

# Evaluation and Impact of the Report “Making the Case for Information: The evidence for investing in high quality health information for patients and the public”

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# Section 1

## Key Points

- 93% of those completing the survey found Making the Case for Information (the report) useful or very useful, summing it up as clear, concise and well written
- 80% had used the report for their own information and reference and 64% had shared it with their organizations
- The impact of the report had varied greatly with some people able to gain resources and influence policy, sometimes on a country wide basis, whereas others had found it lacking in the robust economic arguments or statistics needed to convince funders
- Evaluation participants recommended that next steps for the project should be further research, guidance to raise information standards or lobbying to improve health information provision nationally and locally.

## Section 2

### Executive Summary

#### **Background**

The report *Making the Case for Information: The evidence for investing in high quality health information for patients and the public* was produced in summer 2013 for the Patient Information Forum (PiF) and distributed across the UK. The evaluation has assessed its impact since the launch of the report using both quantitative and qualitative research. This research included discussions with a small number of PiF members/audiences. The points raised and ideas expressed as part of this evaluation are highly valuable and relevant to both the development of this area of work and PiF's overall activities. However due to the limited number of people involved, they should be seen as starting points for further consultation or research with PiF members and other stakeholders.

#### **Who read the report**

The majority of people reading the report were members of PiF but a third were non-members, indicating that the report did reach a wider audience than just PiF members. The majority of readers were involved in information and half were from the voluntary sector. However many respondents undertook roles that included information but were not necessarily their only role. For instance there were GPs, researchers, clinical governance leads and commissioners who had used the report.

#### **What people used it for**

The majority of people had used it to inform themselves and colleagues. For instance, people had used it as references in their work or in presentations. Others had used it specifically in writing business plans and applying for resources but with mixed results. There were examples where the report had been very useful in obtaining resources or influencing policy makers. In other cases it was unsuccessful as it had not been specific enough or did not contain the type of convincing information needed to influence funders and commissioners.

#### **What is needed next**

Many had no plans to use the report further but some were still using it, for instance to develop business plans. There were a number of suggestions on how the next version of the report could be improved. PiF was seen as the main lead in following up the report with effective campaigning and lobbying work.

## Section 3

### Background

#### The report “Making the Case for Information”

The report *Making the Case for Information: The evidence for investing in high quality health information for patients and the public* was produced by the consultancy firm Grant Riches in summer 2013 for the Patient Information Forum (PiF). The report was available in full or as an executive summary. In addition three short briefing documents were produced aimed at health professionals, information specialists and commissioners and policy makers.

The report and its key findings were disseminated to a wide range of stakeholders and interested parties using conventional and social media, networks and contacts, events and presentations and word of mouth. The Patient Information Forum estimate that the report was disseminated to at least 3,000 people and organizations.

A small evaluation research project by an independent researcher has gathered some data on the impact of the report in the year since its launch. In particular the evaluation explored the following aspects:

- Who read the report and used it
- What was their impression of PiF
- What they thought of the report: good and bad and what was missing
- What they did with the report, if anything
- What impact it had in terms of changing attitudes, services or practice
- What readers of the report would like to see happen next

The research involved a relatively small number of people and for this reason, the ideas and issues raised should be seen as starting points for further consultation or research.

#### Methodology

Qualitative and quantitative methods were used. These were:

- A survey. This attracted 32 responses.
- Semi structured one to one interviews. 19 people were telephoned plus one person sent responses via email.

Requests to participate in the survey was sent via email, social media and newsletters and by announcing it at conferences and events, similar to the way the original report was disseminated. Therefore responses were random.

The deadline for responses was extended twice as the original deadline coincided with Easter. However the second extension attracted no further responses. Interviews were targeted to encompass a range of perspectives such as information producers, commissioners, policy makers, researchers and health care practitioners, both at secondary and primary level. Seven of the interviewees were recruited through the survey.

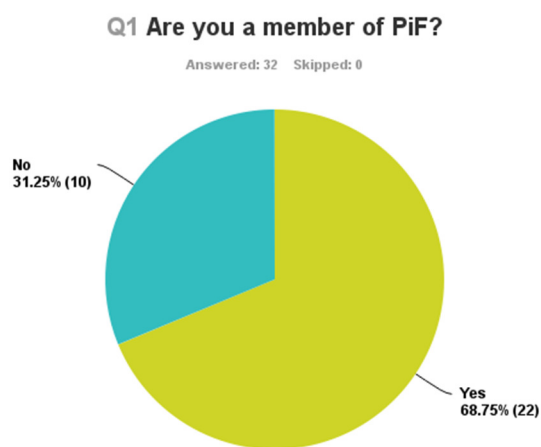
# Section 4

## Findings

### Introduction

The findings section sets out to answer the research questions using both qualitative and quantitative methods. The survey provides all the qualitative data, but comments from the survey also adds to the qualitative data.

#### 4.1 Who Read the Report?



#### Survey

Two thirds of respondents were members of PiF and a third were non-members.

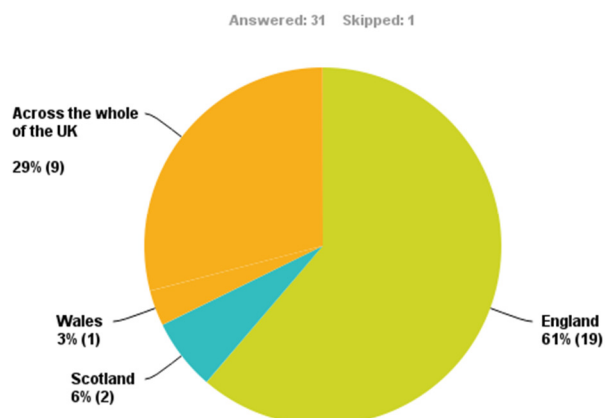
#### Interviewees

3 out of 20 interviewees had not known PiF before the report. 17 were members, with a couple rejoining after the report was produced, one person stating the report was the reason for rejoining.

#### Survey

Almost two thirds of respondents were from England and almost a third were UK wide. There were double the number of respondents from Scotland to Wales but both numbers were very small. No one from Northern Ireland responded to the survey.

**Q3 In what country in the UK do you work?**

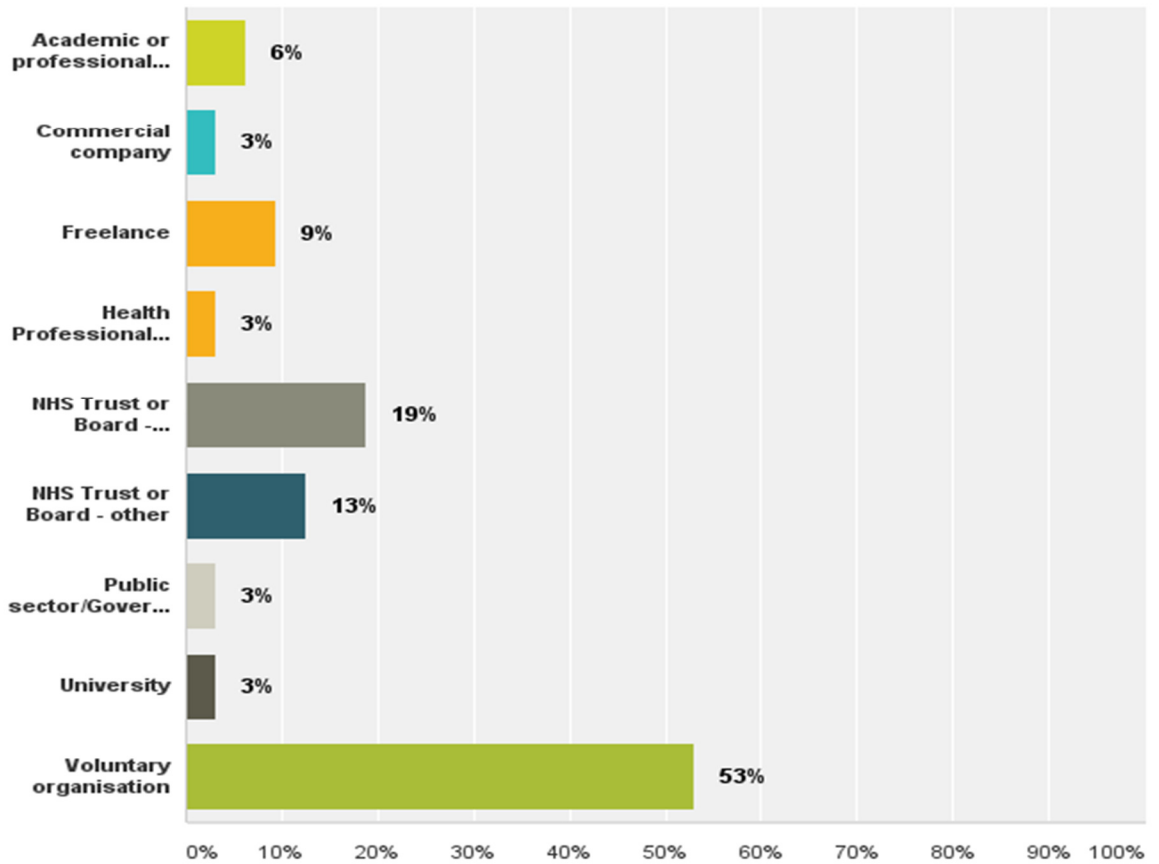


#### Interviewees

There was one interviewee from Wales but no interviewees from Scotland or Northern Ireland.

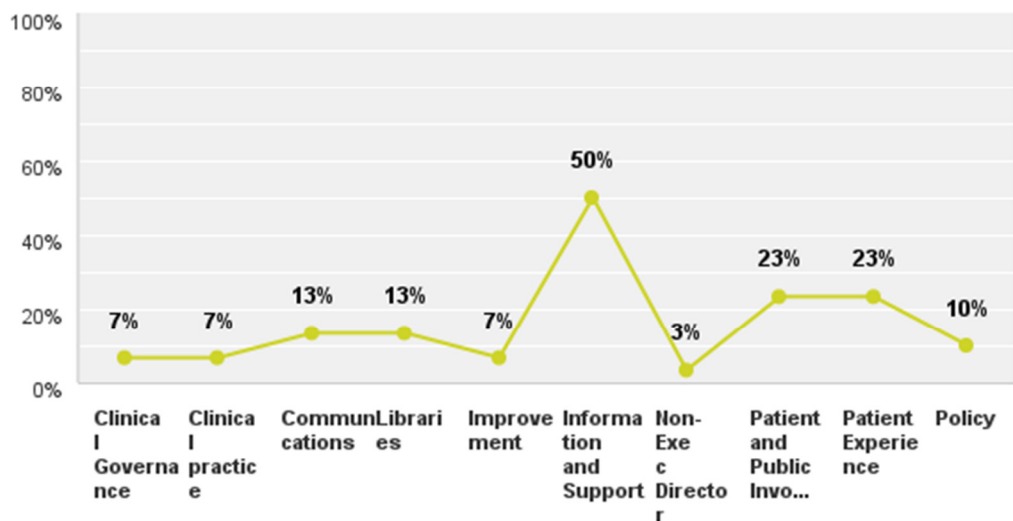
## Q4 What sector do you work in?

Answered: 32 Skipped: 0



## Q5 What area do you work in?

Answered: 30 Skipped: 2



## Survey

The survey used a number of different categories to understand the profile of respondents. Respondents were invited to select as many categories that applied. How respondents categorized themselves was very dependent on the categories offered in the survey. This can be contrasted to how interviewees described their roles. From the categories provided however, over half the respondents were from the voluntary sector and just under a third worked in the NHS. Half also categorized themselves as working in information and support. Almost a quarter worked in patient and public involvement, and the same number selected patient experience. These numbers could have included the same people. However no-one worked in PALS.

## Interviewees

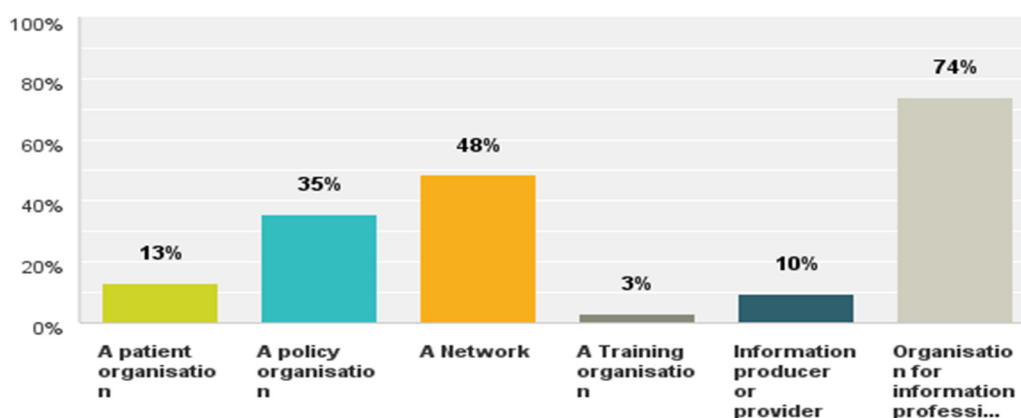
The interviewees were selected to fill some of the gaps from the survey –for instance commissioners, primary care, and health care practitioners. However interviewees also demonstrate the difficulty of people explaining their information roles and the many different roles and experience that people fulfill. The spread of interviewees over the 20 people were:

- 6 information producers from the voluntary sector
- 3 information producers from the statutory sector
- 1 information producer from the private sector
- 3 information providers from the statutory sector
- 3 lecturers/trainers
- 3 researchers/academics
- 4 commissioners (1 CCG and 3 commissioning nationally)
- 6 health professionals (2 General Practitioners, 3 nurses and a dietician)
- 4 policy makers (including 1 international expert)
- 8 information leads for their organizations (5 voluntary sector and 3 statutory sector)

## 4.2 Descriptions of PiF

### Q2 What kind of organisation do you believe PiF is?

Answered: 31 Skipped: 1





## Survey

Almost three quarters of respondents thought of PiF as an organization for information professionals, with almost half classifying it as a network. Over a third thought of it as a policy organization.

## Interviewees

The interviewees mainly agreed that the Patient Information Forum was an organization for information professionals and was a network.

The other strong themes were its role as a lobbying and campaigning organization on the quality of patient information, as well as its cross sector membership (voluntary, statutory and private sector).

There was an understanding of PiF's capacity issues so it "*needed to be strategic*" and it was there to "*call government to account*". For a number of interviewees PiF had a role in ensuring further research happened and that research recommendations were then implemented.

Some of the good things it provided included the newsletter, email alerts, events and the website. One person commented "*there have been improvements to PiF and it is coming into its own - producing credible reports and offering practical support*" (Voluntary sector producer).

There were a number of suggestions on what could be improved. For instance, there was a criticism of having to sign into on line discussion groups which could be cumbersome if you wanted to comment on a number of threads. The same interviewee found it difficult to find people through the website.

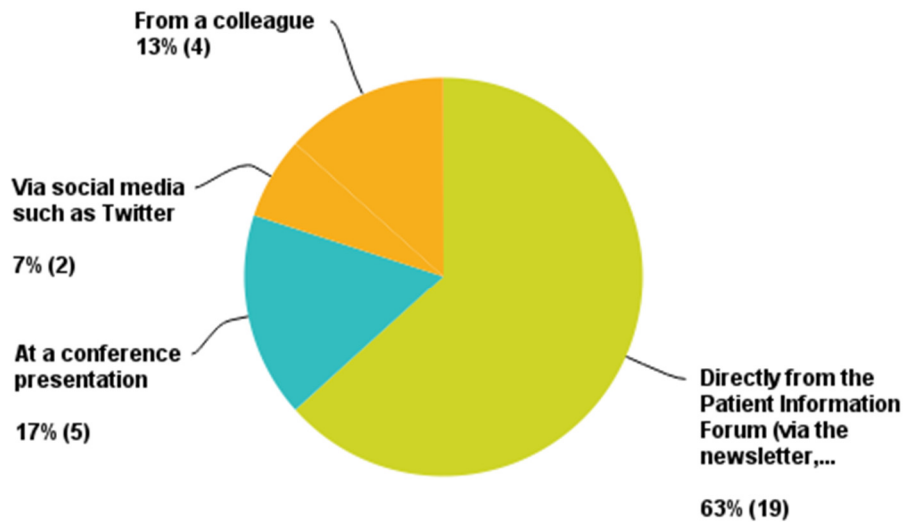
One person thought the profile of PiF needed to be raised, another wanted PiF to be more active on twitter and suggested "*Learn from Boots and Virgin health care on their digital work*" (Provider Statutory sector secondary care). Another said, "*Use digital media more, for instance 50% of calls to the 111 service is via mobiles and therefore having information that can be read easily on a mobile is important*" (Producer Statutory sector).

Another person thought PiF was "*effective in supporting the network in the consumer health field*" but was "*less successful in making the broader case*" (Policy maker Voluntary Sector). One interviewee who had known PiF when at a larger voluntary organization was now in an organization that was too small to afford the fee.

### 4.3 Finding, reading and sharing the report

#### **Q6 How did you find out about the Case for Information?**

Answered: 30 Skipped: 2



#### Survey

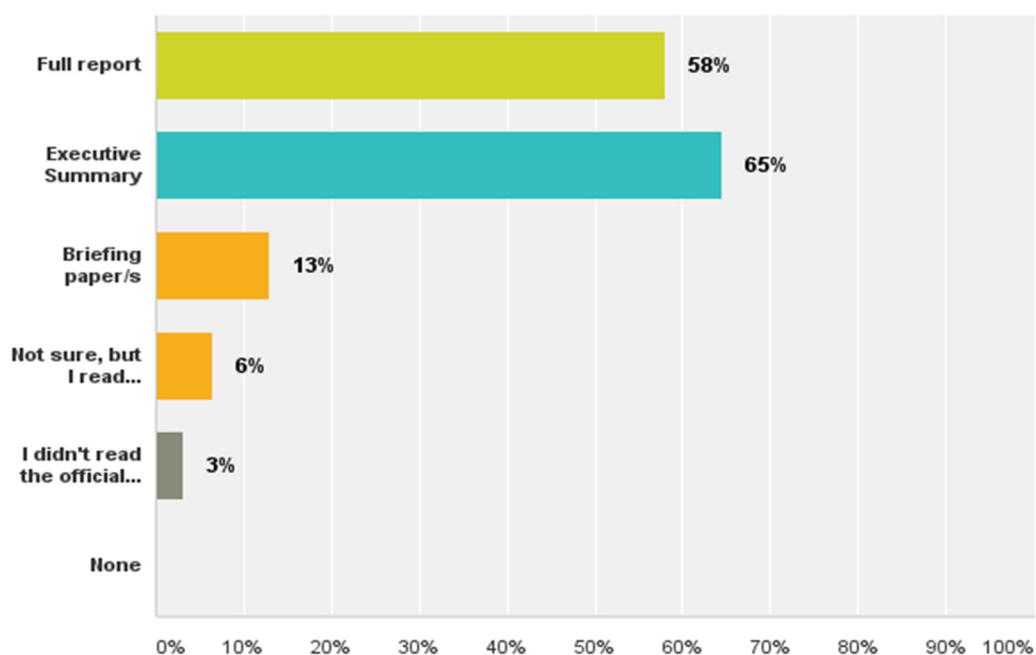
Two thirds of respondents to the survey heard about the report directly from PiF. A smaller number heard about it at a conference presentation and an even smaller number from a colleague. No-one responding had heard about it through an article or from their own organization newsletter or mailing. However, there were respondents who found out about it through social media such as twitter, indicating that this might be a form of communication that does elicit a response.

#### Interviewees

All but two interviewees received the report directly from PiF, and the two that did not received it from members.

## Q7 Which of the Case for Information documents did you read?

Answered: 31 Skipped: 1



### Survey

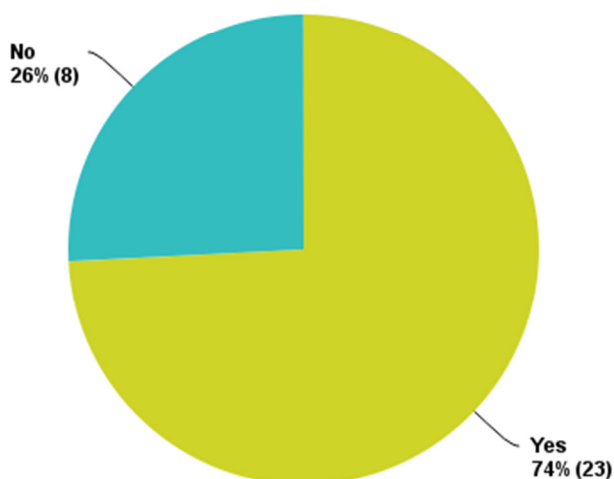
Two thirds of respondents had read the executive summary and just under half had read the full report.

### Interviewees

Interviewees also mainly read the summary although the academic and policy people were more likely to read the full report as well. The majority of interviewees had skimmed the full report. It was seen by many as a good reference document, but the executive summary seemed more useful in either informing others or reminding interviewees of the key messages. One or two interviewees even suggested an even briefer summary. Very few had read the briefing papers. The interviewee from Wales commented that briefing papers for Wales, Scotland and Northern Ireland would have been useful as the main report tended to talk about the English health system. She had had to adapt the report to address the Welsh system.

### Q10 Did you share the Case for Information report with anyone else, or recommend it to anyone?

Answered: 31 Skipped: 1



#### Survey

Three quarters of respondents had shared the report and a quarter had not. Further analysis of the survey found that most people who had shared the report had shared it within their organizations with their colleagues, senior or line managers. A few shared it with networks, or other voluntary organizations. Two people cited it in their PhDs, a few others used it in references in papers or presentations. One person sent it to the Welsh Government through their work in Public Health Wales.

#### Interviewees

A similar pattern was found with interviewees with many sharing the report within their organizations. The NHS Choices Commissioner had seen the summary document “around a lot”.

### 4.4 What did people think about the report?

#### How useful was the Case for Information Report to you?

Answered: 31 Skipped: 1

Not useful	A little useful	Useful	Very Useful	Not sure	Total
0.00%	6.45%	38.71%	54.84%	0.00%	
0	2	12	17	0	31

93% of respondents found the report useful or very useful. Notably well over half of people found it very useful.

## How useful was the Case for Information Report to your organization?

Answered: 31 Skipped: 1

Not useful	A little useful	Useful	Very Useful	Not Sure	Total
3.23%	25.81%	29.03%	35.48%	6.45%	
1	8	9	11	2	31

64.5% of respondents found the report useful or very useful for their organization, with over a third finding it very useful for their organization.

### Positive Comments

Generally both survey responses and interviewees were positive about the report. Many commented on how well it was written and how easy it was to understand. The themes arising from the positive comments were:

- Brings together the evidence
- UK wide
- Only report of its kind
- Well argued

*“It clearly links to other work and evidence and this, alongside the provision of levers for change, gives it credibility and increases its influencing capacity. The report provides a very comprehensive overview of the situation of information at the moment, highlighting the key issues clearly and giving evidence to support the benefits for high quality information provision. It also states the case for “why” information provision is beneficial very clearly and logically, backed up by evidence – such as improving patient behaviour changes, decreasing psychological distress etc.”(Voluntary sector producer.)*

*“The contributors seem very high quality. The report does a good job of highlighting the importance of informed and engaged patients and the benefits that have been shown to come from patient engagement, shared decision making and chronic condition self-management” (International policy maker)*

Some cited different sections or parts that were most useful:

*“recommendations” (works in Public health Wales)*

*“national drivers” (works in health library)*

*“ideas for research” (lecturer and researcher)*

*“the chart on page 48 is the best I have seen in laying out the goals of patient engagement and the role of information in care” (International policy maker)*

### Improvements

There were things that people wanted to see improved but this mainly related to the next version or any update. Although these comments were fewer there were some detailed critiques on both the content and format of the report.

A Clinical governance manager felt it lost credibility when her manager challenged her on why patients had not been involved in writing the report. Quotes from patients on their experiences would, she felt, have given it credibility especially after the Francis report. She also felt that although it was well written it read like it was written by management consultants whose primary knowledge was not in patient information.

A number of interviewees would have emphasized or written more on particular areas such as the responsibility of clinicians, the new NHS landscape, the importance of transparency as the spur to quality, digital information, more on health literacy and decision making, or a précis of the business case.

Another wanted the first 2 pages of the summary to have the economic arguments. The costs of not giving information, for instance medical negligence, which was known about anecdotally, was also suggested by an interviewee. One person wanted references within the text, and another agreed that grading the evidence might be useful to some. Another was looking for “killer stats” that could be used in funding bids.

*“The feedback I had about the report (Executive Summary) is that it is still too long with regard to using it with CCGs and other managers - maybe we need a one page A4 bullet pointed piece which can really quickly get its message to those with little time to consider longer documents.” (Voluntary producer)*

*“To include more arguments for information provision not just a case for producing health information” (works in NHS Health library)*

*“More evidence on the impact that good quality information can make to people's lifestyle choices” (Voluntary producer)*

*“More examples from practice” (Voluntary producer)*

*“The one area in which I found the report to be missing an important component (perhaps I just missed it in my quick re-read) was the lack of focus on the importance of “patient response”. While getting the right information to the right person at the right time is an essential part of patient engagement it only provides half of the effort needed to achieve the value of patient engagement. The other half comes in getting the patient's response to the information back to the prescribing clinicians with whom the patient is working. In other words The Case for Information should include the case for getting the patient's information to the clinician as well” (International policy maker)*

### Other issues

A few people both in the survey and interviews brought up a number of issues that related to information and the report (usually one or two people for each issue).

### **How people get information**

A number of interviewees mentioned the good quality information available in the voluntary sector but that patients don't necessarily get access to it. Either because they don't seek it, perhaps as a response to not being labelled as a condition, but also because

health care professionals don't use it. General Practitioners are seen as a preferred source of information but vary a great deal in what information they provide. For this reason it was suggested that information should be a centrally commissioned service.

### **Health literacy versus patient activation**

Health literacy references were welcomed in the report but there was a concern on the growing use of references to "patient activation" (mentioned more positively by another interviewee). The interviewee, a GP and expert on health literacy, felt it uses the chronic disease model and the patient activation measure used in CCGs is a blunt tool that measures a lot of things together such as empowerment and self-activation. They thought there was a danger of blaming the patient. PiF, they felt, could continue to promote the need to see the importance of health literacy not just information. For example they said "*(I) Had a patient that needed an x ray and sent him to the hospital but he couldn't find the x ray department as it said radiology*". The other interviewee who mentioned patient activation saw it more positively and thought the term patient activation would be more dynamic and produce better outcomes. They were from a chronic disease umbrella group.

### **"Patient" and "information"**

The interviewee who used the term patient activation in a positive way also raised the issue of the report only having impact on a specialist audience of those writing leaflets and websites. The term information was not enough and that there was a need to interrogate information and have knowledge you could act on. They also had a concern that the term "patients" only applied to the NHS world and that user led, disability and learning disability organizations did not use this term. The term "consumer" also provoked some political differences that could alienate some audiences.

### **'Professionalizing' information**

Although most interviewees and survey respondents promoted the need for good quality information the international policy maker sounded a note of caution.

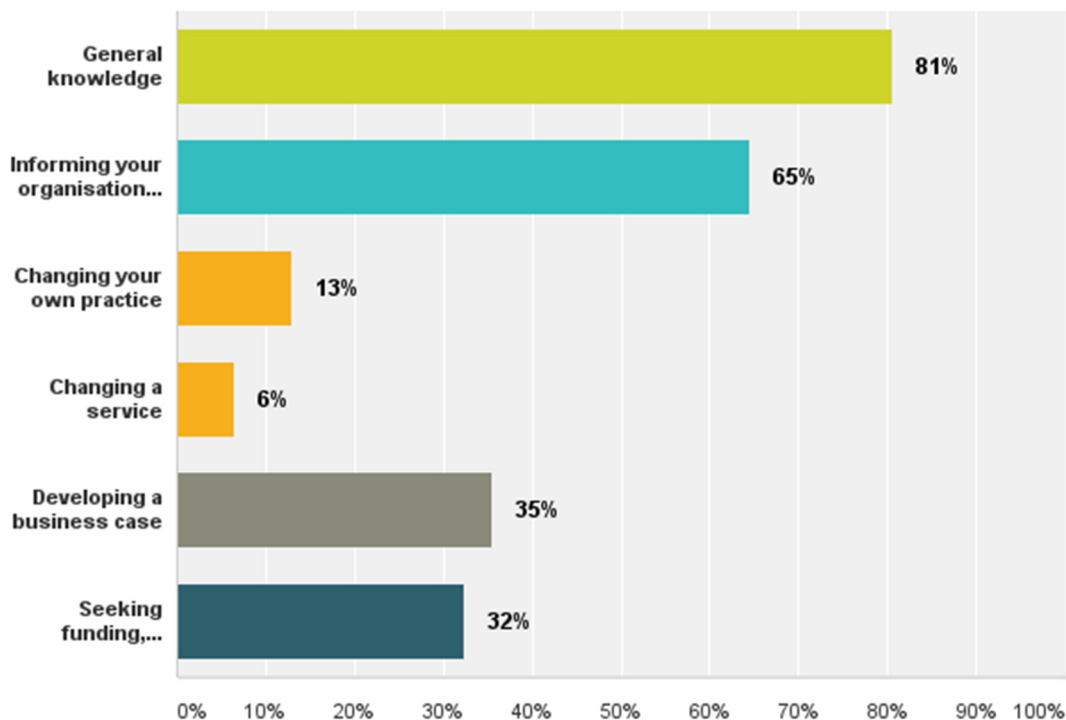
He thought there was "*value in peer-to-peer information, even when quality standards are not followed*".

In addition when the reports says "Information production is a highly skilled activity" he thought "*Just as unchecked "professionalism" by clinicians has been used to disenfranchise people from doing basic self-care and self-management on their own, too much focus on the credentialing of information creators could disenfranchise clinicians from doing their best to educate their patients. While I believe in the art and science of health education as a profession I would not want to preclude others from trying.*"

## 4.5 What people did with the report and the outcomes

### Q13 What did you use the Case for Information report for?

Answered: 31 Skipped: 1



#### Survey

80% of respondents used the report for general knowledge, with two thirds using it to inform their organization about the case for information. Over a third used it to develop a business case and just under a third used it to seek further funding or resources. As respondents were asked to tick as many as applied these indicate the most popular answers with almost all respondents choosing more than one option.

#### Interviewees

There were a number of ways that people had used the report. The most popular was to use it as a reference document for presenting the case for information at events or in documents.

The report had been the subject of a blog to 800 breast cancer nurses and a reference used in a national presentation for University health centers.

A number of organizations had tried to use it to raise funds but were frustrated that the economic arguments did not stack up with commissioners or statistics were not clear enough to use in funding bids. However a number had used it to support bids to appoint information officer posts. In one case this had been successful with posts linked to the Information Standard Certification.



A number of people were using it to inform their organizations' strategy or to write business plans. One organization wanted to use it as a reference tool in reviewing their policy manifesto. One of the PhD students used it to identify her research area.

### **Barriers identified**

- The need to work with local commissioners was seen as problematic.
- The NHS not recognizing they have a problem with patient information and therefore not resourcing or prioritizing it.
- The expense of providing information at a local level when it was available nationally and therefore duplicating it or producing something of inferior quality.
- Many clinicians not wanting to give information and therefore power to patients so they could keep control.
- It was thought that producing a report in itself did not tackle the cultural change needed in behavior and attitudes within statutory organizations.

### **Positive Outcomes**

There are some very specific examples from interviewees where the report has the potential to influence national policy. Examples were the use of it to influence the Welsh Government *"It shifted the conversation from "nice to have" to "core". It needs a strategic approach at Welsh Assembly level. (They are) starting to understand this and (I am) making a stronger case. Macmillan funded The Case for Cancer Information based on the PiF report" (Producer, policy maker working both in statutory and voluntary provision).*

Another example is at NHS England where it is included in NHS England papers and referenced in them as well as *"Used to formulate and guide ideas and thoughts into practice" (NHS England interviewee).*

The report is also being used to develop the business case at NHS Choices. One Trust Information Standard lead was able to use the business case in their successful funding bid for a County wide scheme to scope where patients were getting information from, what the quality of it was, and where they would prefer to get it from. They also applied for and received funding for posts for the Information Standard certification in their own Trust. They cited pages 13 (The business case for investing in consumer health information) and 4 (What is the evidence for investing in high quality health information and why the case is compelling) as the most useful.

## **4.6 What readers of the report would like to see happen next**

Themes identified from the survey were:

- Lobbying with other organizations both locally and nationally to improve patient information
- Examples of where the Case for Information has made a difference
- More primary research on patient information and research projects identified

- Guidelines to raise information standards and to aid consistency across different healthcare providers and a practical toolkit based on the evidence that could be supplied to NHS and other healthcare organizations
- Finding out the efficacy of information prescriptions
- Work on measuring soft outcomes
- Develop more examples of patient information journeys for people with complex health and social care issues
- Support GPs to have the confidence and skills to be providers of information as they are recognized as the preferred source of information by patients
- Provide guidance on how to improve information provision into local communities, such as through CCGs and other mechanisms/organizations.
- Information prescription generators developed by cancer charities should be done for other long term conditions
- Explore the information needs of expert patients
- Demonstrate that patient information in more challenging communities will work if we develop more resources to support health and well-being in those groups who find health messages hard to understand

Interviewees raised many of the same points as in the survey. These included lobbying, raising awareness and updating the report.

There were some contradictions such as one health care professional wanting more guidance in primary care and another saying “no more glossy toolkits or how to packs”. This primary care guidance should be shorter and easy to read, ideally with an overview of the pros and cons of different methods. The GP who suggested this thought some practices would adopt something if they had a “how to” guide. His practice had recently started using twitter and Facebook but he would have found a “how to” guide useful. The interviewee who did not want more “how to” packs was a lay representative with a CCG. He felt something different had to be produced to share ideas. Key questions such as “how do you know it is any good?” needed to be asked and perhaps an assurance framework would be useful.

Suggestions included:

### **Lobbying**

- Make it a call for action and reissue as a campaign up to the general election, for example take the 3 most important things that the Department of health must ensure happens.
- Next iteration of the report engage with NHS England and area teams to get to grips with commissioning and provide examples of information along the patient pathway.
- Potential role in building a campaign on the report as a failure to inform patients and social care users. You can’t do it alone so partner with National Voices, Patient Association.
- Use the Case for Information with the Royal Colleges, Commissioners and Healthwatch
- The DH made investment on information standard so need to capitalize on this –make sure you use the report to influence it

- Health care commissioners and policy makers need to take information seriously and PiF have a role to play in this.
- NHS England needs to incentivize information provision.
- In order for clinicians to take it seriously, it need champions like the Medical Director for NHS England.

### **Raising awareness**

- Bring it to the attention of health care professionals through events, conferences and seminars – précis bits that are useful and key points
- Taking work to wider audience and say *“This is what we learnt”*.

### **Updating or reframing the report**

- Maintain an on line version of the Case for Information with updated references using Web of knowledge as well as PubMed.
- Revise it to include service user voices. An example was to use quotes from patients on where the NHS was failing them in terms of information.
- Follow up by sending to CEOs and ask them how they are using it.
- Take basic material and make it have more impact. Be clearer on the goals – who do you want to influence and why? What do you want them to do? It is a means to an end but what is the end? Make more noise.
- Difficult to do as people feel over worked and can’t have scope to do it- maybe say makes professionals lives better and more rewarding? Therefore Part of the case is to make things better.
- Have call for actions –for example board level champions.

## **4.7 Other reports**

Interviewees were asked if they had come across other reports, papers or evidence on the benefits of providing information and how they compared with “The Case for Information”. Interviewees found this question too general and most could not think of particular reports. *“Lots of reports produced by the King’s Fund and the Nuffield Foundation but The Case for Information fills a gap” (policy maker)*. One person had sent report suggestions to the original researchers, and another was a reviewer of “The Case for Information” so had already made suggestions.

A few reports were mentioned:

- A Cochrane review on information.
- “The Power of Information” by the Department of Health but the interviewee found it “unfocussed and disappointing” with a lot missing.
- “Understanding health Information” by Susie Blunden published by Oxford University Press but it was “about gathering information” and not comparable to “The Case for Information.”
- The King’s Fund on patient activation in their commissioning review. But the comment was that increasing the skills and knowledge of the patient sounded like health literacy.

## Section 4

### Interpretation and Reflections

#### Who read the report and used it?

The survey and interview results indicate that the report was used by a wide range of people involved in information. The survey results found that 53% were voluntary organizations and 22% worked in the NHS. Many people had a number of roles for instance health professionals using or producing health information and voluntary organizations that also produced and provided information. Not surprisingly most people were involved in information or support (50% of survey respondents) and also patient and public involvement and patient experience (a combined 47% of survey respondents). However policy makers and commissioners, a key audience for the report, also had read it. Respondents also had passed on the report or contents to others in their organization or through their networks.

Two thirds of respondents were PiF members and a third were not. The geographical spread across the UK is difficult to assess as no respondents were from Northern Ireland and there were limited numbers from Wales and Scotland. However the survey found that 29% of respondents worked across the UK. The interviewee from Wales had used it successfully with the Welsh Assembly Government and had found it a useful document. Therefore number of responses does not necessary reflect impact or potential impact.

#### What was their impression of PiF?

The Patient Information Forum was seen as mainly a network for information professionals working in the statutory, voluntary and commercial sectors. It was seen to have a key role in lobbying and influencing at mainly a national strategic level. This is further supported by the section on the next steps for the report where many of the tasks fall to PiF to lobby and campaign on patient information.

Another key role, apart from the main role of keeping the network informed, was producing high quality reports and papers to be used to tackle the main issues of good information production and provision. There were a number of suggestions on how PiF could improve its services but overall there was a high level of satisfaction with PiF and some acknowledgement that it was also developing for the better.

#### What they thought of the report

All survey respondents and interviewees thought the report was clear, concise and well written. The survey found 93% of people found it useful (54% of those assessing it as very useful). When assessing its usefulness to their organization these figures dropped to 64% (35% of whom found it very useful).

There were some issues on the format and emphasis of the report with a number of respondents suggesting improvements such as quotes from patients, more economic arguments, references within the text, and more complex examples of patient pathways. Suggestions on improvement reflected the uses made of the report which varied a great

deal from writing funding bids to using it in academic work. The language used in the report and the debate on health literacy and patient activation is rather topical considering the growing use of patient activation. One of the most critical comments was from a policy maker not directly involved in patient information who preferred not to use “patient” or “information” due to the restrictive way both terms could be seen, especially by those who were not information professionals.

### What they did with the report, if anything

Most respondents used the report for their own information and reference (80% of survey respondents). The survey found that 64% used it to inform their organization. Over a third of survey respondents (35%) used it to develop a business case and 32% used it to seek funding.

### What impact it had in terms of changing attitudes, services or practice

The experiences of respondents using the report varied greatly, even when using the report to support the same activity. For instance one producer found the report lacked enough economic data to convince commissioners of the 111 service to include patient information. For another national voluntary organization it lacked the “killer stats” needed to support funding bids to local commissioners for local information officers. But one hospital based information lead used it successfully to gain two information standards officers and a county wide survey of information needs. In Wales it was successful in convincing Macmillan to fund a similar report on cancer. Another area of variation was how it could influence organizations. A hospital based information lead found that the report did nothing to convince clinicians or managers to do things differently, whereas in Wales it had shifted the conversation of the Welsh Assembly Government from “nice to have” to “core”.

### What readers of the report would like to see happen next

Respondents did have various suggestions on what should happen next. Some of these suggestions were very specific and included more research, work with health professionals and various improvements to the report, for instance more economic arguments. There was some synergy between survey and interviewee respondents with a greater emphasis on what PiF should do next. Some people did mention continuing to develop a business case, or use of the report as a reference document for academic work or presentations but the majority had no further plans to use it. However there were a number of suggestions on what should happen next with an explicit and implicit understanding that PiF would take the lead. This was particularly the case for an update of the report, lobbying and raising awareness.

# Appendix I

## Patient Information Forum (PiF)

The Patient Information Forum (PiF) is the UK organization for professionals working in consumer health information. We have 500 members working in all parts of the UK in a wide range of roles that involve communicating with patients and the public about their health. Members come from the NHS, voluntary sector, commercial, independent and public sectors.

PiF's vision is that, "everyone can access relevant, high-quality information and support to help them understand their care and make confident, informed decisions about their health and wellbeing." Our mission is to improve the experience of healthcare for patients and the public by:

- Supporting the provision of high-quality information and its integration into healthcare services
- Championing informed choice in healthcare

PiF works with members to raise standards, spread good practice and raise the profile of consumer health information.

# Appendix II

## Evaluating the Case for Information interview schedule

1. How would you describe your role in relation to patient information? (prompts: producer, clinician, commissioner)
2. Did you read the case for information/which format? (full report, summary/briefing papers) and if so how did you come to read the report (sent direct, recommended by others)
3. Did you know PIF before the report? (prompt what is PIF, what do they do and what do you think of them)
4. What did you think of the report? (prompt; what was good, what was missing or could be improved?)
5. Have you used it and if you have how did you use it?
6. What has been the outcome?
7. Do you have any plans to use the report further?

8. The case report established the evidence for the benefits of providing information and a case for investing, what would you like to see as the next step?
9. What can PiF do to champion the case for information? (For example should we share best practice and/or being lobbying on behalf of PiF members about the importance of information as a therapy)
10. Have you come across any other reports/papers/evidence on the benefits of providing information? If so, what are they, how useful are they, and how do they compare to the Case for Information?

## Appendix III

### Research Methods

It was not intended that the survey response rate reached statistically significant levels. A low response rate can give rise to sampling bias if the nonresponse is unequal among the participants regarding exposure and/or outcome. For many years, a survey's response rate was viewed as an important indicator of survey quality. Many observers presumed that higher response rates assure more accurate survey results (Aday 1996; Babbie 1990; Backstrom and Hursh 1963; Rea and Parker 1997). But because measuring the relation between non-response and the accuracy of a survey statistic is complex and expensive, few rigorously designed studies provided empirical evidence to document the consequences of lower response rates, until recently. Such studies have finally been conducted in recent years, and they are challenging the presumption that a lower response rate means lower survey accuracy. Holbrook et al. (2005), a US study, examined the results of 81 national surveys with response rates varying from 5 percent to 54 percent. They found that surveys with much lower response rates were only minimally less accurate.

In assessing the sampling size for interviews Sandelowski (1995) asserts that there are no computations of power analyses that can be done in qualitative research to determine the minimum number and kinds of sampling units required, and that it is ultimately a matter of judgment. Other academics are more specific in their recommendations, although there is no consensus on a "right" number. Charmaz (2006) suggests that 25 participants are enough to reach saturation. Green and Thorogood (2009) say little new is likely to be found after approximately 20 interviews.

Telephone interviews have been shown to be effective and acceptable in qualitative research. They are cost effective and allow researchers to interview people from a wide geographical area. Some people actually prefer the relative anonymity of a phone interview and are able to focus well on the research questions when they are interviewed by phone. However, telephone interviews have limitations as they do not usually allow for non-verbal clues to be picked up, nor for interviewer and interviewee to build up a rapport so easily. However, Irvine (2010) states that on the whole, concerns about rapport or loss of meaning are somewhat exaggerated or unfounded.