first step in addressing these challenges was to identify a series of challenges facing carers of myeloma patients and confirmed a critical need to provide support and guidance in managing these challenges.

After someone dies – coping with bereavement

This booklet aims to give: practical information about what to do when someone dies; emotional support for people who are preparing to or have lost a friend/relative to cancer and information for people supporting someone who’s grieving. The booklet is for: people preparing to lose a friend/relative as a result of a cancer diagnosis; people who have lost a friend/relative as a result of a cancer diagnosis at any time and people supporting those who are grieving after the loss of a friend/relative as a result of a cancer diagnosis.

‘This is a superb and exemplary resource that will prove very helpful to people dealing with or preparing for bereavement. The layout, structure, tone and content are all excellent. Additional sources of information are listed in detail. The division into sections and subsections means that it is easy to find a particular topic. The booklet is a child-friendly publication about grief, to make it easier for children to understand different aspects of their condition, and discuss with them their families and healthcare professionals. Epilepsy is a complex condition that can affect individuals in many ways. To help children and families understand their condition and associated impacts, we wanted to produce some short animations that are engaging, accessible and widely available. The intended outcomes of the project were for children with epilepsy to have increased knowledge and understanding of their condition and more confidence but also to take part in the management of their condition and to discuss their questions and concerns with parents, teachers and healthcare professionals.

This is a great set of resources. Animation is a very engaging choice for children, and having the voices of children sharing their experiences is extremely effective. Animation has the added benefit of offering the children in question privacy.

An Infopack for carers of myeloma patients
Myeloma UK – September 2016

Myeloma is a rare and incurable cancer, which is very individual, both in terms of the symptoms and complications patients can have and in the way they respond to treatment. About 17,500 people in the UK live with myeloma, and we estimate that about 25,000 people are providing some kind of care to someone with myeloma. Evidence collection through several of our patient and family services, including our Myeloma Infoline and online carer-specific discussion forum group, shows that a myeloma diagnosis affects many people not just the patient. But our research showed that no myeloma-specific publications are aimed at supporting those caring for patients. Last year, our organisation commissioned a piece of research supporting those caring for patients. Last year, our organisation commissioned a piece of research supporting those caring for patients. Last year, our organisation commissioned a piece of research supporting those caring for patients. Last year, our organisation commissioned a piece of research supporting those caring for patients.

This is a great resource which really takes into account the needs of carers of myeloma patients. It provides a very comprehensive overview from looking after your own needs as a carer to financial issues. It was particularly thoughtful of the authors to include a warning statement before the section which contained sensitive information. This is a great resource which you should be proud of producing. This is an excellent, practical, thoughtful and comprehensive publication for a group of individuals who I imagine are quite often overlooked. Well done!”

Animations for children
Epilepsy Action – September 2016

Epilepsy Action produced six short animations, aimed at children aged 7-11 with epilepsy and their families. The aim was to provide child-friendly patient information about epilepsy, to make it easier for children to understand different aspects of their condition, and discuss with them their families and healthcare professionals. Epilepsy is a complex condition that can affect individuals in many ways. To help children and families understand their condition and associated impacts, we wanted to produce some short animations that are engaging, accessible and widely available. The intended outcomes of the project were for children with epilepsy to have increased knowledge and understanding of their condition and more confidence but also to take part in the management of their condition and to discuss their questions and concerns with parents, teachers and healthcare professionals.

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The BMA’s ethics and human rights 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 the BMA’s telephone advice service (First Point of Contact) 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. All of our website resources are publicly accessible.

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.

Human rights
We defend and speak out about human rights. We conduct letter-writing campaigns in response to evidence of abuses of health-related human rights such as breaches of medical neutrality. We respond to cases where doctors are involved, whether as perpetrators or victims of human rights abuses. We participate in the World Medical Association and in the drafting of WMA statements relevant to human rights, and produce reports addressing health-related human rights.
and find their ‘new normal’ faster. The beta web app, Utilising technology that enables day-to-day activity human-centred design principles to create an app fatigue and lymphoedema. This is the problem Consequently many tell us they are struggling to years after their hospital treatment ends. Resources psychological impact of living with breast cancer as before and get ‘back to normal’, the physical and faced with the long-term impact of breast cancer. While many expect to be able to return to their lives and alone as their treatment ends and they are clinical visits and surgery, many women feel isolated and isolated as their treatment ends and they are learning disabilities. This process considered design, content and structure. It included patients from the Trust’s learning disability forensic services and Skills for People Programme Board which is made up of 14 people with learning disabilities who checked that the text and images were suitable for the target audience. ‘Thank you for the opportunity to review these resources. I think they are very good. It’s great to see that such an extensive and high quality evidence-base was consulted, and that people with learning disabilities have been closely involved in developing the resources. I hope they benefit lots of people in lots of good ways.’ BECCA Breast Cancer Care – October 2016 62,000 women are diagnosed with breast cancer in the UK every year, with more than eight out of 10 women surviving the diagnosis beyond five years. But, after the intensive programme of treatment, clinicians often find that many women feel isolated and alone as their treatment ends and they are faced with the long-term impact of breast cancer. While many expect to be able to return to their lives as before and get ‘back to normal’, the physical and psychological impact of living with breast cancer can be profound, and often results in a marked fall in emotional and mental well-being in the months and years after their hospital treatment ends. Resources to support women in this position are often lacking. Consequently many tell us they are struggling to deal with the impact of their cancer returning, and long-term side effects such as menopausal symptoms, fatigue and lymphoedema. This is the problem BECCA is designed to overcome. Our app uses human-centred design principles to create an app for anyone moving forward from breast cancer. Utilising technology that enables day-to-day activity suggestions and trusted information, BECCA enables people to better manage the impact of breast cancer and find their ‘new normal’ faster. The beta web app, launched in October, functions as a digital deck of cards. The information and suggestions within are all created with the assistance of specialist nurses and our expert staff, as well as the input of popular breast cancer bloggers. The design and functionality of the tool is to meet its users’ needs effectively, and inspire them to embrace a positive mind set and take small steps day-to-day, enabling them successfully to self-manage the impact of breast cancer and adjust to life beyond the disease. ‘This is one of the most exciting and fresh things I have ever seen when reviewing resources for the BMA patient information awards. I am really impressed by everything about this resource. At the heart of the project is an admirable desire ‘to create something that isn’t simply innovative but actually meets a significant, outstanding need need of the breast cancer community and improves their lives’. The way the applicant has gone about doing that – involving users in almost every way imaginable and drawing on such a wide range of high-quality information resources, as well as professional input – and I think the applicant’s ambition to make things even better is exemplary. The resource itself seems very good indeed. I hope it helps a lot of people. We will find out, because the applicant has excellent plans to evaluate impact.’ Care after stroke or transient ischaemic attack: what, when and why? Information for patients and their carers Intercollegiate Stroke Working Party, Royal College of Physicians – November 2016 This is an easy read, multimedia informational resource based on the Royal College of Physicians 2016 National Clinical Guideline for Stroke, 5th Edition. The content of this booklet is extracted directly from the full clinical guideline, which provides comprehensive, evidence-based recommendations along the entire stroke care pathway for stroke clinicians. This resource is intended for non-clinicians, such as stroke survivors, family members, and community advocates, and features clinical topics that are specifically pertinent to stroke patients and their carers. The booklet outlines the key standards of stroke care and treatment for adults after a stroke or transient ischaemic attack using pictures, synopses, how-to-readable text for people with communication and cognitive impairments. The primary goal of disseminating this resource is to provide pertinent information about the updated stroke care standards to the general public, with the hope that stroke survivors and advocates may use it to promote improved stroke care and increased awareness in the community. This resource may be also used as a tool for patients to support discussions about treatment options and to inform decisions about care and rehabilitation after being in hospital. ‘I applaud the efforts made to provide this comprehensive information resource in a way which is accessible to the widest range of people, including those with visual and cognitive impairment. A huge amount of information is presented in a clear and accessible way. The involvement of patients and charities representing patient views is excellent as is the wide range of professional input.’ Cerebral Venous Thrombosis (CVT) Salford Royal NHS Foundation Trust – October 2015 Prior to this resource there were no patient-orientated materials available to patients with CVT (cerebral venous thrombosis). Being in hospital for the treatment of an acute stroke can be a confusing time (particularly to the younger patient group that CVT affects), plus the impact of aphaia or memory difficulties can cause problems retaining information provided verbally. Therefore this leaflet aims to provide the means for patients to retain information about their condition and what to expect in hospital. It allows them to explain what has happened to their family later, and ensure they can recall important warnings for the future such as driving regulations, or vigilance against future thromboembolic events. ‘This is very clear and beautifully presented leaflet deliberately setting out to fulfil an observed need. Healthcare professionals were involved and the information is well-referenced. Involvement of patients at every stage of development and evaluation is excellent; small numbers involved reflect the rarity of the condition. Accessibility of the leaflet in print and online formats is good. The excellent content is clearly set out and illustrated and it is well-referenced with a good evidence-base. The feedback from patients is that it is very useful.’ CHANGE Cancer Series Easy Read booklet Macmillan Cancer Support – September 2016 Macmillan previously distributed six large Easy Read books produced by Change. The content of these booklets was broken down into shorter more accessible pdfs. Feedback was sought from learning disability nurses about the updated stroke care standards to the public, with the hope it is given and what to mix the drug with to make it more palatable for the child. The factsheets were written by two paediatric pharmacists on behalf of the CCLG Childhood Cancer Drugs Factsheets Group. They conducted a national survey among paediatric cancer pharmacy units to determine what was already available and agreed that the aim was to produce a standardised series of CCLG drug information factsheets for national content of the booklets. One of the main pieces of feedback was around access – previously the information had only been available online. Based on professionals’ feedback, we decided to produce printed copies that can now be ordered from the Macmillan website. ‘Thank you for the opportunity to review these very good resources. They seem to provide useful information in a friendly way. It’s great to see how much you involve people with learning disabilities in your work and that you are working so hard to ensure it reaches the people who need it, and that it was produced using such a thoughtful and inclusive process.’ Childhood Cancer Drugs Factsheets Children’s Cancer & Leukaemia Group (CCLG) – December 2016 When a child is diagnosed with cancer, parents are suddenly thrown into an overwhelming and unfamiliar medical environment facing new terminology and issues that were unimaginable before diagnosis. Treatment for cancer usually involves chemotherapy which can sometimes start immediately upon diagnosis. This means that while parents are coping with the emotional impact of such devastating news, they also have to come to terms with the challenges of administering and handling cancer drugs at home. Patient information for adults on chemotherapy drugs is readily available from other sources but there is no standardised patient information on chemotheraphy drugs for children. Research conducted by the Centre of Outcomes and Experiences Research in Children’s Health, Illness and Disability in London identified that an information gap existed for patient information on safe handling and drugs for childhood cancer. In addition, a recent CCLG website survey revealed that 92% of parents wanted information on childhood cancer chemotherapy drugs. The CCLG Childhood Cancer Drugs Factsheets fill this gap for parents by demystifying this topic and provides clear factual information on ten common chemotherapy drugs. Each factsheet describes what the drug is, common side effects, what to do if a dose is forgotten, how to safely administer the drug at home. Patient information was also utilised conferences to gather professionals’ feedback on the booklets. We consulted current clinical guidelines when updating the clinical
The PLG (Patient Liaison Group) was established in 2004 to ensure patients are represented within the BMA. The PLG provides the BMA with an informed patient view on matters of interest to the medical profession. It works to inform BMA policy by ensuring that patient views are represented, and also highlights areas of patient concern to the BMA.

PLG members come from a range of backgrounds and draw on their knowledge and experience as patients, carers, advocates and professionals working in a range of health-related fields. The group has seats for 11 lay members and five doctor members who work on a voluntary basis.

For the past 13 years, PLG has provided the patient perspective on a number of issues ranging from seven day services to raising concerns and patient safety. PLG has also organised themed events and workshops on quality care, self-care, five year forward view, patient-centred care and healthcare devolution.

The group works alongside BMA committees on behalf of patients, with representation on key committees including BMA council. PLG is also active in contributing to BMA consultation responses on matters requiring a patient perspective.

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

Childhood epilepsy: A Guide for Parents
Young Epilepsy – October 2016

Epileptic seizures can be truly terrifying to see. Families often feel alone and experience high levels of anxiety. The unpredictable nature of the condition often leaves families feeling a lack of control. As a family, learning to understand their child’s epilepsy can be a daunting and difficult journey. This handbook is one of a great many tools that Young Epilepsy has developed using research and consultation, with real families, to support in making informed decisions. The aim is to support families, one step at a time, as they navigate some of the places and situations in which they will find themselves. This guide has been created to help parents understand how epilepsy presents, how to keep their child safe and about available treatments. It also provides information on living with a child with epilepsy and managing their condition, at school and at home.

‘I think this is a very good resource. It is well-produced, attractive, and easy-to-read and contains a lot of detailed but relevant information. It provides an excellent summary of the key science behind the condition, its diagnosis and management. I think families with children with epilepsy would find this more informative than several more broad guides and resources out there.’

Childhood Stroke Handbook
Stroke Association and Evelina London Children’s Hospital – May 2016

The Childhood Stroke Handbook was developed as part of the Childhood Stroke Project – a collaboration between the Stroke Association and Evelina London Children’s Hospital – that started in 2013. The Stroke Association has well-established life after stroke services to support the needs of adult stroke survivors and their families and had an interest in gaining greater understanding of the needs of children and families affected by stroke in childhood. Evelina London Children’s Hospital has well-established inpatient and outpatient services for paediatric neurology for across London and south eastern England, and children affected by stroke will be admitted for acute care and receive longer term outpatient follow-up. The Childhood Stroke Project Manager is based at Evelina London Children’s Hospital, and the project has encompassed different areas of work: setting up a support service, delivering a research study, facilitating awareness raising and identifying areas for resource development. The Childhood Stroke Handbook was created to help children understand about stroke in childhood. It follows a child’s journey through medical assessments and tests, rehabilitation and therapy, talking about what has happened to them, and returning to home and school. Prior to the development of the handbook there was no resource available internationally that provided this content. It has been written and illustrated to be comprehensible to younger children (older than six years), and can also be understood by even younger children with the aid of an adult reading the text and using the associated pictures. The content is also appropriate for siblings, friends, classmates and the wider family. It can be used by professionals working with young people affected by stroke to help explain their roles (eg therapists or nurses) and also to explain and prepare for specific procedures (eg doctors preparing children for scans or transfusions). The content is designed to be flexible, so families can use different sections as and when they need to. The handbook covers topics identified as important by families and each section includes tips and hints provided by young people on how to manage in different situations (eg getting ready for tests, talking about what has happened to you, identifying goals and progress).

‘This is a good resource for young people and their families. It gives a good basic outline of what a family may face when a child has a stroke. The information is presented in a logical sequence that replicates the ’journey’ the child will make. The
sections ‘what can help’ are very useful and they should help to give the young person a sense that they have some control over what will happen in the future. The planned animations will enhance the resource.’

Clinical trials for pancreatic cancer
Pancreatic Cancer UK – May 2016

This information resource is for anyone affected by pancreatic cancer – including patients and families. The aim of the resource is to support patients and easily finding out about pancreatic cancer clinical trials by presenting lay-friendly information about UK trials in one place. We want more people to know about clinical trials, to be able to discuss this with their medical team, and to be empowered to make informed decisions about their treatment. We aim to do this by providing information about what clinical trials entail, why they are done, and what the benefits might be – including a series of films of nurses explaining clinical trials; a searchable Trial Finder database to enable users to easily search for suitable trials by keyword, cancer stage, or location; an online portfolio of lay-friendly information about individual trials to empower patients to make informed choices and a series of films of people who had taken part in a trial, to give people an idea of what it is actually like to take part in a trial. The Trial Finder is the first database of clinical trials specifically for people with pancreatic cancer in the UK. The UK has around 9,600 new cases of pancreatic cancer every year, and it is the 11th most common cancer, but the treatment options are limited. Surgery is the only treatment which could save lives, but only 8% of people with pancreatic cancer have it. This means that chemotherapy is the main treatment option, but the chemotherapy drugs are available for pancreatic cancer. Clinical trials are therefore an important potential treatment option for many people with pancreatic cancer but our research showed that online information about open pancreatic cancer trials could be difficult to find, and also difficult to understand for a lay audience. A survey carried out by Pancreatic Cancer UK revealed that only 29% of respondents were told about trials by their medical team, and of those who looked into trials themselves, only a third found information that was useful. One third couldn’t find much information, and 24% found information but it was difficult to understand. This resource aims to address these issues. The information is presented as a combination of easy to understand web information, films (to improve accessibility, understanding and engagement), a searchable database, and an interactive map so people can find trials near to them.’

I was very impressed by this website, which takes a potentially complex issue and presents it in a way that will be genuinely helpful to, and supportive of, patients and their families. I like the way it does not seek to influence decisions whether or not to take part; it just seeks to ensure that any decision will be truly informed. Having worked on clinical trials information myself, I know something of how people struggle to understand what’s involved and how to make the decision that is best for them. I think this goes a long way to address that. I like the clean look of the site and the ease of navigation.’

COPD: Living with chronic obstructive pulmonary disease
British Lung Foundation – November 2016

The audience is people affected by COPD (chronic obstructive pulmonary disease), their families and carers. Our Respiratory Health of the Nation research highlighted that an estimated 1.2 million people are living with diagnosed COPD (about 2% of the UK’s population). The aim of this booklet is to provide reliable information about COPD, so that people affected have the knowledge to self-monitor their condition and know where they can get support. It is written to give practical advice – answering questions such as what treatments work and giving tips and quotes from other people living with COPD. More than half of the booklet sets out what people can do to manage their condition. It talks about ways to manage breathlessness, exercising and maintaining of feelings. There’s also clear and graphic guidance about managing a flare-up. Chris and Ian also talk about their experience of living with COPD.

‘This seemed to me an exceptionally clear and helpful leaflet. I wish it had been available back when I was a GP. I have already sent for one for a friend and, after looking at the website, actually made a small donation as I well remember my Grandad who had COPD from the gas and smoking in the trenches in WW1. This is an excellent leaflet. I can’t even find a constructive criticism to make!’

Copying, now your chemotherapy is finishing
Lynda Jackson Macmillan Centre – May 2016

The purpose of this leaflet is to provide a step-by-step guide to patients about their future hospital appointments and caring for any symptoms that may continue after treatment or develop subsequent to completing their cytotoxic chemotherapy. The LJMC 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 two medical oncologists, the gynaecology specialist nurse, chemotherapy specialist nurse, research nurses and outpatient 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.

‘The layout of the leaflet has a clear structure and headings. Patient satisfaction surveys are undertaken to monitor and evaluate the effectiveness of information provided to patients during pre-treatment, treatment and follow-up phases, and feedback about this information leaflet is acquired as part of the process. The evaluation exercises are repeated regularly.’

Could you have Fibroids?
Guy’s & St Thomas’ NHS Foundation Trust – March 2016

Uterine fibroids are one of the most common gynaecological problems in the UK, and symptoms can be severe and damaging to a woman’s quality of life. Variation in access to information and late diagnosis can mean unnecessary suffering and limit treatment options. We worked with women across south east London to develop a patient information leaflet and video to raise awareness and empower women’s conversations with healthcare providers. 10,000 copies have been distributed to GPs and pharmacists and materials are available online. A new patient support group has been set up in response to the call for better peer-support.

‘It is very good: a beautiful leaflet. Well done for really taliking informed choice for these women.’

Cystic fibrosis is here for schools
Cystic Fibrosis Trust – June 2016

The resource is comprised of an A4 folder containing three factsheets and an IHP (Individual Healthcare Plan) and is designed to help teachers/school staff understand what CF (cystic fibrosis) is, how it can affect a child’s daily life at school and what their role is in managing this condition. The factsheets provide brief but essential information about the condition and also draw attention to the treatment burden associated with CF-which can, in itself, cause issues as school such as tiredness and self-consciousness. IHPs are mandatory in schools in England and yet it is thought that many schools do not have plans in place for children with medical conditions (Health Conditions in Schools Alliance). By developing a template specific to CF, the process of completing the IHP should be straightforward, particularly with the input from CF nurses and parents. Having an IHP in place ensures that the school understands what a child needs from the environment and staff to stay well and to get the most out of their school experience.

‘I think the personal plan, which can be filled in, offers an excellent practical aid as part of this resource.’

Dementia Explained
Alzheimer’s Research UK – November 2015

850,000 people in the UK have dementia and an estimated 2.3 million under 18s know someone with dementia. Dementia Explained is a website for children and teenagers who want to find out more about dementia, particularly children who have a relative or someone else in their lives with the condition. We wanted a resource that would help children to make sense of some of the changes that their relative/friend is going through and explain that these changes are the result of diseases that affect the brain. We asked children about the things that they would like to know about dementia and set out to answer their questions as clearly and accurately as possible about the condition. By producing a range of resources including stories, videos, games and information pages, and providing an area in which they can share their own experiences, the website is designed to be as engaging as possible for children of different ages. Alzheimer’s Research UK polling indicates that less than three in 10 parents would feel very confident explaining dementia to their children. Dementia Explained is also a resource for parents to use to help them explain to their children how dementia affects people.
3 I think this is an exceptional resource because it fulfills a much-needed function — to explain dementia to young people — and the way it does it is beautiful to look at, a joy to use, very well-designed and easy to navigate. A huge amount of thought has gone into the creation of the resource by understanding the needs of the target audience and involving them in the creation and development of the resource, as well as providing interactive functions which allow users to contribute to it on a continuing basis. I particularly applaud the thought that has gone into providing information for the three different age categories and providing different ways of accessing the information. As someone who has been in the position of trying to help young children understand dementia in their grandparent I would have loved to have had this resource to use with them. I think the added value of this is that it not only explains, but encourages young people to be active about interacting with people with dementia and encourages a much greater openness about this topic which can be very difficult and confusing to talk about. Not only is the end product fantastic but the process of creating and designing it has been brilliant too.

Depression and Low Mood — a guide for partners
Northumberland, Tyne and Wear NHS Foundation Trust and OnePlusOne — January 2017

This resource is aimed at mental health service users and the public. The series of booklets (23 titles) are used by many primary care and Increasing Access to Psychological Therapy services. The guides offer users the opportunity to find out more about the causes of mental health issues and provide tools to work through feelings and emotions.

‘A beautifully presented and exceptionally well-written leaflet, packed with supportive and useful information and surprisingly easy and pleasant to read. It is rather repetitive but I imagine that is because the same areas are covered under different headings, and maybe there is no harm in repetition. The availability and accessibility is good, including online which is enhanced by videos and offers an opportunity to provide feedback. Plans for evaluating the resource are in place and are good. The further resources offered are also comprehensive and excellent.’

Disease modifying therapies (DMTs) for MS
MS Society — August 2016

The audience is people with relapsing forms of multiple sclerosis, especially those who are not taking a DMT (disease modifying therapy). This redesigned, rebranded and updated edition of an earlier 2015 booklet has as its objectives: to help people with relapsing MS make an informed choice about early treatment with a disease modifying therapy and which DMTs might be right for them; to give reliable and easily understood evidence-based information about the benefits and side effects of available DMTs and of two DMTs presently going through their licensing and approval processes; to provide eligibility criteria for all available DMTs; and to signpost sources of more frequently updated information (eg, the MS Society website) including where they can find out about other drugs that may be available in the future.

‘This resource updates a previous resource but has incorporated feedback from users on the earlier resource. The topic is complicated but the information is presented in a clear manner with consistently used infographics. The resource gives guidance on the side effects and efficacy of the different drugs. It looks to the future: “We hope that the newest ones (daclizumab and ocrelizumab) will become available sometime in 2017 or 2018” and counsels that DMTs may soon be available for progressive MS.’

Eating well with neutropenia: A guide for people with blood cancer
Bloodwise — February 2017

Bloodwise has provided information on a ‘neutropenic diet’ over a long period. But when we came to review and update our information on this topic, it became clear that there was a split between professionals who take a ‘better safe than sorry’ approach to dietary restriction and those who view dietary restriction as unnecessary and a barrier to the maintenance of a healthy weight of immunocompromised individuals. So after consultation with our nurses advisory panel and patients, we decided to develop a resource with a balanced view that is based on evidenced risks of food and drink-borne microorganisms; acknowledges the uncertainty surrounding dietary restriction; supports patients to have an informed discussion with their healthcare team, and balances guidance on dietary restriction with the need to stimulate appetite and eat an enticing, varied diet.

The main responsibilities of the committee include monitoring policy and service trends in community care, advising on resolving problems at the interface of primary/secondary care and social care, identifying unmet needs of care, and promote new approaches to care.

Committee on Community Care

The CCC (Committee on Community Care) is a multi-branch of practice group which includes general practitioners, specialists in elderly medicine, psychiatry and paediatrics, those working in public health and community medicine, palliative care and doctors in training. The committee also co-opts members with particular expertise in aspects of community and social care.

Over the last 12 months the committee has in particular focussed on the following key areas: implementation of the Five Year Forward View, healthy ageing, children and adolescent mental health services, personal health budgets, and social care.

CCC chair, Dr Gary Wannan, is a consultant child and adolescent psychiatrist in central London. He was previously a GP in the Scottish Highlands and has worked in paediatrics. His vision is for doctors to be at the forefront of making community care patient-centered, integrated and of high quality.
treatment. People of all ages get blood cancer. A high proportion of people with blood cancer are over the age of 50 (87%) and the average age of a patient at diagnosis with a blood cancer is 70 years old – but a number of younger people have blood cancer too. Blood cancer does not discriminate by social class although some studies have shown that those living in more deprived areas tend to have poorer outcomes. So when planning and delivering this project we therefore took into account: relative digital literacy of older populations and differentials in functional and health literacy between most affluent and deprived groups. We also aimed to ensure that the resource was available online and in print, easily understandable and felt relevant to people of a variety of ages and backgrounds – explaining tricky concepts as simply and concisely as possible.

The emotional effects of arthritis can have just as much of an impact as the physical symptoms, which is why Arthritis Care has produced a resource on how to create emotional wellbeing. The aim of the booklet is to show those with any form of arthritis that they can take care of their emotional wellbeing through practical steps, many of which can be classed as ‘emotional self-care’. It also aims to validate the spectrum of emotions those with arthritis experience – from diagnosis, through to first flare-up, and those who have lived with their condition for many years. The intended audience is those in all stages of a musculoskeletal condition, although the advice is applicable to anyone who is living with a condition long term.

Feelings Matter: Emotional Wellbeing and Arthritis
Arthritis Care – February 2017

The emotional effects of arthritis can have just as much of an impact as the physical symptoms, which is why Arthritis Care has produced a resource on how to create emotional wellbeing. The aim of the booklet is to show those with any form of arthritis that they can take care of their emotional wellbeing through practical steps, many of which can be classed as ‘emotional self-care’. It also aims to validate the spectrum of emotions those with arthritis experience – from diagnosis, through to first flare-up, and those who have lived with their condition for many years. The intended audience is those in all stages of a musculoskeletal condition, although the advice is applicable to anyone who is living with a condition long term.

First steps to living with COPD
British Lung Foundation – November 2015

This booklet is targeted at people who have just been diagnosed with COPD (chronic obstructive pulmonary disease). It’s intended to be a quick and simple overview of COPD and to introduce people to the idea of self-managing their condition.

‘I like this booklet, and would use it in my practice. Often people who are less well-informed about their health are overlooked (among the many who find information easily online) and this booklet is a good starting point for newly diagnosed COPD. It presents just enough information in clear language: this is particularly well-done, and though some may find it too simplistic, the majority of patients would find it appropriate. There is always need for printed information; it is often easier to read than online, particularly for older people and also can be passed to others – eg family carers.’

For family and friends: when someone close to you has MS
MS Society – August 2016

The audience is family and friends (including carers) of people with MS (multiple sclerosis), especially the recently diagnosed. The focus is on a younger audience (20s, 30s) and before MS has created severe disability. Its objectives are: to reassure and support friends and family members of those with MS by helping them with their emotional reactions to the diagnosis; to decrease their family members’ and friends’ sense of isolation and anxiety; to give families and friends of people with MS a better insight into common post-diagnosis reactions and behaviour and give suggestions of how to cope with these; to inform about the risk of MS occurring in other family members and how to modify MS risk when a close relative has the condition; to offer tips on how to talk about MS with people who have it and overcome communication barriers; to give a summary of current treatment options and potential future developments for people with MS; and to signpost support available for those affected by MS, including for carers.

‘This resource covers an important topic: role of friends and carers – it contains much useful information but it is set out in an attractive format with good use of space and colour. The introductory word from ...’ and the frequent personal comments from patients gives it an immediacy. Frequent tips on how a reader can help someone with MS including a useful ‘what to say’ section are included.’

Genetic testing and hereditary ovarian cancer – a guide for women with ovarian cancer and their families
Target Ovarian Cancer – August 2016

This guide aims to: inform and support women with ovarian cancer through the decision-making process of receiving genetic testing; to provide sources of support/signposting around the emotional and psychological impact a positive or negative result may have on them; to provide information to aid navigation. I liked that the photos aren’t stock images but are women with experience of ovarian cancer. They give a warm and personal feel. It has a lot to commend it, and I was a woman making the decision to be tested or suggesting a family member should be, it would be an invaluable resource. It’s clearly been influenced by women who have been through testing and the feedback from users has been really positive. Well done!”

Heart failure (Health Information Series)
British Heart Foundation – March 2016

This booklet is for people with heart failure and their family and friends. It explains what heart failure is, what causes it, the symptoms, the possible treatments including medicines, and what can be done to help keep the condition under control. The HIS (Heart Information Series) is a well-received, long-standing set of printed resources produced by the BHF (British Heart Foundation) which are also available as printable pdf downloads. With around 2 million booklets ordered each year, this series is considered the backbone of our heart disease information. The HIS series is aimed at heart patients and covers mainly medical topics such as tests, treatments and conditions. Each booklet provides comprehensive and accessible heart health information and is designed for
The whole series has been rebranded and updated. The organisation ran a series of focus groups with patients and healthcare professionals (seven practice nurses and seven hospital cardiac nurses) to get the booklets ‘right for the target audience and fit for purpose’. The BHF also conducted an external evaluation to see how the booklets were being used in a variety of primary and secondary healthcare settings and seek the perspectives and experiences of patients and healthcare professionals with very wide-ranging expertise. The content of this particular booklet in the series was reviewed by two healthcare professionals, a consultant cardiologist and a heart failure specialist nurse from different institutions and by the BHF’s in-house clinical team, which includes dieticians and experts in cardiology and genetics.

The fact that this booklet is part of a larger series means it seems to have benefited from a much larger budget for HCP involvement in the design/content of the whole series than would be possible for a single publication creating a one-off booklet. BHF provides general information about dissemination for all of their HIS resources. It’s hard to think of anything that BHF isn’t doing to ensure their resources reach people. This booklet is very good and provides comprehensive information for anyone with heart failure. The processes used to rebrand and update the series of booklets that this booklet is in are exceptional. I think, as are the processes used for dissemination. It would be very hard to think of ways to improve those processes. I hope the booklet helps a lot of people.

Heart surgery (Health Information Series)
British Heart Foundation – March 2016

This booklet is for adults who are going to have, or have just had, heart surgery. It explains what happens before your operation and during the time you spend in hospital and what to expect once you return home. It also discusses how a cardiac rehabilitation programme can help you after your operation, and what you can do to reduce your risk of further heart problems. The HIS (Heart Information Series) is a well-received, longstanding collection of printed resources produced by the BHF which are also available as printable pdf downloads. With around 2 million booklets ordered each year, this series is considered the backbone of our heart disease information. The HIS series is aimed at heart patients and covers mainly medical topics such as tests, treatments and conditions. Each booklet provides comprehensive and accessible heart health information and is designed for patients to help them understand and cope with their condition. While the primary audience for these booklets is members of the public, healthcare professionals are recognised as the most important intermediary for people accessing them. The HIS series is undergoing a visual and tonal rebrand to make them more accessible, relatable, patient-centred and aligned to BHF-funded advances in medical research. Each booklet is designed to be visually engaging, informative, and accessible to users. The authors aim to: encourage patients to become knowledgeable and understand how their condition, its symptoms, causes, diagnosis and treatments can affect them or their family and friends; to take a leading role in providing relevant and authoritative information on a range of heart health topics; to provide information in a clear and digestible format allowing readers to understand the impact of heart disease and how the BHF can help and support them; to reach new and existing audiences directly and through intermediaries (leg health professionals, community health promoters, corporate partnerships and fundraising).

At the time of writing, 14 booklets have undergone this patient-centred rebranding process, with the remaining booklets in the series to be completed by June 2017.

The entry form gives extensive facts about the resource, including the panel of experts, users and process by which the resource was produced. It gives a very clear explanation of the need to produce the resource, together with information on the number of copies distributed and number of copies downloaded from the website. Of all the resources I reviewed, this was by far the most comprehensively completed entry form. The resource itself is equally impressive. The tone is right, giving the necessary information without being patronising or too technical and it is very well laid-out and easy to read and understand. I was quite surprised, given the size of the resource, how much information is included and just how well-written and laid-out it is. This is a very well thought out and presented resource. A lot of time seems to have gone into the production of this resource, and it was actually a pleasure to review it. The balance of facts and information, alongside real patient stories and graphics, makes it very easy to read the whole resource from start to finish. The signposting for further information is very clear, and there is a good mix of online and other sources of information which takes the broad age range of potential users into consideration.

Hearing Aids: Information for families
National Deaf Children’s Society – June 2016

With the right support there’s no reason for a deaf child to develop language at a slower rate than a hearing child with similar abilities, and hearing aids can help with this. The purpose of this resource is, therefore, to provide parents of deaf children with balanced, accurate information on hearing aids including the different types of hearing aids, how to look after them and how their child can get the best out of them. It aims to give parents the information to empower them to feel confident in making decisions about managing their child’s deafness, in relation to hearing technology. It also meets the National Deaf Children’s Society’s objectives, to develop deaf children and young people’s language and communication skills: to promote the benefits of existing and emerging technologies for the development of language and communication, and deaf children and young people: to enable parents to make informed decisions about hearing technology, and to help parents to understand the issue.

I think this resource has a lot to recommend it, providing a lot of information about using a very complex piece of equipment and I applaud the ambition to empower parents and to try to make sure that deaf children are able to reach their potential through the use of hearing aids. I am sure this will be of use to parents when faced with the prospect of their child needing to use hearing aids.

How is Primary Breast Cancer Treated?
Breast Cancer Care – November 2016

This is a publication for people who have recently been diagnosed with breast cancer. Although suitable for most readers, it has been specifically produced to try to address the health literacy gap whereby up to 61% of the UK population do not have the literacy skills to make effective use of standard health and patient information. When someone is diagnosed with breast cancer, they need to take in an awful lot of complex information. There are many different types of breast cancer and lots of treatment choices to think about, many with potentially serious and far-reaching side effects. It can be overwhelming to even the most literate of readers, especially when experiencing the shock and stress of a life-changing diagnosis. This resource aims to make it easier for people to start understanding some of the details that will help them to make informed decisions on treatment options. It is designed to be either a stand-alone item or to complement our longer more detailed web and hard copy patient information on the same topic, depending on the reader.

I really like the emphasis placed on keeping the information short and simple and aiming at people with low literacy levels while still conveying quite complex information. I also think that the layout of spiral bound and landscape would make it easier for a patient to sit with a health professional and discuss this material together. Considerable thought appears to have gone into planning a deceptively simple resource that looks non-threatening (clear, plenty of space etc) but also that doesn’t insult the intelligence of those needing it. I also like that it feels like a quality resource and has been printed on nice materials. I really found it very interesting and thought-provoking in terms of how information is disseminated to people with low literacy levels. I liked your booklet for a number of reasons – the commitment to presenting complex information clearly and with the aim of targeting all primary breast cancer patients, the simple drawings are wonderful. Your efforts from planning through to dissemination are well-considered and I wish you the best of luck.'
The availability of relevant and reliable health information is a prerequisite for a fully-functioning health system. Without it, health professionals cannot deliver effective, safe and timely care. Patients and other service users also require appropriately-targeted health information in order to make decisions about their own care and the care of those for whom they are responsible. As health information needs change over time, the medical research and publishing communities must keep pace and continue to produce resources which are fit for purpose.

In LMICs (low- and middle-income countries) lack of access to information remains a major barrier to evidence-based health care. The consequences are devastating. Tens of thousands of women, children and men die every day, often because the mother, family caregiver or health worker does not have access to the information and knowledge they need, when they need it, to make appropriate decisions and save lives. Most of these deaths could have been prevented by simple interventions, often available locally.

The BMA International Department is working with external stakeholders both to address the root causes of the crisis and to provide direct assistance to organisations in LMICs where access to reliable and relevant health information is limited or non-existent.

The BMA International and Immigration Department: tackling ‘information poverty’

HIFA (Healthcare Information for All) Since 2008, we have provided strategic and financial support to HIFA, a global multi-disciplinary network of over 14,000 individuals from 172 countries, working in collaboration with the World Health Organization and more than 260 health and development organisations worldwide towards a shared vision. 'A world where every person and every health worker will have access to the healthcare information they need to protect their own health and the health of those for whom they are responsible.

HIFA harnesses the unique experiential knowledge of members to build a global picture of health information needs and develop strategies for meeting them. The BMA’s 2015 Annual Representative Meeting gave unanimous support to HIFA and urges the UK government to prioritise support for initiatives that improve the availability and use of health information.

More information and details of how to apply: bma.org.uk/informationfund

Contact: Arielle Nylander, senior policy advisor, International and Immigration Department arielle.nylander@bma.org.uk

BMA Information Fund

The BMA Information Fund has provided books and other learning resources to health-focused organisations in LMICs and other areas of need. Working with the charity Teaching Aids at Low Cost (TALCI), we invite and consider applications for assistance from the Fund on an annual basis. In 2016, Sri Lanka, Pakistan, Sierra Leone, and Iraq, were among the countries which received donations from the Fund.

More information: hifa2015.org

Contact: Arthi Hartwell, head of international and immigration ahartwell@bma.org.uk

How to make a thickened drink

Sheffield Teaching Hospitals NHS Foundation Trust – January 2016

This project took place in a large NHS teaching hospital. The aim was to provide accessible information leaflets for people with aphasia who have swallowing difficulties (dysphagia). Aphasia is caused by damage to parts of the brain responsible for understanding and using language. We were aware that our existing patient information was not easily accessible to patients with aphasia and that this group of individuals needed information in a more understandable format to explain how to thicken drinks to the consistency recommended by a speech and language therapist. The team wanted to create information in a format, which would support people with aphasia to be involved in decisions about their hospital treatment and their care after discharge from hospital. The resource is designed to be used as part of a supported conversation between a person with aphasia and a speech and language therapist. We developed three leaflets for each of the different drinking consistencies, which a speech and language therapist may recommend after assessing a person.

These are based on the national descriptors for thickened fluids: Stage 1, Stage 2 and Stage 3.

‘It is absolutely clear that a lot of time and effort has gone into the production. There is clear evidence that the resource has been pulled together from a wide team of experts, and has included patients in the feedback process before going to print. It uses very clear, simple language and has the added benefit of pictures to explain the information. It is a really well thought out and well-presented resource.’

I quit – Stop smoking when you’re pregnant

NHS Health Scotland – March 2016

This resource aims to create a powerful and visually-appealing booklet aimed directly at a core group of younger women from lower social economic backgrounds who smoke during pregnancy. The aim was to highlight the harm of smoking to mother and baby, explain the benefits of giving up and signpost the free advice and services available. This group is typically hard to reach, has a low quit success rate and poor engagement with NHS pregnancy smoking cessation services. An advisory group was brought together consisting of five NHS Local Boards with either stop smoking midwives or smoking cessation advisors who worked within the maternity stop smoking services. The first meeting of this group focused on discussing their local offer; ie what resources they used, feedback on the former Health Scotland resource Fresh Start; their thoughts and ideas for the improved resource. The group communicated virtually and commented on the resource brief as well as pretesting ‘mocked up’ copies of the revised resource with their clients, so that users could comment on the design and content of the new resource. Within the pre-testing of the resource, a questionnaire was also used to gather feedback from the health professionals including midwives and smoking cessation advisors working in maternity stop-smoking services. After pre-testing and near to the final product, Professor Linda Bauld, a tobacco control expert commented on the resource. Internally, our public health advisor specialising in tobacco control and our organisational lead specialising on tobacco control also commented on content ensuring that the resource was evidence-informed.

‘This is an important resource, which is well-planned and informative for a target group, often missed by conventional approaches. The information is clear and encouraging. This is a well-researched and well-produced leaflet, and I hope will be very effective in its aims.’

Information about dying from prostate cancer

Prostate Cancer UK – May 2016

Every year 10,000 men die from prostate cancer in the UK. We developed digital information about dying from prostate cancer for men with advanced prostate cancer and their families. This included information about what to expect physically and emotionally, thinking and planning ahead, and supporting someone in their last months and weeks. The aim is that information users would feel that they had enough information about what to expect, what care is available, and where to get more information and support. We ensured that the resource meets this objective by researching user information needs and preferences, scope other information resources, involving users and health professionals at every stage, and evaluating the information thoroughly.

‘This is an excellent resource about a very challenging subject. The content is well-written and accessible, the website design is done well and renders well on a mobile. Links and connections to additional information are included.’
It Starts With Me
Terrence Higgins Trust – July 2016

It Starts With Me is a seminal ‘supercampaign’ aiming to cut new HIV infections through promoting: condom use; increased testing; and starting treatment. The campaign provides HIV prevention and testing messages – focusing on testing, treatment and undetectables. ‘It Starts With Me’ is a call to action, a ‘network of blasters’ which change each quarter. It features members of the target groups as faces of the campaign to mobilise others to take action. The more people who test for HIV, the more people will be diagnosed who didn’t know about their status. This means they can get onto treatment to: keep well and live a normal lifespan and also become uninfected – people who are on treatment with an undetectable viral load cannot pass on HIV. Recent research (the START study) has found that people who start treatment before their CD4 count drops below 350 have a significantly lower risk of illness and death. To reflect this the British HIV Association guidelines have been updated to recommend everyone with HIV starts treatment regardless of their CD4 count. In addition the PARTNER study has found that people who are on treatment with an undetectable viral load cannot pass on HIV. These two pivotal studies have changed the landscape of HIV prevention with treatment becoming a leading element of protected sex alongside condom use. We want people to know the facts about how treatment helps stop the spread of HIV and also the different ways to test – including home testing and postal testing. The campaign features a range of resources – from advertising, booklets, posters, wallet cards and an interactive website to National HIV Testing Week. This takes place each November and raises awareness of the importance of HIV testing and increases opportunities to test in different settings. The campaign has also been broadened out to include African Caribbeans and people from Eastern European countries as we recognise that these communities are also affected disproportionately by HIV. Our resources are available in Swahili, Polish, French, Portuguese and Somali so that we can reach even more people. The campaign first began in 2011 and due to its success has been re-commissioned by Public Health England. Terrence Higgins Trust run the campaign but work in collaboration with other HIV organisations.

‘I am very impressed by the ambition and clear focus of this campaign. The consultation strategy with other agencies is exemplary and the care which has been given to the production of the resources and their distribution over a wide range of media is very impressive. The pictures make good use of patients who represent the target communities. It makes the campaign personal and highlights the need to take individual responsibility. The planned dissemination is fantastic and the applicant gives full details of many different distribution mediums using a wide range of media: posters, popup mini booklets, website, outdoor advertising, t-shirts etc. The producers have worked with many other agencies in HIV Prevention England which allowed them to use their own mailing lists. Resources were available free of charge (except for the t-shirt) and are easily available via a dedicated portal. Partners and non-partnered patients/customers can promote their local activities: eg a clinic can set up fields and promote a local testing clinic. Posters have been made available with a range of models in languages known to reflect key target populations with both prevalence of HIV: Portuguese, French, Swahili, Somali and Polish. The producers have also used a wide range of social media: Facebook, Google ads, YouTube, UK African and gay websites such as Gaydar and direct messaging to members of gay dating sites and apps such Grindr. The message is simple and consistently presented: HIV prevention ‘starts with me’. The graphics, images and personal video stories all support the importance of taking control of HIV prevention.’

Keeping safe: Managing suicidal thoughts
Guy’s & St Thomas’ NHS Foundation Trust – March 2015

In the light of the alarming number of suicides that occur within the UK every year and the increased risk among people with depression and chronic physical health conditions, a team of psychologists within Guy’s and St Thomas’ NHS Foundation Trust, created an information leaflet to provide information and guidance on how to promote the need of help. The purpose was to provide essential information, in the form of a self-help leaflet, for people attending Guy’s and St Thomas’ hospitals, who may become distressed about their health conditions and are having thoughts about ending their lives. It aims to give people pointers about who to talk to and guidance for getting urgent help. The leaflet was also intended to be a useful resource for the trust’s health professionals less experienced in mental health services, to increase their confidence and knowledge of what information to pass on to patients or vulnerable people when concerns were raised.

‘This is a deliberately simple and short resource focused on the prevention of suicide among patients with a long-term physical health problem. The amount of information given is concise. That is intentional, so that key messages are conveyed without extraneous material.’

Lack of insight after brain injury
Headway – the brain injury association – August 2016

This fact sheet has been written for family members and friends of a brain injury survivor who lacks insight into how their brain injury has affected them. For instance, a person who has anger issues after their brain injury may fail to recognise that they have this problem, and consequently refuse to accept professional support. The fact sheet explains the nature of this issue to family and friends who otherwise commonly struggle with understanding why their relative/friend is not acknowledging the issue, and often misinterpret the behaviour as ‘denial’. The fact sheet therefore explains what lack of insight is, as well as offering a range of useful tips on how to support the brain injury survivor with this issue and how best to approach a situation in which the brain injury survivor lacks insight. The fact sheet also explains the legal frameworks that are in place to protect people who are at risk due to their lack of insight after brain injury, for instance if someone does not have the capacity to understand why a particular financial decision will put them at risk and does not realise that they are unable to make such decisions because of their brain injury. This section of the fact sheet avoids using legal jargon and illustrates the factsheet with a case study, therefore making the information accessible to readers.

‘This is a well-written resource, focused on advice for relatives, friends and carers of people with a lack of insight after brain injury. The advice is concise and helpful, with cross-references to other sources of more detailed guidance. There is a clear definition of lack of insight, and useful advice about strategies for supporting people with a lack of insight and the legal frameworks that can protect such people.’

Living with lung cancer
Royal Castle Lung Cancer Foundation – August 2016

This booklet is part of our Lung Cancer – Answering Your Questions pack. It is produced with input from people affected by lung cancer and lung cancer experts. It has undergone a rigorous assessment to produce clear, accurate and up-to-date information. The key target audience is anyone affected by lung cancer. This could be the general public concerned about the risks of developing lung cancer, those who have had a diagnosis of lung cancer and those who care for someone affected by lung cancer. The booklet is designed to support and empower anyone affected by lung cancer to make informed decisions about the practical and emotional impact of coping with a lung cancer diagnosis. To help inform patients, this enables them to ask questions and discuss their concerns.

‘This comprehensive resource is very well put together and includes some thoughtful extra sections, such as information on benefits and lists of tests.’

Living with pulmonary fibrosis: What you need to know
British Lung Foundation – September 2016

The audience is people living with an interstitial lung disease, including idiopathic PF (pulmonary fibrosis), their families and carers. The aim of this booklet – and its accompanying online version – is to provide reliable information about IIPs (interstitial lung diseases). There are more than 200 different types and they are a complex group of disorders. They include idiopathic PF, hypersensitivity pneumonitis, PF associated with connective tissue disease, pneumoconiosis and drug induced PF. The resource is designed to help people affected to get a precise diagnosis, to understand the implications of living with and having a lung disease. For the first time there’s a clear lay explanation of the different terminology (under what is PF) which is available nowhere else. Patients are frequently confused about the terminology surrounding their diagnosis. We’ve also included a clear classification of common interstitial lung diseases to help with this. Also for the first time there’s a detailed information on ways to help someone with PF breathe.

‘This is a very nicely presented resource with lots of information for the user, carer or family members along with a number of diagrams and information on where to get further help and support. Because a number of different types of illness are covered within the one resource, there is a lot of information to digest but it is all very well written and is easy-to-read and understand. It is a really well thought-out and well-produced resource which is very nicely laid out, with a good balance of text, diagrams and explanations of some quite complex medical terms. The patient involvement and feedback used during the production process is clearly evidenced. There is a lot of signposting for users and their carers to be able to obtain further information and support.’
The videos are excellent and very clear language is conveyed and I think a great deal of thought has been put into it. Written in straightforward language that is easy to understand; only include UK lymphoma trials and studies and offer the flexibility to search through the trials by lymphoma sub-type or the status of the lymphoma, or by age group or by location, whichever way is preferred by the end-user; provide accurate, authoritative and accessible information. All of our trials records are researched for accuracy and written in plain English. We update the site monthly with updates to the trial summaries, including new trials and updating details in existing trials. We also add several news stories each month.

We aid decision-making by including a step-by-step guide to getting involved in a clinical trial. The site includes information about why trials are done, what is involved in participation, what you can expect, things to think about etc.

I think this is an unusual resource and it is really well done – a great deal of work has gone into the planning and execution of the website, the sections are clear and easily navigable, a lot of information is conveyed and I think a great deal of thought has been given to evaluation and feedback as well. I found it a really interesting resource and was impressed by the hard work behind it. I really like your levels of testing, testing and testing again as well as your record keeping when it came to keeping consistency. Good luck!

Making sense of mindfulness

Mind – April 2016

The practice of mindfulness has grown rapidly in recent years. In recognition of the growing movement, we want to make sure people had access to clear and accurate information about what this treatment is and how it can be useful. Existing information tended to be scientific and based on academic evidence rather than the practical ways in which mindfulness could help people. This resource aimed to put the user first by including blogs and stories to engage people and provide practical advice. It aims to explain mindfulness and the different forms it can take and how to practice mindfulness as well as sign posting useful contacts and support available. It is aimed at people with mild to moderate mental health problems, or people in recovery who may benefit from practicing mindfulness. It may also help family and friends.

‘The authors seem to have gone out of their way to give both sides for mindfulness training. Quality of life issues are well-covered and thoughtful. It includes a very good video which gives the user perspective.’

Managing family life and cancer

Children’s Cancer & Leukaemia Group (CCLG) – December 2016

Hearing that your child has cancer is one of the hardest and loneliest things a parent can face. More than 30 children are diagnosed each week in the UK and Ireland and the aim of this practical guide is to give help and support during this difficult and overwhelming time. Many families feel that everything in their life is changing and they need to embrace a whole new cancer world as well as coping with family life. Normal everyday life can be affected with changes to daily routines with hospital visits, stress on relationships, childcare problems, work and financial problems. This is a practical information resource written and reviewed by parents to help and support other families faced with a childhood cancer diagnosis. Clinically reviewed by medical experts, this booklet covers all aspects of family life that are affected such as dealing with diagnosis, telling family and friends, coping with stress, asking for help and advice and tips on how life can be made easier for the family while the child is on treatment. Interspersed within the main text are shared tips and advice gained from parents portrayed in a modern messaging style design for visual impact. Each section is also colour-coded for easy access to the relevant sections. We signpost throughout the booklet to other sources of information which parents might find useful, particularly for the sections on coping with stress, and we also include a map listing all the local charities supporting children with cancer throughout the UK and Ireland. By including tips and advice from parents, this booklet aims to not only help parents manage family life but also to positively reinforce the message that families can still enjoy family life during this challenging time.

‘This is a thoughtful and thorough resource with a clear parent-to-parent vibe. A wealth of real experience and practical advice shines through.’

The National Rheumatoid Arthritis Society – October 2016

This booklet is produced to educate and raise awareness about JIA (juvenile idiopathic arthritis) with teachers, school staff (any education setting) and inform parents and carers how best to support their children and young people while at school. The booklet follows an easy-to-read format and each page clearly indicates whether that page is written for the family while the child is on treatment.

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‘This is a thoughtful and thorough resource with a clear parent-to-parent vibe. A wealth of real experience and practical advice shines through.’

Mermaids Website

Mermaids – February 2015

The website has information, links and leaflets and documentation aimed at young people, parents and professionals supporting transgender or gender creative children and young people.

The aim of the resource is to empower and enable parents and young people to achieve the best outcome in a family-friendly supportive environment and where prejudice and discrimination is rife. The resources for professionals are to help them to learn more about the field so they can support and enable children and young people in a more effective and empathic manner.
Miscarriage – support for young people

The Miscarriage Association – June 2015

It is estimated that one in four pregnancies end in miscarriage. A further 2% are ectopic or molar pregnancies, in which the baby cannot survive. We tend to use the term ‘miscarriage’ to describe all these kinds of pregnancy loss. Our research showed that our information did not provide enough support for specific issues faced by young people in particular. They were often very isolated, unable to speak to family and without strong relationship support. The pregnancy may have been unplanned and people around them often viewed the loss as ‘lucky’. The purpose of the resource is to give relevant and accessible information on pregnancy loss for teenagers. The intended audience is young people – although some elements of the resources are relevant for our wider audience. The information was developed for 16-21 year olds but we hope that those under 16 will find them helpful too. Young people accessing the resource should feel more informed, less isolated and able to seek further help. After extensive consultation with young people we published a suite of resources for young people, accessed from a youth hub: abracketed information on miscarriage after unplanned pregnancy; a series of short films and a booklet to tell us any concerns they had around money and mental health. The response was rapid and extensive, and highlighted the areas which we needed to cover. It aims to explain the relationship between money worries and mental health and to provide advice and suggestions on how to address potential issues. It is aimed at anyone living with a mental health problem who is concernto involve parents from the start who had already been through the journey to help develop the information resource. We interviewed parents of five children with a brain or spinal tumour about their experiences and they told us what life was like for them and what they learned along the way. Using these valuable personal insights from other parents, we were able to identify key themes and structure the booklet so that it met the information needs of parents at every step of their child’s healthcare journey. Their tips, feelings and family photos are shared throughout the booklet to help readers feel less lost and alone at this difficult time. The booklet was designed in warm soft colours which feels gentle but uplifting at the same time reflecting the editorial tone of voice used within the text. We signpost throughout the booklet to other sources of information which parents might find useful, particularly for the sections on talking to your child and going back to school.

Move more: your guide to becoming more active

Macmillan Cancer Support – 2016

The Move more guide aims to encourage and support people who’ve had a cancer diagnosis in becoming more active. It also encourages family and friends involvement. The guide will involve parents from the start who had already been through the journey to help develop the information resource. We interviewed parents of five children with a brain or spinal tumour about their experiences and they told us what life was like for them and what they learned along the way. Using these valuable personal insights from other parents, we were able to identify key themes and structure the booklet so that it met the information needs of parents at every step of their child’s healthcare journey. Their tips, feelings and family photos are shared throughout the booklet to help readers feel less lost and alone at this difficult time. The booklet was designed in warm soft colours which feels gentle but uplifting at the same time reflecting the editorial tone of voice used within the text. We signpost throughout the booklet to other sources of information which parents might find useful, particularly for the sections on talking to your child and going back to school.

My child has a brain or spinal tumour: A guide for parents and carers

Children’s Cancer & Leukaemia Group (CCLG) – January 2017

Hearing that your child has a brain or spinal tumour is one of the hardest and loneliest things a parent can face. Between 400 and 500 children are diagnosed each year in the UK and the aim of this parent’s guide is to give a guiding hand and accompany future parents through this journey. Childhood cancer and treatment can have many different short and long-term effects such as hair loss and fatigue. But, children with a brain tumour can be left with long-term issues such as difficulties with learning, emotions and behaviours that require support such as rehabilitation and therapy. My child has a brain or spinal tumour is a practical information resource to help and support parents and families faced with a childhood brain or spinal tumour diagnosis. Clinically reviewed and updated by specialist experts across the UK, this booklet gives a comprehensive overview of the conditions, diagnosis, treatment and rehabilitation of brain tumours, as well as how to look after the child, parents and the rest of the family. We wanted to address all of these important and complex issues in a sensitive, honest but positive and informative way. Our key content strategy was to involve parents from the start who had already been through the journey to help develop the information resource. We interviewed parents of five children with a brain or spinal tumour about their experiences and they told us what life was like for them and what they learned along the way. Using these valuable personal insights from other parents, we were able to identify key themes and structure the booklet so that it met the information needs of parents at every step of their child’s healthcare journey. Their tips, feelings and family photos are shared throughout the booklet to help readers feel less lost and alone at this difficult time. The booklet was designed in warm soft colours which feels gentle but uplifting at the same time reflecting the editorial tone of voice used within the text. We signpost throughout the booklet to other sources of information which parents might find useful, particularly for the sections on talking to your child and going back to school.

myTube – a patient information website to inform the decision to have a gastrostomy tube placed for people living with Motor Neurone Disease

Sheffield Teaching Hospitals NHS Foundation Trust – December 2016

The myTube project had two key objectives. First, to offer a web-based education resource on gastrostomy tube feeding for people living with MND (motor neurone disease). Secondly, we wanted to further explore and develop our model of user-centred design and user-led research implementation. This involves taking current research and asking patients and carers to translate this back into user-friendly educational materials. The co-design process led to an educational resource rich in user-friendly information, offered in bite-sized sections, within an easy to navigate website structure. Videos are the chief mode of information delivery, enabling users to hear from other people living with MND using gastrostomy feeding tubes and view how they have adapted home enteral feeding into their day-to-day lives. The myTube website offers a new approach to patient education and decision support, melding best clinical practice and key research findings with the experiences of patients and carers, expressed through a range of engaging short documentary style films. Making the decision to have a gastrostomy feeding tube placed is a complex and emotive choice for patients to make. Recently the large scale, multi-centre research project, Prodas, specifically addressed the timing of gastrostomy feeding tube placement. The project team wished to build on the learnings of developing myNIV, a web-based information resource providing information to patients and carers about non-invasive ventilation (NIV) (www.niv.mynd.org.uk). The strong ethos of user involvement and user-centred design was re-engaged again. They worked with patients, carers and healthcare professionals to develop a website to inform the decision to have a gastrostomy feeding tube placed. The current evidence base on gastrostomy use in MND was used as the
**About BMA House**

BMA House is a grade II listed building in central London’s fashionable and historic Bloomsbury. Home to the prestigious British Medical Association, BMA House was designed in 1911 by the famed architect Sir Edwin Lutyens and has been the Headquarters for the BMA since 1925.

Highly accessible, the venue has a superb location just a short walk from the Eurostar (at nearby St Pancras), as well as Russell Square, Euston and King’s Cross stations. Ideal when you have delegates coming from across the UK.

Offering 29 unique event spaces, including two private outdoor areas, BMA House has the versatility to act as the setting for a wide range of events, including conferences, dinners, private parties, receptions and weddings.

**Conferences and meetings**  
BMA House is a favourite for conferencing, boasting an impressive range of larger rooms suitable for lectures, presentations and talks.

Conference spaces include the magnificent Great Hall (maximum capacity 297 conference-style) and the Council Chamber (fixed capacity for 97) which come equipped with features such as an electronic voting system and individual laptop and microphone connections for delegates. There are also 11 different purpose-built meeting rooms, the largest of which can accommodate up to 65 people in board room style.

Event spaces are fitted with state of the art audio visual technology as well as free wifi for all standard requirements. A team of friendly and very knowledgeable in-house technicians are also on hand to offer guidance and support for any event.

**Corporate and private events**  
Adorned with high ceilings and magnificent decorative features, BMA House provides an opulent setting for both corporate and private events. BMA House boasts five different event spaces, as well as outdoor entertainment facilities and a creative in house catering team. The venue can tailor for any event; from private dinners and cocktail parties, summer soirées and barbecues, to Christmas parties and stylish evening receptions. With capacities ranging from 20 to 320, this historical central London venue is ideal for both intimate gatherings and larger scale corporate affairs.

**Summer and outdoor parties**  
Ideal for summer parties and outdoor events, BMA House offers two beautiful and peaceful outdoor spaces, namely the Courtyard and Garden; a remarkable asset given its central London location. Built on the foundations of the house where Charles Dickens wrote classics such as Bleak House and Great Expectations, the Garden is a picturesque secret spot located to the side of BMA House. With a capacity of 90, it is suited for reception drinks, barbecues and cocktail parties. Surrounded on three sides by the majestic walls of BMA House, and on one side by an ornate iron gate, the Courtyard is a glamorous location for a reception or standing buffet. Perfect for larger scale outdoor events, given it has a capacity of 320.

A dedicated planning team  
When you organise an event at BMA House, you will have the assistance of an in-house events team, which encompasses catering, audio visual support and the services of a dedicated event planner who will work with you from concept to fruition of your event.

Menus are created by our in house caterers who have a focus on British produce and healthy eating. They have created seasonal menus which are notable for their innovative design, stunning presentation and high quality ingredients. BMA House has been accredited with a silver rating under the Green Tourism Scheme due to its dedication to placing sustainable and ethical practices at its forefront. Ingredients are sourced locally and sustainably wherever possible and supportive of Fairtrade tea and coffee growers. In addition, all food waste is composted and all glass bottles recycled.

**Weddings**  
The historic BMA House is an idyllic location for weddings. The venue holds a wedding licence for four of its feature rooms: Great Hall, Snow room, Paget room and The Prince’s Room, all of which retain many of their original listed features. BMA House has a maximum capacity of 200 for a ceremony and wedding breakfast. However, it is also ideal for smaller, more intimate gatherings and larger scale corporate affairs.

The Prince’s Room has, for example, a maximum capacity of 60 for a ceremony. BMA House is also a fabulous location to hold a private outdoors drinks and canapé reception. In addition to its splendid interiors, The Courtyard and Garden, both provide a stunning setting for wedding photographs and pre-dinner drinks.

If you would like a guided tour of our building to discuss any plans you have for meetings and events please email or phone and we will be delighted to help you.

**Get in touch and let us assist you**  
Call 020 7874 7020 or visit www.bmahouse.org.uk

**BMA House**  
BMA House, Tavistock Square, London, WC1H 9JP
Neuromuscular conditions family information videos

Muscular Dystrophy UK – October 2015

Muscular Dystrophy UK have created seven short online condition-specific videos, and one video on best-practice healthcare, focusing on the importance of multi-disciplinary team care for people with muscle-wasting conditions. The videos are aimed at the 70,000 people in the UK living with neuromuscular conditions, their families, and community health professionals. We know that in four patients with muscle-wasting conditions have never seen a neuromuscular specialist and we created these videos to ensure that people diagnosed with long-term degenerative neuromuscular conditions have a full understanding of their prognosis, and what healthcare is available. The videos, which all feature specialist neuromuscular health professionals and people living with neuromuscular conditions, discuss what it is like to live with the condition and the importance of accessing specialist healthcare.

We know that an increasing number of individuals and families affected by neuromuscular conditions will search for information online. From feedback at our patient information group meetings we know that videos are a popular way of sharing information about neuromuscular conditions and are considered by many people to be more accessible than traditional sources of information, including fact-sheets. Therefore we felt that by creating videos that showed the services on offer, and the benefits of attending them, would improve the integration between patients and the NHS. This not only improves a patient’s quality of life, but also reduces cost pressures on the NHS from unplanned emergency admissions.

The development process is thorough and the videos feature health specialists and patients. They are marked by a high level of patient involvement and focus on living a fulfilling life. They present a consistent message of the importance of multidisciplinary working. The production standards are high and I think the videos are well-judged in terms of content and presentation.

Nutrition

NAM – August 2016

This booklet is for people living with HIV in the UK. Medical advances in this treatment and care have transformed the outlook for people diagnosed with HIV. Someone diagnosed with HIV in the UK, who has access to HIV care and takes treatment as prescribed, can expect to live just as long as their HIV-negative peers. Living with HIV now means managing a long-term condition and significant numbers of people living with HIV are entering older age. In this context, lifestyle factors such as diet, smoking and exercise are really important, as they have such an impact on good overall health. This booklet aims to support people living with HIV to focus on what they eat and to maintain a healthy weight, whether they have been recently diagnosed with HIV or have been living with HIV for a long time. For some people, receiving an HIV diagnosis is a moment when they take stock and consider their health and what changes they can make. A generation of people living with HIV were diagnosed early in the epidemic and didn’t expect to live into their 50s, 60s and 70s. For this group – and older people diagnosed with HIV recently – the motivation for lifestyle changes may be connected to a diagnosis or wish to avoid co-morbidities such as diabetes and heart disease.

Good nutrition has an important role to play here too. In the main, healthy eating advice for people living with HIV is the same as it is for people who do not have HIV. There are some specific issues – such as managing side-effects of medications which may affect nutrition (e.g. nausea, vomiting and diarrhoea), and medications that have to be taken with food – but in general, the booklet aims to reassure people that normal healthy eating advice applies to them and that a balanced diet does not have to be complicated or expensive. The broader aim of this booklet (and the series it is part of) is to support people living with HIV to have productive discussions with their healthcare providers and to make informed decisions about their health, healthcare and well-being.

“This is a well-produced booklet, as I would expect for an Information Standard approved organisation. It is packed full of useful information.”

Olly Being Brave And Chemotherapy

Molly Olly’s Wishes – January 2017

This resource aims to help children to understand the side effects of chemotherapy through the story of Olly being brave. Its aim is to provide a child-friendly communication of the stages of treatment and interventions. The book’s aim to acknowledge the worries and feelings a child may be having and to provide a supportive narrative to enable them to make sense of their experiences. The illustrations of the book are designed to normalise the hospital setting and present an empathetic experience for the reader through the emotional experiences of the characters. It informs the young patients about scans and the MRI (magnetic resonance imaging) machine that is used, and what a biopsy is. It also explains what chemotherapy will do to the cancer (tumour), hopefully making it smaller and smaller. Olly gets tired and feels sick and loses his hair. All of a sudden he is fed up with being brave. It addresses the difficult question of why me? What happens when you feel miserable and angry and none of the grown-ups seem to be listening? Then, everyone stops and listens to Olly. They explain why his hair is falling out and why his mouth is sore. Olly then tries to focus on what he enjoys doing, and that makes him feel a bit better. It shows that through better communication and explaining things in a simple way, it makes the patient feel less scared and more in control of their situation. It puts the child back in the centre of the narrative. Much is said about putting patients at the centre of what happens in a hospital, and that is exactly what this book is trying to endorse. Recent publicity on the massive improvements at Birmingham Children’s Hospital have illustrated what can happen as a result of patient lead/centred care with amazing results.

‘This is one of the best resources I have reviewed. I am very impressed by the range of appropriate health professionals who have been involved in this resource. The authors have clearly gone to great lengths to involve users. The resource is written for children and is written in very child-friendly terms. The story it tells is positive without ignoring the difficulties children face. This balance is difficult but the authors have managed this very well. The cuddly toy (with central lines) is very child-friendly and appropriate for the story that accompanies the toy. Much thought has clearly gone into the design of the toy and in helping children accept their treatment and altered body image. It is very impressive.’
The purpose of Olly the Brave and The Wigglys by Diane Maybey, is to help and inform children and their families around the procedure for having a Hickman line. The book explains to children in simple terms and on their level, why it is necessary and what it is for. It takes the central character on a journey through the procedure and the emotional issues around having a line for the individual and those around them. The book evolved after first-hand experience of the charity’s founder, Molly Ollerenshaw, who was diagnosed at the age of three with a Wilm’s tumour. Molly then spent the best part of five years undergoing treatment and had several Hickman lines. The information available was very matter of fact and clinical and therefore not engaging for a small child. Children as well as adults need to be as informed as they can be to reduce the emotional distress that the situation creates. The book by its very character is more like an everyday storybook that would ordinarily read or be read. This makes the experience less intimidating and less scary. The book is aimed at children up to the age of 12 and above where appropriate.

“This is a lovely story book with an accompanying toy. It’s designed to be read with a child, which enables them to ask questions and allows parents and professionals to use the story to find out what their child understands and feels. The toy is soft and tactile so that children will want to hold it. Using it alongside the story book means that children can see what the Hickman line will look like and to use it to act out thoughts and feelings. It’s well-pitched at younger children; the author’s notes help parents and others get the most from it. It’s presented in bite-sized chunks of information; the tone is supportive, warm and reassuring but it doesn’t steer away from difficult feelings and ideas. It talks about cancer and what it is in a way that’s easy to understand and helps children to understand the rules about having a Hickman line through the main character’s talk with a friend. It’s non-threatening but realistic and truthful. The illustrations are friendly and well-drawn and used appropriately to illustrate the story. It includes also little drawings for children to find in the story to give it added interest. It uses the child’s and parents’ voices throughout to good effect and, as well as discussing the main procedure, the book is centrally about dealing with thoughts and feelings, and helping children to explore these. It’s based on the experiences of a little girl who had a Hickman line for many years and users have been involved throughout the process of development. That insight is clearly visible in the content and production of the resource.”

Pain and pancreatic cancer

The UK has around 9,600 new cases of pancreatic cancer every year, and it’s the 11th most common cancer. 80% of pancreatic cancer patients are not diagnosed until the cancer is at an advanced stage. Pain is one of the main symptoms of pancreatic cancer – about 70% of people have pain at diagnosis. This information resource is for those people with pancreatic cancer pain, and their families and carers. We carried out scoping work and telephone interviews with people affected by pancreatic cancer, which identified that although there is a lot of information about cancer pain, there is no specific information about pancreatic cancer pain. Pancreatic cancer can cause some specific issues around pain – eg pain linked to the digestive problems that the cancer causes. Our research also showed that pain can be a big concern for these patients. This booklet aims to address these gaps in information. It seeks to inform and empower patients and their families, so that they understand pancreatic cancer pain and can access the support they need. The booklet explains what pain is, what causes it, the different types of pain and how it can be managed. It also provides information about talking about pain, and coping with pain. It emphasises the importance of getting help early to get pain under control and treat it more effectively.

“This is a really well put together resource: information is clear and detailed, the tone is reassuring without patronising, and the evidence-base and its gaps are dealt with very well. It’s well-presented and includes thoughtful extra material like a list of MDT (multi-disciplinary team) members. It is an excellent leaflet which is really well put together, with comprehensive and supportive information. I particularly liked the ‘questions to ask’ box in each section.”

Personality Disorders

Rethink Mental Illness (Advice and Information Service) – October 2016

The factsheet is primarily aimed at people living with a personality disorder but could also be for family members or health professionals. It aims to educate the reader about the different types of personality disorders, including information on the causes, treatments and risks and complications. Feedback was provided by a therapist who practices cognitive behavioural therapy and eye movement desensitisation and reprocessing therapy and an adult social care commissioner.

People are keen to manage their own health needs and conditions as much as possible. In addition, current health policy consistently highlights the need to ensure that patients are supported to play an active part in their own health, care and support.

People should have access to the information they need to be able to do this and the provision of high quality accessible information by health professionals is critical to delivering good person-centered care.

The Information Standard is a certification programme for all organisations producing health and care information for the public. It helps anyone to quickly identify reliable and good quality evidence-based health and care information through an easily recognisable quality mark.

Any organisation achieving The Information Standard has undergone a rigorous assessment of their information production process to check and ensure that the information they produce is high quality, evidence-based, balanced, user-led, clear and accurate and can be understood and used by the people it is written for.

Contact us for more information at: england.informationstandard@nhs.net
What happens before your operation

Test can feel scary and unfamiliar, especially

November 2016

Guy’s and St Thomas’ NHS Foundation Trust) –

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on ART and side effects. That guide was authored

HIV i-Base – December 2015

Pocket size: ART and quality of life

HIV i-Base – December 2015

This resource is a reduced version of a more
detailed and longer HIV-i-Base treatment guide
on ART and side effects. That guide was authored
by Simon Collins, a leading long-term treatment
advocate with expertise on HIV treatment,
including being a co-author on UK and European

guidelines for HIV treatment. The larger resource

was also reviewed and supported by a medical

advisory board that included UK doctors

responsible for this area.

‘I really like this – it’s colourful and attractive, and

is informative in a very approachable way. It would
work as an introduction, an aide-mémoire or, for

some people, be as much information as they want.

I like the way the information is broken up by page
in bite-sized chunks.’

Pre-assessment and operations: what to expect

at Evelina London

Evelina London Children’s Hospital (part of
Guy’s and St Thomas’ NHS Foundation Trust) –

November 2016

Coming to hospital for an operation or planned
test can feel scary and unfamiliar, especially
for a child. What happens before your operation
and on the day of your operation are specially
made patient information films, designed to
be watched by families with their child to help
prepare them for a stay in hospital. The films fulfil
three main objectives: preparing young people
and their families for pre-assessment and a
procedure or operation in a fun and friendly way
to reduce anxiety; maximise staff time by providing
practical information to families upfront,
answering frequently asked questions in advance;
supporting a project to improve pre-assessment;
and providing a visual pathway. A review of patient information found
that existing information was variable, excessive
and repetitive. As a result of this review all
information has been updated, including the films
which provide information in an engaging and
accessible format. If a child and their family are
anxious this can lead to confusion and anxiety
in the anaesthetic room directly before a procedure.
When a parent becomes anxious it affects how
a child behaves as they instinctively pick up on
their feelings. Older children in particular can
become combative, making it an unpleasant
experience for all. Increased levels of anxiety can
also cause a greater ‘stress response’ to surgery
which is detrimental to recovery. Filmed at Evelina
London Children’s Hospital and using real staff,
the films aim to put families at ease by helping to
combat the anxiety of the unknown. Presenting
the information in a friendly, colourful and upbeat
way, was a deliberate tactic to engage young
people in a potentially daunting and scary topic.
By being able to visualise their experience, coming
into hospital should feel more familiar and less
scary. There is very little time to psychologically
prepare patients and their families for a procedure
and anaesthetists do not routinely have time to
visit wards. The films can support this by preparing
a family before their visit, making sure that key
information is delivered before a patient reaches
the anaesthetic room. The films are relevant to
a very wide audience – over 10,000 operations
or procedures are carried out at Evelina London
Children’s Hospital annually, with the majority
requiring a pre-assessment.

‘This is an impressive and clearly effective resource.
The idea was innovative and the consultant who
initiated it went the extra mile to put in the effort
to develop this resource. The engagement of the
whole team of staff many of whom took part in
the video shows commitment and enthusiasm for the
idea. Their research showed that no other similar
resources have been made. They have engaged a
very professional company to produce the video
and used user views and feedback to inform the
content. It’s a delightful production they would be
well-pleased to see if my child was going in to
hospital. The team should be commended on their
commitment and enthusiasm for this production,
and their care and concern for their patients and
their families. The involvement of patients and their
families in its production adds to its value as you
can be sure you are providing the right information in
an accessible format for the intended audience. The
plan for promotion, dissemination, and gathering
of feedback and evaluation is very thorough, and
it has involved patients and their family and friends
and addresses the emotional impact of a cancer
diagnosis. This is not a short article
which can cover all the information,
and to personalise their pack. Prompt lists of
questions they may want to ask their specialist
and space to record the answers are included.

The pack is designed to be easy to dip in and out of,
and with clear signposting to Breast Cancer Care’s
websites and further information sources, it shows
patients where they can access additional help if
they need it. This resource is in its fifth edition.

‘This is an excellent resource for patients and
should be short-listed in my opinion. It is clear
from the supporting information that patients
have been asked what they would like to know and
that changes have been made as a result of their feedback. It is
very nice to have an application where a full cycle
has taken place and for them to have formally
evaluated the resource. It is a strength of this
resource – the fact that all patients can add information to the
resource – this makes it very patient-centred. It is
thoughtful and helpful.’
For many years, the BMA has supported the members of the profession who are in hardship, and the education of medical students. These activities have been organised under the charity umbrella of BMA Charities, but this is made up of different charities which fund and deliver three main charitable purposes:

Helping medical students
Students studying to be doctors face a number of challenges, not least the cost of tuition fees. Many students have done a previous degree and then entered medicine later, meaning that they are currently unable to claim a tuition fee loan, and their main source of income is a maintenance loan, which is insufficient to meet their fees. In 2016, BMA Charities gave grants to help 92 students, at a cost of £184,700.

Helping refugee doctors
When refugees who have a medical qualification come to the UK, they are unable to work as doctors until they have satisfied the GGMC requirements for registration, a process which is lengthy, difficult and expensive for the refugee doctors, despite discounts offered by the GMC to some of its exam fees. In 2016, BMA Charities gave grants to help 31 doctors, at a cost of £39,250.

Helping doctors’ families
Doctors who are not in work, whether because of health problems, refugee status or other reasons, may find it impossible to gain funding through welfare and benefit systems for items such as disability equipment, if equipment or school uniforms. In 2016, BMA Charities gave grants to help 22 children of doctors, at a cost of £22,400.

Ms Marian Flint
BMA Charities, BMA House, Tavistock Square, London WC1H 9JP
E: mflint@bma.org.uk
T: 020 7383 6142

Dr Andrew Mowat
Chairman

Primary Hyperparathyroidism

Hypopara UK – October 2016

The leaflet aims to provide information and advice about primary hyperparathyroidism for people who have, or are in the process of being diagnosed with, this condition. It provides some background information and advice and also discusses when treatment is needed and the types of treatment available. As the current guidelines on this condition are quite out-of-date, this leaflet was peer reviewed by national experts in the field and is intended to stand as an interim measure providing reliable and updated information until the new NICE guidelines are published.

“This is a clear and well-researched short overview of the condition and treatment possibilities. It is well-written, well-laid out and presents the facts in a neutral way.”

Recovery

Rethink Mental Illness (Advice and Information Service) – October 2016

This factsheet is intended to provide an overview into what recovery from a mental illness might mean. It explains how you can view your recovery, set goals and make lifestyle changes. It is intended for people who have been diagnosed with a mental illness.

“This is a very useful resource: clear, simple language and tone are used throughout. It is of particular importance that these fact-sheets are available to download from the website. Given the stigma still associated with mental illness, the ability to access initial or continuing information from a computer is essential.”

Reduced fetal movement campaign/Movements matter

Tommy’s – February 2016

The RFM (Reduced fetal movement) campaign was designed to raise awareness among pregnant women of the importance of reporting reduced fetal movement in pregnancy. RFM can be an impending warning of fetal death. The campaign arose from Tommy’s involvement in the NHS England Saving Babies’ Lives Care Bundle on reducing stillbirth. From our close links with pregnant women and midwives we knew that misinformation and inaccurate messaging was prevalent around fetal movement and we persuaded the group to expand on their original plans, which were for a leaflet only, to include a digital campaign. The resources were developed by Tommy’s in partnership with NHSE (NHS England). On a shoestring budget, the digital campaign went on to reach 6m women across the UK. In all the RFM resource bundle was delivered in three parts: a leaflet, Feeling your baby move is a sign that they are well; an animation and digital campaign: #movementsmatter; a downloadable pdf: Reporting reduced fetal movement. What happens next? Raising awareness among pregnant women of the importance of self-monitoring the movement of their unborn baby and reporting reduction in movement can allow timely clinical intervention to save the baby’s life if necessary. The original intended audience for the RFM messaging was all pregnant women. In a second phase of the campaign we specifically targeted Afro-Caribbean women, who are almost twice as likely to suffer a stillbirth. The key messages aimed to challenge inaccurate but prevalent thinking: movements slow down naturally in the third trimester because the baby ‘runs out of room’; as long as a woman can count 10 movements in two hours the baby is OK; a home Doppler can provide enough reassurance; and there is no urgency to report reduced movements. It also sought to empower women to monitor their own baby’s pattern of movements and report any reduction, by reassuring them that they would not be ‘wasting time’ if they did so.

“All methods of dissemination (leaflet, poster, animation) make it very easy to pick up the key message about being aware of baby’s movements and reporting anything unusual straight away. The target audience is very clear in headline words and graphics.”

Rita May’s Story: Radiotherapy at Weston Park Hospital

Radiotherapy Department, Weston Park Hospital, Sheffield Teaching Hospitals NHS Foundation Trust – April 2015

The video is based on Rita’s personal experience of radiotherapy at Weston Park Hospital. The aim is to raise awareness of radiotherapy and to help to dispel widely held myths and beliefs about Weston Park as a cancer hospital and radiotherapy as a treatment option. The intended audience is primarily newly-referred patients and their families and friends. To a lesser extent it is hoped that the video may be seen by a wider population via YouTube, helping to increase awareness of radiotherapy and to give the wider public a more modern view of this treatment modality.

“This resource is very clear, concise and easy to digest with down-to-earth language. I like that a Northern accent is used!”

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School and cystic fibrosis: a guide for parents from pre-school to primary

Cystic Fibrosis Trust – June 2016

This guide is aimed at parents of children with CF (cystic fibrosis) who are starting pre-school or primary school. We know from our helpline and from CF centres, where care for this condition is so often managed, that the transition from home into school (or pre-school) can be very stressful for families and sometimes worrying for school staff, CF nurses, and sometimes CF physiotherapists. Work with families and schools to make this as smooth as possible. But, we identified a gap in consistent information to support CF teams and parents through this transition. This booklet aims to address the key concerns that parents expressed to us in the consultation (including infection control and management of diet at school) and to do this through provision of clinical and experiential information. It’s designed to complement the work that the CF teams do with parents and schools. The resource covers families from the point of looking for a school, applying for a school, managing CF at school and moving through into later years at primary.

“...is a great resource. It is very clear and will be a great comfort to parents of children with CF who have to make difficult and emotional decisions about their child going to school. It includes lovely pictures of real children and also cartoon images.”

Self help for tinnitus (Easy Read)

British Tinnitus Association – September 2016

There is no cure for tinnitus, but understanding and management tools can lead to relief from symptoms enabling people with tinnitus to lead a good quality of life. The intended audience for this leaflet are people with a learning disability. The prevalence of hearing loss in people with a learning disability is up to 40% and this often goes un- or misdiagnosed. Hearing loss is the biggest causal factor in tinnitus. Up to 80% of people with tinnitus have a hearing loss. Tinnitus is a difficult condition to comprehend and deal with. People hear strange noises in their head that no one else can hear and yet they cannot articulate the problem. They may report feeling scared and confused, they become unable to sleep and find it difficult to concentrate. People with a learning disability struggling with their tinnitus are even more disadvantaged by the lack of information targeted at them to help them understand and cope. One support worker for a person with a learning disability told us their client’s GP believed that they had a mental illness, not tinnitus.

“This resource will look quite different from some of the other entries for this year. But it looks the way it does because it has been co-designed and tailored to the preferences and needs of the group in question (people with learning disabilities). The development process is exemplary because the team has clearly seen their end goal as not the resource itself — but as how people can change their lives, as a result of the resource. As a result the team have invested a lot of effort into the early stages and activities such as dissemination and evaluation, working with user groups to really get to the bottom of what the challenges are that people with learning disabilities face in this area, what can help, and how best to communicate this in a way that is accessible and has impact. This is a carefully thought out work tool designed to change people’s lives and for that it deserves a commendation.”

Simple steps for good bowel health

Bowel Cancer UK – December 2016

The Simple Steps for Good Bowel Health booklet was developed to help promote information to the general public on how to promote good bowel health and reduce the risk of bowel cancer. Around half of all bowel cancers could be prevented by having a healthier lifestyle, including eating a healthy diet, doing more exercise, cutting down on alcohol and stopping smoking. The resource provides simple and easy steps which people can incorporate into their everyday lives. It includes information on the digestive system, recommendations on what to eat and what to limit to maintain a healthy diet, and what to aim for in terms of exercise and being a healthy weight. One of our key objectives was to make the booklet accessible, easy-to-read, engaging, bright and clear. The booklet is a revision of the original resource, which was first published in 2011. The current booklet is version 3. Since its creation, the booklet has consistently been our most popular health information resource. We know that bowel cancer is treatable and curable and people can take steps to prevent the disease. We therefore felt it was important to update the booklet and distribute it further.

“This is a great resource. The clear, bright design is appealing and will encourage the general public to pick it up. I like the way the booklet is laid out, with a new topic addressed on each page. The use of colour and font also aids navigation. The language is clear and engaging, with explanations of diet terminology. The content is supported by high quality evidence and has been reviewed by a range of experts as well as the target audience. The good use of white space, font size and overall design makes the booklet accessible and easy-to-use.”

So what is MND, anyway? A guide for young people affected by motor neurone disease (MND)

Motor Neurone Disease Association – March 2016

Developed for young people aged 13-18, this guide is designed to help them manage the impact of a diagnosis of MND (motor neurone disease) in their family. Exploring emotional and practical support, this visual guide answers the questions most likely to be asked. Parents, guardians, and health and social care professionals may also find the guide helps them communicate about the disease and plan for a rapidly progressing disease that affects the brain and spinal cord. It attacks the nerves that control movement so muscles no longer work. It can leave people locked in a fading body, unable to move, talk and eventually breathe. Some people may experience changes in thinking and behaviour, with a proportion experiencing a rare form of dementia. This means a diagnosis of MND in the family is a distressing time for everyone, but young people can feel confused and may even blame themselves if unformulated. As care needs increase over time, young people often get involved. In some cases, they become the main carer. Information to support their needs, in a friendly format, can help them adjust to the changes and find help. Appropriate information and support may also help lessen future trauma for young people in the years after bereavement. Note pages for questions, contacts and tracking are included, in case the reader is referred to a diagnosis of MND in the future. 

National Cochlear Implant Users Association (NCIUA) – March 2015

The booklet is aimed at anyone who is thinking of having a CI (cochlear implant) or anyone who wants to better understand what it is like to have one and to hear with one. The purpose is to provide as much information as possible to anyone who wants to know more and stems from the realisation that the experience is unique to those who have a CI and it is their personal experiences that often answer the questions that people have. We are the only national organisation in the UK which represents CI users and our mission is to offer advice or information to anyone who has or is considering a CI.
This is a very good, detailed guide – aimed very well at young people. It is rich with personal experiences and deserves recognition. It is an excellent resource; the effort put into creating this resource is exceptional.

Spinal Muscular Atrophy Type 4

Spinal Muscular Atrophy Support UK – June 2016

This was written for adults affected by an adult onset form of SMA (Spinal Muscular Atrophy) called SMA Type 4. It is also helpful for family, friends, colleagues and health and social care professionals supporting an individual affected by SMA Type 4. The aim of the leaflet is to provide a summary guide to the condition, daily living suggestions and further sources of support and information.

This resource provides comprehensive and accurate information on a rare condition. The information is very comprehensive – and would be a lot for patients to take in at one go – but is all relevant and is all information which would be difficult to find elsewhere. It encompasses sensitive and accurate recognition of the progressive nature of the condition and options for support.

Subarachnoid Haemorrhage: a guide for patients and carers

Brain & Spine Foundation – February 2015

This booklet provides information on subarachnoid haemorrhage (SAH) for patients and their families, friends and carers. It provides information on the acute stage of SAH, describing the condition, what happens in hospital, tests and investigations and possible treatments. It also provides information on recovery from SAH, common symptoms and feelings and returning to everyday life. Sources of further support and information are listed in the Useful contacts section of the booklet. The aim of the booklet is to reduce uncertainty and anxiety for people affected by SAH. All of our publications are accredited by NHS England’s Information Standard. We are regularly assessed on our adherence to the Standard’s information production guidelines, which include requirements for meaningful health professional and user involvement.

This resource seems to offer a comprehensive resource for patients and, from the entry details, it is clear that patients value it. It is balanced and strikes a good balance between honesty and being positive.

Supporting children and young people close to someone with motor neurone disease (MND)

Motor Neurone Disease Association – January 2017

This information forms part of a wider provision to support children, young people and young carers. It was developed for professionals working with children or young people under 25 years of age. Professionals may be working within various settings including education, training, employment, health, youth, pastoral or social care.

This guide is designed to help these professionals improve understanding of MND (motor neuron disease). It explores the impact of the disease on a person, and how this might be felt by a child or young person. It explores emotional and psychological effects, physical health needs, young carers and other practical issues. It hopes to focus the reader in greater detail on areas of life affected.

This visual guide hopes to increase understanding of MND and provides guidance on interventions that may improve outcomes for children and young people. MND is a fatal, rapidly progressing disease that affects the brain and spinal cord. It attacks the nerves that control movement so muscles no longer work. It can leave people locked in a failing body, unable to move, talk and eventually breathe. Some people may experience changes in thinking and behaviour, with a proportion experiencing a rare form of dementia. This means a diagnosis of MND in the family is a distressing time for everyone, but children and young people in particular may experience feelings such as confusion, anger or fear. As care needs increase over time, children and young people often take on care tasks including the care and support of younger siblings. In some cases, they become the main carer. The guide may support professionals working in children and young people’s services and help them identify early interventions and support options. It may support planning for future help. Early support and information may also help lessen future trauma for young people in the years after bereavement. The overall aim of the guide is to enable professionals to support children, young people and their families affected by MND to adjust to a diagnosis of MND in their family and prepare for the challenges that lie ahead, explore how to access support, especially if they are involved in care tasks as a young carer or young adult carer; raise awareness of and support access to early help with emotions and look towards their own sense of wellbeing; find ways to manage the
Supporting children when a parent has had a brain injury

Headway – the brain injury association – December 2016

This booklet has been written to provide information and guidance to parents, families and friends of a child whose parent has sustained a brain injury. It provides information covering all stages of a parent’s experience of brain injury (from admission to hospital to long term changes) and focuses on the impact that this has on the child. The booklet starts with information on how differently aged children are affected by a parent being in hospital and what can be done to offer age-appropriate information and support to the child during this time. After this, information on visiting a parent in hospital is offered with key tips on how to make this as comfortable as possible for the child. Information on the impact of a parent returning home after a discharge from hospital is covered, and finally a chapter is dedicated to children taking on the role of a young carer and where support can be sought with this. The booklet is written to address the commonly overlooked fact that the family network around a brain injury survivor, including children, often requires as much support as the survivor themselves. Relevant support organisations are listed throughout the booklet, directing readers to sources of further support.

‘This excellent resource involves the mother of a child whose father sustained an injury. It is available in many different formats; social media, Headway website, via a helpline, via 120 support groups, free download, or print copy.’

Targeted therapies for lung cancer

Roy Castle Lung Cancer Foundation – November 2016

This resource aims to increase patient awareness and support those with, or supporting those with, non-small cell lung cancer whose tumours test positive for specific genetic mutations – such as EGFR (Epidermal growth factor receptor) and ALK (Anaplastic lymphoma kinase) – who are getting or about to get a targeted therapy. It is also used as a supportive resource by lung cancer clinical nurse specialists talking through treatments and options with patients.

‘This booklet deals specifically with medicines, so some of the language such as the names of medicines don’t easily off the tongue, but this publication does its best to make the subject as readable and easy to understand as possible. I particularly liked the way side effects of the various medicines were given in detail, thus providing the patient with an all-round picture of the advantages and disadvantages of the treatment. It is well-written, balanced publication and it was good to see all the side effects clearly set out as well.’

The Fontan procedure or Total Cavopulmonary Connection (TCPC)

Little Hearts Matter – February 2016

The target audience are families of children with a single ventricle heart condition who are approaching their Fontan operation. Children born with only one working pump in their heart (single ventricle heart disease) have a series of operations that aim to make the best use of the one pump that they have. The Fontan procedure is one, and can be for some the last, of their planned operations. For many children, this operation is performed just before they start school having last had surgery in infancy. The preparation for this operation is complex and the stay in hospital over the treatment period is often extensive.

Families approach this operation with fear and a lack of understanding. The booklet aims to answer common questions about the procedure by providing information on the signs and symptoms indicating surgery is necessary, the operation, what a child and their family can expect to happen when they go into hospital, how to prepare for the hospital admission and what changes they may notice afterwards. This will hopefully reduce some of the fear experienced and help to empower families to take an active part in the care needed throughout the experience.

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The Parkinson Magazine (Winter 2016/2017)

Parkinson’s UK – February 2017

This resource aims to help people living with Parkinson’s cope better with the condition and take control of their lives, as well as encourage hope. It does this by: giving information about living with Parkinson’s, ways to manage the condition and take control (based on our Information Standard accredited information); describing how others cope; encouraging the sharing of advice and experiences; and informing readers about relevant news, including advances in research. The magazine has a circulation of 30,000 and is sent to every member of Parkinson’s UK.

‘This is a useful and entertaining resource. It lists its patient contributors clearly and their contribution is useful. The articles are informative and topical, I can see that it will be welcomed by Parkinson’s UK members.’

The Story of Neuroman and Selective Dorsal Rhizotomy

Alder Hey Children’s NHS Foundation Trust – October 2016

This resource was developed following multiple requests from our young patients who attend multiple consultations and investigations. The children were willing to know in detail what the purpose of the clinics and examinations were and what we were planning to do. Another request came from a young child who had undergone the procedure herself and was willing to have more details about the procedure. These requests, coming directly from our young patients, are very infrequent and our communication efforts are usually directed to the parents. Considering the level of engagement from the children, we thought we were dealing with a category of patients who clearly desired to be involved in the planning and decision making. Also, this is a procedure which requires cooperation from the patients themselves in view of the extensive rehabilitation process associated with it. The aim was to provide a booklet that would inform children what the SDR (selective dorsal rhizotomy) procedure involves both before and after surgery using age-appropriate language and child-friendly illustrations. The purpose was also to support children in their decision whether or not to go ahead with the procedure.

‘This is a lovely children’s story based on the experience of two real patients and where the characters are real hospital staff. It is a real example of responding to patient need. It is really well-executed, especially the way that the characters are real clinicians. This does somewhat make it specific to Alder Hey and to right now as staff may move on, but this is a small matter.’

Thinking of starting a family? A guide for adults with cystic fibrosis and their partners

Cystic Fibrosis Trust – June 2016

This guide aims to empower people with CF (cystic fibrosis) and their partners to make informed family planning decisions. Advances in life expectancy and developments in assisted reproductive technologies have resulted in many people with CF having, or planning to have, families. The provision of information hasn’t kept pace and we were aware through our helpline and social media channels that the CF community wanted non-judgemental, clinical and experiential information on this topic. Our aim in developing this booklet was to fill this significant information gap.

‘This is an excellent resource which gives many viewpoints from CF sufferers and partners who have made a life-changing decision to have a child. It is clear and easy to understand. I like the pictures of real people as well as the cartoons.’

Tinnitus activity book (Key stages 3–4)

British Tinnitus Association – September 2016

The leaflet will provide a reliable source of information and support for children affected by tinnitus providing them with the tools they need to better understand and manage their tinnitus, targeted in a way they understand and find interesting. The exercises are designed to guide the child into developing a management strategy and appropriate techniques to manage their tinnitus and to reduce the distress and intrusiveness it can cause.

‘This is a well-produced resource which is specifically targeted at young people. The consultation process with healthcare professionals and young children is thorough and demonstrated by the appropriateness of the content. It is an activity book which encourages children to think about their treatment. I think it is successful in meeting its objectives.’

Congratulations!

National Voices commends all of the entrants to the 2017 BMA Patient Information Awards

National Voices is the coalition of charities that stands for people being in control of their health and care.

Whether it is shared decision making in the GP surgery, multidisciplinary team-working in the hospital, or co-designing services with the public, involving people is not a ‘nice to do’, it is a ‘must do’.

Information which enables people to make decisions about their lifestyles, health, care and support is an essential aspect of person-centred care.

Our mission is to work in partnership to make person-centred care a growing reality.

We do this by:
- Influencing policy We speak up on behalf of patients, service users, carers and the bodies that represent them. We work with national decision makers in government, as well as health and social care professionals.
- Improving practice We raise awareness of person-centred approaches, work to improve professional development, and guide the design of local services.
- Promoting a powerful role for the voluntary and community sector We are a conduit between national decision makers and our network of voluntary sector professionals and experts. We work with charities and community organisations to enable people to manage their health in ways which matter to them, through our Wellbeing Our Way programme.

Is your organisation a member of National Voices? If not, join us: nationalvoices.org.uk/membership

info@nationalvoices.org.uk

@NVtweeting
BMA Foundation for Medical Research

The BMA Foundation for Medical Research is a charity that awards grants and prizes for pioneering medical research. The BMA has been awarding research grants since 1839, and was one of the first professional organisations to award scholarships and prizes to encourage and further medical research.

Today, approximately 12 research grants totalling just over £600,000 are awarded each year to medical doctors and research scientists, all funded by past bequests to the BMA Foundation. The grants fund basic and clinical medical research, covering a diverse range of research topics, from heart disease to neurological disorders to cancer. The grants are awarded to clinical academic doctors and research scientists, and aim to support grant winners in their research aims and career development.

The impact of BMA Foundation funding has been wide ranging across medicine and healthcare. Research projects supported by the foundation have led to the discovery of new treatments for a wide range of medical disorders, from heart-related diseases to neurological disorders to cancer. These discoveries have ultimately raised clinical standards, disease outcomes and improved patient care.

How to apply

The BMA Foundation grants are advertised widely in the British Medical Journal, on the BMA Foundation website www.bmafoundation.org.uk, and externally. Details of the grants on offer can be available from September each year. The online application system opens in December, and the deadline for submitting applications is early March. Grants are available for a maximum period of three years.

Full details can be found on the BMA Foundation website or by contacting E: researchgrants@bma.org.uk T: 020 7383 6341

Past winners

'The rhino-virus studies led to the identification of viruses being a major cause of asthma exacerbation and identification of a defect in interferon-beta production, thereby reducing the innate immune system response to viruses. This discovery has led to the development of inhaled beta-interferon as a new treatment for virus-induced exacerbation.'

Prof S Holgate, previous winner of the HC Roscoe grant for research into upper respiratory disease

'The project identified for the first time the effects of alcohol on first trimester placental development and also nutrient transfer across the placenta.'

Dr Rukshana Shroff, previous winner of the Eyck & Strutt grant for kidney research

'The project identified for the first time the effects of alcohol on first trimester placental development and also nutrient transfer across the placenta.'

Dr Clare Tower, previous winner of the Harper grant for research into alcohol related diseases

Travelling, going on holiday and lung cancer

Roy Castle Lung Cancer Foundation – November 2016

After a diagnosis of lung cancer, many people feel unable to travel, and those who do want to travel can find it hard to access lung-cancer-specific information that would support them to make plans and go on holiday. This booklet is intended to be a comprehensive resource to support people with lung cancer, their family, friends and carers, covering many aspects of travelling or going away for a holiday, from deciding if you are well enough to go, to where would be good destination. It also looks at aspects of the pros and cons of travelling by car, coach and boat, as well as detailed information about flying. We hope this booklet will open up opportunities to travel and go on holiday to people who may otherwise not have considered it possible or worth the effort. A large section at the end offers many suggestions for travel insurance companies and some of the many issues people face when wanting to travel with lung cancer, including how to find a supportive insurance broker. It highlights risks and offers suggestions to reduce them, and gives a structured pull-out section for information about medical conditions and treatments, and emergency contacts for people to fill in and take with them on holiday.

'This is a really good resource. It manages to express very clearly, without prententational tricks or false emphasis, a lot of information that could be tedious and mundane. The layout and structure are really helpful and I imagine this will benefit a lot of people who need every bit of help they can find. This is a great booklet with plenty of well-organised and helpful information. I've recently lost two good friends to cancer and resources like this are precious to people who are struggling. The booklet is very readable.'

Type 1 diabetes: School Residential Trip Tool

Diabetes UK – January 2017

The resource is a tool for parents of students with type 1 diabetes to use with their schools in the planning and during school residential trips. It has been designed to give a balance of practical and personalised information to take the stress out of planning and ensure students with diabetes can fully take part in successful and productive school residential trips. The tool was developed in partnership with parents, diabetes clinicians and schools. It was initially tested as a pilot digital tool in 2016. Feedback from the pilot was incorporated in the final product which was launched as a print and digital tool in January 2017. It is intended for: parents of children with type 1 diabetes; schools supporting children with type 1 diabetes; paediatric diabetes nurses and children living with type 1 diabetes.

'This is a very good resource which is clear and easy-to-read. It has a good contents page leading to bold headings and each section heading has a different colour band.'

UK Guide to PrEP

HIV i-Base – November 2016

PrEP has been available in the UK since 2012 and a leading UK study reported in 2014 that all participants would receive immediate PrEP due to dramatically greater impact on reducing HIV transmission than when the study was designed. Also importantly, PrEP can be brought online by anyone in the UK, and this aspect of access to and use of PrEP clearly needed an up-to-date community resource. The publication was primarily produced for people buying PrEP online but also to support health workers at sexual health clinics, in supporting these people. PrEP is notable for wide use by individuals – and data from two European studies showing two very different dosing options. We also wanted to explain the complex dosing options clearly. Subsequent reports on a dramatic drop in HIV incidence in London clinics during 2016 has been attributed to widespread use of PrEP. The resource was jointly produced by community advocates, doctors, researchers, health workers, and people who use PrEP. This included several sexual health clinics and the two leading professional organisations for health workers involved in HIV and sexual health (BHIVA and BASPH). It also involved lead researchers from the UK PROUD study and community activist from I want PrEP now and Prepster.

'I found this resource incredibly easy-to-read and understand with lots of signposts suggesting where more information might be found if needed, and other organisations to contact with further questions or specific queries. I also liked the statement on the front of the resource explaining that research is updating more frequently than printed copies of the resource might be, and giving web resources to ensure the reader had the most up-to-date information available. This is a very good resource.'
Understanding Progressive MS

MS Society – August 2016

The audience is people with progressive forms of MS (multifocal sclerosis). Its objectives are to inform people with progressive MS about the nature of their condition, including its possible causes, its potential course and symptom management; to help them understand the diagnostic tests and ways of measuring progress of the condition, including the Expanded Disability Status Scale; to highlight common reactions to a diagnosis of progressive MS, potential coping mechanisms and sources of support; and to inform people with progressive MS of the current state of research into treatments, including stem cell treatment, disease modifying therapies and myelin repair.

‘I liked this resource. It is one of a recently revised series which shares a user-led production methodology. I think this user-led process has determined the content which focuses on areas which are likely to be of concern. It also features recent research which is summarised for the reader. The graphics are well used to explain scientific concepts.’

Understanding Prosthetic Reconstruction

Guy’s & St Thomas’ NHS Foundation Trust – December 2016

The Understanding Prosthetic Reconstruction pamphlets aim to help patients understand the options for replacing a missing part of their body (artificial anatomical body parts ie noses, eyes, ears) that have been lost to cancer. Traditionally, this is only explained verbally to patients during a consultation. There can be an overwhelming amount of information to take in, particularly for patients who are about to undergo surgery for removal of tumours. Having to adjust to a changed face or features is a very difficult and distressing experience for patients. This resource will enable patients to take information away and read it in their own time. These pamphlets can also be shared with family and friends to help them understand what the patient will experience, as sometimes this is difficult for patients to discuss with family. Each pamphlet includes three pamphlets, each is designed to explain the loss of a specific body part (ie nose, eye, and ear) and a fourth pamphlet about relevant images especially the audiogram chapter.

Understanding your prostate cancer

Prostate Cancer UK – July 2016

The aim of the animation is to offer an alternative to written information for men newly diagnosed with prostate cancer and their families, at a point (point of diagnosis) when they can help the man understand their diagnosis, feel empowered to make informed decisions in a way that they can understand. The animation is designed to explain the process of treating prostate cancer at the right time and the right way. It explains about the diagnosis, the treatment, the side effects of their chemotherapy, as well as users. The design is mostly clean and crisp, and the content is mostly well-structured, meaning readers should be able to find the information they need quite easily. I think this is a good resource and I hope it proves helpful to readers and adds to the quality of the research that is being undertaken.

Why do some men leak after surgery? How to manage leaking urine – an artificial urinary sphincter

Prostate Cancer UK – January 2017

Urinary incontinence is a common side effect of prostate cancer treatment – specifically surgery to remove the prostate. It can be short-term or long-term and it is something that we know men can find very difficult to deal with. We produce information on ways to manage continence but have feedback that some information is still difficult to understand and that men would like more anatomical information about why they are leaking. The objectives of the animations are: to help explain why incontinence happens and explain some of the complex medical procedures that can help men manage it and to give men and their families an alternative to written information with clear visuals that can help understand incontinence and be more confident to explore options of self-management and medical treatment.

‘I liked these simple and direct animations. They deal with common interventions for urinary leaking after prostate cancer and the process is explained clearly. The voiceover is friendly and authoritative.

Work and finance: Before, during and after a stem cell transplant

Anthony Nolan – December 2016

This is for stem cell transplant patients returning to work and their employers. During the recovery from a stem cell transplant patients experience a wide range of side effects, including fatigue that can affect their ability to return to work. This can often result in feelings of anxiety and stress, especially due to the financial need to earn a living. From patient feedback we have identified that some employers are unaware of the persistent nature of some of these side effects and the challenges faced by stem cell transplant patients upon their return to employment. The patient booklet has been produced to be given to employers, it is for departments and line managers when the patient returns to work. It provides key information and insight into the transplant process and the impact it could have on their employee. It helps to identify the support that an employer has a responsibility to provide for their returning employees. The employer booklet has also been produced after feedback about the size of the full guides. The aim of these versions was to provide the patient and employer with the most important and relevant information in a format that was easy to access immediately.

‘The booklet is useful and there’s a lot of helpful information. The language is pretty clear and the tone is pleasant and relaxed, though never familiar.’
Young person’s guide to lymphoma
Lymphomas Association – January 2017

Lymphomas are the most common group of cancers in teenagers and young adults (15-24 years old) and the third most common group of cancers in childhood (0-14 years old), after leukaemia and brain tumours. Every year in the UK, about 150 children and more than 450 teenagers and young people develop lymphoma. Our booklet for teenagers and young people, called ‘Your person’s guide to lymphoma’, was due for revision. Health professionals rated it highly and in 2015-2016 we sent out more than 3,000 copies. But, while clinicians felt the content suited a young adult audience, some of them felt the design was childish. With the new edition, our key objective was to expand the appeal of the Young person’s guide to lymphoma to ensure it is a valuable resource for a broad teenage and young adult age group (13-24 years old), that informed them about their lymphoma and helped with self-care. After research, we arrived at three specific points we wanted the book to accomplish: to be useful – people liked to carry the information around, refer to it and share it with others and make notes; to provide easy to understand content in bite-size chunks that don’t overwhelm readers; people wanted to read relevant sections in isolation at a particular time, flick back to them when needed, skip sections entirely and find out where to get more information and to appeal to a wide age group.

‘This is an outstanding publication. The content, layout, design, use of colour and navigational aids are exceptional. The result is a publication which the Lymphomas Association should be rightly proud of, but it is also one that would be immensely valuable to its target audience. It has a real “pick me up and read me” feel to it, which I would see as particularly important given the age range of the target population. It is an outstanding publication, which has come a very long way from earlier editions. The feedback received has been employed to very good use. It contains a wealth of well-constructed and valuable information, but it is in the layout and design that this publication really stands out. Exceptional in every way and I am delighted to see the continuing commitment to continue its success available in hard copy for users, as well as an online version. As an information manager/producer, now retired, I would have been extremely proud to have been associated with this publication. Many congratulations.’

Your body, intimacy and sex
Breast Cancer Care – May 2016

Breast cancer and its treatments can cause many physical and emotional changes. This booklet outlines how these changes can alter the way someone feels about their body, and how this may affect sex and intimacy. It is aimed at anyone coming to terms with changes to their body and body image after breast cancer. The first part of this booklet looks at the physical changes someone with breast cancer may face after breast cancer treatment. It offers tips on coping with physical changes and getting used to these changes. The second part of the booklet is about how treatment for breast cancer may affect someone’s sex life or intimate relationships, and offers tips on sex and intimacy after treatment. It also covers the effects of breast cancer on intimate relationships, for those in a relationship and those who are anxious about starting a relationship in the future. Also a ‘prompt list’ is at the end of the booklet that may help people to talk about changes to their body or sex and intimacy with a healthcare professional.

‘This is an excellent resource that covers what some people would find to be an awkward topic in a straightforward and friendly way, giving emotional support and constructive advice on how to improve life. It’s available in a range of formats. The resource was co-produced by an in-house senior clinical nurse specialist, with input on a draft version from an external oncologist, a clinical nurse specialist and a psychosexual therapist. It was a delight to review this booklet and I hope it helps a lot of people in lots of good ways.’

Your breath test
British Lung Foundation – July 2016

Our online breath test is a quick way for people to find out if they should get their breathlessness checked out by a healthcare professional. We want to: increase the public’s awareness that feeling short of breath can be a symptom of something more serious, including lung conditions and heart disease; encourage people to understand things that may affect their breathlessness; and drive earlier diagnosis. We help people to decide if their shortness of breath is worth checking out. And potentially how they can make changes to their lifestyle to reduce their feelings of not having control of their breathing. We know that many people with lung conditions remain undiagnosed. Many people accept that feeling short of breath is part of getting older. Long-term breathlessness affects about 10% of the population and 30% of

Reviewers of the Year Award
This 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.

Special award – children
This award is for resources which are aimed at children and which are innovative or particularly well-suited for their audience.

Special award – 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 – Easy Read
This award is for a resource which uses accessible information or uses adaptive information.

Special award – ethics
This award is for resources which deal with ethical aspects of patient care such as issues surrounding mental capacity, genetic screening, confidentiality etc. It can be either aimed at the individuals themselves or their carers or could be a training resource for professional who work in this area.

Special award – innovation
This award is for a resource which presents or disseminates information in a new or original way which increases its impact. This is an award for a resource which will score highly in terms of its content but will also show an innovative approach to its production or dissemination. This might include innovative use of technology (such as web animation or interactive e-books) to maximise engagement with the intended user or innovative use of technology (such as apps, 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.

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 (among 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 – 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 – trusts
This award is for resources which are produced by trusts.

Special award – user engagement
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, user input is solicited/encouraged, the resource is incorporated into the resource and the steps taken to ensure that users of different ages, backgrounds and perspectives provide input.

Special award – young adults
This award is for resources which are aimed at young adults and which are innovative or particularly well-suited for their audience.
older people. The test is completed online, and takes less than five minutes. At the end you get a personalised report, with the option for this to be emailed to you for future reference. It asks 10 questions based on the MRC breathlessness scale and other factors that can contribute to getting out of breath regularly. In addition to the main message, your results are tailored to give your BMI and relevant links to information on our website, as well as other sources of help. 

Thank you for the opportunity to review this interesting resource. The breath test you’ve created seems well-suited to achieving your aims in a way that is, I would imagine, quite ground-breaking. The development process you used seems excellent, especially the way you involved and learnt from so many users. The test itself seems really easy-to-use. This is a great resource and I hope it helps a lot of people to take action that changes their lives for the better.’

Your diet and lifestyle: living with and beyond bowel cancer

Bowel Cancer UK – January 2017

The primary audience of the booklet is people who have been diagnosed with bowel cancer, who want to find out more about how diet and lifestyle might help them cope with possible symptoms and side effects. The booklet also provides valuable information to health professionals, which could be used as a basis for future discussions with patients. Over 260,000 people living in the UK today have been diagnosed with bowel cancer, and we know from focus groups and patient insight that there is an appetite for this type of diet and lifestyle advice among bowel cancer patients.

Prior to this booklet, a review of the available resources revealed a handful of materials aimed at reducing the risk of bowel cancer, but very little information was tailored specifically for bowel cancer patients. The booklet covers a wide range of topics, such as diet after a bowel cancer diagnosis, including during treatment, with a stoma, and how to manage side effects such as loss of appetite, weight gain or loss and cancer related fatigue. It also clearly laid-out and easy to navigate. A lot of work has gone into getting this right. Its excellent positive tone comes across in the idea that ‘it’s never too early or too late to ask for help.’ I think the guide would come across as encouraging to someone feeling down or anxious. It had excellent input at different levels and its style clearly went into the sensitivity of the topic and the different ways it might be received by men and women, this being reflected in the various user focus groups consulted and the section Men and women are different. Promotion and dissemination of the guide has made good use of Age UK’s extensive network.

Your teeth you are in control

University of Sheffield – November 2015

Over half of British children report being moderately or highly anxious about a dental visit, which can have negative impacts on quality of life and often remaining dental anxiety as adults. This psycho-educational resource aims to reduce dental anxiety in children by providing information, facilitating patient-dentist communications and offering evidence-based psychological techniques. This is the first dental resource to ever address this issue, and it comprises three inter-related components: i) a self-help information guide for dentally anxious children aged 9-16 years, which includes an innovative and interactive ‘message to dentist’ section; ii) a guide for parents/carers to better understand and supports informed discussions and decision making between patients and clinicians. Our overall objective is to help people understand what to expect, what they’re consenting to, and what they can ask their research team. Ultimately we hope this will help to reduce anxiety and fear and help patients make informed decisions and take an active role in their own healthcare. When planning and delivering this project we took into account the relative digital literacy of old populations, making sure that information is just as easy to access on and off line, as well as potential differentials in functional and health literacy between most affluent and deprived groups. Keeping this in mind, we designed the product for print (booklet) as well as online (pdf) and made sure it was easily understandable and felt relevant to people of a variety of ages and backgrounds explaining tricky concepts as simply and concisely as possible and taking into account a broad range of views by making sure we have diverse representation and skill sets among our professional and lay reviewers.

‘This is a very useful booklet for patients considering taking part in a clinical trial. It covers all of the areas that a patient might have questions or concerns about. The comments from patient ambassadors would help to reassure prospective clinical trial patients. The additional links for those who want further information are also useful and the area for notes at the back make it easy for people to note down questions they may have.’

Your home and your lungs

British Lung Foundation – February 2016

This information is targeted at people living with a lung condition who want to know the common triggers, signs, and symptoms of flare-ups of their symptoms so they can avoid them. But it is also relevant to anyone who is interested in the quality of the air they breathe inside their home. The aim is to alert people to think about what affects their breathing when they’re at home and to help them decide what they can do to minimise risks to their lung health.

‘I think this resource is good: it is attractive and written clearly, providing what seems to me to be about the right level of detail for a general audience.’

Your mind matters

Age UK – September 2016

This new guide is aimed at people over 50 who want to know more about how to look after their mental wellbeing. It’s also a helpful resource for family, friends and carers who may be concerned about the wellbeing of an older person or want to know more about how to support them. We’ll know how important it is to look after our physical health but looking after our mental wellbeing is just as important. This guide aims to raise awareness of the importance of mental wellbeing, helping people identify their risk and encouraging them to seek help if they are concerned. This guide is written in plain English and is intended for someone with little or no previous knowledge.

‘This is a good, balanced introduction to well-being for older people. It is written in simple, clearly laid-out and easy to navigate. A lot of work has gone into getting this right. Its excellent positive tone comes across in the idea that ‘it’s never too early or too late to ask for help.’ I think the guide would come across as encouraging to someone feeling down or anxious. It had excellent input at different levels and its style clearly went into the sensitivity of the topic and the different ways it might be received by men and women, this being reflected in the various user focus groups consulted and the section Men and women are different. Promotion and dissemination of the guide has made good use of Age UK’s extensive network.’

Your guide to clinical trials

Bloodwise – February 2017

Blood cancer is the third biggest cancer killer in the UK. Clinical trials are the only way that we can develop new treatments – and improve existing ones – for blood cancer patients in the future. As a research charity, Bloodwise strongly supports the entry of patients onto clinical trials, while also acknowledging our responsibility to make sure that everyone who takes part is well-informed of the risks and uncertainties and feels safe and in charge of their own medical care. In 2015, Bloodwise conducted a wide-ranging study into the needs of people with blood cancer which included quantitative and qualitative research with patients, carers and the general public. This research identified a number of key issues around the understanding of – and access to – clinical trials. On the surface, blood cancer patients appear to be relatively engaged with clinical trials. But, when patients discussed clinical trials in our focus groups there was a mixed reaction. While Bloodwise has offered basic information on what to expect from clinical trials for a number of years, it became clear that providing clear, easy to understand information on clinical trials in a way that could engage everyone affected by blood cancer should be a priority for us. We therefore began a comprehensive rewrite of our clinical trials booklet, with the aim of developing a resource that explains: what clinical trials are, why they’re important, and how they’re run; the risks and how these are mitigated in practice; what to expect before, during and after the trial, and supports informed discussions and decision making between patients and clinicians. Our overall objective is to help people understand what to expect, what they’re consenting to, and what they can ask their research team. Ultimately we hope this will help to reduce anxiety and fear and help patients make informed decisions and take an active role in their own healthcare. When planning and delivering this project we took into account the relative digital literacy of old populations, making sure that information is just as easy to access on and off line, as well as potential differentials in functional and health literacy between most affluent and deprived groups. Keeping this in mind, we designed the product for print (booklet) as well as online (pdf) and made sure it was easily understandable and felt relevant to people of a variety of ages and backgrounds explaining tricky concepts as simply and concisely as possible and taking into account a broad range of views by making sure we have diverse representation and skill sets among our professional and lay reviewers.

‘This is a very useful booklet for patients considering taking part in a clinical trial. It covers all of the areas that a patient might have questions or concerns about. The comments from patient ambassadors would help to reassure prospective clinical trial patients. The additional links for those who want further information are also useful and the area for notes at the back make it easy for people to note down questions they may have.’

‘Thank you for the opportunity to review this resource, which I think is very good. It’s great to see that there is a multidisciplinary team of healthcare professionals and several members of the target audience were involved during the development of this resource, and that the content is based on an extensive literature review. The booklet manages to cover a lot despite itself being quite short. It’s also good to see that readers are encouraged to seek more tailored information from their own healthcare team and signpost who is the appropriate professional to consult to provide further information. This is applaudable, because a lot of organisations signpost only to their own information, which I think is wrong. I think this is a very good booklet and I hope it goes on to achieve great things for lots of people.’

Your guide to dental trials

Your guide to clinical trials

Bloodwise – February 2017

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BMA board of science

The BoS (Board of Science) supports and promotes medical science on behalf of BMA members. It provides the BMA’s main interface between the profession, the government and the public, on science, health education and any public health matters falling within its remit. Through undertaking research and publishing evidence-based recommendations for action, the board is able to advise and lobby governments on key issues that concern the medical profession and impact on healthcare in the UK.

Its broad remit allows it to be reactive to issues that are of current public interest, and proactive in signposting potential areas of concern for the medical profession. To date, the BoS has produced or commissioned work on a diverse range of topics including nutrition, alcohol, tobacco, children’s health, road safety, and many more.

A key focus of the board’s work is lobbying for evidence-based public health policies. For example, it has supported the introduction of a wide range of tobacco control measures, from smokefree public places to standard ‘plain’ packaging. It has also focused on measures to improve children’s diets, supporting the plans for a sugary drinks levy and sugar reformulation programme.

Poverty and health

In June 2017 the board published a briefing Health at a price – reducing the impact of poverty. The paper outlined the different ways poverty can impact on people’s physical and mental health, and explored actions that can be taken to prevent and mitigate this.

Analgesic use

The board has developed complementary policy briefings exploring ways of supporting improvements in analgesic use. These focused on supporting safer prescribing of analgesics for chronic pain, and improving access to pain relief at the end of life, and were published in March 2017.

Current ongoing board of science workstreams include: unmet women’s health needs; prescribed drug dependence, the health impact of air pollution; antimicrobial resistance; e-cigarette regulation; mental health (and parity of esteem with physical health); illicit drug use; and vaccination.

You can find out more about the board on the BMA website bma.org.uk.
The BMA Junior Doctors Committee

The BMA Junior Doctors Committee (JDC) is formed of representatives from all four nations of the United Kingdom, and works with a variety of agencies from each respective health system to bring forward improvements for all junior doctors. The JDC has a number of different committees at national and local levels, with active and knowledgeable representatives that uphold the interests of juniors and support their peers.

The JDC has contested contracts it sees as being damaging to patients and doctors, as well as opposing wholesale education and training reforms that threatened the careers of tens of thousands of doctors in the present and the future. As further NHS changes are worked through by NHS Improvement, Health Education England (HEE), NHS Employers, and their respective equivalents in the other nations of the United Kingdom, the JDC engages with all at the highest level to ensure that changes are made in the interest of patients and staff.

The JDC is a respected voice for juniors and the profession more widely for championing improved terms and conditions of doctors, including those on training programmes. The JDC has been active in pursuing flexibility and improving work-life balance for trainees, with the committee placing the issue at the forefront of contractual negotiations in England during 2015 and 2016. The committee driving this agenda led to the creation of the Enhancing Junior Doctor’s Working Lives’ group, where the JDC worked with HEE, the General Medical Council (GMC), Academy of Medical Royal colleges and others to take steps towards increasing flexibility and working conditions for trainees.

By keeping in regular contact and building collaborative relationships with the leadership of key organisations such as the GMC, NHS England and the government, the JDC is advancing the needs of the health service and the profession in a diplomatic and effective way that has yielded results. Influencing these organisations and their leaders has resulted in changes of policy, such as the launch of the Emergency Medicine pilot in England that is trialling wider access to less than full time training, and a renewed focus on mental health concerns for the trainee workforce.

Reforms in England, such as the introduction of a renewed Code of Practice with performance indicators that allow scrutiny of the performance of HEE’s local offices and employers on provision of information to trainees, have been brought into the system as a result of campaigning and action. This scrutiny is now being sought across the four nations so that all junior doctors will be able to benefit from greater transparency around information that will allow them to have more control over their immediate future.

JDC representatives continue to lead the conversation on further reforms regarding improving the provision of education and training, ensuring improved support for doctors to return to training after time out, and for the annual review of competence progression to be reformed in order to ensure that the process is fit for the purpose of assessing doctors – both those working full time and less than full time – fairly, effectively and efficiently. Meanwhile, business as usual activities such as helping resolve industrial issues at the local level, and influencing positive changes to the rules that govern postgraduate education continue, with the committee leading the professions’ charge to see improvements to working conditions for all junior doctors, and a demonstrable improvement in patient care.