

# Information Prescriptions

## 'From Theory to Practice' Workshop Report

Developed by a partnership of the Association of the  
British Pharmaceutical Industry,  
Ask About Medicines and Cancerbackup  
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The origins of this report lie in a workshop, co-hosted by the ABPI, Ask About Medicines and Cancerbackup to discuss the role and application of information prescriptions for people with cancer, held in London on 22 May 2006.

The organisers would like to thank all who participated and shared their experiences and views.

# Executive summary

People with cancer are now faced with more choices about their treatment and care than ever before. However, many people with cancer and their carers are still not getting the basic information that they need to guide their decision-making.

The idea of information prescriptions arose from the need for people with cancer to have access to information that is more directly relevant to their diagnosis and personal circumstances, so that they are better equipped to make decisions about their treatment and future. This concept was taken forward by the Department of Health's information strategy White Paper, *Better information, better choices, better health: putting information at the centre of health*<sup>1</sup> in December 2004 and has since been restated in the 2006 White Paper *Our health, our care, our say: a new direction for community services*.<sup>2</sup>

The information prescription was originally envisaged as a source of personalised information that lays out clearly and simply the salient points about an individual's diagnosis and points the way to other relevant sources of high-quality information and services.

Information prescriptions are in their infancy, but a few innovative healthcare professionals working in cancer centres and cancer units have demonstrated their usefulness. So far, these healthcare professionals have been working in isolation and it was thought that they could gain from sharing their experiences. Therefore, a partnership of the Association of the British Pharmaceutical Industry (ABPI), Ask About Medicines and Cancerbackup hosted a workshop entitled *Information Prescriptions "From Theory to Practice"*, to bring cancer healthcare professionals together with other interested parties, including the Department of Health (DH), to discuss their experiences and the practicalities of extending the use of information prescriptions.

The workshop demonstrated that different visions of the information prescription are emerging, from free-form sketches to tick-box forms. This may reflect the variety of professionals involved, as much as the needs of people with cancer. One thing that the examples that were looked at have in common is the need for a well-resourced local information service to support the delivery of the information that is identified in the prescription. Very little has been done so far either locally or nationally to evaluate the impact of information prescriptions or to quantify the resource implications. Going forward, evaluation should be a top priority.

Encouraged by the enthusiasm and ideas generated by this meeting, the ABPI, Ask About Medicines and Cancerbackup are now calling upon healthcare professionals providing information to people affected by cancer to support this initiative and to begin piloting and evaluating information prescriptions for all people with cancer and their carers as soon as possible. To meet this objective, the partnership is offering knowledge support to healthcare professionals in cancer centres and cancer units working or wanting to begin work on information prescriptions.

# Introduction

People with cancer are faced with treatment decisions to a greater extent than almost any other group of patients, and many have to make important choices in confusing, and sometimes fast-moving, circumstances. Faced with an uncertain future, people with cancer and their carers require clear and pertinent information to help them to deal with their feelings of fear and to regain control over their lives.<sup>3</sup> However, information and communication issues continue to be a source of frustration for many people with cancer.<sup>4</sup> Either information is not applicable to their particular circumstances, or it is not available in a form and at a level that is accessible for them and their carers.



From left: Joanne Shaw – Chair, Ask About Medicine, Mary Simpson – Department of Health Lead for Information for Choice Strategy, Richard Tiner – Medical Director, ABPI and Joanne Rule – Chief Executive, Cancerbackup

Concerned about this, in 2005, the ABPI, Ask About Medicines and Cancerbackup formed a partnership to show their commitment to improving information provision for people with cancer. Their first collaborative survey, *The Cancer Information Maze*,<sup>5</sup> confirmed the difficulties that many people still have in accessing relevant information about their condition and its treatment, including the need for high-quality information on medicines and their effects.

The huge public and political interest in this report led the partnership to investigate initiatives that could improve the knowledge and understanding of people living with a diagnosis of cancer.

One of these was the potential of the information prescriptions as recommended in the 2006 government White Paper *Our health, our care, our say*<sup>2</sup> as a means of improving information and access to information for a whole range of patients and their carers, including those with cancer.

The DH has recently set up an Information Prescriptions Project Working Group, headed by Mary Simpson from the Department of Health User Experience and Involvement Group, to support the development of information prescriptions for people with long-term health and social care needs and their carers, and to better equip them to make necessary choices and decisions about their care and future life.

The Coalition for Cancer Information, chaired by Professor Mike Richards, National Cancer Director, has set up a working group to bring together, oversee and facilitate the various initiatives, within all healthcare settings, concerned with introducing patient information prescriptions for those affected by cancer. This partnership is represented on that working group by Cancerbackup.

On 22 May 2006, the ABPI, Ask About Medicines and Cancerbackup initiated a workshop involving representatives from selected cancer centres and the DH, to discuss the introduction of information prescriptions for people with cancer around the country. Their findings and recommendations are detailed in this report.

# The information agenda

The right to an 'informed choice' in healthcare is established in the 2004 White Paper *Choosing health: making healthy choices easier*<sup>6</sup> as one of the core principles of the government's drive for a new approach to healthcare in the 21st century.



Mary Simpson,  
Department of Health Lead for Information for Choice Strategy

The government has made 'putting information at the centre of health' a key component of its health agenda for the 21st century.<sup>1</sup> However, to make that change, the DH acknowledges that the quality of information and ease of access to information will need to be improved. In its 2004 strategy document, *Better information, better choices, better health: putting information at the centre of health*,<sup>1</sup> the DH sets out the need for new systems that are capable of creating reliable, consistent and credible information that is delivered to people at the right time and place and that enables them to make choices and to take an informed role in their care.

The DH has identified a number of initiatives to improve the quality and delivery of information for patients. Information prescriptions are one of these, along with other planned schemes, including power questions, the health search engine, a community information bank and the information accreditation scheme. Together, these will form the basis of the new improved information system for health and social care.

The newly formed DH Information Prescriptions Project Working Group is currently looking into the introduction of information prescriptions for people with long-term conditions, such as cancer. They are considering a number of issues, among which are:

- How do we match information prescriptions with patient care pathways?
- How do we get the content right for the different stages of cancer care?
- How do we ensure a person-led rather than a service-led approach?
- How do we ensure that people get the support they need to use the information?

## What are information prescriptions?

Information prescriptions are designed, in part, to inform people with cancer about their health and to signpost them to further information, services and support in a highly individualised fashion. They may be delivered by a healthcare professional following a discussion with a patient during an initial consultation or during any further discussions about diagnosis, treatment options, concerns and queries.

Many people with cancer feel that information provided to them about their health is too general and unhelpful as it does not apply to their particular situation or diagnosis. Information prescriptions are designed to be personalised and localised in a way that has been difficult or impossible to offer before. Importantly, information prescriptions are intended to help people to access health care, social care and other support in a more accessible and coordinated way.

# The information agenda

At present, there is no standard format for information prescriptions. Both fixed and free-form versions have proved valuable in use in centres around the UK.

## Information prescriptions in practice – examples from the cancer services

Information prescriptions are in their infancy but are already being pioneered by small numbers of cancer centres across the UK. Some of their experiences were shared at the meeting and are outlined below:

### A non-specialist cancer unit

At Oldchurch Hospital in Romford, Essex, part of the Barking, Havering and Redbridge NHS Trust, Donna Hurley, a Macmillan Information Officer, has been using an information prescription for people diagnosed with skin cancer, after realising that many people received no information from the time of diagnosis until after their surgery. Barking, Havering and Redbridge NHS Trust exists across four sites, including a community clinic run by GPs at which outpatient mole removal is performed. Those patients who require plastic surgery attend a fifth site.



The information prescription designed by Oldchurch Hospital is based on a simple tick-box format, which is quick and easy to use across all the sites. The prescription includes sections for recording the diagnosis, investigations to be carried out and agreed treatments, with contact details for an information officer who can provide further information relevant to the individual's circumstances. The prescription is filled out by consultants at the time of diagnosis and the patient is requested to contact the information officer who provides appropriate information by phone, mail or face-to-face, depending on the patient's choice.

Overall, the information prescriptions proved highly valuable in promoting first contact with the hospital's cancer information service, although language acted as a barrier to uptake in some parts of the Trust for people who did not speak English as a first language. Of the 107 people who were diagnosed with cancer during the course of the test period, 52 got in contact to request further information. Some patients were also picked up through multidisciplinary-team referrals. One area of feedback was that people with cancer were just as concerned about what to tell their children or how to obtain financial support as they were to get information about their disease, and this need should not be overlooked.

This pilot offers valuable learning – perhaps, most importantly, the need to obtain consultant buy-in and a clear explanation of the consultant's part in the process. There was a strong feeling that information should be dispensed by knowledgeable staff, and in particular that clinical nurse specialists play an important role in dispensing such information. Ultimately, it was agreed that there was a real need to work closely with all staff involved in providing information and support to people with cancer.

# The information agenda

It was noted that healthcare professionals, in particular those who move between multiple sites, often prefer to use electronic information resources as it may be easier to print off copies than to make photocopies.

Donna Hurley's observation was that in this particular NHS Trust, which serves a diverse population, the lack of translated information led to a poor uptake by some parts of the community. Information needs to be made available in languages and formats that are appropriate to the needs of diverse communities.

## A specialist cancer unit

Professor Nick James from the Institute for Cancer Studies at the University of Birmingham has developed a less structured form of information prescription to record the plan of management that is developed with the patient during their consultation. The version used at the Queen Elizabeth II Hospital in Birmingham includes space for handwritten diagrams and flowcharts, and is linked to the patient consent process. Professor James feels that a less structured approach gives greater flexibility, especially for people further down the treatment pathway – for example, at times of relapse or change of therapy.



Professor Nick James,  
Institute for Cancer Studies at the University of Birmingham

According to data collected from the Queen Elizabeth II Hospital in Birmingham, people value information received from their consultants or specialist nurse the most and are more likely to be encouraged to seek out information if instructed to by their doctor.<sup>7</sup> Information prescriptions are completed in triplicate during the consultation, with copies being provided to the patient, cancer nurse and the patient's file.



The information room  
Queen Elizabeth II Hospital, Birmingham

Information prescriptions can be provided during consultations with minimal demands on time and resources, although Professor James acknowledges that he is in the fortunate position of having an extra computer terminal that is dedicated to information provision in his consultation room. The cancer centre at the Queen Elizabeth II Hospital in Birmingham also contains a dedicated information room, adjacent to the consulting rooms, in which people with cancer are able to pick up a tailored information pack – consisting of a mixture of web-based information and traditional booklets and leaflets. Patients can discuss their needs with a dedicated patient information team, consisting of a paid manager and volunteer staff. Information provided includes non-medical topics of importance to the individual, such as transport, benefits and holiday insurance. Data shows that once introduced to the information room, people are more likely to return there on subsequent visits.

# Applicability for all

The need for information prescriptions to benefit all sections of the population was stressed by all participants at the meeting.

Black and minority ethnic (BME) groups were highlighted as having particular information requirements. Cancer is the second most common form of death within BME communities and, in the 2000 census,<sup>8</sup> 7.9% of people with cancer were found to be from BME groups. This number is expected to increase as more people from these groups adopt western diets and habits.

In general, BME patients and their carers receive less information about their condition and its management than white people, and translated materials that are given are of poor quality.<sup>9,10</sup> Overall, BME patients are:

- Less likely to be given written materials to take away from their consultation<sup>9</sup>
- Less likely to understand diagnosis and treatment options<sup>8</sup>
- Generally, provided with poor-quality translated written materials<sup>10</sup>

The workshop attendees therefore concluded that personalised information prescriptions could be of great benefit to these people.

## Meeting the information needs of diverse communities

Jackie Beavan, Communications Training Project Manager for the Pan Birmingham Cancer Network, has been involved in PROCEED (Professionals Responding to Cancer and Ethnic Diversity), a joint initiative between the Universities of Birmingham and Nottingham and Cancer Research UK.

This project confirms that there are wide cultural variations in the perception of cancer and in people's attitudes towards interventions and decision-making. PROCEED identified a number of areas in which healthcare professionals could improve their interactions with black and minority ethnic (BME) people with cancer.



Jackie Beavan, Communications Training Project Manager,  
Pan-Birmingham Cancer Network

First, the use of interpreters could be improved. PROCEED found that there was a lack of training in the use of professional interpreters and awareness of the value that they bring to a consultation – in particular, their professional obligation to remain impartial. Also, there was often a lack of forward planning to predict when interpreters would be needed, leading to underuse on occasions.

Family members or friends were frequently used for interpretation, sometimes inappropriately, leading to problems with confidentiality and the accuracy of translation. It was pointed out that informal interpreters may not understand or be able to translate accurately the medical terminology involved, and also may sometimes superimpose their own values and views, whether intentionally or not.

# Applicability for all

The PROCEED project also identified that professional uncertainty was hampering interactions with both patients and their families or carers. Surprisingly, they found that cultural awareness training may lead healthcare professionals to become less confident rather than more competent in such interactions and that this could result in them being overly cautious about offending people with cancer. The initiative suggests that any cultural awareness training should be combined with development of appropriate communication skills.

Jackie Beavan raised the following points regarding written information for BME groups, which may be of relevance to information prescriptions:

- The information needs of BME people are highly individual
- There is a need to identify how much an individual wants to know and how much they want their families and carers to be involved
- The need for interpreters should be anticipated
- Some languages do not have a written script; therefore, alternative means of communication need to be considered
- Bilingual advocates or link workers may be needed
- People who speak community languages may not be literate in them, so written information in these languages may not always be the best option
- Cultural “fact files” can occasionally be helpful if used appropriately, but may lead to stereotyping or over-simplification of complex issues
- A mixed-format approach may work best, such as combining healthcare professional advice with written material and a videotape in the appropriate language
- It is important to be aware of the range and content of materials available so that appropriate information can be selected
- Question and answer formats are highly accessible
- Use of plain, direct English should be encouraged, for example, using the pronoun “you”, as in, “You can discuss this with *your* doctor.” rather than “*Patients* can discuss this with their doctor”

# Moving forward

## Putting theory into practice

Moving the information prescriptions from an interesting concept to a useful practical aid for patients will require an intensive period of testing and evaluation. The following recommendations were developed by the partnership from the Information Prescriptions “From Theory to Practice” workshop to help healthcare professionals who are interested in piloting information prescriptions for people with cancer:



## Format

The format of information prescriptions can be flexible. They can be structured or non-structured according to need and preference.

Information prescriptions should:

- Provide enough space to reference information resources on medicines, treatments and options for the way forward, as well as details of support available and how to access it
- Be simple and easy to complete, not adding excessively to the length of the discussion with the patient or carer, and clear for the individual to follow
- Be linked to patient information pathways (different information needs at different stages)
- Be personalised and linked to the availability and organisation of local service provision – including voluntary services
- Have a consistent identity that is easily recognisable, as this is a concept that may be transferable for use in other disease areas and by Primary Care Trusts

It was noted that, in some cases, the format of any information prescriptions developed may differ because of the location in which they would be given to people with cancer-specialist and non-specialist cancer centres may have different services, resources and support available to them.

## Delivery

- People value information resources that have been recommended by their doctor. As such, any healthcare professional delivering an information prescription and/or the related information and support to the patient should try to ensure that their patient's doctor is directly involved in or supportive of the information prescription
- Consultants that are supportive of the information prescription process are more likely to empower their patients to seek information and support independently of their healthcare professional teams

# Moving forward

- Clinical nurse specialists have an important role in providing information and support for people with cancer. They may supply information prescriptions directly or may be part of the information and support referred to within a prescription
- Healthcare professionals who provide information prescriptions should ideally have a good knowledge and understanding of both health and social services, and should be able to refer the patient to other sources of support outside their area of expertise
- The provision of information prescriptions requires training and support to ensure that the information is appropriately tailored for the individual
- Patient information centres may have a role to play in helping people with cancer to generate their own information prescriptions, as well as fulfilling information prescriptions supplied to patients by others



## Piloting

- Pilot schemes, with good evaluation criteria, are seen as a priority in rolling the information prescription scheme forward nationally
- Healthcare professionals in cancer networks with a keen interest in providing information prescriptions for patients with cancer should lead the pilots, working with their teams to develop feasible and practical solutions that work within the information pathways
- BME groups have specific information needs, as well as individual ones, and it is suggested that they should be prioritised. Recommendations include:
  - Better use of advocacy and translating services (and training in their use)
  - Separating out the needs of people with cancer from those of their families/carers
  - Ensuring that resource centres are provided with quality materials in a range of languages and formats

# Moving forward

- Healthcare professionals should consider rolling out information prescription pilots across more than one tumour type
- It would help to identify the ways in which people will 'qualify' for an information prescription and to make sure that provision is available for each of these

## Getting your centre involved

- Before starting, ensure that all staff understand the term 'information prescriptions' and the thinking behind it
- It is worth checking whether anything similar already exists locally, which could be adapted
- To encourage adoption, it may be worth linking the uptake of information prescriptions to existing professional schemes, e.g. Cancer Peer Review,<sup>11</sup> Commission for Healthcare Development Standards<sup>12,13</sup>
- It may also be useful to build in the provision of patient information to the process of informed patient consent
- Information prescriptions should be built into your overall information agenda – for example, patient information pathways
- An exchange of experiences with healthcare professionals working in other cancer centres may be useful and Cancerbackup can also help with this

## Points to consider when developing an information prescription for your centre

- Existing work on patient information pathways in your cancer network will help you to decide which tumour sites you will use to pilot information prescriptions
- A process for designing and agreeing the format and content of your information prescriptions will need to be set up
- The resources and support that are available for people affected by cancer in your locality and the healthcare professionals who will be providing information prescriptions within the pilot will affect the format and design
- The content of the information prescription will be influenced by the patient information pathway relevant to people affected by cancer in your locality, and the type and level of information to be included
- Consider information prescriptions for carers within one of your pilot tumour sites
- Existing local cancer information centres could be used for people to get their prescriptions fulfilled, providing that the centres are sufficiently resourced
- Regardless of where people with cancer come into the system, they should be offered an information prescription
- Identify support organisations, both locally and nationally, that will be recommended and agree how their details will be included in the information prescription
- Consider how people with cancer will be enabled to discuss the information they receive with their healthcare professionals

# Moving forward

## Evaluation

- Evaluation is an essential part of an information prescription pilot scheme and the process should be as rigorous as possible and built in from the start
- Agree how the process of evaluation will occur and who will be responsible
- Agreed measurables should include:
  - Number of prescriptions distributed
  - Number of prescriptions fulfilled (% take up)
  - Measure of usage of information (was it read? was it useful? reasons for non-use?)
  - Measure of clinician and patient satisfaction

## Next steps

It is recommended that setting up an information prescription pilot scheme be carried out in 7 steps:

- Step 1** Appoint an individual or team to drive the concept forward
- Step 2** Ensure that the necessary information infrastructure is in place to fulfil the prescription for all target groups
- Step 3** Plan how the information prescription fits within the existing care and information pathways and develop a feasible and practical solution
- Step 4** Identify whether extra resources will be required and where these should come from
- Step 5** Agree on the format and content of the prescription
- Step 6** Build the necessary buy-in and commitment from your consultants and cancer teams and gain final agreement on provision of the information prescription
- Step 7** Plan for an evaluation within a fixed time frame

Contact Elizabeth Lodge, Partnerships Manager at Cancerbackup, for advice and knowledge to support healthcare professionals either interested in setting up a pilot of information prescriptions in cancer or already working on similar initiatives:  
Tel: 020 7920 7258, Email: [elodge@cancerbackup.org](mailto:elodge@cancerbackup.org)



# Moving forward

## Checklist for setting up an Information Prescription Pilot Scheme

Recommendations from the Information Prescriptions 'From Theory to Practice' workshop report

- Is everybody in your team/centre/Trust clear what is meant by the term 'information prescription'?
- Does anything already exist that is like an information prescription and can be developed?
- Have you talked to colleagues in other cancer centres about their experience of information prescriptions?
- Have you contacted Cancerbackup to register your interest in being kept up-to-date with developments elsewhere and to share what you learn from your pilot/s?
- Have you decided which tumour sites to use to pilot information prescriptions?
- Have you talked to all the healthcare professionals linked to the chosen tumour sites to gain their support?
- Have you set up a process for designing and agreeing both the format and content of your information prescriptions?
- Will your proposed information prescriptions meet the needs of the diverse communities within your locality?
- Will you supply a different information prescription for carers?
- Do your information prescriptions encourage dialogue between people with cancer and healthcare professionals?
- Have you included details of local and national support organisations for people with cancer/carers in the information prescription?
- Have you set up a process of evaluation for the information prescriptions?

# Conclusions

The findings of this meeting support guidance from the Department of Health that timely and appropriate information is a key need in cancer care and that information prescriptions could be a valuable tool to enable this.

Isolated uses of information prescriptions show their potential to add value for people with cancer. There is a need to take them into the wider community in a properly piloted manner, which allows for supported introduction and proper evaluation.



As cancer is at the forefront of the information agenda, it is hoped and expected that the piloting of information prescriptions with cancer care providers will provide valuable lessons to extend this scheme to other long-term conditions.

The ABPI, Ask About Medicines and Cancerbackup partnership call upon healthcare professionals providing information to patients with cancer across the UK to support this initiative and to take prompt action to explore how to bring information prescriptions to everyone diagnosed with cancer and the people who care for them.

# Contributors

Thank you to everyone who participated and shared their experiences at the *Information Prescriptions "From Theory to Practice"* workshop.

## Co Chairs

**Joanne Rule** Chief Executive, Cancerbackup

**Joanne Shaw** Chair, Ask About Medicines

## Presenters

**Mary Simpson**, Department of Health Lead for Information for Choice Strategy. The Information for Choice team is implementing a range of projects about making information more accessible to members of the public and health and care professionals.

**Donna Hurley**, Macmillan Information Officer at Oldchurch Hospital, where there is a Cancer Unit. Donna set up a Cancer Information Centre at the hospital in June 2005 and began a trial of information prescriptions in January 2006.

**Professor Nick James**, Professor of Clinical Oncology, Queen Elizabeth II Hospital, has a specific interest in patient information provided via the web, and co-founded CancerHelpUK. He has been working on information prescriptions and similar ideas for the past 5–10 years.

**Jackie Beavan**, Communications Training Project Manager, Pan Birmingham Cancer Network, is based in the Department for Primary Care and General Practice at the University of Birmingham. She was part of the project team that researched and developed the PROCEED training package .

**The Association of the British Pharmaceutical Industry** ([www.abpi.org.uk](http://www.abpi.org.uk)) is the trade association for about a hundred companies in the UK that produce and research prescription medicines. As part of its role, it has worked with Datapharm to provide an online resource [www.medicines.org.uk](http://www.medicines.org.uk) to help patients access information on medicines.

**Ask About Medicines** ([www.askaboutmedicines.org](http://www.askaboutmedicines.org)) is the independent campaign to increase people's involvement in decisions about their use of medicines. The aim of the campaign is to contribute to people's ability to control their own health and healthcare through better understanding of what medicines do and how to make the most appropriate use of them.

**Cancerbackup** ([www.cancerbackup.org.uk](http://www.cancerbackup.org.uk)) is the only national charity that specialises in providing information about all types of cancer. All Cancerbackup services are free for people with cancer and their relatives and friends. These services include a freephone information service, staffed by cancer nurses, available on 0808 800 1234 (Monday-Friday, 9am-8pm) and a number of local cancer information centres offering information and support on a drop-in basis.



#### Further reading:

Full slide presentations from the workshop can be found at:

[www.cancerbackup.org.uk](http://www.cancerbackup.org.uk)

[www.askaboutmedicines.org](http://www.askaboutmedicines.org)

Copies of *The Cancer Information Maze* report are available from Cancerbackup; Tel: 020 7920 7258 or via the website [www.cancerbackup.org.uk](http://www.cancerbackup.org.uk)

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