



Patient Information Forum

For everyone involved in health information and support

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Summary Report PIF Executive Circle Meeting

Measuring the impact of information: What evidence is required to enable sustainable investment in health information and support?

*Tuesday 28 February 2017; 1.15-4.00
kindly hosted by MHP Communications*

Introduction

During 2017 one of PIF's key objectives will focus on how we can help our members, and the wider health information sector, to measure and evaluate the impact of the health information and support they provide.

Measuring the impact of information is one of PIF's [strategic priorities](#). We believe this is the key to future investment in high-quality health information and support, improved outcomes for patients, and a higher profile for health information and support professionals.

The PIF Executive Circle meeting held on 28 February 2017 set the context for PIF's work in this area, shared two approaches to measuring outcomes for patients, and invited attendees to discuss what evidence or impact needs to be measured and who needs to be influenced by this measurement.

This report provides a summary of the key points presented and discussed at the meeting.

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A) Setting the context

Sue Farrington, Chair, Patient Information Forum (PIF)

<https://www.pifonline.org.uk/wp-content/uploads/2017/03/1-Sue-Farrington-presentation.pdf>

The UK policy landscape makes clear references to the importance of health information for patients, carers and service users. For example, it is included in the [NHS Five Year Forward View](#), and enshrined in the [NHS Constitution](#) as a patient's right.

However, when investment is required, information becomes a nice to have, rather than a must have. Improving the impact measurement of high quality health information and support is an important step towards addressing this, and ensuring the policy rhetoric becomes a reality for people across the UK.

In January 2017 PIF ran a survey with PIF members and non-members which asked 'Does your organisation measure the impact of information and support?'

70% of respondents said that they did measure the impact of information and support. 15% responded that they did not measure, and 15% did not know.

Respondents were measuring a wide range of impacts, including whether information supported informed decision making, improved knowledge and understanding, and improved quality of life.

However, the survey also revealed a level of confusion about what is meant by the measurement of impact. Many respondents reported they measured their information by website hits or numbers of people reached, rather than the impact the information had made to a patient's experience or outcomes.

When asked what impact would need to be measured in order to improve investment in information, survey respondents identified that being able to evidence how information contributes to changing behaviour, increased engagement, ability to self-care and self-manage, and the impact on quality of life.

B) Measuring patient value

Ian McKenna, General Manager, Galen Research

<https://www.pifonline.org.uk/wp-content/uploads/2017/03/2-Ian-McKenna-presentation.pdf>

Ian shared [Galen Research's](#) work, developing disease-specific patient (and carer) value measures. These are used by pharmaceutical companies as part of clinical trial studies to measure patient experience.

They are also increasingly being used to measure the value of services. For example, in a COPD setting, establishing patient value associated with using a range of different services, and to support a council to identify and fund the services that matter to patients.

Ian compared a clinical model of evaluation with a patient needs-based approach. The clinical model focuses on illness, symptoms, and function, and how clinical interventions impact these. It is centred on the evaluation needs of the clinical team, and designed for use in a clinical setting.

The needs-based approach Galen Research undertake focuses on items identified by patients as being important. It therefore looks at needs rather than functioning. It is holistic and considers both the impact of the illness and the treatment.

The measures are developed by patients for patients, through semi-structured interviews. During these conversations, patients rarely talk about symptoms. They talk about losses and relationships. Illness limits a patients' ability to fulfil the things that are most important to them, including maintaining relationships, autonomy, safety, socialising with others, identity and purpose.

Galen develop their patient value measures by putting these needs at the centre. It is important to ensure that the measures are developed by patients with different genders and backgrounds. Their measures are culturally adapted to be as relevant as possible to different communities.

In discussing how to measure the impact of information through a patient value approach, Ian reflected on the challenge of identifying the difference that you can attribute to health information versus the other interventions a patient will receive.

He identified important considerations as including: the need to measure before and after health information provision; the potential inclusion of a control group to measure impact of information on those who received it versus those who did not – in order to help isolate the impact of information.

C) A theory of change and outcomes measurement framework approach for MS information provision

George Hoare, Consultant (Measurement & Evaluation), New Philanthropy Capital (NPC)
<https://www.pifonline.org.uk/wp-content/uploads/2017/03/3-George-Hoare-presentation.pdf>

George shared with the meeting a joint project with NPC, MS Society and the MS Trust, to create a theory of change and outcomes measurement framework approach for the provision of information to people with MS.

Theory of change is a description of how and why a desired change is expected to happen. It defines long term goals, and then maps back to identify necessary actions and pre-conditions to achieve that change.

This project focused on mapping the theory of change behind the provision of information to people with MS.

The presentation outlined the key steps in the project: map theory of change; prioritise what will be measured; choose the level of evidence; choose what tools will be used to collect the evidence.

The theory of change for this presentation was developed through a workshop with a wide range of MS stakeholders.

It is important that the level of evidence agreed upon, and the tools identified to collect the evidence, are proportionate and affordable. In this project the MS Trust and MS Society have designed evaluation approaches based on their own capacity.

With the MS Society and MS Trust working together to develop a shared measure and understanding of impact, there is the potential to demonstrate stronger impact messages.

Using a theory of change can help present impact findings to external or a public audience. A theory of change identifies a logical and plausible theory or chain of thinking to help to communicate the impact of your activities. Where information is a contributory factor towards improved experience and outcomes, rather than the whole answer, this approach can have real value.

D) Discussion summary

Attendees were then split into two groups and asked to discuss the following questions.

1. What evidence or impact needs to be measured to enable sustainable investment in health information and support?

- Positive impact on quality of life
- People have more confidence to make decisions that are right for them
- Cost benefit
- Patient experience
- Patient safety
- Patient's ability to make an informed choice
- Enables self-care/ self-management

- Encourages best practice
- Helps adherence to medication regime
- Patients feeling supported to be involved in decision making *to the extent they want to be*
- People understand more about their condition
- Confidence to ask questions
- Evidence of reaching widest possible social spectrum
- Value of providing good information support at an early point in a patient's experience, evaluated over time.

2. What other external factors or challenges need to be considered

- If the information isn't getting to people, how can you measure its impact? it's not the information's fault
 - Multiple services and channels of information, hard for patients to find information they need
 - Importance of information at the point of consultation, should leave the consultation with information or signposting
- How the information is or isn't delivered can affect its impact
 - Danger of information overload, if too much is given, or the wrong information is given, can have a negative impact
 - How can you tell what is credible, reliable information?
 - Skills involved in creating good information
- Importance of information in giving patient confidence to ask questions and feedback
 - Fact and evidence is not always enough, it's how the information is presented
 - People can be drawn to information that reinforces their own beliefs about health
 - Need patient to trust/feel comfortable with the organisation, to give feedback on the information provided

3. Which organisations, or professions, need to be influenced to increase investment in health information and support?

- Stakeholders could include policy makers, patients, carers, health and care professionals, commissioners, employers, pharmaceutical industry, insurance companies, NHS Trusts leaders, VCSE sector, health researchers, information professionals, medical colleges.
- Different stakeholders will want different things from the evidence, how will PIF project manage competing (or conflicting) outcomes to be measured? For example, if clinical team wants information to support clinical best practice, but a patient group wants to improve quality of life.

- Focus on smaller number of conditions that have significant impact on health economy and map impact of information provision for them.
- Validated tools – are a challenge and might not measure the things you want to measure

E) Useful documents

- **NPC guide to Theory of Change**
<http://www.thinknpc.org/publications/theory-of-change/>
- **NPC guide to impact measurement**
<http://www.thinknpc.org/publications/npcs-four-pillar-approach/>
- **Big Society Capital Outcomes matrices**
<http://www.thinknpc.org/publications/mapping-outcomes-for-social-investment/>
- **A theory of change and outcomes measurement framework approach - Information provision for people with MS**
<http://www.thinknpc.org/publications/information-provision-for-people-with-multiple-sclerosis/>
- **PIF Case for Information**
<http://www.pifonline.org.uk/wp-content/uploads/2014/11/PiF-Case-for-Information-Report-Final-Full-Report.pdf>
- **PIF & MHP Is knowledge power? report**
<http://www.pifonline.org.uk/wp-content/uploads/2015/03/Is-knowledge-power.-Using-information-and-support-to-empower-patients..pdf>

F) Organisations represented by meeting participants

- AbbVie Ltd
- All Party Parliamentary Health Group
- Arthritis Care
- Breast Cancer Care
- Galen Research
- I Want Great Care
- MHP Communications
- MS Trust
- New Philanthropy Capital

- NHS England
- NICE
- Patient representatives
- Royal College of Obstetricians and Gynaecologists
- Royal College of Physicians
- SeAp Advocacy
- Synexus Clinical Research Limited
- Tommy's
- UCB Pharma Ltd
- University of Salford