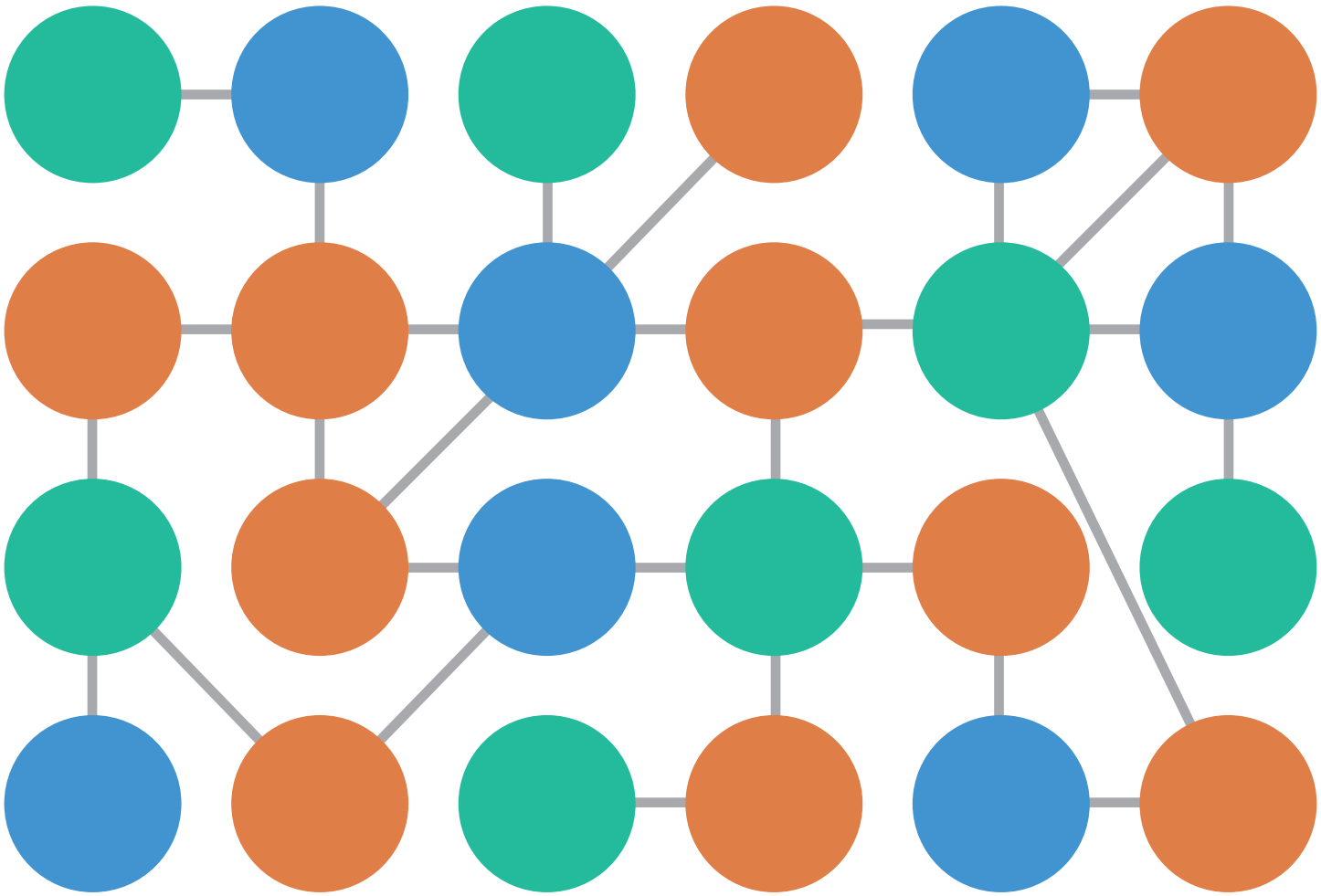
The Patient Experience Library

June 2016

Healthwatch: ***the power of the network***



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Acknowledgements

We wanted to produce this assessment of the Healthwatch reports output from an independent perspective so we have not had any formal liaison with Healthwatch during the preparation of this paper.
We have, however, had many informal discussions with people from around the Healthwatch network both before, and since, the launch of the Patient Experience Library. We are grateful for the informative and insightful comments that they have offered, much of which has informed the content on the following pages.

Foreword

Healthwatch – the network of around one hundred and fifty local Healthwatch organisations and the umbrella body Healthwatch England – is three years old.

It was launched in April 2013 as a consumer champion for health and social care, with powers under the Health and Social Care Act 2012. Its job is to ensure the voice of the consumer is strengthened and heard by those who commission, deliver and regulate health and care services.[i]

The timing of the network's launch was significant. Just two months earlier, in February 2013, Sir Robert Francis had published his ground-breaking report on the inquiry into serious failings at the Mid Staffordshire NHS Foundation Trust.[ii] A key recommendation was that "Results and analysis of patient feedback including qualitative information need to be made available to all stakeholders in as near "real time" as possible".[iii]

Healthwatch is a major source of qualitative information on patient experience. Three years on from the Francis Inquiry report, and the launch of Healthwatch, it seems timely to consider the power of the network.

Our approach

About us

We built the Patient Experience Library following discussions with Healthwatch England in 2014. By then, the new network had been going just over a year and was already producing a substantial body of work. But there was no single place where their hundreds of reports could be logged, stored and easily retrieved.

We offered to help with the problem, and spent a year developing a means of identifying every single Healthwatch report ever published. We then worked out how to catalogue and index each one, so as to enable fast, precision searches of the whole body of knowledge.

By the end of 2015, we were ready to launch the Patient Experience Library, and were delighted that Healthwatch England became our first subscriber.

We also published our first report, drawing on the library's content to produce a "state of the nation" overview of the UK's collective intelligence on patient experience. Our "2015 Digest" showed that Healthwatch was the biggest single contributor to the qualitative evidence base.

About this paper

Being counted the biggest single contributor could be seen as a great achievement – a real feather in the cap of the Healthwatch network. It could equally well be met with the question, "so what?".

It is that question "so what?" that motivated this paper.

We wanted to dig a bit deeper into the Healthwatch network – to see whether, and to what extent, the whole might be greater than the sum of its parts. The library gives us a unique overview of the Healthwatch reports output – there is no other place in which the network's whole body of work can be viewed. So we have trawled the library to see how examination of three years' worth of reporting could aid an understanding of the power of the Healthwatch network.

We hope that our findings will help the further development of policy and strategy on patient voice.

Summary

Healthwatch – the network of around one hundred and fifty local Healthwatch organisations and the umbrella body Healthwatch England – is three years old. It was launched in April 2013 – just two months after publication of the report of the Francis Inquiry.

We developed the Patient Experience Library to give a unique overview of the Healthwatch reports output – there is no other place in which the network's whole body of work can be viewed, all at once. We have sifted through three years' worth of reporting to make an assessment of the power of the Healthwatch network. We found the following:

Strengths

- Healthwatch is the biggest single contributor to the qualitative evidence base on patient experience.
- It offers a vital corrective to the kinds of statistical analysis on which performance indicators are usually based, and which can be manipulated and misinterpreted.
- It has the ability to build a comprehensive picture of patient experience – across services and geography, and over time.
- It can look at the whole patient journey, as opposed to taking snapshots of experience within separate services.
- It follows principles of localism, and has the flexibility and responsiveness to be able to pick up topics for inquiry as they emerge in each local Healthwatch area.

Weaknesses

- There is an inconsistency of quality across the Healthwatch body of work. Many reports are excellent – others perhaps show some room for improvement.
- There is an inconsistent quantity of report output from one local Healthwatch to another – from three reports to 134 reports over the same three year period.
- Timeliness of publication is an issue – most reports appear on local Healthwatch websites very promptly, but some appear weeks or even months after the date that is printed on the document.
- Many local Healthwatch are looking at similar patient experience topics. But there is little sign of a planned and systematic joining-up of the local Healthwatch effort – either within the Healthwatch network, or with other parts of the scrutiny and regulatory framework.
- The Healthwatch output fits classic definitions of "grey literature". Individually, the reports have value to local audiences. But because they are not available collectively, the network cannot present a combined body of work with a much greater strategic value and impact.

Developing the network's potential

Bringing the network's grey literature out of the shadows – making it very easily accessible to much wider audiences – is key to developing the longer term potential of the Healthwatch network. There are opportunities to:

- Maximise the impact of the best performers, making the network's best work easily available to service providers – wherever they are.
- Contribute to professional development – giving people on both clinical and managerial courses access to the whole Healthwatch body of knowledge as source material for essays and dissertations.
- Prompt academic inquiry – helping researchers to conduct scoping reviews to identify gaps in knowledge, or look for patterns that can prompt a question.
- Strengthen policymaking – helping civil servants, special advisers and think tanks to formulate evidence-based policy.
- Sustain funding – helping funders to get a better sense of the network's value through improved visibility of the combined body of knowledge.
- Protect the legacy – ensuring that a huge amount of valuable learning does not get lost over time.

The Healthwatch network has come a long way in its first three years, producing an unrivalled amount of qualitative evidence on patient experience. A key question for the longer term must be how to develop the potential, not just of each local Healthwatch, but of the whole network.

This may mean thinking about how to make the network's key asset – its collective intelligence – work harder. One of the first steps might be to bring it out of the realms of grey literature, and into the light.

The Healthwatch Output[iv]

Total volume

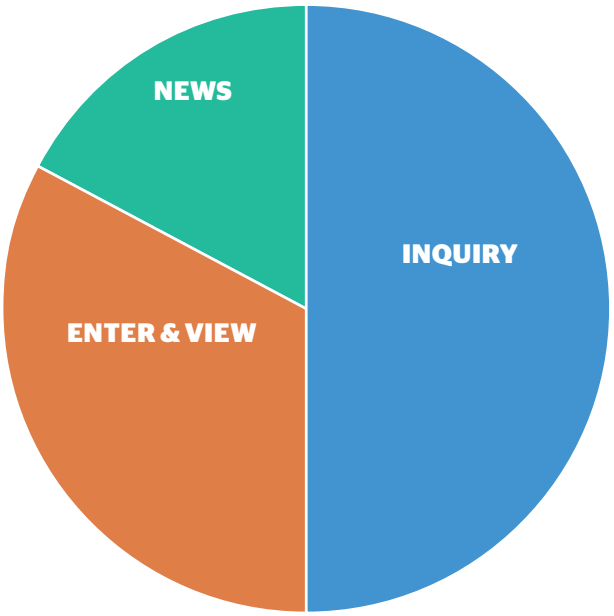
During its first three years, the Healthwatch network across England published around 5,000 documents on patient experience.

Approximately half of these were inquiry reports, usually with findings and recommendations, based on questionnaire surveys, focus groups, mystery shopping exercises and so on.

A further third were Enter and View reports – summaries of visits to health and care premises to talk to patients and service users.

The remainder told patient stories more informally through news items and case studies.

REPORT TYPE

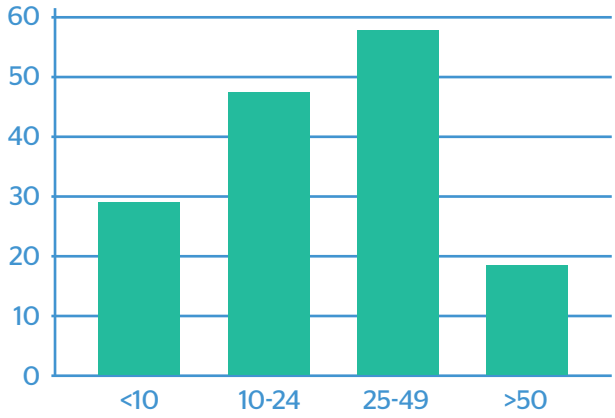


Local Healthwatch output

The number of reports published by each local Healthwatch over the last three years varies quite considerably. At the top end of the scale is a local Healthwatch that has produced 134 reports – an average of 45 per year. At the other end is a local Healthwatch that has published three reports in three years.

Of course, quantity is not the same as quality and it could be that those producing fewer reports are also producing higher quality reports. However, it is not clear that this is the case.

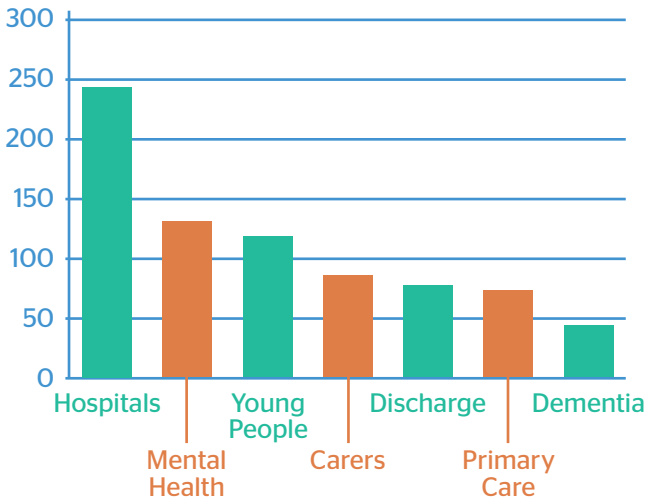
NUMBER OF REPORTS PER LOCAL HEALTHWATCH



Top topics

One of the strengths of Healthwatch reports is that they often follow the patient journey across a range of services (for example through discharge from hospital and into the care of community services). But this can make it difficult to identify a clear focus for some reports. Where there was a clear primary focus, we found that the top topics were as shown in the Report Topics graph.

REPORT TOPICS



Specialist topics

The topics featured above cover the experiences of large numbers of people in services that are commonly used. But Healthwatch excels in getting to much smaller numbers of people who may find it more difficult to be heard. Examples of groups and experiences that have been brought to light by the network include[v]:

- TB services for vulnerable people
- Tongue-tie procedures
- How the ex-Gurkha community access and experience health and social care services
- Patient feedback on Specialist Stroke Rehabilitation
- Experiences, views and opinions of people using Gender Identity Services

Analysis

1. Strengths

SCALE

A key strength of the Healthwatch network is undoubtedly the large quantity of evidence on patient experience that it produces every year, from every part of England, and across all health and social care services.

Healthwatch is the biggest single contributor to the qualitative evidence base, and without its reports, the whole sector would have a poorer understanding of the good and bad of service provision, from the patient's point of view.

QUALITATIVE EVIDENCE

There is a tendency within the NHS to regard statistical data as "hard" and "robust" and to see patient testimony as "soft" and "anecdotal". But the recent Carter Review exposed the unreliability of statistical evidence, commenting that "*hospitals and commissioners were often looking at different datasets and from different perspectives with inevitable disagreements.*"[vi]

Equally, a report from Dr. Foster has shown various ways in which performance statistics can be manipulated, including bullying of staff, "gaming" waiting time and mortality data, distorting patient pathways to meet treatment targets, and arguing about data quality in order to divert attention from poor care.[vii]

Healthwatch evidence provides a vital corrective to the kinds of statistical analysis on which performance indicators are usually based. Importantly, this point was picked up by the Francis Inquiry, with the observation that the Board and management of the Mid-Staffordshire NHS Trust failed to spot poor performance because they "*chose to rely on apparently favourable performance reports by outside bodies, such as the Healthcare Commission, rather than ...feedback from staff and patients*".[viii]

REPEAT INQUIRY

Many of the reports cover well-trodden ground: experience of GP services, mental health services, care homes etc. But it is important that Healthwatch repeatedly revisits familiar territory. As with the CQC inspection programme, routine inquiry helps to build an aggregated picture of service quality – across services, across geography and across the years. The ability of Healthwatch to build a comprehensive and longitudinal picture of patient experience is very much part of its power.

PATIENT JOURNEY

Healthwatch is not the only body monitoring patient experience. Mechanisms such as Patient Opinion and the Friends and Family Test also provide useful feedback. But these tend to produce snapshot views of one service at a time. Healthwatch, by contrast, has the ability to look at the whole patient journey.

A good example is Healthwatch England's "Safely Home" report which followed people from hospital and care settings back into community care and their own homes.[ix] The report demonstrates the value of a carefully constructed study, gathering evidence from multiple locations around the local Healthwatch network, and tracking patient experience through a series of services and procedures. It is unlikely that the resulting insights could have been gained from snapshot comments offered through on-line tools.

LOCALISM

A key strength of Healthwatch is localism – that is to say the lines of inquiry for local Healthwatch are influenced primarily by local issues and concerns.

National health charities and think tanks tend to take a national overview on the topics they cover. The Care Quality Commission works mainly on routine cycles of inspection. Mechanisms such as the Friends and Family Test and Patient Opinion are reactive and therefore somewhat random.

Healthwatch, on the other hand, has the flexibility and responsiveness to be able to pick up topics for inquiry as they emerge in each local Healthwatch area. This may be from feedback that is received by the local office – but many local Healthwatch are additionally guided by panels of local people who help to decide priorities for inquiry.

A further consideration is that other health charities tend to work from the perspective of their own charitable causes and interest groups (cancer, sight loss, diabetes etc). Healthwatch is more free-ranging, and can articulate the experiences of people who are largely unrepresented by mainstream health charities. Who but Healthwatch, for example, would tackle topics such as Healthwatch Manchester's examination of overseas students' experiences of access to healthcare?[x]

2. Weaknesses

QUALITY

A consideration of effectiveness has to start with the question of quality. The Healthwatch network produces a lot of reports – indeed, it is the biggest single contributor to the UK's qualitative evidence base on patient experience. But are the reports any good?

We detected an inconsistency of quality across the Healthwatch body of work. Many reports, undoubtedly, are excellent – we have featured a few of them in our top picks of the patient experience literature from 2015.[xi] Others perhaps show some room for improvement.

It is surprising, for example, to see reports being published without a date on them. The value of something like an Enter and View report could easily be compromised if the date of the visit is not known.

We have found reports with errors in spelling and grammar, indicating a lack of attention to proof reading. The quality of design and layout is also very variable, with some reports looking highly polished, while others are little more than basic Word documents. We have noticed that some reports are published on local Healthwatch websites, then re-posted (sometimes more than once) with minor revisions – indicating that proof reading and correction is ongoing, even after the initial publication date.

Report structure is another factor. Some reports are very clear about matters such as the rationale for conducting the report, the local and/or national context, and the inquiry method employed. Others seem to present their findings with little or no introduction, leaving it unclear as to why time and money were spent on the exercise.

QUANTITY

The "Healthwatch Output" section above indicates an inconsistent quantity of report output from one local Healthwatch to another. As with quality, some degree of variation is only to be expected. But the variation at the extremes – from three reports to 134 reports over the same three year period – may merit a closer look.

TIMING

We have tried to get a sense of the time lag between the carrying out of an inquiry and the publication of the inquiry report. It would clearly make sense for reports to be published promptly, while the data in them is fresh. This would also tie in with a key recommendation from the Francis Inquiry – that "*Results and analysis of patient feedback including qualitative information need to be made available to all stakeholders in as near "real time" as possible.*" [xii]

It can be hard to make a systematic assessment of the timing of report publication, partly because of inconsistencies in how reports are dated. However, we can say that while most reports appear on local Healthwatch websites very promptly, some appear weeks or even months after the date that is printed on the document.

CO-ORDINATION

It is clear from the "Report Topics" graph in the "Healthwatch Output" section above that many local Healthwatch are looking at similar patient experience topics. Sometimes this is co-ordinated from the national level, as with the Healthwatch England "Safely Home" exercise.[xiii] At other times, a group of local Healthwatch may band together to look at an issue of common concern across shared services or geography. However, there is little sign of a planned and systematic joining-up of the local Healthwatch effort – either within the Healthwatch network, or with other parts of the scrutiny and regulatory framework (e.g. Care Quality Commission).

We have noted, above, that an important strength of Healthwatch is localism – its ability to detect and respond to local issues as they arise. But it is not clear whether the resultant miscellany of reporting is a matter of strategy or chance.

COLLATION

The Healthwatch network has produced approximately 5,000 reports on patient experience in its first three years. But they are not collated. They are published across 150 websites, all of which are designed and structured differently. They are not catalogued or indexed.

This is what academics describe as "grey literature" – that is, publications that may, individually, have value as sources of knowledge, but whose value is undermined because they are hard to find. The New York Academy of Medicine has stated that "*grey literature publications are non-conventional, fugitive, and sometimes ephemeral*".[xiv]

The Healthwatch output fits classic definitions of grey literature, being unconventional and hard to find. Individually, the reports have value to local audiences. But because they are not available collectively, the network cannot present a combined body of work with a much greater strategic value and impact.

Developing the network's potential

In the preceding pages, we have listed what we see as the strengths and the weaknesses of Healthwatch, based on its reporting output. There is a great deal in the network's favour, and it is clear that, were it not for Healthwatch, the qualitative evidence base on patient experience would be much poorer.

The fact remains, though, that the quantity and quality of reporting across the network is inconsistent. And while some variation is only to be expected, there are big gaps between the best and the worst performers.

Performance variations at the local level may well need to be addressed as Healthwatch moves beyond its start up period. These are operational considerations. There is, at the same time, the strategic question of how the potential of the whole network – collectively – can be developed. A central factor in this respect is the visibility and accessibility of the network's most important asset: its combined body of knowledge.

In the section on "weaknesses", we noted that the Healthwatch reports, being scattered across 150 different websites, have no presence or value as a whole body of work. Academics call this "grey literature".

The Wikipedia entry for grey literature describes it as publications that "*...lack a systematic means of distribution and collection. The standard of quality, review and production of grey literature can vary considerably. Grey literature may be difficult to discover, access and evaluate.*"[xv] This perfectly summarises the current state of play with Healthwatch reporting.

Bringing the network's grey literature out of the shadows – making it very easily accessible to much wider audiences – is key to developing the longer term potential of the Healthwatch network. Here are some ways in which greater access to the Healthwatch intelligence could enhance the power of the network:

MAXIMISE THE IMPACT OF THE BEST PERFORMERS

An excellent report like that on women's experiences of maternity services in Reading[xvi] will have lessons for managers of maternity services right across England. But it is unlikely that service managers outside Reading will know that the report even exists. The network will be stronger when it can make its best work easily available to service providers – wherever they are.

CONTRIBUTE TO PROFESSIONAL DEVELOPMENT

The network's combined body of work could be used to underpin professional training and development throughout the health and care sector. People on both clinical and managerial courses

are being taught about the importance of patient experience. Their learning could be strengthened if they had easy access to the whole Healthwatch body of knowledge as source material for essays and dissertations.

PROMPT ACADEMIC INQUIRY

Researchers are always looking for the next big question that needs answering. Often they conduct scoping reviews to identify gaps in knowledge, or look for patterns that can prompt a question. Healthwatch is the biggest single contributor to the UK's qualitative evidence on patient experience, and could reinforce academic inquiry by making its collective intelligence more easily available to researchers.

STRENGTHEN POLICYMAKING

Civil servants, special advisers and think tanks need to formulate evidence-based policy. Healthwatch is a perfect test lab for looking at policy successes and failures from the patient's point of view. But only if policymakers can quickly search the network's whole evidence base for the topics they are interested in.

SUSTAIN FUNDING

We have made the case in "What Price Patient Voice?"[xvii] that the value of Healthwatch – locally and nationally – is poorly understood by its funders. Helping them to get a better sense of the network's value depends on helping them to see, and get hold of, the whole network's assets. Improved visibility for the combined body of knowledge could mean improved chances of future funding.

PROTECT THE LEGACY

The predecessor to Healthwatch was the Local Involvement Network (LINk). At the time of the transition to Healthwatch, the Local Government Association was keen that the LINk legacy should be protected and carried forward.[xviii] However the local LINks – like local Healthwatch – had no common repository for their combined evidence, so there is in fact, no common legacy. A huge amount of valuable learning has simply been lost. Healthwatch could be working now to ensure that its own legacy does not – at some future point – go the same way.

Conclusion

The Healthwatch network has come a long way in its first three years, producing an unrivalled amount of qualitative evidence on patient experience.

Much of its work is excellent – and while there are some inconsistencies in the quality of reporting, these should not be insurmountable.

Healthwatch is now moving out of its start-up phase and should be in a position to start setting longer term goals. While its initial focus may have been on developing the potential of each local Healthwatch, it may now want to consider how to strengthen the power of the network as a whole.

This may mean thinking about how to make the network's key asset – its collective intelligence – work harder. A useful first step might be to bring it out of the realms of grey literature, and into the light.

References

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ii Report of the Mid Staffordshire NHS Foundation Trust Public Inquiry House of Commons, 2013

iii Ibid, recommendation 255

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v The Tuberculosis Endemic: A Review Of TB Services For Vulnerable People. Healthwatch Hackney, November 2015

Tongue-tie procedures in Cheshire East. Healthwatch Cheshire East, November 2015

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A report about the experiences, views and opinions of people using Gender Identity services in England. Healthwatch Devon, February 2016

vi Operational productivity and performance in English NHS acute hospitals: Unwarranted variations. An independent report for the Department of Health by Lord Carter of Coles, February 2016. Page 7

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viii Mid Staffs hospital scandal: the essential guide. The Guardian, February 2013. http://www.theguardian.com/society/2013/feb/06/mid-staffs-hospital-scandal-guide

ix Safely Home: What happens when people leave hospital and care settings? Healthwatch England, July 2015

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xiv New York Academy of Medicine. http://www.greylit.org/about

xv https://en.wikipedia.org/wiki/Grey_literature

xvi The experience of Reading women who have been diverted from giving birth at their place of choice. Healthwatch Reading August 2015

xvii What Price Patient Voice? Patient Experience Library, May 2016

xviii LINk Legacy How do we make sure the organisational memory of LINks is carried forward? Local Government Association, November 2012