



## **Information Prescriptions**

**The Role of the Voluntary Sector - Workshop**

**31 July 2007, Goodenough College, London**

**Report for Department of Health**

24 August 2007

working with you

to improve social results

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## Introduction

This workshop brought together representatives from the voluntary sector, who were either engaged with individual pilot sites, or part of the Steering Group or Working Group. The Department of Health was keen to learn more about the perspective of the voluntary sector to inform its preparation for national roll-out.

The workshop objectives were to:

- share insights across the sector;
- identify lessons learnt during the development phase of the IP pilots -
  - progress and key achievements
  - barriers and gaps;
- capture the contribution of the voluntary sector to the development of IPs;
- explore opportunities and challenges for the national roll-out of IPs;
- agree support needs and actions to support information prescribing during the remainder of the pilot programme.

The workshop began with small group discussions of what success would like, and what the experiences to date have been in trying to deliver IPs successfully in the pilots. Most of the rest of the day was taken up with small group discussions of key aspects of IPs on four themes: understanding user needs and addressing inequalities; producing directories of information (including governance); balancing local and national content; and prescribing and dispensing. The final plenary session was a short discussion on the benefits and costs of IP to the voluntary sector. An OPM facilitator supported each of the group and plenary discussions throughout the day. This report provides a summary of each of the discussion sessions.

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## Main messages from the workshop

Participants were broadly in agreement that there is a significant need and potential for voluntary sector involvement in IPs, but that there were a number of critical issues that need working through.

**Success for users** was defined as empowering individuals to ask for and receive high quality tailored information and support via an appropriate channel. **Success for the voluntary sector** was thought to include building closer relationships with statutory bodies in order to provide holistic support to individual service users, and greater acknowledgement for and awareness of the work done by voluntary organisations to inform and support individuals. **Success for the health and social care sector** was thought to encompass stronger ties across different organisations, improved skills among professionals to assess and respond to user needs and greater awareness of information resources. Connecting up across different organisations, and persuading all professionals of the value of IP, remains a challenge for pilot sites. However, the enthusiasm of some staff and many users reinforces the value of the concept.

Participants thought that IPs have the potential to **address inequalities** provided that disadvantaged groups are carefully targeted. Users must be offered a range of channels for receiving information, and some will need substantial additional support. Community and voluntary organisations were thought to be best placed to provide this more intensive support, and needed to be involved not only in dispensing but also in encouraging people to access services in the first place.

When thinking about **directories of information**, participants were keen to ensure that there was clarity about the information needs that could be met by an IP. Some also advised against ruling too much material out, and suggested that the national directory should be an information hub, rather than being the single approved information source. There needed to be clear processes for collating, assessing and up-dating information, monitoring performance and ensuring ease of access for professionals and users.

In some settings, **prescribing and dispensing** can be done in one place – more frequently, users need to be signposted to other resources or organisations for dispensing. Some of the obstacles hindering the process are practical – such as lack of time or IT facilities. Given the challenges in getting these and other processes right, it was suggested that the roll-out needs to be developed incrementally.

Finding the right **balance between what is determined nationally, and what locally**, is very difficult. Even agreeing on a sensible definition of what local means is a challenge. Either the

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architecture by itself, or the architecture and condition-related content as well as standard information around, for example, benefits, should be developed nationally. There should be some form of local discretion to select from the agreed resources. Information about local services should also be generated locally, building on existing local authority databases.

Finally, the participants discussed the **benefits and costs** of national implementation. IP could help forge closer connections and synergies between the voluntary and statutory sectors. It might also increase the demands on voluntary organisations, or create divisions within the sector between approved and non-approved providers of information and support.

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## Workshop sessions

### Success elements of IPs and IP systems

Participants were asked to consider what success might look like for users, the voluntary sector, and the health and social care sector. The main points from these discussions are clustered thematically below.

#### User focused

- They have the user at the centre (e.g. *“think about what would be useful to a child with cancer and for its carers”*).
- They have to be dynamic – responding to the needs of users as these evolve.
- They include feedback loops where users comment on what is useful and what is not.
- They empower users not only to ask for the information they need, but also to demand a better service from their professionals and to engage more fully with the self management of their condition.
- The prescribing and dispensing processes should facilitate a conversation between the professional and the patient or client, which fosters better understanding on both sides and gives the individual confidence to ask for what they need.
- Users have all the information that they want about their condition, when they want it, and in a form which works for them to use and share with other professionals if needed.
- They develop users’ capacity and confidence to ask the right questions.

#### Quality of information

- They provide reassurance that the information sources are of the right standard and up-to-date.
- They are clear about which information is robust, by using an accreditation system or kite marks.
- They are informed by what has been found to work through reviews of a wide range of evidence sources.
- There are processes in place for dealing with misinformation and its consequences.

#### Range of information

- They also allow *“open source information”*. This may vary more in quality but will be important to some people. Given the variation in quality, such information needs to be accompanied by an indication of its reliability or value.
- They are on-going – you keep on learning if you want to.
- They avoid overlaps of information.
- They should not overemphasise health or medical conditions but rather should cover a broader spectrum. There is a risk that because health and medical information has been codified more extensively, it will take priority in information directories.

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- They include information about legal rights (e.g. your rights as an employee to look after a child with long-term illness) as well as promote what is good practice (e.g. what leading employers offer).
  - They balance national and local information.
  - All IPs should contain standardised core information for the condition, relevant to the individual's circumstances (eg point on care pathway), and specific information responding to other needs.

### **Accessibility**

- They enable access.
- There need to be targeted "*fulfilment portals*" which make sense to different user groups.
- There is support in place to help people follow through and access the information.
- They encourage membership of support organisations, giving users access to an on-going supply of tailored information and support.
- They have special processes to reduce social exclusion and inequalities. This means including access to advocates and similar face-to-face services.
- Individuals from some communities, such as some BME communities, may be reluctant to access services at all. IPs should create new routes into services for such users.

### **Multiple providers**

- They create "*seamlessness across services*".
- They connect different information systems. They create a "*whole system source*" across different services.
- They stimulate an improvement in professional skills to both assess information needs and give appropriate information and support.
- Giving information becomes a "*must do*" in the statutory sector, not just an optional extra.
- The responsibility for information provision is shared. The statutory sector needs to be responsible for core information, leaving the voluntary sector to provide a complementary service, offering support and developing innovative ways of sharing information and responding to more specific information needs.
- They explain what is available from whom (e.g. what can different services/professionals do for you).
- There is greater awareness of the range of information and support organisations linked to different conditions, among both users and professionals in the statutory sector.
- The statutory sector needs to take responsibility for information in partnership with the voluntary sector, and not simply signpost to voluntary sector organisations. In practice, this means responding to a breadth of information needs and allocating funding to, for example, purchasing leaflets if they are found to be particularly useful.
- There need to be diverse delivery models, not only through health and social care systems but other organisations such as CABs.

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- There should be scope for volunteers, health advocates and other trained lay people to provide IPs.
  - IPs will place great pressure on the voluntary sector. The voluntary sector is highly supportive, but there needs to be scope for SLAs or other processes for managing funding and performance.
  - GP practices are a major challenge. There should be information champions in practices and GPs also need incentives (QOAF points). GP practices could be linked up to local fulfilment centres.
  - You can track what has been given by whom and when by different providers across the health, social care and voluntary sectors.

### **Branding and promotion**

- IPs need to be branded and promoted nationally and locally.
- There needs to be a “*national vocabulary and brand*”.
- Promotion of IP needs to take place at all levels, including in schools.

## **Achieving success – experiences so far**

Participants were asked to reflect briefly on the primary achievements and challenges of the pilots to date.

### **Achievements:**

- A significant achievement has been successful engagement with users. Many of those consulted are very positive about IPs and feel that IPs meet a real need not only for information but also for reassurance and support.
- A particular contribution of the voluntary sector has been to challenge statutory partners to think in new ways about their service users. For example, getting to re-think the language they used (changing the name from Information Prescriptions).
- Involving voluntary sector partners in the delivery of IPs offers service users a choice. Some users will prefer to receive information from statutory partners, while others feel more comfortable accessing voluntary or community based organisations.
- Most has been achieved in those areas where there are champions, able to galvanise interest and co-operation from colleagues, senior staff and partners.

### **Challenges:**

- There have been significant difficulties in getting professional buy-in, especially from consultants and GPs.
- It has also proved difficult in some cases to persuade professionals to discuss or respond to information needs which are beyond their professional expertise.
- Sites have found it hard to provide templates in different formats to meet particular needs, partly for reasons of time and budget.
- Timeframes for the project and capacity within project teams remain an on-going concern.

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## Development sessions

In each of the development sessions, participants were asked to think about:

- the approaches being developed in the pilot sites;
- the support needed for IPs in order to maximise success;
- the key messages for the national roll-out.

## Understanding user needs and addressing inequalities

### Meeting user needs

- The existing dynamic between health professional and patient often reflects an actual or perceived power imbalance. IPs could redress this balance. IPs could take the onus away from individuals to “*get up the courage*” to ask for what they need, by providing them with implicit permission to question professionals. Currently service users are often seen as awkward if they do ask questions.
- IPs have great potential to help disadvantaged groups, but these groups will only benefit from IPs if they are targeted specifically. Many do not even have an access point into the system, so IPs need to be linked with outreach activities by community based organisations or local authority community development and outreach workers.
- If the success of the programme is calculated on the basis of volume (ie the number of IP recipients) then disadvantaged individuals will be overlooked, because reaching them and meeting their needs is more resource intensive.
- There needs to be follow up support to encourage people to access and use the information.
- “*Supplying information is the start of a relationship, not the end of the story.*”

### Channels and format

- There must be a variety of channels – no one channel will work for every user. There needs to be an evaluation of the channels which are appropriate for particular users.
- More specifically, there should not be an over-reliance on the web – many individuals still do not have internet access or IT skills. This holds true both for potential users and some professionals.
- There needs to be extensive and careful user mapping, followed by consultation to determine what channels are needed by and appropriate for, different needs (eg language needs, low literacy, sensory impairment etc).
- Take up rates by particular communities of each channel needs to be monitored, and delivery mechanisms adapted where necessary.
- All users should be asked what format they want the information to be given to them in – the options will include, for example, which language and medium. These preferences should be stored with the patient or client record for reference.

### Organisations and processes

- It is important that there are sufficient checks and balances in the system to quality assure all the information provision – the responsibility should not be delegated down

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to community level organisations unless they are linked back into the governance and monitoring arrangements of the rest of the sector.

- This work needs to be part of someone's job – and on the agenda for the commissioners – not just an add-on or an option.
- People from disadvantaged groups often have multiple health needs, as well as complex needs in other areas, therefore the connection between the IP processes and templates and information sharing protocols across different conditions need to be strong.
- There are significant training needs associated with working with disadvantaged groups or those with special needs.

## **Directories of Information**

### **Content**

- At the core, directories should be user-focused. They should contain good information with links to other useful sources and organisations and helplines.
- Directories can contain clusters of information which is geared around common issues. There could be algorithms which select suitable materials on the basis of assessment questions. Directories could also be built around client segmentation.
- There should not be an assumption that national sources always are better than local ones; if a source is good, it should be included regardless of the reach of the organisation.
- There is a fear that by opting for a "Rolls Royce" model of directories, many information sources will be excluded; it may be better to have a network of networks, rather than a single source to which everything else has to conform.
- Is there a distinction between national directories of information and local directories which offer signposting to local services/sources, but not information content?

### **Usability**

- Directories need to include "*maps of where to go*" built on directories of services produced by PCTs and local authorities. Could this be linked to automated searches (e.g. by postcode)?
- Whatever is produced, it needs to be effective for GPs.
- Directories need to offer guidance on how to use information (e.g. help people to self-service or deep-service).
- We need to be realistic – IPs cannot do everything; we need to be clear about what is in and what is out

### **Processes and policies**

- Good directories require these processes: i) clear processes for collating information; ii) clear and transparent assessment/QA processes; iii) ease of access for professionals and users; iv) a sustainable updating process; v) governance which monitors and reviews performance and which has user involvement at its core.

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- The link to the Information Accreditation Scheme is important - but if this does not come into operation until summer '08, will it delay IPs?
  - Directory governance needs to have a strong local component. Could there be a role for scrutiny committees or LINKs?

## Prescribing and Dispensing

### Settings

- In a number of environments IPs fit well into existing cultures (e.g. specialist nurses, services which involve intense treatments – often involving specialist multi-disciplinary teams; mental health services). Often in these settings, prescribing and dispensing can be achieved in a seamless way or at least on-site (e.g. through an information centre).
- In most settings, there is more of a separation between prescribing and dispensing.
- There are many practical obstacles (e.g. no IT, no printers, nobody in charge of necessary infrastructure) to putting an IP prescribing or dispensing process in place.
- To what extent should users have a choice over where they go for their prescription and collection of information? There certainly needs to be some flexibility. It would be helpful to have a range of fulfilment points, some of which should be community based (one-stop-shops; LIFT projects; libraries etc).
- There also should be open access points or processes so that people can self-service.

### Benefits for the user

- It is desirable for IPs to be part of a dialogue. This has positive outcomes for both user and provider.
- Prescribing needs to be tangible. It needs to “*mean something*” more than just making information available.
- You need to be able to measure uptake and actions taken for specific communities, so as to track any differential impact on particular groups.

### Other considerations

- The processes - and roll out - needs to be developed incrementally.
- There need to be clear underlying and guiding principles for delivering IPs.
- There need to be a wide range of channels available to ensure that people with disabilities, low levels of literacy etc can use IPs.
- A major challenge is the recording of IPs. Most organisations do not have adequate IT processes. Furthermore, information cannot be connected up – how important is it to record? Some felt this was very important, because each professional in contact with an individual should be aware of what information has been shared.
- Although there should be different models to allow for variations in settings and needs, there also should be a common core. The ratio of core to variable content will need to be based on a good understanding of what works (e.g. uptake and outcomes).
- Could there be client-based information folders?

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- There is a need to track the contribution of the voluntary and statutory sectors to the process, and align resources appropriately.
  - While sign-posting is inevitable if the prescribers are GPs or other professionals with very brief contact time, there was a concern that signposting to multiple organisations is unsatisfactory for the user. For example, to meet all their information needs, a user might be signposted to five different organisations.

## **Balancing local and national content**

### **National versus local**

- Participants recognised the difficulty of balancing the need for consistency and assured quality with the benefits of local discretion and tailoring. Some felt that condition related and standard information (for example around benefits) should broadly be agreed at national level, while information about local services should be produced at the local level. However, even if there was to be a nationally agreed sets of condition related resources, there could still be local discretion in selecting which best meets a user's needs. For example, there might be three approved leaflets on caring for someone with dementia, each of which has a slightly different style or emphasis and therefore is suited to different audiences. Some felt it might be more appropriate to think of the architecture of the information directory to be agreed at national level, which would then be populated locally.
- The key principles drawn from Macmillan's work with the cancer networks on information pathways are: evolution (don't expect to do everything at once, create opportunities to build in the learning); service user input; local involvement; and multi-disciplinary participation.
- If local authorities were given the task of providing information about all the community and voluntary organisations in an area, this would simply require them to do what they already do but in a more rigorous way, and to feed their databases into a system accessible by a wider network of professionals.

### **Choices and quality**

- There will be less choice about information sources if a condition is very unusual
- Assuming that issues of quality have been resolved, who has the right to say what should be included on the IP? The issues around choice need to link into the governance process.
- Professionals will want to have a sense of ownership – not be told this is the only piece of information you can give out on this topic. Some recipients of IPs will also want to have a say.

### **Governance**

- There was some discussion about the appropriate body to take responsibility for overseeing local information generation, quality assurance and up-dating. While there was

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general agreement that IP should piggy back on existing structures, it was less easy to determine which structure is most suitable. Suggestions included SHA, PCT or local authority boundaries. How is information governed if it is not part of the NHS? The composition of these oversight groups was a matter of some debate. Did there need to be expert input for each condition? How do you build in user involvement - through a separate process, with PALS or LINK.

- The commissioning arrangements at national and local level also need working through.

## **Benefits and Costs**

- It is difficult to have a sense of the demand on the voluntary sector caused by IPs and there is potential for the reputation of voluntary organisations to be damaged if they cannot respond to the volume of requests. High levels of demand could cause websites to crash, helplines to be blocked, supplies of leaflets to run out, and those asking for information or support to be turned away.
- The accreditation process for information providers may set up rivalries between voluntary sector organisations, and may exclude smaller organisations who cannot afford to be accredited. Numbers of contacts with organisations which are not accredited may go down, even if they are the best option for some individuals.
- There is a distinction to be made between the different ways in which the voluntary sector can contribute: information generation; information review and quality assurance; information provision; and support. These different tasks require different funding models. Smaller organisations are best suited to the latter two, and larger, often national organisations can do all five. Organisations might be paid for numbers of contacts, the development or sharing of information, or to provide a particular service such as an additional helpline or outreach service in primary care settings.
- There were also concerns that funding might be available initially and then withdrawn, with voluntary sector expected to take up the slack.
- There is significant potential for health inequalities to be increased, particularly if the roll-out is rushed, rather than delivered in stages.

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# Appendix 1: Programme

*Goodenough College, 31 July 2007*

## **Objectives**

National and local voluntary sector organisations are involved in developing and piloting information prescriptions in most of the 20 pilot sites. This workshop is for voluntary sector organisations and is intended to:

1. Share insights across the sector.
2. Identify lessons learnt during the development phase of the IP pilots
  - a. progress; key achievements
  - b. barriers and gaps
3. Capture the contribution of the voluntary sector to the development of IPs.
4. Explore opportunities and challenges for the national roll-out of IPs.
5. Agree support needs and actions to support information prescribing during the remainder of the pilot programme.

## **10.00 Coffee & Croissants**

Informal networking

## **10.30 Introductions and Overview**

### **Defining Success**

Successful outcomes for users, the voluntary sector and health/ social care

## **11.15 Achieving Success**

An exploration of experiences of developing IPs.

## **12.00 Break**

## **12.15 Development Workshops**

**Theme 1: Understanding user needs and addressing inequalities**

**Theme 2: Producing directories of information (incl. governance)**

## **13.00 Lunch**

## **13.45 Development Workshops**

**Theme 3: Balancing local and national content**

**Theme 4: Prescribing and dispensing**

## **14.30 Feedback**

Feedback of key messages from the four thematic workshops

## **15.00 Break**

## **15.15 Benefits and Costs of IP for the voluntary sector**

## **16.00 Close**

## Appendix 2: Attendance list

Organisation	Name	Surname	Email
Rethink	Rebecca	Arici	rebecca.arici@rethink.org
Long-term Medical Conditions Alliance	Andy	Ball	AndyBall@ltca.org.uk
Citizens Advice	Marolyn	Burgess	marolyn.burgess@citizensadvice.org.uk
MacMillan Cancer Support	Ruth	Carlyle	rcarlyle@macmillan.org.uk
RNID	Louise	French	louise.french@rnid.org.uk
CLIC Sargent	Susan	George	susan.george@clicsargent.org.uk
Asthma UK	Nicola	Kingston	nkingston@asthma.org.uk
Cancer Research UK	Martin	Ledwick	Martin.Ledwick@cancer.org.uk
Cancer BackUp	Anna	Leibowitz	aleibowitz@cancerbackup.org
RNID	Helen	Liles	helen.liles@rnid.org.uk
Cancer BackUp	Elizabeth	Lodge	elodge@cancerbackup.org
Arthritis Care	Abigail	Page	abigailp@arthritiscare.org.uk
Cancer Research UK	Debbie	Rodbard	Deborah.Rodbard@cancer.org.uk
RNIB	Rebecca	Sheehy	Rebecca.Sheehy@rnib.org.uk
Diabetes UK	Bridget	Turner	Bridget.Turner@diabetes.org.uk
Rethink	Mick	Wallace	<u>Mick.Wallace@rethink.org</u>

## Appendix 3: Evaluation responses

Total responses 15 – 94% of all attendees.

### Q1: How would you rate the learning sets on the following?

	Excellent	Good	Satisfactory	Poor
A. Introduction and overview (responses: 15)	13%	53%	33%	0
B. Defining success (responses: 15)	7%	53%	40%	0
C. Achieving success (responses: 13 – 2 blank responses)	7%	53%	27%	0
D. Development workshops 1 (responses: 14 – 1 blank response)	13%	53%	27%	0
E. Development workshops 2 (responses: 14 – 1 blank response)	13%	40%	40%	0
F. Benefit and costs (responses: 14 – 1 blank response)	7%	33%	53%	0

### Q2: Venue, facilities and organisation?

	Excellent	Good	Satisfactory	Poor
A. Administration (including booking/pre programme information)	20%	73%	7%	0
B. Venue	40%	60%	0	0
C. Catering/quality of food	40%	60%	0	0

### Q3: Do you have any other comments or suggestions?

- Broader recruitment across social care (e.g. crossroads, carers, N&K, etc). Not just health charities would aid discussion.
- As a new attendee I found the workshop very informative.
- For me, very interesting to see where people are up to.
- It feels that some of these questions are premature. Waiting just until the pilots can be fully received would be more helpful – the roll out would not happen prematurely before these discussions have been revisited.
- Very useful – well facilitated.
- Would have been useful to have a wider range of attendees from different sectors/backgrounds.
- Yes – run a similar day again but expand the number and variety of voluntary sector organizations invited.

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- Not really sure we covered all this but still found the discussions interesting, if somewhat daunting!
  - Short notice. Good/useful event + good to raise Q's + issues. Bit more structure around Q's would be helpful – as easy to go off tangent.