An impact analysis report of HQIP's Service User Network: Involvement at HQIP

March 2017

Prepared by SUN members

HQIP
service user network

"Patient and public involvement has never been more important. The relationship and approach HQIP takes with its Service User Network members is an excellent case of best practice, and one which the NJR endeavoured to replicate when it established its own Patient Network."

James Ludley, senior communications officer, National Joint Registry

HQIP Healthcare Quality Improvement Partnership

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1 Introduction

The HQIP Service User Network has been working alongside HQIP since 2009, with over 40 active members.

We meet formally in London two-to-three times a year and members are involved throughout HQIP work as follows:

- Giving a patient perspective in project groups (advisory groups, steering committees, task and finish groups)
- Participating in HQIP responses to national consultations so that the SUN view is incorporated
- Attending, participating and presenting at events with/ on behalf/for HQIP to reinforce the message that patients are important
- Contributing to resource development from leading on content to commenting on drafts to ensure they are relevant and readable by the public

The SUN was very involved in developing the HQIP PPI strategy (first written in 2014). As part of the PPI framework: Principles; Purpose, Presence, Process and Impact, SUN members decided to run a task and finish group to do an impact analysis on SUN involvement at HQIP.

1.1 Purpose of this report

This impact analysis report has been compiled by the SUN members to indicate the range of work that we have undertaken, which we think has been of great value to HQIP.

Whilst we are clearly supportive of HQIP and its work, we are also a group of 'critical friends' who feel we have a strong enough relationship with the organisation to be able to offer constructive criticism that will be taken in spirit with which it is intended.

We have broken involvements down into three main areas covering the past 24 months (September 2014 – September 2016).

- **Project involvement**
- **Event participation**
- **Resource development**

1.2 Main activities

From 2014-16 SUN involvement has been largely in the production of publications; website development and e-Learning. The impact of SUN involvement is clear from the comparison of before and after documents and comments recorded.

The inauguration of the updated website has made it possible to obtain some quantification of downloads of publications, the requests for further clarification and hits on specific web pages (SUN and PPI resources). It can indirectly demonstrate whether the items we are involved with actually have any impact in the wider world. The statistics for website access have been included in *Appendix 2* to this report, where four of the six pages receiving the most visits are ones on which SUN has had an input.

A response to a cost benefit analysis raised the prospect that SUN resources might be more usefully deployed on specific task and finish groups, responding to consultations and potential projects, such as the development of this report. This can be more effective for both HQIP and SUN members, rather than financing quarterly meetings. Other examples are teleconferencing, email discussions, and exchange of draft and updated documents; this includes the development of resources and work related to the PPI in commissioning project.

1.3 Members' experience

Within the SUN membership, many people have personal experience of a range of health conditions, and can help with practical advice that can be offered in respect of how patients are involved in their treatment and care.

Other members' experiences may be more closely aligned with work undertaken within clinical settings to investigate, analyse and propose courses of action, experience which could be a resource for shared decision making to improve patient experience and outcomes.

These activities have the double benefit for HQIP of:

- Demonstrating PPI in action, giving practical examples of how PPI can be successfully implemented

- Extending knowledge of HQIP into spheres of medical provision where its impact can be increased by demonstrating its practical approaches to service improvement

2 Resources

Since HQIP began a comprehensive review of all its guidance in 2013, members of SUN have been invited to assist in the work, either by direct invitation in view of their personal experience or by offering their general patient perspective on a voluntary basis. In the following documents various SUN members contributed directly to the content (photos, text, and stories) and also constructively criticised content, layout, colours, legibility, readability. In these examples we participated at various stages:

- Workshops – we were able to meet professionals face to face in extended dialogue to explain our ideas, needs and thoughts

- Consultations – we were able to look at draft reports and documents, taking the users perspective on the content and posing typical questions before they were expensively put into production

- Input – we gave a practical, user related focus to the outcomes of each document

The following three resources are specific to PPI:

Introduction to quality improvement for patients and public – eLearning

Developing a patient and public involvement panel for quality improvement

Patient and public involvement in quality improvement

2.1 Other resources

SUN were also involved in the development of the following resources as follows:

- *Clinical Outcomes Publication – style guide*
  Consultation with SUN, including a consultation period focused on various styles in the presentation of analysis of data, and an interactive workshop to clarify how best to convey these ideas

- *A guide to quality improvement methods*
  This document, which has the second highest number of hits on the website, received detailed comments from three SUN members – about the methods that had been chosen, the explanations of each and suggestions about consistency and the format of the presentation. Comments were considered and changes made as a result so that users were able to quickly identify the more appropriate techniques for their project

- Social Care audit guides – initially drafted in 2012, these were revised this year, partially as a result of feedback from SUN via a SUN meeting with HQIP Board member and National Voices representative (Robert Johnstone) in attendance. A thorough review has been undertaken by three SUN members and these comments have been recorded and acted upon

  – *Social care audit for leaders*

  – *Social care audit in practice*

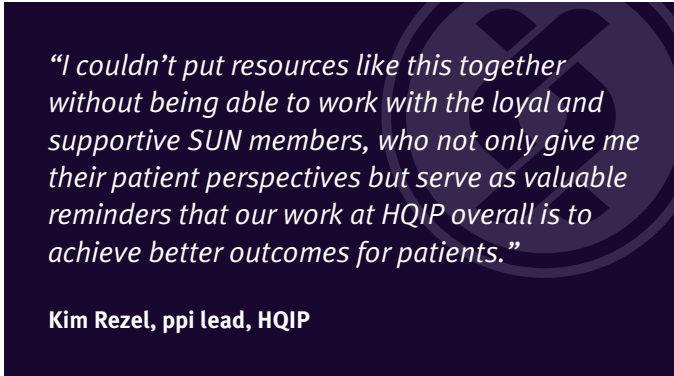 – *Social care audit in practice – summary guide*

Due for publication in March 2017

- Information Governance – patient leaflet (publishing later in 2017). This guide has been updated and redrafted many times over the past two years, but SUN members have been directly involved in the development of the patient leaflet which is a template for organisation to use for their patients about the patient role in clinical audit and around consent

2.2 Impact

The involvement of SUN members in a range of roles in the above resources has meant that:

- The relevance of the content has been scrutinised by 'non-professional' people who see the topic from a different and a fresh perspective, raising questions and queries that those more closely associated with the project may just have accepted

- The resources of HQIP are being deployed more effectively. The publications, are clearly focused and do not need further proof reading

- Case studies have been included, based on the actual work of SUN members, which will encourage PPI involvement by NHS Trusts and demonstrates that PPI contributors do add value

- The language used is more easily understood by all readers

"I couldn't put resources like this together without being able to work with the loyal and supportive SUN members, who not only give me their patient perspectives but serve as valuable reminders that our work at HQIP overall is to achieve better outcomes for patients."

Kim Rezel, ppi lead, HQIP

3 Project membership

3.1 Website development

The website development was an iterative process over several months. All the webpages and links were tested for the various audiences on as many devices and platforms as possible; desktop, laptop, tablets (iPad, Android) and smartphone. A range of search engines were used (Chrome, Safari, Firefox, Internet Explorer and Windows). This was an interesting and sometimes challenging experience as some pages worked on some devices and platform combinations but not others. The links to other sites was also challenging, not always working initially.

A lot of work went into the text and colours to create the site for everyone, for example, we spent a lot of time on the colours for dyslexic and scotopic sensitivity viewers and the font size to ensure that it could be changed to meet the needs of each reader. Making it easy-read was quite time consuming, particularly as we tried to fit with HQIP's colour scheme.

This feedback proved valuable in creating a website accessible to the people for whom it was intended. The PPI related web pages have had a noteworthy number of viewings (hit rate) with 40% resulting in a document being downloaded. We cannot, at this stage, yet understand how people use the information, however to download would imply some form of intent. Some future exercise may be to ascertain the uses made of web pages.

3.2 PPI in commissioning project

This has resulted in PPI now being an inherent part of the whole tender process, HQIP are running a pilot with trained SUN members to participate in the scoring of tenders as well as developing a process to ensure PPI in the specification development stage and in the contract monitoring. This outcome, which will bear fruit in the coming years, resulted from questions being raised by SUN members and the appropriate HQIP staff coming to a SUN meeting. From a constructive dialogue, the staff took our thoughts away and returned at a subsequent meeting to discuss how they could be implemented in a practical way.

> *"Interaction with HQIP's Service User Network (SUN) has helped to shape how service users engage with and contribute to the NCAPOP programme along the commissioning pathway."*
>
> **Nicholas Holmes, contracts and procurement manager, HQIP**

3.3 Steering group roles

Clinical Outcome Review Programmes – Independent Advisory Groups

Mental Health

Medical and Surgical

CQC project – Advisory Group

Clinical Outcomes Publication

Social Care project – Care Audit advisory group

National Advisory Group for Clinical Audit and Enquiries (recently disbanded)

3.4 Impact

In all of the above examples willing dialogue between SUN members and the professional staff undertaking the work has resulted in outcomes that:

- Ensure there is a focus on the need of the patient and the public rather than a concentration on the needs of the professionals providing the service

- Has enabled the inclusion of PPI in areas of activity, for example, commissioning, where it had not previously been formalised – and shown that it was possible to meet the needs of both PPI and underlying service

- Has shown, again, that the real-life experience of SUN members can have a great value in ensuring that work commissioned by or undertaken by HQIP has outcomes that are relevant to the needs of patients

"SUN members are valued participants of the Independent Advisory Groups that help HQIP govern the Clinical Outcome Review Programmes. These programmes can deal with difficult issues and SUN members bring an important perspective in managing them. They are able to support and challenge when necessary. Our discussions and decision making are made better and richer because of their participation."

Tina Strack, associate director, HQIP

4 Events

SUN members participated in the HQIP conference in 2014 by contributing in workshop discussions, and participated in the final plenary panel session.

SUN members have attended and contributed at the HQIP AGM October 2015 and 2016. This year, presenting this report.

4.1 Events where SUN members have presented:

Harrogate to the local Foundation Trust – Patient and public involvement in local and national clinical audit projects – September 2014

Kent Community Healthcare – October 2014

Junior doctors conference, Leicester – November 2014

Audit Conference London – March 2015

Royal Free Hospital, London 'Meet the Audit Team' – March 2015

UCL partners – Embedding patient and public involvement in quality improvement and training at HQIP – July 2016

Patient Information Forum – Involving users in creating health information – London September 2016

4.2 Impact

SUN members are willing, and have the experience from other areas of their working lives, to be able to undertake presentations to professional bodies identifying the benefits of PPI. Using SUN members' contributions has the benefits of:

- Supporting HQIP staff at events, working with them together beforehand on presentations to ensure that the typical questions that might may arise are anticipated and can be included in the initial presentation

- Being available to give real life examples of how PPI can be conducted, able to allay the misapprehensions of some professional staff and remove the barriers to enable about the time taken to good practice and to undertake PPI

- Show that those people who promote PPI are fundamentally supporting the medical professionals to maximise positive user outcomes within the financial constraints of the NHS

> *"I'm very proud that service user involvement is truly embedded in all HQIP's work. In communications this has been strategic (website development for instance), but tactical support has been just as valuable – such as when SUN members have supported us ad-hoc at exhibitions and conferences, proving both highly knowledgeable and great ambassadors for HQIP."*
>
> **James Thornton, communications manager, HQIP**

5 Areas for improvement

We are aware that the HQIP Board see PPI as a constructive activity within the broader medical sphere, and that they demonstrate in its own work that PPI is welcomed and encouraged through the National Voices representation on the Board.

There have been some good examples of HQIP and SUN working together which has seen SUN involvement in the HQIP national conferences; AGM attendance; membership of important groups and responses from HQIP to SUN on topics such as the social care project.

An effort was made for either a Board member or a senior staff member to attend most SUN meetings, however this is an area that can be improved and SUN also recognises that we need to make a more concerted effort to invite attendance from the CEO and Board. The Member's attendance has given us some direct insight into the thinking of the Board, which we welcome. Their presence also gives us an opportunity to discuss our ideas to take back to the Board. We would like to recommend that a Board member attend SUN meetings once a year and that the CEO also attend once a year. The new SUN chair will be more proactive in sending invitations.

5.1 Support SUN can offer:

SUN members are experienced and are involved in many national, regional and local projects outside of HQIP; therefore we would like to support HQIP in other ways as suggested below:

- Raise awareness of HQIP work
- Bring fresh ideas to HQIP for further investigation, advisory papers, etc
- Being a constructive critical friend
- Provide a useful communications network to promote HQIP
- Allow us to share our experience and expertise more than we do at present; many of us have membership of other health sector related groups, e.g. through the Medical Royal Colleges which should foster and encourage two-way conversations on health improvement
- The work we are currently engaged in with respect of commissioning of new projects will hopefully give us an insight into forthcoming areas of work to which we can contribute our skills and knowledge, and may even assist HQIP itself in bidding for future contracts by demonstrating the patient focus in its

workThat there is a potential for SUN members to assist in the dissemination of the outcomes from Clinical Audits, initially in those areas where members are based

5.2 Current relationship with HQIP

Generally there is a good working relationship between HQIP and SUN, as has been highlighted. In the development of this report HQIP and the Board have been both supportive and keen to hear the outcomes. We presented some of the findings at the AGM and a SUN member recently attended the Board meeting to discuss the recommendations. We are pleased to be seen as valued contributers to the organisation and hope for the collaboration to continue.

In previous years the relationship between SUN and the Board has been low-key, where we have been less proactive and have not come forward with possible new initiatives. Equally our views have not been sought from the Board and we think that regular attendance at the SUN meetings and the move to have three SUN meetings a year, will improve this. We would like to perhaps, receive a Board agenda and a timely reminder of when the minutes are available so that we are able to formulate a view and give comments to these discussions at appropriate opportunities.

5.3 Advisory group

Originally, HQIP established an overarching advisory group that would guide the organisation and offer support in achieving its aims and objectives. SUN were involved in this group, but meetings were irregular and were perhaps too broad in its remit. HQIP has now determined that a number of topic specific advisory groups will be established with the same, but focused, aim. For example; a Methodology Advisory Group (MAG) has been created to advise HQIP on all methodology related issues. SUN is already recognised as one of these advisory groups and the HQIP Board have acknowledged the significant contribution that SUN makes to HQIP activity. The Board have extended an invitation for SUN members to also be represented as part of the membership of any other advisory groups established and will seek nominations from SUN for members to join each of the topic specific advisory groups. A SUN member has since joined the afore-mentioned MAG.

6 Recommendations for the future

1. That we will undertake reports such as this one, on an annual basis to be presented to the AGM so that the Board and wider stakeholder membership are aware of our work as we were able to do in 2016 to 2017.

2. That the Board show how relevant they feel our work to be by inviting our comments on current items being discussed by the Board and potential new areas of work. This is partially done through Board attendance at the SUN meetings but we would like to encourage more proactive collaboration by the Board approaching SUN members for comments with advance notice so that we are able to respond with more structured and considered feedback.

3. The staff within HQIP continue to be invited to SUN meetings so that members gain a greater understanding of their work areas and identify where we can compliment their work to achieve better outcomes for HQIP.

4. That SUN members are encouraged to bring back to their meetings the lessons learnt from their work with external organisations and vice versa. This can be fed into the HQIP agenda for further work areas as well as giving examples for inclusion on the HQIP website of positive outcomes from PPI activity across the NHS.

5. That SUN members, when meeting with external groups, use the opportunity to promote the work of HQIP – to assist in this our members will brief HQIP staff, via the PPI lead, of what is being discussed (excluding confidential items) so that an agreed input to the other organisation can be put in place.

Appendix 1 – Membership of external organisations by SUN members and distribution of members in the UK

A.1 Membership of other groups by SUN members

This listing indicates the range of other activities that HQIP SUN Members' were involved in as at 17 September 2016. At national, regional and local levels there are clearly many linkages that could be beneficial to HQIP in spreading knowledge of its work and in bringing information back to the Board future commissions.

Academic Research – Leicester University

Berkshire Mental Health User Group – member and secretary

British Orthopaedic Association. 'PPI in MSK'

Cancer Research Institute Consumer Forum (PPI)

City University (monthly)

CQC – Specialist Advisor and HQIP Lay member

Crohns & Colitis UK Volunteer & National Conference London Presentation

Foundation Trust Member local hospital Trust

Greater Manchester Collaborative (HAELO) – Medicines Safety Project/Change Sciences. (PPI Award)

Staffordshire Healthwatch

Independent Advisory Group for the National Clinical Enquiry into Patient Outcome and Death – Lay member

Independent Advisory Group - Clinical Outcome Review Programmes projects – Lay member

IMPACCT Advisory Group, palliative care research

Joint Health & Wellbeing Strategy for a local authority

Lancaster Hospital (Morecombe Bay) Internal Inspection

Leeds Clinical Research Facility Executive (lay member)

Manchester Dental Hospital: Patient Representative Research Department

Marie Curie Expert Voices Group (terminal care)

NHS England. Workshop; Citizens Panel. X2

NICE Lower Back Pain Guidelines Development Group

NICE Quality Standards Advisory Committees

NICE Guidelines Development Group for Care of the Dying Adult

National Institute for Healthcare Research – NIHR – lay reviewer, PPI member on Programme Grants for Applied Research funding panel National

NCRI Clinical and Translational Radiotherapy Working Group

PPI in Research Group – Leeds

PPG : GP Practice – several in different areas of the country

Royal Colleges of Medicine

- RCP Patient and Carer Network Revalidation Executive Committee
- RCP Nuclear Medicine Professional Standards Committee
- British Nuclear Medicine Society – Council and Standards Committee
- RCP Dermatology Professional Standards Committee
- RCP: IBD patient focus group
- RCP Future Hospitals
- RCP Special advisory Committee
- RCP: Joint Strategic Health Committee RA
- RCP: Special Advisory Committee RA
- Royal College of Radiologists' Lay Members Network
- Academy of Royal Colleges. Patient Liaison Committee

Queen Mary's and Bart's University, Public & Patient Advisory Group – London

Queen Mary's University (5 sessions)

SEND (Special Educational Needs) Tribunals & First Tier Mental Health Tribunal

Social Care Institute for Excellence (SCIE) Co-production Network

Social Work Journal – contributor to

Wigan Borough CCG PPI Forum x 2

Wigan hospitals – Patient Audit, PLACE assessments x 2

Wrightington Wigan & Leigh NHS FT. Medicines Safety Committee, Audit Chairs & Leads Committee

Wrightington Hospital proposed MSK patient Panel

A.2 Distribution of Members of SUN group across the UK

Region	Number of active members
London and SE	7
South West	5
North West	8
North East	1
West Midlands	2
East Midlands	1
East Anglia	2
Yorkshire and Humberside	5

In order to improve dissemination of HQIP and SUN activity a positive recruitment drive in the less represented areas would seem sensible.

Appendix 2 – Web site visit numbers

Data 01 Sept 2015 to 31 Aug 2016:

	Page views	Unique page views
Developing-a-patient-and-public-involvement-panel-for-quality-improvement	1025	781
Case studies	3265	2717
E-learning-introduction-to-quality-improvement-for-patients-and-the-public	2000	1406
Guide-to-quality-improvement-methods	2911	2517
How-to-develop-patient-friendly-clinical-audit-reports	111	85
Introduction-to-quality-improvement-for-patients-and-public	1677	1191
Patient-and-public-involvement-in-quality-improvement	1213	965
Understanding-clinical- audit-online-learning-for-patients	487	344

- 855 unique pageviews of Service User Network page (*www.hqip.org.uk/involving-patients/service-user-network/*)

- 678 unique pageviews of the video blogpost (*www.hqip.org.uk/news-events/news/news-health-service-user-network-video-showcases-new-patient-involvement-guides/*)

- 299 views of Welcome to SUN video on YouTube

- 458 contacts in WebActivate who have visited the SUN page
  – Patient/patient representative – 30

- 325 UK visits to eLearning 'Introduction to QI' (01 Dec 2015 to 31 Aug 2016)

- 118 completed 'Introduction to QI' assessments

HQIP Healthcare Quality Improvement Partnership

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