

Listening differently to users

Assessing the feasibility and value of
real-time reporting of the experience of
people receiving care in the last year of life

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Foreword

Receiving and responding to feedback from patients is a vital component of high quality care. Historically there have been concerns that this is difficult to achieve for people who are very unwell or approaching the end of their life.

I am therefore delighted to introduce this important report which suggests otherwise and indeed confirms its value for patients. For that reason I urge a wider consideration of its findings and recommendations. The report describes a project which has collected feedback from patients, their families and carers about their experience of the care they received in a variety of settings – at hospital, in their own home, care homes and hospices. Importantly, this feedback was collected in real time to allow the care teams to act immediately and/or to make long term plans where necessary. This approach was piloted county-wide in Lincolnshire, and as such offers some valuable insights into the opportunities and challenges that exist prior to a wider roll out of such a system in the future.

The report also identifies some challenges to be addressed before any wider roll-out. In the main these relate to complex and variable local governance procedures and to difficulties in securing commitment from executive leadership at local level to support the project implementation. Further consideration is also required of ways to provide such a system in a cost effective way.

However, the project has confirmed that people close to the end of their lives are willing and keen to discuss their experience of care. The addition of information from projects such as this to the findings of the National Survey of Bereaved Relatives will enable commissioners and providers of end of life care to ensure that the care is focussed directly on the needs of patients and their families.



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Introduction and background

This paper reports on the findings of a Real Time Reporting pilot project developed by the National End of life Care Programme (now part of NHS Improving Quality), Marie Curie Cancer Care and Help the Hospices working in partnership. The aim of the project was to find more effective ways to collect, analyse and present data on the experience of people receiving care in their last year of life, as a basis for service improvement.

The report makes some recommendations for future actions, reflecting the findings of the pilot project. We believe that this will be of interest to NHS England, regulators as well as to a wide range of provider organisations delivering end of life care who wish to know more about the experience of the people who receive their care, and how it can be continuously improved.

The findings from this pilot project are timely. Health and social care strategies, both local and national, recognise that how patients experience the care they receive is a vital measure of its quality and are calling for greater awareness and information about users experiences. Yet, there is widespread acknowledgement of the challenges associated with capturing meaningful and timely feedback from those within the last year of life, resulting in relatively poor data in this area. Some significant efforts have been made to redress this gap through the National Survey of Bereaved Relatives Survey¹. Even so, data collected by these surveys to date are retrospective, gained via carers who serve as proxies and collected after the person to whom the data relates has died.

It is within this context that this project was initiated. The partners sought to identify, implement and evaluate a system which could present end of life care providers with timely, current, reliable and systematic data about the experience of care on the part of patients as well as their family and carers, in order that partners could respond accordingly.

The pilot was carried out across a range of care services operating in Lincolnshire. It captured the views of patients considered to be in the last year of life as well as their family and carers. The pilot had two phases, run over 3 months and 4 months respectively between 2012–2013.

¹ Office for National Statistics (2012). National Bereavement Survey (VOICES).

Establishing a pilot project

Project aims and objectives

The project sought to encourage the collection of data from patients thought to be in the last year of their life, which could be examined at local, regional and/or national levels. It wanted to learn more about the experiences of people receiving end of life care and to explore whether similar strategies for collection, collation and dissemination could work in the variety of settings in which end of life care is offered. Most importantly it wanted to consider how system-wide improvement of end of life care could be effected by high quality feedback of patient and carer experience.

For these data to be of most value, they must be incorporated into a cycle of collection, analysis and collation of meaning, and most importantly action must be taken to address any shortfalls in quality. Ideally these processes happen in a timely manner. Importantly the sources of these data will reflect the many different contexts in which patients receive care and be comparable across settings.

The principal aim of the pilot was to ascertain the acceptability and utility of a real time survey and reporting system to capture the experience of patients receiving care towards the end of their life as well as that of their families and carers.

The overarching objective of the project was to provide individual organisations with up-to-date, reliable and systematic data about how their users experienced their care. This would then form a basis for improvement and change where such experience was unacceptable.

A further objective was to understand how such data, considered in a more collective way could inform the development of care strategies at local, regional and national levels.

It was anticipated that the pilot would provide valuable evidence for both national and local stakeholders engaged in end of life care including:

1. the acceptability of the survey methodology to patients and carers in different care settings
2. the value and quality of data collected to the organisations
3. the feasibility of acquiring data, via a core survey, which would be of value both locally and nationally
4. the opportunities and challenges for national rollout of real time reporting.

The project plan

A steering group was established in late 2011, comprising representatives of the different organisations involved and other key individuals bringing additional skills to the discussions (see Appendix 1 for details).

Customer Research Technology Ltd (CRT) was contracted to provide the technological and survey development expertise. CRT conducted the real time survey, processed the survey data and shared the survey findings. CRT subcontracted Ipsos MORI to provide advice regarding questionnaire design for the real time survey. Ipsos MORI was also responsible for qualitatively evaluating the real time survey.

The steering group then chose Lincolnshire for the pilot site, reflecting its history of strong interagency working amongst the key service providers of end of life care. The steering group met local stakeholders to hear their feedback formally on at least four occasions in the lifetime of the project. In addition the project manager engaged more regularly with stakeholders on an informal basis to learn about their experiences of the project and its outcomes.

The pilot embraced four different care settings in which end of life care is commonly provided in Lincolnshire – care homes, individuals' own homes, hospices (day hospices and inpatient units) and hospitals.

The pilot project in practice

Project methodology

The survey issued to patients, their families and carers was developed with some input from Ipsos MORI with contributions from the Lincolnshire partner organisations, expert users and members of the steering group. The work of VOICES¹ provided valuable reference material. Further changes were made to the survey after phase one, drawing on feedback from the Marie Curie Cancer Care Expert Voices Group together with the local user group, Lincolnshire Cancer Forum and project volunteers.

The survey included a core set of questions for use across all care settings and an additional set of questions developed for each of the settings (Appendix 2). It also contained the Friends and Family question developed by NHS England.

The main medium used to collect feedback was a handheld electronic tablet but alternative options were made available including a paper or web-based survey.

Staff and volunteers were recruited to facilitate the delivery of the survey. They attended a two hour workshop which explained the purpose of the survey, how to carry out survey interviews and how to use the hand held device to capture the data. They were issued with guidance about how to seek support or advice in the event of any distress on their part or in the light of any unexpected findings during the course of administering the survey.

Choice of sites and criteria for selecting participants

Seventeen sites participated in the project, offering a variety of settings across a wide geographical area, including:

- Six Care Homes
- The catchment areas of three Palliative Care Clinical Nurse Specialist teams based in the community
- Two Community Hospitals
- Three Acute Hospitals
- One Hospice Inpatient Unit
- Two Hospice Day Therapy Units

Staff working on each of these sites were asked to identify people for the survey by applying the 'Surprise Question' ("Would you be surprised if this patient died within a year?") to everyone in their care and then inviting them or their carer/s to participate. An information pamphlet was given to all those invited to participate.

Data collection

Care settings used a variety of means to gather data:

- Care homes used a mixture of volunteers and a designated senior member of staff.
- Community staff invited people to self-complete the survey while visiting their patients at home.
- Hospices used designated staff members caring for the person and volunteers.
- Hospitals used volunteers trained by the hospice.

Survey responses were entered directly onto the electronic tablet by the person receiving care, by their carer or by the trained volunteer assisting the person. CRT undertook the data analysis and provided results when the number of responses was meaningful (greater than five responses in total). The results were fed back to each of the care setting managers via Microsoft Excel summary tables of all responses and themed dashboards.

¹ Office for National Statistics (2012). National Bereavement Survey (VOICES).

Using the results

The feedback was presented in a range of formats as illustrated in Appendix 3.

For the purpose of this report, the results have been anonymised so that care settings cannot be identified. Local services received information on a monthly basis in a variety of formats, including any verbatim comments received (see Appendix 3 for examples). Changes over time as well as the most recent findings were presented in the reports.

The reports were sent directly to all local managers as well as their named senior colleagues involved in the pilot. It was then the responsibility of the organisations to decide how to use the feedback, and with whom to share it. In the hospital, by way of example, managers shared feedback from patients with the ward team as part of their monthly review of care.

Learning from the pilot project

Review of the data and discussion with key local stakeholders in Lincolnshire highlights the following findings from the pilot in relation to its original aims.

Uptake of the survey and acceptability of the survey methodology in different care settings

- In phase 1, 236 people completed the survey across all care settings. Of these, 67% were the person receiving care and 33% a family carer.
- In phase 2, 325 people completed the survey – of these 85% were the person receiving care and 15% a family carer.
- The majority of respondents in both phases were women (60%) with the majority of respondents being aged between 65–94 years.
- On average the number of returns per month over both phases was consistent at 78. See Figure 1, Appendix 3 for a breakdown of responses per setting and by phase.
- The first question of the survey records whether the person wishes to complete the survey. The data suggests that all who were surveyed were happy to do so. Feedback from the volunteers indicates that very few people declined to take part, although not all volunteers recorded this number.
- No concerns were expressed by anyone about the appropriateness of being asked to engage with the survey. Any refusals to take part were attributed to physical ill-health.
- The vast majority of returns were made using electronic tablets. No paper surveys were returned and only 5% of the responses were via the web link.

The value and quality of the data collected

The data collected in the project captured the experiences of a diverse group of people. Of those who responded and confirmed their diagnosis (n=224) 41% had a cancer diagnosis, 51% had other illnesses, 3% did not know their own or their loved one's diagnosis and 5% preferred to not to say. The second pilot cohort included a higher proportion of people with a condition other than cancer.

In addition to numeric data, the survey also captured valuable comments about the experience of care and how the service could be improved.

Examples of feedback received about how care could be improved:

"[I would like] more information regarding the rights of the patient. Am [I] allowed to walk outside during the late evening or at night if it would relax or ease [my] situation, without disturbing other patients."

Hospital patient

I would like to have received more physiotherapy."

Day hospice patient

Acceptability and value of the 'Friends and Family' test

- The 'Friends and Family' test gave an aggregate score of 75% of individuals who would recommend the service to their family and friends. Of the total number of participants, 96% of those receiving care responded to this question and 92% of the family/friend/carer of the person receiving care.
- Overall people receiving care and their families and friends found the care 'good' to 'excellent'. (See Figure 4, Appendix 3)
- 32% of respondents made a contribution to the open text question; of those, 64% were from those receiving care.
- The narrative element of the survey makes valuable reading and analysis of these narratives highlights elements of care which are particularly important to patients and family carers. The comments primarily focused on:
 - The experience of the care received
 - The care environment
 - Concern about staffing levels

Examples of comments received via the 'Friends and Family' test:

"I am not happy in the ward environment as there are not many patients that are able to talk to me. I do not feel that there is enough privacy on the ward for me if I need to discuss confidential matters with the staff. My relatives are able to talk away from the ward."

Hospital patient

"I feel the staff are pushed to the limit, and more are needed."

Hospital patient

Coming to [the hospice] has made my life worth living. I never wanted to live the way I am but the hospice –its staff and volunteers have helped me so much. My OT and physio have helped me so much."

Patient attending day hospice

Acceptability of the wording of the survey

The feedback from phase 1 identified the wording of the survey as 'too professional in language', and requiring simplification. The questions were refined with input from local and national patient and carer groups and also using the valuable insight from the volunteers who had administered the survey. Once this adaptation had taken place, the survey was considered highly acceptable and appropriate for use across the various settings included in this pilot.

Unexpected learning

One of the unexpected findings of the project was that of the invaluable role of volunteers trained to support the process. Their value was multi-faceted, including:

- Instilling confidence in individuals who were reticent about the value of contributing their views and particularly those without family or friends.
- Reporting any concerns that individuals had voiced to them with their permission, in order that they could be resolved. For example, one patient surveyed was anxious about going home and being a burden on the family. The volunteer, with the patient's permission, raised this with the staff nurse who responded immediately by offering reassurance to the patient that his concerns were indeed understood and would be addressed.
- Providing social support as part of the process.
- Working collaboratively with staff to identify individuals for whom the survey might be appropriate.

Moving forward beyond the pilot project

What worked

The findings of this pilot project suggest that the method of survey delivery and the medium of hand-held electronic tablets for collecting the views of patients or carers regarding their experience of care was very acceptable across all four care settings.

Moreover participating sites stated that the approach used to invite, engage and support participants gave rise to a greater number of completed surveys than is traditionally the case, and that the open text boxes offered greater opportunity for capturing individuals' experiences.

The pilot also suggests that it is possible to develop some standard questions that have value across a variety of settings that deliver end of life care. If this is the case then the opportunity exists to collect similar data from different providers that can be compared at local, regional and national levels as part of a benchmarking process. Some links with related questions in national tools rating end of life care, such as the End of Life Care Quality Assessment Tool, are also possible.

The questions in the survey have benefitted from ongoing improvement based on feedback from volunteers and other local stakeholders. Others interested in developing similar surveys may wish to draw on the questions developed in this project as a starting point for their own.

Inclusion of the 'Friends and Family' question offers findings that can be useful to future surveys. There is evidence from this project that the question is acceptable to people reflecting on care at the end of life.

The process by which data were entered locally, collated centrally and reported to identified managers allowed for high quality data to be collected and shared. Where local service managers accessed the data, it was found to be

useful and informative. There is some evidence from this pilot of the value of real-time feedback, as opposed to retrospective evaluation. On a number of occasions, feedback from patients highlighted issues or concerns that could be addressed immediately in a way that would be unlikely through the use of paper-based surveys.

There was strong interest on the part of staff to receive feedback and to consider service improvements in the light of the feedback. It was understood that a minimum number of returns were required before significant changes would be considered.

There is clear evidence from the pilot that volunteers are highly valuable in the process of seeking feedback about patient experience of care, and are seen as such by both care teams and participants in the survey. Their involvement was seen as "therapeutic", and often added value to the experience of care on the part of the patient. Specifically volunteers' ability to identify real concerns on the part of patients or family carers and to alert staff to these concerns is notable. Their offer of time to people who were often lonely in hospital was also a common theme noted by volunteers and staff. Finally their offer of help to patients with completing the survey, as someone outside of the care team, is not to be underestimated. Completion levels were much higher in settings where volunteers were used, as opposed to those where staff introduced the survey or undertook it with patients.

The locality wide approach to planning and implementing the survey and reviewing the results proved valuable at a number of levels. Meetings drawing on staff from hospitals, the local hospice, care homes and community services were useful in establishing a shared vision for end of life care. Shared training and utilisation of volunteers across different settings further strengthened local partnerships and the potential for further collaboration.

What needs further consideration

Despite the overall success of the pilot project already described, some key challenges were encountered, which would need to be carefully considered and resolved before a wider roll-out could be undertaken:

- The findings from this pilot indicate that undertaking this survey process would require both strong local engagement and high-level national coordination to realise its potential.
- Executive commitment and leadership at local level is essential to ensure that use of the survey is fully supported and that findings are used to inform quality assurance at board level.
- Maximising the number of respondents from each setting is key. More than 5 people per care setting completing a survey within a month are required to make responding feasible.
- Care staff and their managers need to be alert to a tendency to, and the implications of, being overly protective towards patients and carers. They should avoid making assumptions about who is invited to participate in surveys and understand that where this occurs it will have implications for the robustness of the data collected.
- Staff caring for vulnerable people in their own homes may feel compromised or ethically challenged if they are personally required to ask their clients to participate in a survey about the care they are offering. Where this is the case, a tried and tested alternative, used by Marie Curie Cancer Care since 2011, is the use of volunteer-led telephone surveys.
- Local governance procedures are complex and highly variable, and may require more time and attention than anticipated in order to prevent significant delays in implementing surveys that are electronic in nature.
- In phase 2, the need to meet new governance requirements and to deal with issues relating to local Wi-Fi connectivity significantly delayed the start of the collection of data from people at home or in community hospitals. As a result, there is minimal data from these two settings for the second phase.
- Technical issues, such as local access to Wi-Fi, may impact on the possibility of services receiving real time data. Local support and buy in from IT leads is essential to resolve any such barriers as they occur.
- Very few people made use of the web-based feedback surveys which prompts consideration of whether this option was promoted sufficiently, or whether it is simply unattractive or inaccessible for a generally more elderly population. This needs further exploration.
- Further thought is required to anonymise data collected locally so that it can be used for the purposes of benchmarking locally, regionally and nationally. Opportunities exist to learn from other national benchmarking programmes.
- It is clear that this project has been relatively resource intensive – at coordination, project management and financial levels.
- At the end of the pilot, the providers of the hardware and software, CRT, offered a costing proposal for consideration. If the reporting system was commissioned at scale, e.g. for up to 600 organisations with one central system license, this would average out at between £2,000 and £3,000 per organisation per annum, which includes the first tablet. Additional tablets including the survey application are £50 per month each. There is the capability for one tablet to serve several wards/ departments as required. Different IT solutions and their costs should be investigated prior to further rollout.
- In any plans for replication of such a survey volunteer surveyors should be considered as important players. Their recruitment, training, deployment and support needs would have to be costed.

Conclusion

The case for real-time reporting as part of a robust quality assurance system is well established in some parts of healthcare and is increasingly being adopted as a core instrument of feedback across the UK². The key learning from this pilot suggests that such a methodology is acceptable to people who are elderly and frail or in the end of life phase of care and that such individuals wish to share their personal experiences as do their carers and family members. The value of clear and concise wording, free from professional jargon, has been highlighted through feedback on the part of local participants and can make a significant difference to the level of uptake of a survey.

The additional findings about the value of volunteers in the process of seeking feedback is worth highlighting. Their contribution to high levels of uptake as well as a positive experience on the part of those participating suggests a model for replication in any wider roll-out.

What is less clear is how such a roll-out would be implemented and resourced. This project shows that success lies in both bottom-up and top-down engagement. Those planning and reviewing care at board level must buy into the process, seek and reflect on the data generated and drive service improvements accordingly. Frontline staff must want to hear about user experience, encourage feedback, embrace the data that is generated and be enabled to find timely solutions to individual patient concerns and dissatisfaction.

A wider roll-out will need to examine two areas in greater detail; a variety of cost effective IT solutions that will allow data to be entered locally but received, aggregated and presented centrally and a system for returning collated information to providers in close to real-time. There is scope for cost efficiency when these processes are scaled up to cover larger numbers of patients and services.

In the meantime this pilot project has provided a good starting point for arguing the value of such an approach and the requirement for investment into exploring its opportunities for roll-out further.

² Robinson and Tyndale-Biscoe (2013). What makes a good hospital? Patient and staff experience CHKS June 2013

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Appendix 1: Project members

Steering Group

- Claire Henry, then Director of National End of Life Care programme (NEoLCP) – a Co-Chair, now Chief Executive Officer of the National Council for Palliative Care
- Dr Teresa Tate, then Deputy National Clinical Director for End of Life Care and Medical Adviser, Marie Curie Cancer Care – a Co-Chair
- Dr Heather Richardson, National Clinical Lead, Help the Hospices
- Claire O'Neill, Patients and Families Involvement Development Manager, Marie Curie Cancer Care
- Glenis Freeman, Project Associate, NEoLCP
- Katie Lindsey, Programme Manager, NEoLCP
- Professor Margaret Holloway, Social Care lead, NEoLCP
- Gerry Mahaffey, then Assistant Director Carer Services Patient and Family Engagement, Marie Curie Cancer Care
- Jason Davidson, Snr Social Worker, St Joseph's Hospice, London

Supported by

- Project Manager Marie Cooper, Help the Hospices

Pilot site Organisations

Care Homes

- Becksid – North Hykeham (Order of St John's Trust)
- Hartsholmes House – Lincoln (Order of St John's Trust)
- Foxby Court – Gainsborough (Order of St John's Trust)
- Grosvenor Hall – Lincoln
- East Holme – Lincoln
- Eresby Court

Lincolnshire Community Health Services

United Lincolnshire Hospitals NHS Trust

St Barnabas Hospice Inpatient Unit and Day Therapy Unit

Project consultants

Customer Research Technology (CRT) and Ipsos MORI

Technical note

CRT were contracted to provide the technical expertise and conduct the real time survey, process the survey data and share the survey findings. CRT subcontracted Ipsos MORI to provide advice regarding questionnaire design for the real time survey.

Ipsos MORI was also responsible for qualitatively evaluating the real time survey. They did this via a mix of face-to-face observations, face-to-face interviews and telephone interviews with staff and volunteers responsible for administering and managing the survey, the project manager and CRT staff. In total 36 interviews were conducted.

Ipsos MORI researchers also observed two feedback meetings with those administering the survey and the Steering Group. The evaluation fieldwork took place between September and December 2012, and July and October 2013.

The findings in this report draw on, but are not taken directly from, the survey results or evaluation findings.

Appendix 2: Survey Review Document

Survey Created: 14 May 2013, 11:38

Survey Changed: 13 Sep 2013, 09:37

Client: EOLC RTR

Survey: Care in Acute and Community Hospital Phase 2 V1

Start Message: Tell us what you think

End Message: Thank you for your response

1. Are you happy to participate in this survey?

(Multiple Choice, select one only)

- Yes
- No

Route to: End.

2. Are you at ...

(Multiple Choice, select one only)

- Boston Hospital
- County Hospital Louth
- Grantham Hospital
- John Coupland Hospital, Gainsborough
- Johnson Community Hospital, Spalding
- Lincoln Hospital
- Skegness Hospital

Route to: Q3.
Route to: Q5.
Route to: Q5.
Route to: Q5.
Route to: Q5.
Route to: Q4.
Route to: Q5.

3. Which ward are you on ...

(Multiple Choice, select one only)

- 6A and B
- 7A
- 7B

Route to: Q5.
Route to: Q5.
Route to: Q5.

4. Which ward are you on ...

(Multiple Choice, select one only)

- Dixon Ward
- Hatton Ward
- Lancaster

Route to: Q5.
Route to: Q5.
Route to: Q5.

5. Would you like to complete ...

(Multiple Choice, select one only)

- Patient survey
- Carer survey

Route to: Q31.

6. Who will be completing the survey? Are you ...*(Multiple Choice, select one only)*

- A person receiving care
- A carer, responding on behalf of the person receiving care
- Staff, responding on behalf of the person receiving care
- Someone else, responding on behalf of the person receiving care

Route to: Q8.

7. Thank you for helping with completing this questionnaire. Please try to reflect the view of the person receiving care as much as possible.*(Multiple Choice, select one only)*

- Continue

8. Overall, do you feel you were treated with respect and dignity while in the care of staff?*(Multiple Choice, select one only)*

- Yes, all of the time
- Yes, some of the time
- No
- Don't know

9. Overall, to what extent are you satisfied with the symptom relief you receive, for example for pain or sickness? This could be through medication, massage, advice or anything else?*(Multiple Choice, select one only)*

- Very satisfied
- Fairly satisfied
- Neither satisfied nor dissatisfied
- Fairly dissatisfied
- Very dissatisfied
- Don't know / not applicable

You are now going to read a set of statements. Please indicate to what extent you agree or disagree with each.

	Strongly agree	Tend to agree	Tend to disagree	Neither agree nor disagree	Strongly disagree	Don't know
10. The staff caring for me have the information they need about me to deliver my care effectively.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. The staff caring for me provide timely responses to my care needs.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

And again, please indicate to what extent you agree or disagree with each.

	Strongly agree	Tend to agree	Tend to disagree	Neither agree nor disagree	Strongly disagree	Don't know
12. I have been given enough information to help me make decisions about my future care.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13. I am involved in decisions about my treatment and care as much as I would like to be.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

14. On balance, do you think that you are currently being cared for in the right place? By the right place, we mean the place where you can receive the best possible care.

(Multiple Choice, select one only)

- Yes, definitely
- Yes, probably
- No, probably not
- No, definitely not
- Don't know

15. Are you in your preferred place of care?

(Multiple Choice, select one only)

- Yes, definitely
- Yes, probably
- No, probably not
- No, definitely not
- Don't know

16. If there is one thing not currently in place that would improve your care and comfort, what would that be?

(Open Ended)

- Free Format Text

To what extent do you agree or disagree with each of the following statements?

	Strongly agree	Tend to agree	Tend to disagree	Neither agree nor disagree	Strongly disagree	Don't know
17. The hospital ward is a welcoming and supportive environment.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

	Strongly agree	Tend to agree	Tend to disagree	Neither agree nor disagree	Strongly disagree	Don't know
18. My relatives and I have sufficient privacy in our discussions with hospital staff.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
19. The hospital facilities for my relatives are adequate.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

20. Have you had a conversation with hospital staff about planning your discharge from hospital?

(Multiple Choice, select one only)

- Yes
 No
 Don't know / can't remember

Route to: Q22.

Route to: Q22.

21. Would you say that you and your relatives were involved too much, too little or about right in planning your discharge from hospital?

(Multiple Choice, select one only)

- Too much
 About right
 Too little
 Don't know

22. If a friend or family member required similar care in the future, how likely is it that you would recommend the hospital to them?

(Multiple Choice, select one only)

- Extremely likely
 Likely
 Neither likely nor unlikely
 Unlikely
 Extremely unlikely
 Don't know / not applicable

23. Please give us the reason for the answer you have given.

(Open Ended)

- Free Format Text

24. Overall, to what extent are you satisfied with the support provided by the hospital for the family member(s), friend(s) or neighbour(s) that care(s) for you?

(Multiple Choice, select one only)

- Very satisfied
 Fairly satisfied
 Neither satisfied nor dissatisfied
 Fairly dissatisfied
 Very dissatisfied
 Don't know / not applicable

25. And now a few questions about you. What do you understand your main diagnosis to be?

(Multiple Choice, select one only)

- Cancer
- Heart disease
- Lung disease
- Dementia
- Neurological disease
- Kidney disease
- Stroke
- Other
- Don't know
- Rather not say

26. Are you...

(Multiple Choice, select one only)

- Male
- Female

27. What was your age on your last birthday?

(Multiple Choice, select one only)

- Under 16
- 16–24
- 25–34
- 35–44
- 45–54
- 55–64
- 65–74
- 75–84
- 85–94
- 95 or over

28. To which ethnic group do you consider you belong?

(Multiple Choice, select one only)

- White
- Mixed / multiple ethnic groups
- Asian / Asian British
- Black / African / Caribbean / Black British
- Other ethnic group

29. How was your experience of using this touchscreen survey device?

(Multiple Choice, select one only)

- Very good
- Fairly good
- Neither good nor poor
- Fairly poor
- Very poor

30. Please tell us your reason for the answer you have given.

(Open Ended)

- Free Format Text

Route to: End.

31. What is the relationship with the person you support or care for? Are you...?*(Multiple Choice, select one only)*

- Their spouse / partner
- Their child
- Another family member
- Their friend
- Their neighbour
- Someone else

32. Overall, do you feel that the person you care for is treated with respect and dignity while in the care of staff?*(Multiple Choice, select one only)*

- Yes, all of the time
- Yes, some of the time
- No
- Don't know

33. Overall, to what extent are you satisfied with the symptom relief (for example for pain or sickness) provided for the person you care for? This could be through medication, massage, advice or anything else.*(Multiple Choice, select one only)*

- Very satisfied
- Fairly satisfied
- Neither satisfied nor dissatisfied
- Fairly dissatisfied
- Very dissatisfied
- Don't know / not applicable

You are now going to read a set of statements. Please indicate to what extent you agree or disagree with each.

	Strongly agree	Tend to agree	Tend to disagree	Neither agree nor disagree	Strongly disagree	Don't know
34. The staff caring for the person I care for have the information they need about them to deliver care effectively.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
35. The staff caring for the person I care for provide timely responses to their care needs.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

And again, please indicate to what extent you agree or disagree with each.

	Strongly agree	Tend to agree	Tend to disagree	Neither agree nor disagree	Strongly disagree	Don't know
36. I have the necessary information to be able to support the person I care for with their care needs.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
37. I am involved in decisions about the treatment and care of the person I care for as much as I need to be.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

38. On balance, do you think that the person you support or care for is currently being cared for in the right place? By the right place, we mean the place where they can receive the best possible care.

(Multiple Choice, select one only)

- Yes, definitely
- Yes, probably
- No, probably not
- No, definitely not
- Don't know

39. Is the person you care for currently in their preferred place of care?

(Multiple Choice, select one only)

- Yes, definitely
- Yes, probably
- No, probably not
- No, definitely not
- Don't know

40. What type of additional support or advice, if any, would be useful to support you in caring for the person you care for?

(Multiple Choice, multiple answers allowed)

- Sitting service to enable you to go out
- Financial advice
- Legal advice (e.g. making a will)
- Personal counselling for you
- Practical help (e.g. with housework, picking up prescriptions)
- Befriender visits to your home
- I don't need any additional support

41. If there is one thing not currently in place that would help you as a carer to improve the care and comfort of the person you care for, what would that be?

(Open Ended)

- Free Format Text

To what extent do you agree or disagree with each of the following statements?

	Strongly agree	Tend to agree	Tend to disagree	Neither agree nor disagree	Strongly disagree	Don't know
42. The hospital ward is a welcoming and supportive environment.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
43. Medical and nursing staff are helpful in answering my questions.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
43. The hospital facilities are sufficient for my needs.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

45. Do the nurses looking after the person you care for introduce themselves to you?*(Multiple Choice, select one only)*

- Yes
 No
 Don't know / can't remember

46. Overall, to what extent are you satisfied with the choice of food provided for the person you care for at the hospital?*(Multiple Choice, select one only)*

- Very satisfied
 Fairly satisfied
 Neither satisfied nor dissatisfied
 Fairly dissatisfied
 Very dissatisfied
 Don't know / not applicable

47. If a friend or family member required similar care in the future, how likely is it that you would recommend the hospital to them?*(Multiple Choice, select one only)*

- Extremely likely
 Likely
 Neither likely nor unlikely
 Unlikely
 Extremely unlikely
 Don't know / not applicable

48. Please give us the reason for the answer you have given.*(Open Ended)*

- Free Format Text

49. To what extent are you satisfied with the support you receive from the hospital?

(Multiple Choice, select one only)

- Very satisfied
- Fairly satisfied
- Neither satisfied nor dissatisfied
- Fairly dissatisfied
- Very dissatisfied
- Don't know / not applicable

50. And now a few questions about the person you care for. What do you understand the main diagnosis of the person you care for to be?

(Multiple Choice, select one only)

- Cancer
- Heart disease
- Lung disease
- Dementia
- Neurological disease
- Kidney disease
- Stroke
- Other
- Don't know
- Rather not say

51. Are they...

(Multiple Choice, select one only)

- Male
- Female

52. And what was the person you care for's age on their last birthday?

(Multiple Choice, select one only)

- Under 16
- 16-24
- 25-34
- 35-44
- 45-54
- 55-64
- 65-74
- 75-84
- 85-94
- 95 or over

53. And which ethnic group do you consider they belong to?

(Multiple Choice, select one only)

- White
- Mixed / multiple ethnic groups
- Asian / Asian British
- Black / African / Caribbean / Black British
- Other ethnic group

54. How was your experience of using this touchscreen survey device?

(Multiple Choice, select one only)

- Very good
- Fairly good
- Neither good nor poor
- Fairly poor
- Very poor

55. Please tell us your reason for the answer you have given.

(Open Ended)

- Free Format Text

Appendix 3: Sample of results

Figure 1: No of responses received by setting, phase and participant

Setting	Number of valid responses		Resident/patient		Family, friend or carer	
	Phase 1	Phase 2	Phase 1	Phase 2	Phase 1	Phase 2
Care home	28	90	14	54	14	36
Home	85	8	44	4	41	4
Hospice inpatient unit	13	31	11	18	2	13
Hospital day therapy unit	43	64	33	51	10	13
Hospital	67	132	55	122	12	10
Total	236	325	157	249	79	76

Figure 2: Details of the participants (2nd phase)

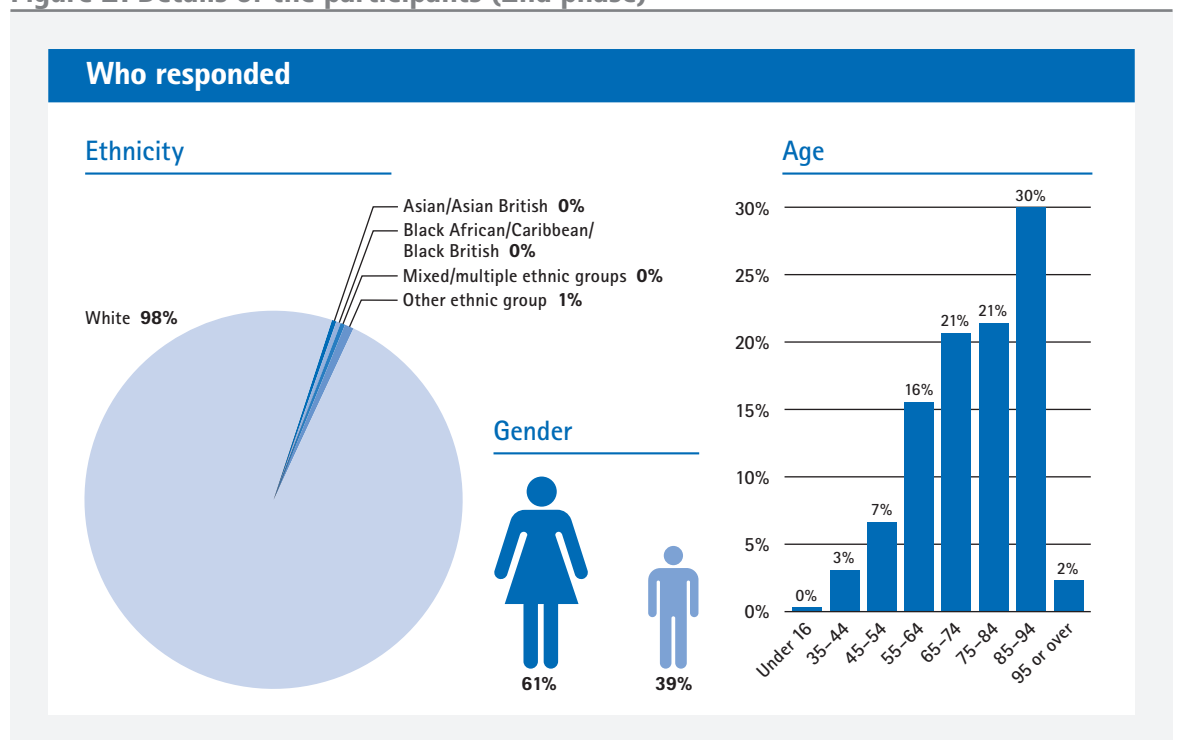


Figure 3: Friends and Family results

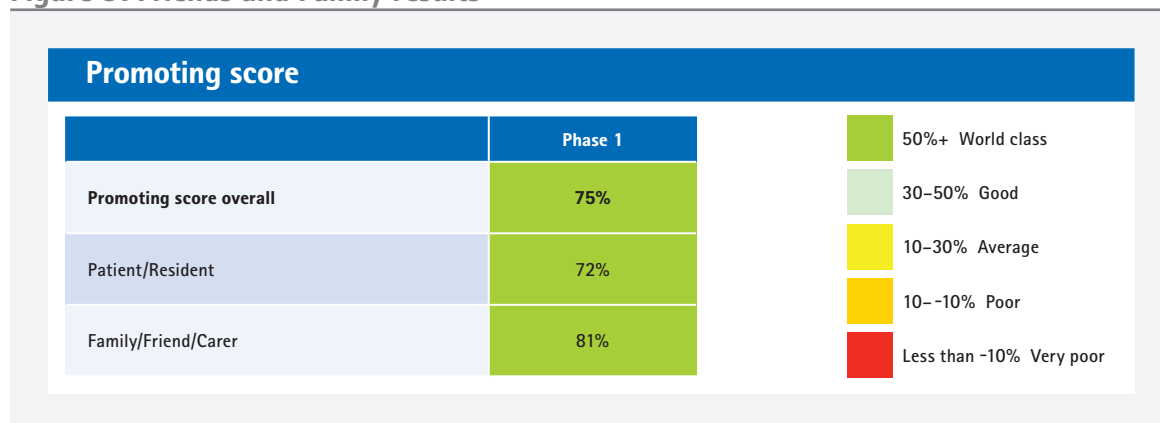


Figure 4: Overall satisfaction score

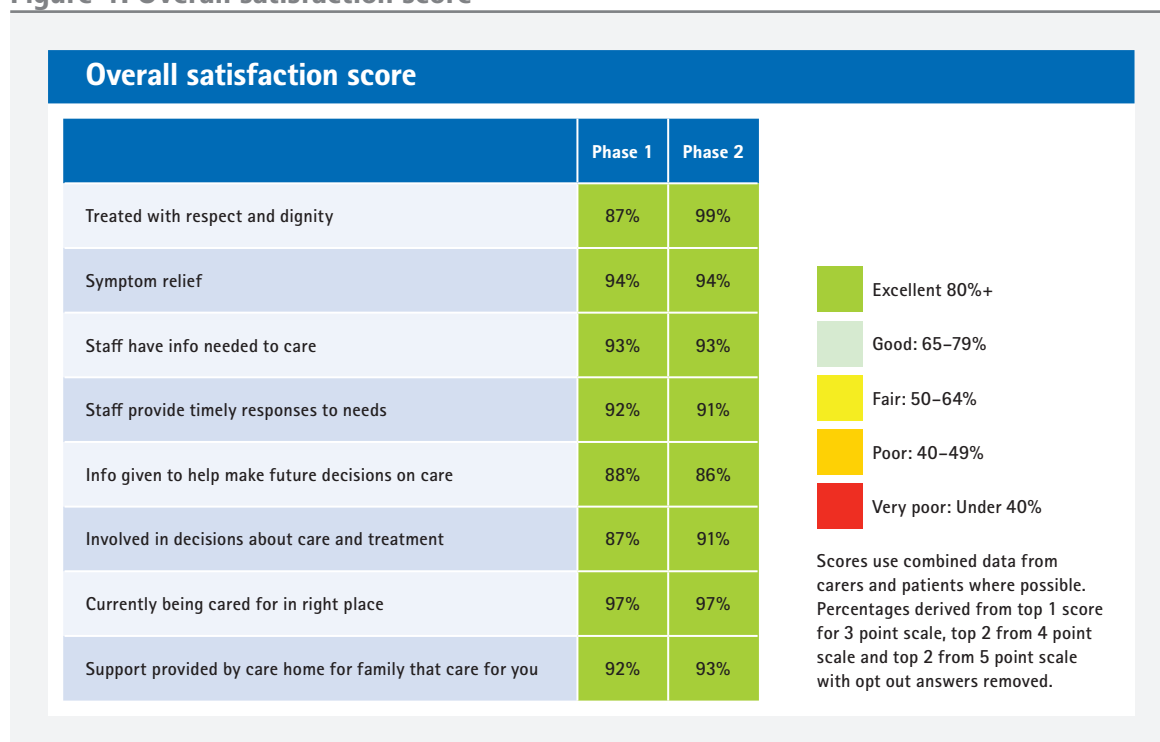


Figure 5: Benchmarking satisfaction score

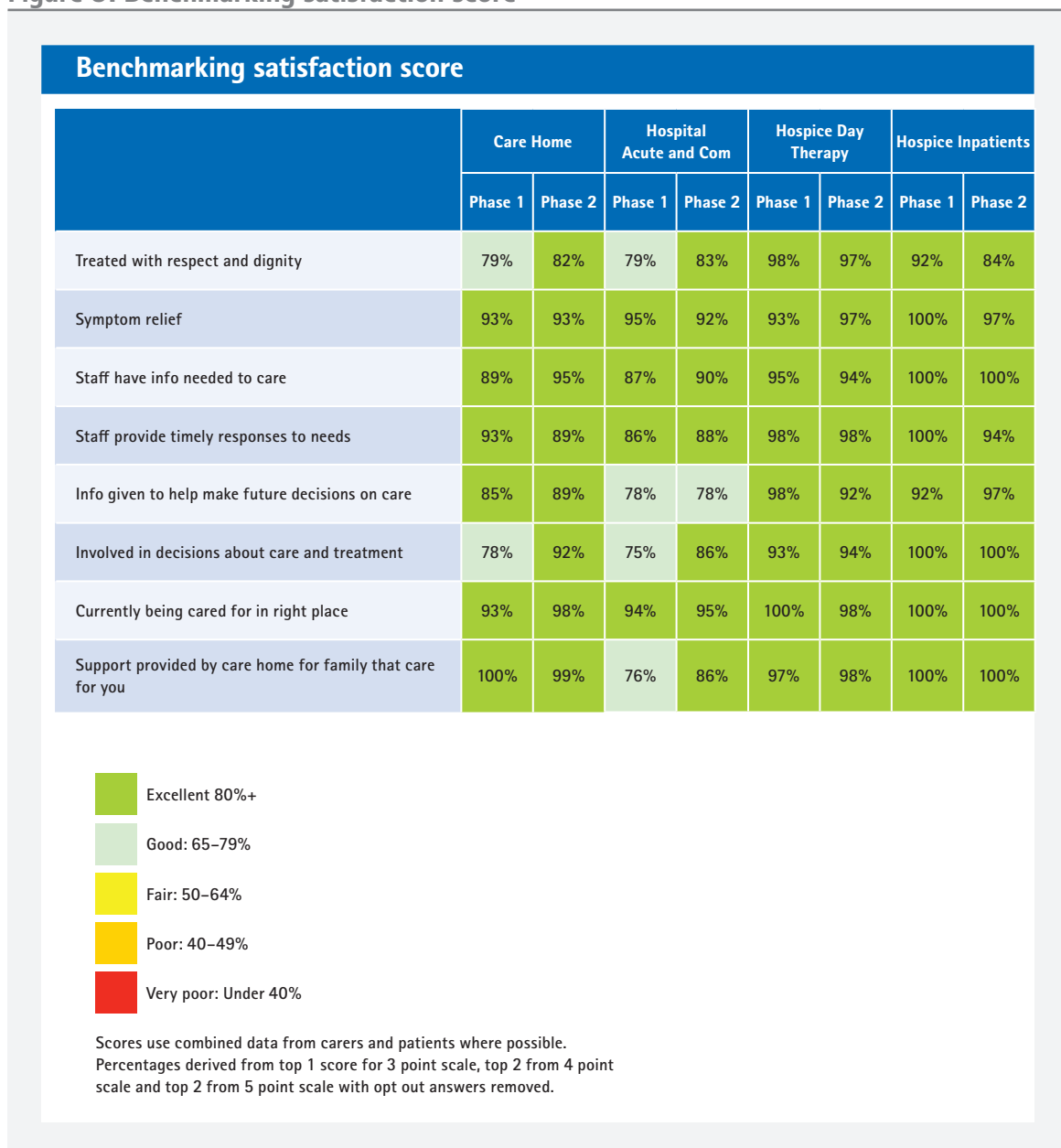


Figure 6: Dashboard

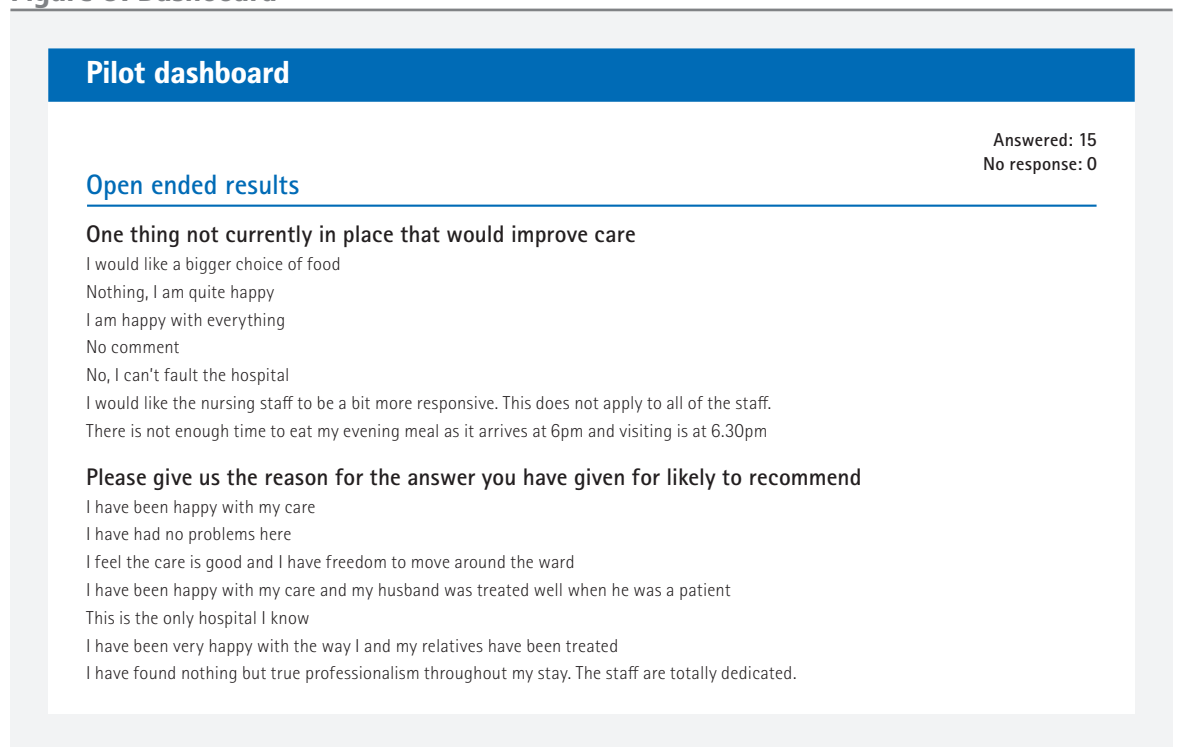


Figure 7: Pilot dashboard

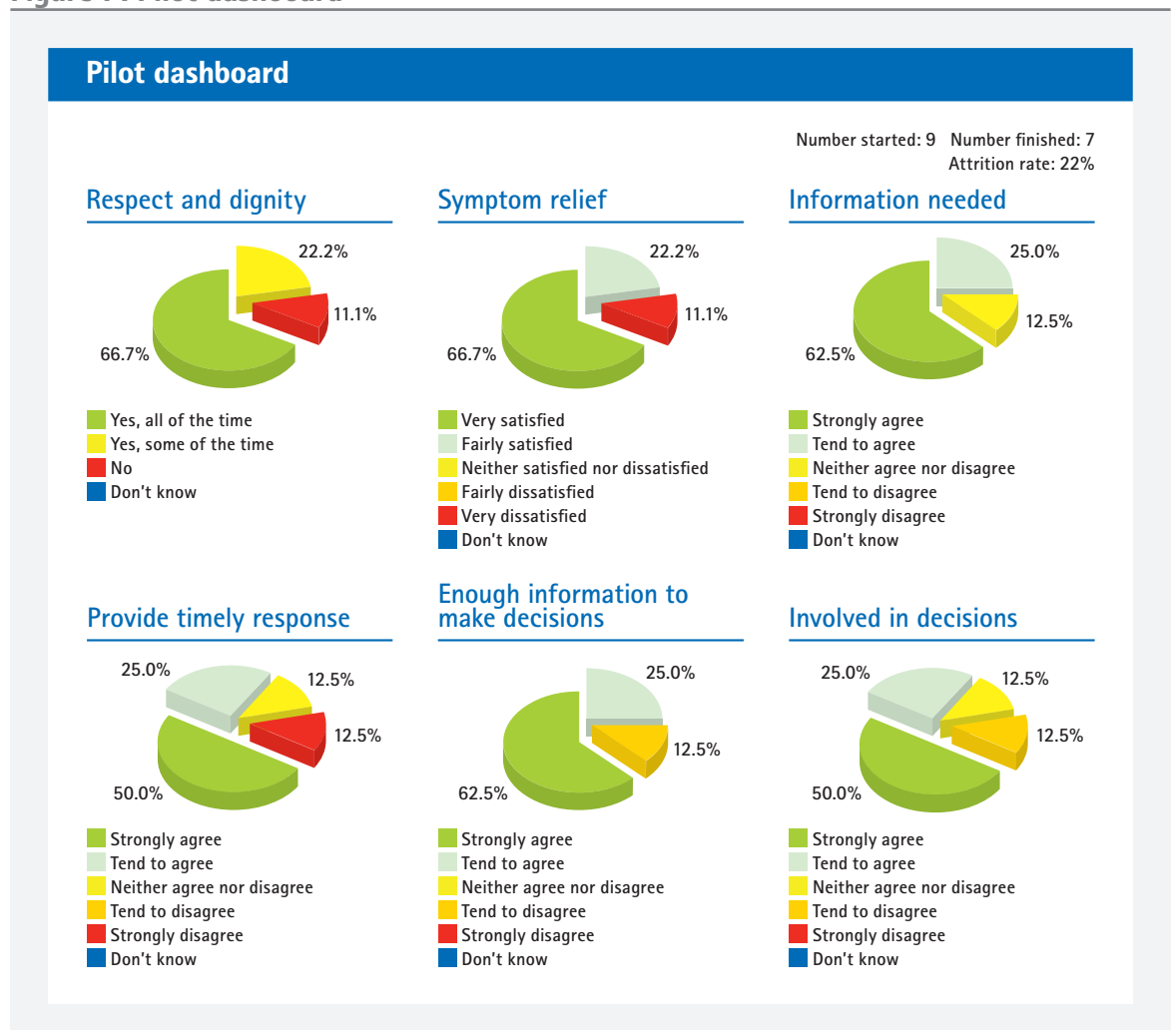


Figure 8: Pilot dashboard providing details of data over time

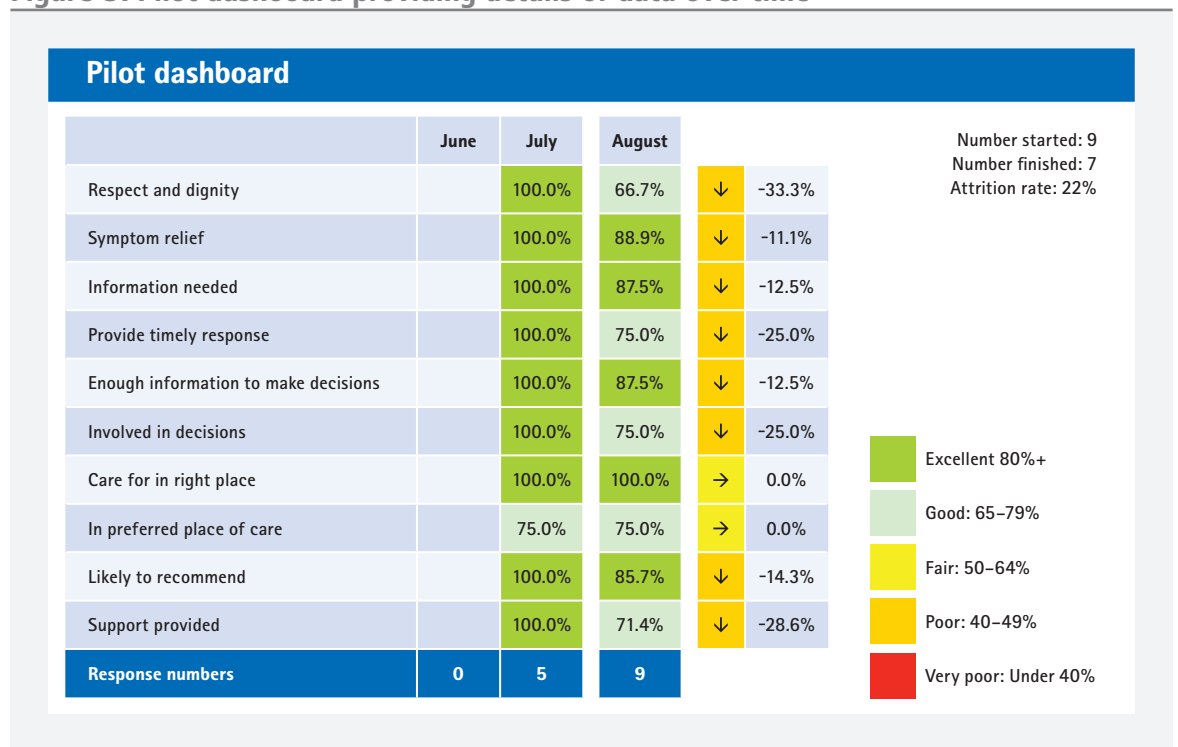


Figure 9: Word cloud example



**For more information contact:
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NHS Improving Quality provides improvement and change expertise to help improve health outcomes for people across England. It has brought together a wealth of knowledge, expertise and experience of a number of former NHS improvement organisations, including the former National End of Life Care programme.

Parts of the programme's work now continues with NHS Improving Quality.



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Help the Hospices is the UK's leading charity for hospice care which supports and champions the work of over 200 member hospices. We work with our members and other organisations as they strive to develop and improve hospice and palliative care throughout the UK and across the world.

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