Review of factors important in use of survey data for quality and performance improvement

Report from literature review

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October 2014
Working Paper 2898
This is an independent report commissioned and funded by the Policy Research Programme in the Department of Health. The views expressed are not necessarily those of the Department.

Thanks are due to Juliette Malley, the MAX project manager, for instigating this work, to Stacey Rand for sharing the results of her work regarding a review of the literature on the quality of life of people with learning disabilities, and to Rosalyn Bass for technical support at the early stages of the literature search. We would also like to thank Dr Karen Jones for her comments on the manuscript and Jane Dennett for proofreading it.
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Introduction

In recent years, two surveys have been introduced in England that specifically assess outcomes of social care delivery. The Adult Social Care Survey (ASCS) is distributed annually among a sample of users of publicly-funded services, and the Personal Social Services Survey of Adult Carers in England (PSS SACE) is distributed to a sample of informal carers who have been assessed or reviewed by local authorities (LAs). ASCS was sent to 197,055 users in 2013/14, and the PSS SACE was sent to 126,755 informal carers in 2012/13; 73,815 services users and 57,860 carers responded (Health and Social Care Information Centre, 2014, 2013).

This new approach to measuring the effects of social care provision is reflected in the national Adult Social Care Outcomes Framework (ASCOF), introduced in 2011. The objectives of ASCOF are to monitor services, inform national and local policy-making, and facilitate transparency and accountability (ASCOF 2014/15, Department of Health). Data from the ASCS and PSS SACE feed directly into a number of ASCOF indicators, and policymakers are particularly interested in the quality of life measures summarised as indicators 1A and 1D (ASCOF 2014/15 Handbook of Definitions, Department of Health). The current policy emphasis on improving outcomes, set alongside the time, effort and resources required to conduct the two national surveys, mean that it is important to make the best use possible of data obtained from the surveys.

Anecdotal evidence suggests that LAs have difficulties in using the data for local decision-making and service improvement. To help support LAs, the Department of Health commissioned the Maximising the Value of Survey Data in Adult Social Care (MAX) Project. Funded through the Quality and Outcomes of Person-centred Care Policy Research Unit (QORU), MAX aims to identify what problems LAs have in using the data and to develop survey toolkits to help LAs overcome these challenges, thus optimising their use locally. The literature review described below aims to identify factors important in using quality of life and other survey data, as well as customer/patient feedback data, for performance, quality and service improvement initiatives. The research question can be phrased thus: how can organisations be supported to use quality of life survey data for performance and quality improvement.
Search methods and results

Two searches of electronic databases were conducted between May and August 2014. The first search was to establish the scope of the literature on uses made of quality of life survey data. The following concepts were identified from the research question: survey, data, performance, improvement, plan and quality of life. These were broken down into searchable terms: survey, questionnaire, data, finding, result, performance, quality, service, improvement, plan, programme, methodology, quality of life, QOL, QoL, and qol. Details of the first search results and search strategy can be found in Figure 1 and Appendix A. It should be noted that only one relevant article was identified.

In the absence of a robust body of evidence focusing on quality of life surveys, the second search used the same databases but expanded the original terms to include articles where any survey data (i.e., not just QoL) had been used for service or performance improvement. Four sources were explored to identify relevant articles: electronic databases, reference lists, colleagues and contents of peer-reviewed journals. A total number of 465 articles were sampled from electronic database searches (see Appendix B for details). The titles and abstracts were reviewed, and 38 were selected for full text review (see Figure 2). A hand search of reference lists from the 38 articles revealed 14 more articles. Discussions with colleagues then identified a further 11 articles. Finally, the contents pages of selected peer-reviewed journals were searched separately using all the search terms. Five percent of journal articles were sampled from the three largest peer-reviewed journal searches (n=196). The remaining articles were retrieved from other peer-reviewed journals (n=186). Thus, 407 articles were identified through a hand search, colleagues and via contents pages of selected peer-reviewed journals (see Figure 3 and Appendix C for details). On reviewing the titles and abstracts of these 407 articles, 14 articles were identified for full-text review. Therefore, in total the second search identified 52 articles for a full-text review, including the one identified in the first search. Finally, 37 articles were excluded following a full-text review, leaving 15 articles to be discussed in this paper (see Figure 4).

In both searches, the default publication years were used and the following exclusions were applied:

- Studies conducted outside the UK, Europe, USA, Canada, and Australia.
- Articles written in languages other than English

Titles and abstracts were screened to exclude articles that:

- Were duplicates

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1 Sampling of articles from the Cochrane Library was based on the most relevant ten per cent of articles to the search objective.
• Reported studies focusing on interventions
• Were theoretical rather than empirical

For the purposes of the review, it was assumed that Western countries would have a higher homogeneity in terms of social and health care provision than the rest of the world. Thus, articles from countries other than specified above were excluded. Articles in languages other than English were excluded. This is a common exclusion criterion (Centre for Reviews Dissemination, 2008) which avoid cost associated with translation. In addition, articles reporting interventions and theoretical were excluded as they were no relevant to the purpose of the review, which was to explore use of QoL data.
In summary, 226 articles were identified in the first search and, following a review of the titles, abstracts, and full text, 225 articles were excluded (see Figure 1).

**Figure 1. Search 1 - study selection process from electronic database**

<table>
<thead>
<tr>
<th>Total citations: 226</th>
</tr>
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<tbody>
<tr>
<td>CRD: 0</td>
</tr>
<tr>
<td>Campbell Library: 0</td>
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<tr>
<td>Cochrane Library: 168</td>
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<tr>
<td>PUBMED: 0</td>
</tr>
<tr>
<td>PsycINFO: 50</td>
</tr>
<tr>
<td>Social Care Online: 8</td>
</tr>
</tbody>
</table>

- Removed 6 duplicates
- Number of articles: 220
- Removed 30 by excluded countries
- Number of articles: 190
- Removed 160 by title
- Number of articles: 30
- Removed 29 by abstract
- Number of articles: 1

**Figure 2. Search 2 – study selection process from electronic databases.**

<table>
<thead>
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<th>Total citations: 465</th>
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<tr>
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<tr>
<td>Cochrane Library: 59</td>
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<tr>
<td>PUBMED: 177</td>
</tr>
<tr>
<td>PsycINFO: 158</td>
</tr>
<tr>
<td>Social Care Online: 71</td>
</tr>
</tbody>
</table>

- Removed 361 by title
- Number of articles: 104
- Removed 66 articles: 2 duplicates 11 unable to access 53 by abstract
- Number of articles: 38
Following a review of the full texts, 37 articles were excluded, resulting in 15 articles being selected as relevant to the research question (Figure 4).

The articles were published between 1996 and 2014. Seven articles were from the USA.
(\(n = 7\)), seven from Europe (England, \(n = 4\); the Netherlands, \(n = 2\); and France, \(n = 1\)), and one from Australia. Most of the studies were based in a health care agency (\(n = 12\)), with just three studies concerning social care. Topics included the uses made of patient satisfaction surveys (\(n = 5\)), using data for quality improvements (\(n = 4\)) and implementing patient-reported outcomes or experiences (\(n = 2\)).

This paper will present the findings from the literature review. The next section focuses on how quality of life survey data have been used to inform performance and quality improvement in social care. The fourth section summarises barriers and facilitators to using other survey data, and dissemination activities. Identifying these factors has led to suggestions on how the MAX Project could help LAs use survey data for policy and practice changes; these are discussed in the final section.
Using quality of life data in social care

The literature searches identified only two examples of the use of quality of life (QoL) data to support the development of social care policies and practices. Both focus on services for people with intellectual or development disabilities (IDD) in the USA and were described by Keith and Bonham (2005). As this research was particularly relevant for this review, further information was sought by following up references cited in the text, and accessing the linked websites.

The first project was run by ARC, a not-for-profit advocacy organisation in the USA, in partnership with the Nebraska Department of Health and Human Services. Quality of life for people with IDD is measured using an adaptation of an existing questionnaire (Schalock & Keith, 1993; Keith et al., 1996 cited in Keith & Bonham, 2005). The questionnaire covers eight core domains – satisfaction, productivity and competence, empowerment and independence, social belonging, rights, economic security, growth and development – with a composite score derived from all eight domains reflecting a ninth measure of total wellbeing. The survey has been administered four times to all users of community services (1998, 1999, 2001 and 2004) and to a matching sample of non-IDD community participants in 1999 (Keith & Ferdinand, 2000 cited in Keith & Bonham, 2005).

The main use of the data is to feed into Provider Profiles, a document containing information on Nebraska’s community-based service providers for people with IDD. The Provider Profiles function as consumer reports containing detailed information about service providers to inform service users’ decision-making and inform providers’ activities to improve their performance.

Another example of the use of QoL data to underpin care practices cited by Keith and Bonham (2005) is the Ask Me! Maryland project (see also Schalock & Bonham, 2003). It is an ongoing project run by the ARC of Maryland and sponsored by the Developmental Disabilities Administration (DDA) of the state of Maryland. Every year between 1000 and 1500 service users are randomly selected from the community providers serving at least ten people. Again, QoL is measured in eight domains (although the questionnaire has undergone some revision over time; see Bonham et al., 2010 retrieved from bonhamresearch.com): interpersonal relations, social inclusion, self-determination, rights, material wellbeing, personal development, emotional wellbeing, physical wellbeing. It is important to note that service users are involved in all stages of the project. Trained individuals conduct interviews at the data collection phase, and service users are also members of the panel which reviews the survey results, and makes decisions regarding service and performance improvement plans.

As with the Provider Profiles in Nebraska, the Ask Me! Project publishes an annual report, which contains provider-level survey results and additional provider information (http://www.bonhamresearch.com./Level%201/AskMe.htm). Both the Nebraska and
Maryland projects’ resources support public accountability, better access to informed decision-making, and help raise public awareness of QoL among social care service recipients.
Barriers and facilitators to using survey data

The majority of the remaining articles included in the review described studies set in health care facilities but all have a role to play in informing the MAX project about how best to support LAs in using the ASCS and PSS SACE data for local policy-making and improving users’ quality of life. Across the studies, two broad topics were identified – organisational culture and resources – where barriers were found that would inhibit the use of survey data to enhance performance or quality. However, looking across the studies, factors and activities could also be identified that would facilitate the use of survey data. These papers also highlight the importance of disseminating the right information as widely as possible.

Organisational culture

Barriers

In its broadest sense, organisational culture is the way an organisation conducts its business and treats its employees, customers and the wider community. Davies and colleagues (2000) suggest that it includes

- shared beliefs, attitudes, values, and norms of behaviour. Thus, organisational culture is reflected by a common way of making sense of the organisation that allows people to see situations and events in similar and distinctive ways (Davies et al., 2000, p.111)

Three studies found that where the ideas lying behind the use of patient attitudes as an instrument of change were not prevalent throughout organisation, change was less likely to happen. In a qualitative study on patient survey leads’ attitudes towards the national patient survey programme, Reeves and Seccombe (2008) found that organisational culture was cited as one of the most common reasons for patient survey results not being used to improve performance. Survey leads emphasised the importance of considering patients’ views, but felt that this understanding was not common throughout the organisation and that a culture change was required. Similarly, Davies and Cleary (2005) found that poor acceptance of person-centred decision-making prevented change. In an early hospital-based study, Tasa et al. (1996) found that staff members were afraid that the data could be used punitively, as a ‘hammer…to beat them over the head with’ (p.60).

There was also strong support in the literature reviewed for the role of staff members’ attitude towards patient feedback (Boyer et al., 2006; Davies & Cleary, 2005; Quinn et al., 2004; Tasa et al., 1996). All four articles mention clinicians’ scepticism about the survey results reflecting their performance, for example:

- Generally speaking, people agree with the data; they just don’t think it applies to them (Davies & Cleary, 2005, p.430).
Two articles mention physicians’ defensiveness when faced with negative patient feedback (Davies & Cleary, 2005; Tasa et al., 1996). Staff often felt that patients did not understand their work pressures (Tasa et al., 1996) and they doubted patients’ ability to assess the quality of specialised care or the staff members’ skills (Boyer et al., 2006).

**Facilitators**

Commitment of senior management and leadership are key to ensuring the organisational culture can promote the use of patient-level survey data on quality of life and experiences (four studies).

Two qualitative studies conducted in the USA found that leadership commitment to customer-focused improvement facilitated the implementation of action plans, which in turn identified the steps to be taken to move the organisation forward (Davies & Cleary, 2005; Tasa et al., 1996). There are similar findings for UK health care organisations (Reeves & Seccombe, 2008). Coulter et al. (2014) argue that strong, committed senior leadership is crucial in strategic planning to improve the patient experience.

Leadership by example was considered essential to bring clinicians on board new projects (Davies & Cleary, 2005). A case study published by the Robert Wood Johnson Foundation (2011; cited in Coulter et al., 2014) presents an example of a physician implementing a new patient information package in the Minnesota-based Stillwater Medical Group in the USA. The rise of patients reporting they had received information that was easy to understand from 84 to 98 per cent had a positive effect on patient satisfaction, and prompted the introduction of similar packages for users across all clinical areas. Here, the presence of a dedicated champion was a key part of the strategy to improve patient experience (Coulter et al., 2014).

There is also some evidence to suggest that discussing survey results in staff meetings can have a beneficial effect on the way survey data are used to drive forward improvements (two articles). Again, this will happen only if there is commitment from senior staff. In hospital wards where survey results were discussed in staff meetings there was an improvement in average Nursing Care Scores (Reeves et al., 2013). In a study of staff perceptions and use of patient satisfaction surveys in a French hospital, the staff who participated in meeting discussions were more likely to use patient feedback in their practice. Interestingly, the declared use of patient feedback was most often among male professionals who have worked in the hospital for over ten years (Boyer et al., 2006).

Each of the studies cited above show that organisational culture is not set but can move toward acceptance of patient survey data as a tool for performance and quality improvement. Action plans derived from survey findings provide a useful focus, but require commitment from senior management personnel that, in turn, will generate support among
other staff members. Dedicated champions can act as guides through the implementation process and can help shift attitudes by pioneering strategies to be adopted in other operational areas.

**Resources**

**Barriers**

Across the studies, a number of resource-related factors associated with use of patient feedback data were identified as barriers. The most commonly mentioned was lack of time ($n = 3$); specifically, a lack of time to synthesise and disseminate reports (Davies & Cleary, 2005), and lack of time ‘to link data to improvement[s]’ (Tasa et al., 1996, p.60). In a study of staff perceptions of patient surveys, Dutch GPs considered them resource intensive and saw little reason for change on receipt of patient feedback (Wensing et al., 2003). Interviewees in two studies quoted both competing demands and the skills required to analyse data as obstacles to survey data use (Reeves & Seccombe, 2008; Tasa et al., 1996).

Another resource-related factor underpinning poor use of patient survey results for change and quality enhancement is lack of knowledge about how to use the data (four articles). In three studies, although staff were enthusiastic about the use of patient survey or feedback, they had difficulty interpreting and translating the data into actions (Reeves & Seccombe, 2008; Tasa et al., 1996; Wensing et al., 2003). In another study, 13 out of 14 staff members interviewed thought that working with survey data required special expertise (Davies & Cleary, 2005).

**Facilitators**

Coulter et al. (2014) suggest adequate resourcing is one of the essential components of strategies aiming to improve patient experience. The barriers identified above suggest investment is required not only in additional staff time to work in this area, but also in training staff to analyse the data, to understand the results, and then in knowing how to translate findings into action.

The studies identified a number of initiatives. Training for all clinicians to help them interpret, analyse and use survey data was key to implementing KILK, an innovative web-based patient outcome survey that generates patients’ electronic profiles (Haverman et al., 2014).

The Maryland Ask Me! Project also runs a central quality assurance training session prior to the survey, and regional workshops throughout the year. These cover the following areas: the importance of QoL for state-funded service users; information on the QoL concepts and measurement; how to read and interpret the findings; and how to use the findings in
planning and service improvement. Importantly, each service provider receives a report containing the detailed survey results. This includes a comparison of their average QoL scores with all other providers funded by the DDA, a comparison of service users’ and a matched community sample’s scores for individual questions, and a confidentiality-protected dataset of individuals’ responses.

During the workshops, providers compare their users’ average QoL scores to those for other state providers, and look for trends in the longitudinal QoL data. They learn to assess whether the results reflect their goals, examine their goals’ appropriateness, and consider how their services could be changed to improve users’ quality of life. Together, these processes ensure the results of the Ask Me! project are used to underpin the development of providers’ performance improvement programmes.

One way of addressing the issue of lack of time and skill is to create a central team responsible for data analysis, interpretation and reporting of survey findings. The Planning, Research and Evaluation (PRE) division in Sonoma County in the state of California has proved a successful illustration of this approach. PRE is responsible for developing data-based initiatives and proactive programme planning and implementation, and carries out research to support evidence-based policy changes and decision-making (Harrison, 2012). A central resource such as this may facilitate better co-operation and collaboration with other organisations such as the local Healthwatch, in line with the current policy on supporting integrated care (ASCOF 2014/15, Department of Health).

Further analysis of survey data can be conducted to understand how to improve standards of care (n=2). Commonly NHS inpatient survey results are reported using descriptive statistics, as described in a literature review on the inpatient survey programme (DeCourcy et al., 2012). In that review, the authors found only nine out of 41 papers used more sophisticated analyses such as inferential statistical tests or regression analyses. One Australian study explored associations between the domains of care and a satisfaction survey for patients in their mental health hospital. The analysis revealed three areas that predict overall satisfaction: service provided by support workers, availability of support services after discharge, and feeling safe and secure at the hospital. Following these results, the mental health hospital introduced interventions to improve care in these areas (Brunero et al., 2009). More detailed analysis of quality of life data generated by the Ask Me! Maryland project also shows how services could be improved (Schalock & Bonham, 2003 cited in Keith & Bonham, 2005). The analysis found that interpersonal relationships (that is, relationships with staff, friends, family and romantic relationships) was the largest predictor of users’ personal development, followed by respecting users’ rights, and their physical wellbeing. Providers, therefore, should focus their efforts on these aspects, which in turn would support users’ personal development.
Dissemination

Dissemination is, of course, key to using quality of life and other survey information to bring about change. If staff and users do not know about the survey findings, they cannot be included while developing improvement plans; reach, format and comprehensibility are important considerations.

The extensive training and workshop programme employed by the Ask Me! Maryland Project is a good example of ensuring that information reaches all stakeholders, and service users are included at all stages of survey design, implementation and review (Keith & Bonham, 2005). Tasa and colleagues (1996) suggest that ‘the intensity, savviness and quality of patient feedback dissemination strategies influence the usefulness of the feedback’ (p.66). In this study, the extensive efforts to provide patient feedback to nurses resulted in a change in nurse attitudes and behaviours, and subsequently informed development and implementation of improvement action plans.

Two other articles provided examples of how survey results are used and disseminated within organisations (Peak & Sinclair, 2002; Quinn et al., 2004). Summaries of results are distributed to internal and external stakeholders. The senior management team identifies areas of weakness based on fewer than 90 per cent of positive responses and develops actions plans which are reviewed by the Board of Trustees (Peak & Sinclair, 2002). The second paper presents an elaborate dissemination plan of the report containing survey results. A tailored report is distributed to staff members at all levels of the organisation and is presented and discussed at staff meetings, including senior management and clinical groups meetings. Areas of concern are identified based on pre-defined criteria, and appropriate action plans are devised and implemented at different levels of the organisation. Similar to the previous example, a member of staff is assigned responsibility over problem areas identified, and the feedback from action plans is discussed at meetings. In addition, programme managers select up to five survey items for improvement, and employ quantitative methods to track changes. This dissemination strategy enables efficient goal setting and monitoring, and has resulted in a number of successful changes; for example, improvements to the hospital food services. Both examples demonstrate that having a well-defined strategy for survey results dissemination and use is important to ensure an efficient application of the survey findings.

The way information is disseminated is also important; five articles provided strong evidence that appropriate reporting of survey findings is associated with use of those data to inform performance and quality changes ($n = 5$). In the USA, the Massachusetts Health Quality Partnership devised a reporting framework suitable for the participating hospitals and the public (Rogers & Smith, 1999). The emphasis was on preserving detail without oversimplification of the results in a manner that highlighted the hospital’s strengths and weaknesses. The project divided performance measures into three categories: medical, surgical and maternity, enabling a clear comparison of results between the hospitals. In
addition, responses to survey questions were aggregated into separate scores for seven dimensions of care. These dimensions informed prospective patients about how hospitals might engage with a patient’s needs, and moreover facilitated improvements in the care delivery by highlighting areas of concern. As a result of this project, participating hospitals used patient survey results to identify areas needing improvement, and designed and implemented a number of initiatives to tackle these.

In the UK, healthcare staff find the red-amber-green (RAG; or traffic light) system helpful for benchmarking – comparing local areas – and in tracking trends over time (Reeves & Seccombe, 2008). Here, scores for each question are categorised as red if they fall within the worst 20 per cent of trusts, amber if within the middle 60 per cent of trusts, and green if their results are within the top 20 per cent of trusts for that indicator. This descriptive system of benchmarking and comparing data over time is also used for the electronic profiles generated by the KILK patient-reported outcome programme in the Netherlands (Haverman et al., 2014). Notably, two studies found that aggregated information that suggested a general problem or overall dissatisfaction was perceived by staff as being unlikely to lead to any action. Reporting findings for smaller units or for patient groups meant it was more likely to be used (Davies & Cleary, 2005; Reeves & Seccombe, 2008). French hospital staff also reported paying more attention to results for their department rather than the overall hospital results (Boyer et al., 2006).

While this review focuses on academic research literature published in peer-review journals, there are examples of reports using a range of devices to present data in the ‘grey’ literature. Both are examples from the USA and both focus on services for people with IDD where there has been a considerable amount of work undertaken on communicating results appropriately. The first example is linked to research already reported here: the Maryland Ask Me! Project. The annual report includes the background information about the survey methods and QoL domains, as well as the results for individual providers. It is an important source of information for service users and their families, but also allows providers to monitor their performance and identify their strengths and weaknesses. Policy-makers from the DDA use the report to establish gaps in current policy and practice, to develop appropriate training and target resources. Indeed, the DDA encourages the providers to use the data to inform their outcome-based Quality Assurance Plans, which are a state-wide requirement. The 2011 annual report can be found here http://www.bonhamresearch.com./Level%201/AskMe.htm.

The second website, identified by a colleague and again from the USA, reports on National Core Indicators (NCI). This is a multi-state joint initiative to develop indicators that measure the performance of services for people with IDD. The NCI handbook on how to use survey results effectively suggests sharing survey results online and in a widely accessible format. The authors recommend the use of icons and photographs of individuals familiar in the local area to facilitate understanding of the survey reports. The authors provide an example of a consumer-friendly report from Pennsylvania. The NCI handbook can be found here
How MAX could help

MAX is a time-limited research project. Team members cannot offer support and advice over a number of years, but instead one of the project aims is to develop a ‘toolkit’ that contains advice and guidance that will support use of the ASCS and PSS SACE data. The focus is particularly on helping LAs to make the best use of the data to improve the quality and performance of LA-funded services, thus improving users’ QoL. In this paper, we have reviewed the academic literature on using QoL and other surveys to identify what has worked in other research projects. From the literature, we have identified five broad tasks that MAX could potentially provide support through a ‘toolkit’.

A guide to analysis

One way to enhance the use of survey data for planning and quality and performance initiatives is to undertake further data analyses. The Ask Me! project discussed above provides a good example which, coupled with an extensive dissemination programme, showed providers where to focus their improvement efforts for greatest effect (Keith & Bonham, 2005; see also Schalock & Bonham, 2003). Findings from the advanced statistical analysis also play an important part in the development of DDA’s improvement plan and training programme. For England, LAs could develop a series of pre-defined questions of interest; an example might be: which factors are the most influential on service users’ QoL? The MAX project team could support LAs by developing a step-by-step guide that demonstrates how to conduct analyses to address these questions, and perhaps create an electronic tool to facilitate data analysis.

Collecting and analysing additional data

The literature search identified some studies where additional data have been gathered to add depth to user surveys to help identify areas needing attention and courses of action. This has included focusing on smaller groups of patients or users, looking at specific questions raised by the survey data, or supplementing the quantitative data from surveys to explore areas not covered by the survey. The methods of qualitative data collection have included: focus groups (Quinn et al., 2004; Tasa et al., 1996); comment boxes (Reeves & Seccombe, 2008; Tasa et al., 1996); and compliments and complaints (Tasa et al., 1996). Interestingly, the authors of two articles argue that gathering information on staff attitudes and perceptions could be an additional source of information on patient/customer experience, and suggest that staff surveys should be conducted alongside patient/customer surveys (Peak & Sinclair, 2002; Quinn et al., 2004). For England, Coulter and colleagues (2014) suggest that links between patients’ experience and staff experience gathered
through NHS surveys could be examined for additional insights. The MAX Project team could help LAs maximise the use of such data by producing a guide on the different methods of collecting qualitative data and a step-by-step guide to qualitative data analysis.

**Helping engagement with stakeholders**

Engagement at all stages of the survey process has been shown to be important (Keith & Bonham, 2005). Local authorities need to identify all stakeholders and how they could become involved in the survey process. The Max Project team could support LAs by creating stakeholder maps and engagement plans that LAs could use prior to the survey to identify stakeholder groups and their needs, and how the survey process could address these. This might include adding questions to the survey that reflect particular local issues. This would ensure the best use is made of the survey, maximising the use of the data for local needs, in turn helping to meet the aims of ASCOF (ASCOF 2014/15, Department of Health).

**Designing provider profiles**

Another use made of survey data for quality and performance improvement is in producing information about providers. Two studies identified the way Provider Profiles were developed in which the QoL survey data enhanced the usual range of provider details such as the date of inception, type of provider, services offered, and number of service users per year. For England the addition of data from an in-depth analysis of the ASCS and PSS SACE, including the QoL results, would give users far more information to help them choose services, as well as compare service providers, and with national and regional averages. Other information could be included, such as the implementation and measurement of performance or quality improvement activities, or activities addressed at improving QoL. The MAX Project could facilitate the production of these profiles by developing an electronic proforma. For service providers, such individualised information would help make the data easier to understand and thus easier to use for quality or performance action plans.

**Helping to develop dissemination formats**

A more general role that the MAX team could undertake within its ‘toolkit’ activities is in helping to develop a dissemination strategy. The literature reviewed showed that appropriate reporting can increase the likelihood of the use of survey results for performance and quality improvements. Several authors commented that engagement is increased when the content and format of reports match the needs of target audiences. The MAX project could develop a guide on how to create and use presentation techniques, such
as infographics, effectively. There may be scope to create an electronic proforma for graphs and charts. In addition, a guide could be produced on how to best approach reporting for different types of audiences to maximise reach for both internal and external target audiences.
Conclusion

This literature review has focused on peer-reviewed journal articles using systematic methods to search a wide range of commonly-used databases. The aim was to identify evidence-based activities undertaken to support organisations to make the best use of quality of life survey data to improve service quality and performance in social care. The literature on using QoL data in social care services was sparse and related to services for people with IDD. The search was therefore widened to include the use of other patient-level survey data in health care organisations and internationally. Five activities have been identified, each supported by good quality research. The next task is to consider these findings in the light of work already undertaken within the MAX project, and to consider the skills and resources within the MAX project team and so make decisions about which tasks and activities can be included in the forthcoming toolkit.
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Appendices

This review has used systematic methods to identify relevant literature, with clear inclusion and exclusion criteria. The focus has been on peer-reviewed articles published in journals identified through well-established databases and search engines. A member of staff experienced in designing search strategies supported the early work. The title and abstract sifts were undertaken by one researcher from the MAX project team.

Appendices A-C describe the databases and search strategies employed. Appendix D shows the topics covered by the articles excluded when the full text was read, and Appendix E gives a short overview of the articles included in this review.
Appendix A: Search 1

The databases below appear in chronological order in which they were searched.

**CRD Centre for Reviews and Dissemination (DARE, NHS EED, HTA)**

15/05/2014

(survey or questionnaire)

AND

(data OR finding* OR result*)

AND

(performance OR quality OR service)

AND

(improvement)

AND

(plan* OR programme* OR methodology*)

AND

(quality of life)

0 results

**The Campbell Library**

16/05/2014

(survey OR questionnaire) AND (data OR finding* OR result*) AND (performance OR quality OR service) AND (improvement) AND (plan* OR programme* OR methodology*) AND “quality of life”

0 results

**PUBMED**
29/05/2014
(survey OR questionnaire)
AND
(data OR finding* OR result*)
AND
(performance OR quality OR service)
AND
(improvement)
AND
(plan OR programme OR methodology)
AND
(“quality of life” OR “QOL” OR “QoL” OR “qol”) 
0 results
(plan OR programme OR methodology)

AND

(“quality of life” OR “QOL” OR “QoL” OR “qol”)

8 results

PsycINFO
30/05/2014

(survey OR questionnaire)

AND

(data OR finding* OR result*)

AND

(performance OR quality OR service)

AND

improvement

AND

(plan* OR programme* OR methodolog*)

AND

“quality of life” OR “QOL” OR “QoL” OR “qol”

50 results

Cochrane Database of Systematic Reviews
05/06/2014

(survey or questionnaire) and (data OR finding* OR result*)

AND
(performance OR quality OR service) and improvement and (plan OR programme OR methodology) AND "quality of life" 168 results
Appendix B: Search 2

Expanded search of electronic databases excluding the search terms related to 'quality of life'. The databases below appear in the chronological order in which they were searched.

PsycINFO

13/06/2014

(survey OR questionnaire)

AND

(data OR finding* OR result*)

AND

(performance OR quality OR service)

AND

improvement

AND

(plan* OR programme* OR methodolog*)

158 results

CRD Centre for Reviews and Dissemination (DARE, NHS EED, HTA)

14/05/2014

(survey or questionnaire)

AND

(data OR finding* OR result*)

AND

(performance OR quality OR service)

AND

(improvement)
AND
(plan* OR programme* OR methodology*)
0 results

Social Care Online
14/06/2014
survey OR questionnaire
AND
data OR finding* OR result*
AND
performance OR quality OR service
AND
improvement
AND
plan OR programme* OR methodology*
71 results

The Campbell Library
16/06/2014
survey OR questionnaire
AND
data OR finding* OR result*
AND
performance OR quality OR service
AND
improvement
AND
plan OR programme* OR methodology*
0 results

Cochrane Database of Systematic Reviews
16/06/2014
survey OR questionnaire
AND
data OR finding* OR result*
AND
performance OR quality OR service
AND
improvement
AND
plan OR programme* OR methodology*
586 results

To test the relevance of the articles retrieved, they were sorted by relevance to the search terms using the websites’ default sorting strategies. The top ten percent of the articles (n=59) were then reviewed by title but none were found relevant for the review. This result indicates that the database search identified all the relevant literature and the remainder 90 percent of articles from these this database were not reviewed.

PUBMED
16/06/2014
(survey OR questionnaire)

AND

(data OR finding* OR result*)

AND

(performance OR quality OR service)

AND

(improvement)

AND

(plan OR programme* OR methodology*)

177 results
Appendix C: Search of selected peer-reviewed journals

The search results are presented chronologically, and the journal titles are ordered alphabetically within each search date. These searches included the search terms related to ‘quality of life’ to establish the scope of the literature outside of the electronic databases already searched in Search 1.

Table 1. Hand search of selected peer-reviewed journals.

<table>
<thead>
<tr>
<th>Date of search</th>
<th>Journal title</th>
<th>Search terms used</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>25/06/2014</td>
<td>Australian Social Work</td>
<td>quality of life survey questionnaire performance service improvement plan programme methodology</td>
<td>14</td>
</tr>
<tr>
<td></td>
<td>European Journal of Social Work</td>
<td>quality of life survey questionnaire performance service improvement plan programme methodology</td>
<td>819 *</td>
</tr>
<tr>
<td></td>
<td>Journal of Evidence-Based Social Work</td>
<td>quality of life survey questionnaire performance service improvement plan programme methodology</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>Journal of Policy Practice</td>
<td>quality of life survey questionnaire performance service improvement plan programme methodology</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>Journal of Social Service Research</td>
<td>quality of life survey questionnaire performance service improvement plan programme methodology</td>
<td>18</td>
</tr>
<tr>
<td></td>
<td>Social Work in Health Care</td>
<td>quality of life survey questionnaire performance service improvement plan programme methodology</td>
<td>43</td>
</tr>
<tr>
<td></td>
<td>Social Work in Public Health</td>
<td>quality of life survey questionnaire performance service improvement plan programme methodology</td>
<td>16</td>
</tr>
<tr>
<td>26/06/2014</td>
<td>International Journal of Healthcare Management</td>
<td>&quot;quality of life&quot; AND data OR survey OR questionnaire AND performance OR service OR quality AND improvement AND plan OR programme OR methodology</td>
<td>89</td>
</tr>
<tr>
<td></td>
<td>Journal of Organisational Transformation and Change</td>
<td>&quot;quality of life&quot; data survey questionnaire performance service improvement plan programme methodology</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>Maney Publishing's online platform, includes journals: International Journal of Healthcare</td>
<td>&quot;quality of life&quot; OR &quot;QOL&quot; OR &quot;QoL&quot; OR &quot;qol&quot; AND data OR survey OR questionnaire AND performance OR service OR</td>
<td>0</td>
</tr>
<tr>
<td>Source</td>
<td>Search Terms</td>
<td>Results</td>
<td></td>
</tr>
<tr>
<td>---------------------------------------------</td>
<td>-----------------------------------------------------------------------------</td>
<td>---------</td>
<td></td>
</tr>
<tr>
<td>European Journal of Social Work</td>
<td>quality AND improvement AND plan OR programme OR methodology</td>
<td>41</td>
<td></td>
</tr>
<tr>
<td>Maney Publishing's online platform, includes journals: International Journal of Healthcare Management, Journal of Care Services Management, etc.</td>
<td>Same search terms as above but not restriction to search location (searched ‘anywhere’ on the website)</td>
<td>1257 *</td>
<td></td>
</tr>
<tr>
<td>Quality of Life Research</td>
<td>&quot;quality of life&quot; AND data OR survey OR questionnaire AND performance OR service OR quality AND improvement AND plan OR programme OR methodology</td>
<td>1849 *</td>
<td></td>
</tr>
<tr>
<td>Research on Social Work Practice</td>
<td>&quot;quality of life&quot; AND data OR survey OR questionnaire AND performance OR service OR quality AND improvement AND plan OR programme OR methodology</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td>Social Work Research</td>
<td>&quot;quality of life&quot; AND data OR survey OR questionnaire AND performance OR service OR quality AND improvement AND plan OR programme OR methodology</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td></td>
<td>4111</td>
<td></td>
</tr>
</tbody>
</table>

* To test the relevance of the articles retrieved, the articles from the three largest sources (i.e. European Journal of Social Work, Maney Publishing, and Quality of Life) were sorted by relevance to the search terms using the websites’ default sorting strategies. The top 5 per cent of the articles (41, 63 and 92 articles respectively) were then reviewed by title but none was found relevant for the review. This result indicates that the database search identified all the relevant literature and the remainder 95 per cent of articles from these three sources were not reviewed.
Appendix D: Articles not included in the review

Table 2. Breakdown of the articles read but not included in the review by topic (n=37).

<table>
<thead>
<tr>
<th>Topics</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>Quality improvement initiatives in healthcare</td>
<td>14</td>
</tr>
<tr>
<td>Quality improvement collaboratives in healthcare</td>
<td>6</td>
</tr>
<tr>
<td>Organisational learning and readiness for change</td>
<td>3</td>
</tr>
<tr>
<td>Development of clinical indicators</td>
<td>1</td>
</tr>
<tr>
<td>Research proposal</td>
<td>1</td>
</tr>
<tr>
<td>Conceptual article on knowledge sharing</td>
<td>1</td>
</tr>
<tr>
<td>Article on implementation theory</td>
<td>1</td>
</tr>
<tr>
<td>Evaluation of teamwork building programme</td>
<td>1</td>
</tr>
<tr>
<td>Perceptions of 'culture' within NHS</td>
<td>1</td>
</tr>
<tr>
<td>Theoretical paper on knowledge management</td>
<td>1</td>
</tr>
<tr>
<td>Theoretical paper on use of GP practice data</td>
<td>1</td>
</tr>
<tr>
<td>Review of innovation studies in health care</td>
<td>1</td>
</tr>
<tr>
<td>Topics</td>
<td>N</td>
</tr>
<tr>
<td>--------------------------------------------------------</td>
<td>----</td>
</tr>
<tr>
<td>Development of patient survey</td>
<td>1</td>
</tr>
<tr>
<td>Report from survey of LA carers' leads in England</td>
<td>1</td>
</tr>
<tr>
<td>Case study of patient survey in drug addiction clinic</td>
<td>1</td>
</tr>
<tr>
<td>Theoretical paper on QoL domains</td>
<td>1</td>
</tr>
<tr>
<td>Review of studies on implementation of EBP</td>
<td>1</td>
</tr>
<tr>
<td>Total</td>
<td>37</td>
</tr>
</tbody>
</table>
Appendix E: Summary of review articles

Table 3. Details of articles reviewed.

<table>
<thead>
<tr>
<th>Authors</th>
<th>Field</th>
<th>Summary</th>
<th>Category</th>
<th>Country</th>
</tr>
</thead>
<tbody>
<tr>
<td>L. Boyer, P. Francois, E.</td>
<td>Health care</td>
<td>Study of care providers’ perceptions of and use of patient satisfaction surveys</td>
<td>Survey</td>
<td>France</td>
</tr>
<tr>
<td>Doutre, G. Weil, J. Labarere</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>S. Brunero, S. Lamont,</td>
<td>Health care</td>
<td>Study exploring satisfaction with quality of care, staff, environment and discharge among acute mental health hospital patients</td>
<td>Survey</td>
<td>Australia</td>
</tr>
<tr>
<td>G. Fairbrother</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>A. Coulter, L. Locock, S.</td>
<td>Health care</td>
<td>Authors claim that patient experience data collected over the last 10 years are underused for service improvement. They propose creation of a national centre of patient/user experience.</td>
<td>Opinion paper</td>
<td>England</td>
</tr>
<tr>
<td>Ziebland, J. Calabrese</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>E. Davies, P. D. Cleary</td>
<td>Health care</td>
<td>Study aimed to develop a framework of factors affecting the use of patient feedback and survey data in quality improvement. Interviews with healthcare staff were conducted to identify difficulties and successes in use of patient feedback or survey data for quality and performance improvement.</td>
<td>Interview</td>
<td>USA</td>
</tr>
<tr>
<td>A. DeCourcy, E. West, D. Barron</td>
<td>Health care</td>
<td>Review of publications on the national inpatient survey. The majority of the publications were reports of the survey results, which used mostly descriptive statistics. The authors conclude that the survey has not been fully exploited for standards improvement in the NHS.</td>
<td>Literature review</td>
<td>England</td>
</tr>
<tr>
<td>Authors</td>
<td>Field</td>
<td>Summary</td>
<td>Category</td>
<td>Country</td>
</tr>
<tr>
<td>----------------------------------------------</td>
<td>--------------</td>
<td>---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
<td>--------------</td>
<td>-----------</td>
</tr>
<tr>
<td>L. Harrison</td>
<td>Social Work</td>
<td>Article presents Planning, Research and Evaluation department of Human Services Department in County Sonoma, California, USA. It illustrates the use of a centralised inter-departmental division for data-based strategic planning, decision making,</td>
<td>Case study</td>
<td>USA</td>
</tr>
<tr>
<td>L. Haverman, H. A. van Oers, P. F. Limperg, C. T. Hijmans, S. A. Schepers, S. M. Sint Nicolaas, et al</td>
<td>Health care</td>
<td>The article describes the implementation of KLIK, a web based programme for collecting patient reported outcomes. KLIK generates eprofiles consisting of patients’ responses on a number of scales, including health-related QoL.</td>
<td>Methods paper</td>
<td>the Netherlands</td>
</tr>
<tr>
<td>K. D. Keith, and G.S. Bonham</td>
<td>Social care</td>
<td>The article presents two projects that measure QoL of individuals with learning disabilities (LD). The data is used for identifying predictors of quality outcomes, creating service provider profiles, comparing LD with non-LD people, developing performance standards, informing decision-making, and quality and performance improvement initiatives.</td>
<td>Case study</td>
<td>USA</td>
</tr>
<tr>
<td>T. Peak, S. V. Sinclair</td>
<td>Social care</td>
<td>The study presents the use of a satisfaction survey in a nursing home distributed annually to three stakeholder groups: residents, family and staff.</td>
<td>Case study</td>
<td>USA</td>
</tr>
<tr>
<td>G. P. Quinn, P. B. Jacobsen, T. L. Albrecht, B. A. Bell Ellison, N. W. Newman, M. Bell, et al</td>
<td>Health care</td>
<td>The article presents a real-life example of the Moffitt Cancer Centre in Florida, USA, which employs an elaborate continuous quality improvement programme where patient satisfaction survey plays a crucial role.</td>
<td>Case study</td>
<td>USA</td>
</tr>
<tr>
<td>Authors</td>
<td>Field</td>
<td>Summary</td>
<td>Category</td>
<td>Country</td>
</tr>
<tr>
<td>-------------------------------</td>
<td>---------------</td>
<td>---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
<td>-------------------</td>
<td>------------------</td>
</tr>
<tr>
<td>R. Reeves, I. Seccombe</td>
<td>Health care</td>
<td>The study aimed to assess attitudes of senior healthcare management towards the national patient survey programme in England. It identifies barriers and facilitators to using survey results and provides a list of recommendations for improving patient survey programmes.</td>
<td>Interview</td>
<td>England</td>
</tr>
<tr>
<td>R. Reeves, E. West, D. Barron</td>
<td>Health care</td>
<td>A pilot study assessing whether different types of patient feedback delivery to nurses had different effect on quality of care. Facilitated patient feedback (written results of survey combined with ward-level meetings) led to improved patient experiences.</td>
<td>Survey; meetings</td>
<td>England</td>
</tr>
<tr>
<td>G. Rogers, D. Smith</td>
<td>Health care</td>
<td>The article presents the process of development of a programme to measure and disseminate hospital patient experiences.</td>
<td>Case study</td>
<td>USA</td>
</tr>
<tr>
<td>K. Tasa, G. R. Baker, M. Murray</td>
<td>Health care</td>
<td>The article presents a case of a hospital and its use of extensive patient feedback, including survey, focus groups and complaint/compliment system, for quality improvement initiatives. They use the case study to generate 5 propositions about the use of patient feedback for quality improvement.</td>
<td>Case study; interviews and document analysis</td>
<td>USA</td>
</tr>
<tr>
<td>M. Wensing, E. Vingerhoets, R. Grol</td>
<td>Health care</td>
<td>The study examines GPs’ perceptions of and reactions to patient survey feedback. After receipt of patient feedback, GPs regarded the patient survey as of relevance for their practice; they perceived it as resource-intensive and saw little reason for change.</td>
<td>Survey</td>
<td>the Netherlands</td>
</tr>
</tbody>
</table>